

Health and Human Rights Journal

JUNE 2022, VOLUME 24, NUMBER 1

*This issue is dedicated to the memory of Paul Farmer, Editor-in-Chief,
who died on 21 February 2022 while working in Rwanda*

SPECIAL SECTION

COMPULSORY DRUG TREATMENT AND REHABILITATION, HEALTH, AND HUMAN RIGHTS

*in collaboration with the Joint United Nations Programme for HIV/AIDS (UNAIDS) Regional
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Health and Human Rights Journal (online) ISSN 2150-4113

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**SPECIAL SECTION
COMPULSORY DRUG TREATMENT
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FOREWORD

In Memory of Paul Farmer, Who Believed the Future Could Be Different

JOSEPH J. AMON AND CARMEL WILLIAMS

On February 21, 2022, *Health and Human Rights Journal's* editor-in-chief, Paul Farmer, died in his sleep while working in Rwanda.

In addition to his role at the journal, Paul was Kolokotronis University Professor and chair of the Department of Global Health and Social Medicine at Harvard Medical School, chief of the Division of Global Health Equity at Brigham and Women's Hospital in Boston, and co-founder and chief strategist of Partners in Health.

Paul followed Jonathan Mann as the journal's editor. Not long after taking on this role, he gave tribute to Mann by delivering the inaugural Jonathan Mann lecture at Drexel University, the journal's co-publisher. The talk was introduced by Lydia Mann, Jonathan Mann's daughter.

In her introduction, Lydia said that her father believed that becoming a public health professional

implicitly places you on the side of those who believe that the world can change. Every act challenges the apparent inevitability of the world as it is and the natural history of illness, disability and death. At a profound, even instinctual, level people become health professionals to struggle against the weight of human suffering and thereby place themselves among those who intervene in the present because they believe the future can be different.

This desire to fight against the “apparent inevitability” of the world, and against those who would deny the poor the right to health or access to medicines, was at the heart of Paul's writing and work. He challenged global health leaders to answer why it was acceptable that some individuals had access to information, to prevention, and to the best care possible while others did not. Whether it was HIV, tuberculosis, or COVID-19—in Haiti, Rwanda, or the United States—Paul, like his predecessor, forced people to see not just the proximate determinants of health but also the underlying structural and political determinants that public health professionals often believe are beyond their scope of work.

For Paul, the notion that health is a human right was obvious. But it was also profound, and it had consequences for how he believed public health should be taught, how global health should be delivered, and how public health practitioners should engage individuals, communities, and policy makers. Paul's writing over the past two years illustrates the current issues he was absorbed by and highlights his blunt assessment of where we are failing.

On COVID-19, Paul foresaw the massive challenge it would be to vaccinate the world. At the time of his death, only 12% of the population in low-income countries had received at least one dose of a vaccine.

JOSEPH J. AMON is senior editor of *Health and Human Rights Journal*, as well as director of the Office of Global Health and a clinical professor at Drexel University Dornsife School of Public Health, Philadelphia, USA.

CARMEL WILLIAMS is executive director of *Health and Human Rights Journal*, FXB Center for Health and Human Rights, Harvard University, Boston, USA.

In high- and upper-middle-income countries, this figure was 79%.¹ Recognizing this, Paul advocated a temporary intellectual property waiver for COVID-19 vaccines. Paul and co-authors said, “The longer states stall, the more people die needlessly. COVID-19 has repeatedly shown that people without access to resources such as strong health systems, health workers, medicines, and vaccines will preferentially fall ill and die. For too long, this cycle has been ‘other people’s’ problem. It is not. It is our problem.”²

Paul also focused his attention on the patterns of racial disparities of COVID-19 in the United States. To address the structural racism causing these disparities, Paul and his co-authors advocated racial justice interventions and reparations for Black Americans that could decrease COVID-19 and other public health risks.³ He wrote about the need to address the risk of COVID-19 in jails and prisons in the United States through vaccination and decarceration: “On the grounds of scientific evidence and our ethical responsibility to protect the vulnerable and the public at large, we can use our influence to demand” these changes.⁴ He wrote, too, of the need to protect health workers, globally, from COVID-19 infection.⁵

Beyond the issue of COVID-19, Paul championed other health issues he believed received insufficient attention, including the capacity of the global health workforce, the long-term impact of Ebola in West Africa, and the myriad health consequences of poverty in Haiti.⁶ He wrote of the millions of people globally who suffer needlessly from a lack of access to palliative care.⁷ He also recognized what he referred to as “the moral case for global mental health delivery” and the structural violence that is often committed on people with mental illness, occurring at the intersection of deprivation, exclusion, and discrimination.⁸

Focusing too much on specific health issues, though, misses the important holistic view that Paul brought to public health. Paul was skeptical of what he described as “narrowly defined technological fixes,” which, while effective and affordable, are often put in silos and traded off against one another, a process that ultimately fails to deliver

the comprehensive public health systems that communities need.

Under Paul’s editorship, the journal flourished, reflecting his wide interests and underlying belief in the importance of strong health systems. His influence expanded the readership beyond academic circles to practitioners and activists working in both the Global North and the Global South. He insisted the journal be open access to readers and contributors so that lack of financial resources could never stop good research from being published or read.

His leadership will be missed, but his legacy will continue. For years to come, his articles and books will remain prescribed reading in university courses. They will continue to inspire students and global health practitioners and leaders and will help guide those who hold governments to account for their human rights duties. In addition to remembering his hard work, dedication, sense of humility, humor, and optimism, we must emulate his spirit. Along with his innumerable colleagues, friends, and admirers around the world, in our sadness and shock at Paul’s sudden death, we strive to keep alive his belief that the future can be different.

Journal will draw on global expertise

At this time of change, the publishers of *Health and Human Rights Journal*—the François-Xavier Bagnoud Center for Health and Human Rights at Harvard University and the Dornsife School of Public Health at Drexel University—are welcoming an executive editorial committee to provide support, leadership, and guidance. The members of the committee have been selected to provide regional, ethnic, gender, and professional and academic diversity.

The journal’s subject, health and human rights, necessarily calls for interdisciplinary expertise, reflecting the indivisibility of human rights. Its commitment to publishing work that promotes equity in health both globally and nationally requires a deep understanding of public health, and its social determinants, as objects of social and economic rights. Global inequities, and local ones

that manifest as a lack of access to health care and inadequate standards of living, reflect historic and ongoing power imbalances. Understanding and overcoming these human rights challenges requires research and advocacy that address legal, health, political, and economic determinants.

Our newly appointed editorial committee reflects this breadth of expertise. Consisting of Tlaleng Mofokeng, Sharifah Sekalala, Anand Grover, and Varun Gauri, the committee brings a wealth of practical, theoretical, and grassroots knowledge to the journal. They join at a time when the journal seeks to reach out to more readers and authors, especially those from the Global South.

Tlaleng Mofokeng from South Africa is the fourth and current United Nations Special Rapporteur on the right to health, the first woman to hold this position. Known for her advocacy for universal health access (especially for rural women whose access to holistic quality health care is limited), sexual and reproductive health rights (including safe abortion), and inclusive gender-affirming health, Tlaleng also implements “advocacy-in-practice” training for health care professionals. As a medical practitioner herself, her areas of focus have been on gender equality, health policy, health systems, and the politics of health. In her words, “I have a goal of realising substantive equality through addressing structural and indirect discrimination and identifying the power dynamics that have perpetuated the systems and patterns of privilege and disadvantage that outlives formal colonialism.”

Sharifah Sekalala, a professor of law at Warwick University, United Kingdom, is an interdisciplinary researcher working at the intersection of international law, public policy, and global health. Sharifah uses a human rights lens to focus on intersectional vulnerabilities, including in a current project on the transnational movement of digital health data and how African states can ensure future rights to data from digital health applications. Her vision is influenced by Paul Farmer’s early work: “Unlike a lot of the earlier work on rights, it was very applied and focused on the right to health as a specific right. For me, as a scholar from the Global South, this was nearer to my lived experiences of rights

and enabled me to redirect my academic focus.”

Varun Gauri, a senior fellow in the Global Economy and Development program at Brookings and a lecturer of public and international affairs at Princeton University, describes Paul’s work on HIV medications as inspiring: “He changed the world by showing that AIDS treatment was possible in low-income settings at a time when many individuals and large organizations were deeply skeptical. It gave those of us who hoped for a better, more encompassing solidarity something to point to, strive for, and remember.”

Anand Grover was the second person to hold the aforementioned Special Rapporteur mandate (2008–2014). He co-founded a nongovernmental organisation in India, the Lawyers Collective, which promotes human rights, especially on issues relating to women’s rights, HIV, tobacco, LGBT rights, sex workers’ rights, drug users’ rights, and access to medicines. He has argued several landmark cases in the field of human rights law, including cases related to mass eviction, the environment, HIV, LGBT rights, and opposition to patents for essential life-saving drugs. Anand also brings publishing experience to this position, having been a founding editor of a constitutional law and human rights online publication in India, *The Leaflet*.⁹ He supports the range of article formats offered by the journal and hopes to increase its diversity of contributors and board members.

We look forward to working with the new committee to expand our readership and the journal’s accessibility to researchers, activists, health workers, and lawyers working globally to promote the right to health.

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Human Rights Implications of the Digital Revolution in Health Care in India

DEEKSHITHA GANESAN

Abstract

The COVID-19 pandemic has ushered in rapidly evolving developments in digital health, and governments around the world are experimenting with different ways of introducing technological tools in the management and delivery of health care services. India, among the countries that faced one of the most serious outbreaks in the second wave of the pandemic, recently rolled out the National Digital Health Mission, which promises an integrated but federated digital architecture and a digital health ecosystem that will solve the information asymmetries of the health care sector in India. While the promises of the National Digital Health Mission are many, India's experience with using another digital tool during the pandemic—the CoWIN portal for vaccine management—alerts us to the human rights concerns of rapid introductions of digital tools to address infrastructural and governance challenges in health care. This paper attempts to take a closer look at these two digital tools and the potential human rights implications of the National Digital Health Mission, particularly for the right to health.

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Competing interests: None declared.

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Introduction

The COVID-19 pandemic has tested countries across the spectrum of public health preparedness. The successive lockdowns and the rapidly spreading virus called for measures that could match its speed of transmission, and digital technologies emerged overwhelmingly as vital tools. From contact tracing, identifying clusters, triaging, and risk management to telemedicine, countries experimented with a range of digital technologies such as geolocation, big data analytics, and information communication technologies, with varying levels of success.

As a pioneer in the use of digital technologies in governance in the Global South, India rolled out many tools. Undoubtedly, these tools were released rapidly in response to a crisis, yet their speedy delivery might alert us to the fact that they were not developed overnight. Digital technologies have been increasingly deployed in health care in India in recent years. For instance, the National Health Policy of 2017 formally floated the idea of a digital health ecosystem for the first time, and the central government rolled out the National Digital Health Mission (NDHM) in 2021. The NDHM seeks to create a single, integrated digital health infrastructure and allocate a health ID to every individual along the lines of Aadhaar, India's controversial biometric identification mechanism, which has been criticized both for engendering the exclusion of vulnerable groups from welfare measures and for enabling a surveillance state.¹

The digital interventions in health care management suggest an ongoing digital revolution rather than isolated measures in response to a crisis. The impetus provided by the pandemic for the use of digital technologies and the experience of their associated fallouts during the COVID-19 crisis therefore present key moments to interrogate the frequently advanced notion that digital technologies are a panacea for all governance challenges. In the context of health care, the COVID Vaccine Intelligence Network portal (CoWIN), which the Indian government introduced to coordinate vaccinations, and the NDHM offer a glimpse of the

many concerns that arise when relying on digital technologies to manage the delivery of health care, such as the absence of robust informed consent procedures, data protection concerns, the exclusion of vulnerable groups, and low levels of internet penetration and digital literacy. While anxieties around data protection and the right to privacy are well founded, this paper argues that the rapid digitalization of health care could have grave implications for the right to health.

The paper begins with an overview of the status of health care and the COVID-19 crisis in India. It then briefly evaluates CoWIN and provides an overview of its aims and functions, key concerns, and human rights implications. The focus then shifts to the NDHM to explore the history of its development, its key goals and functions, and potential concerns with its development and use. The final section comments on the NDHM's implications for securing the right to health and offers some key considerations.

The COVID-19 experience and the state of health care in India

India witnessed at least two major waves of the COVID-19 crisis—first between March and September 2020 and then between March and June 2021. The second wave in particular unleashed extreme devastation, and the rapid spread of the virulent and highly infectious Delta variant was worsened by severe shortages of hospital beds and oxygen, as well as high rates of physician fatigue, leaving many people stranded outside hospitals and in their homes without medical care.² During 2020 and 2021, the number of deaths in India were estimated at around 4.74 million by the World Health Organization, while the Indian government has maintained the official overall number of deaths in this period to be 481,000. The second wave laid bare India's poor public health readiness for a country that was thrown headlong into a crisis but for which it arguably had at least a year to prepare.³

This background to the second wave of the pandemic and the experience with the COVID-19 crisis provides the setting to assess the country's

need for and approach to the digital revolution in health care. Health care delivery in India is divided into public and private components, and the public provisioning of health care has slowly moved toward providing only those services that the private sector has been unable or unwilling to provide. Public health care is available in urban and rural areas; in the latter, it typically takes the form of primary health care centers that provide only basic facilities. The majority of private hospitals are concentrated in metropolitan and tier-two cities. In urban and rural areas, private medical practitioners and local clinics are the first point of contact for immediate medical care.⁴ India's 2021-22 budget expenditure on health care was only 2.1% of GDP, far below the 5% recommended by the World Health Organization. Further, more than 60% of health care spending is out of pocket; the bed-to-population ratio is 0.7 per 1,000; and there is about one doctor per 1,000 people.⁵

Undoubtedly, the health care sector in India faces many challenges, such as a shortage of manpower and health infrastructure, low access to quality health care in rural areas, and dispersed information on the health needs of individuals—but digital technologies present viable solutions to only some of these concerns. It is worth mentioning that this paper acknowledges that digital technologies can play an important role in strengthening public health services and in planning for future large-scale health emergencies. That said, based on the experience of the CoWIN platform and the design of the NDHM, as explored in the following sections, the paper challenges the embedding of technology in the state's imagination of development, which results in the painting over of serious structural concerns.⁶

Access to vaccines and the CoWIN platform

The first wave of the pandemic in India began to wane by September 2020, even as a number of countries began battling a second wave shortly after. In early 2021, as the prospect of effective vaccines seemed certain and in light of the low number of cases, India began exporting doses of vaccines

manufactured by the Serum Institute and Bharat Biotech.⁷ However, by March 2021, the second wave overwhelmed the strained health care system, and public and private hospitals alike struggled with serious shortages of oxygen and hospital beds. Large-scale vaccination was indispensable to control the situation, which was complicated by two factors—the unavailability of sufficient vaccines to inoculate enough of the population in the 18–45 age group, as well as the central government's constantly changing decisions both on the purchase of vaccines for allocation to state governments and the possibility of direct sale by the vaccine manufacturers to listed private hospitals.⁸

This background provides essential context for understanding the distribution of vaccines through CoWIN. CoWIN is a cloud-based solution meant to coordinate, implement, and evaluate COVID-19 vaccinations.⁹ The portal, which has now been made open source, can create and authenticate users, register bulk and individual beneficiaries, schedule vaccination sessions, and manage the distribution, monitoring, and wastage of vaccine stocks. Many of CoWIN's features are not public facing. The most controversial aspect of its use, particularly from a human rights perspective, was its role in managing the registration of users for vaccination.

According to India's COVID-19 vaccination guidelines, an individual is required to self-register on the CoWIN website or the Aarogya Setu mobile application by providing demographic details such as one's name, date of birth, and address, and by uploading proof of identification, including but not limited to their Aadhaar number. Although the CoWIN website now has a simple privacy policy, when the application was first rolled out, no separate privacy policy accompanied it and instead a link was made available to the NDHM's Health Data Management Policy, a nonbinding guidance document.¹⁰ One possible, but unconfirmed, reason for this could be that the initial registrations for the NDHM were undertaken through CoWIN when individuals offered their Aadhaar number as the primary form of identification, demonstrating the close linkages between these two digital health technologies.

At the time of booking one's appointment, the applicant could select the preferred state or private facility to receive the vaccine, but not the timeslot. The CoWIN system allowed only those who had preregistered to proceed for vaccination; walk-in vaccinations were not permitted, though some facilities for on-site registration were made available in public hospitals.¹¹ Private hospitals charged a fee for vaccination, and those who could afford the vaccine were encouraged to visit these hospitals, though the guidelines state that every person is entitled to a free vaccine.¹² Vaccine certificates were also made digitally available, which individuals could download onto their phones. Unlike paper documents, these digital certificates are claimed to be enduring and unique, linked to each person's abstracted digital identity, easily storable, processible, and commodifiable if necessary.¹³

The CoWIN portal was riddled with problems as vaccine slots ran out at dizzying speed. Individuals who could access smartphones and book a slot reported discrepancies in the information on available slots and complained that the app would frequently crash. Further, prebooked appointments did not guarantee a vaccine since slots were often overbooked and stocks were rapidly exhausted.¹⁴ Even as the second wave began to ease, preregistration on the CoWIN app was the only guaranteed way to receive the vaccine.¹⁵ Health care professionals who were managing distribution in private hospitals also reported challenges with using the portal on a smartphone, frequent power outages that interfered with internet connections, and bottlenecks when the portal became unresponsive.¹⁶ In areas with poor internet connectivity, insistence on preregistration through CoWIN led to delays in vaccination.¹⁷ Further, the distribution of the vaccines through private vaccination centers led to a concerning occurrence of fake vaccines and mobile apps, contributing to vaccine hesitancy.¹⁸

Recognizing that it would not be able to address all these issues, the government released an application programming interface (API) to enable developers to build other tools and software that could interact with CoWIN, illustrating the

notion of participatory "government as platform" that emphasises collaborative technologies to solve collective problems.¹⁹ Third-party developers were given access to the CoWIN master database, which was to be the "single source of truth," to carry out modifications.²⁰ They were permitted to retain copies of data relating to their customers to ensure that citizens had a consistent view of their own record, subject to the terms of service and supported by their privacy policy.²¹ Soon, third-party tools that facilitated alerts on available vaccination slots, scheduling appointments, downloading vaccination certificates, and managing workflow became available. However, these too were accessible only for the those who had steady internet access and the skills and knowledge to access CoWIN with ease.

This method of distributing vaccines does not comport with the right to health as guaranteed by article 12 of the International Covenant on Economic, Social and Cultural Rights.²² The right to health at all levels, including the allocation and distribution of essential medicines and vaccines, requires ensuring availability, accessibility, acceptability, and quality.²³ During the distribution of the COVID-19 vaccines in India through CoWIN, these elements were not sufficiently foregrounded: the availability of vaccines was not properly planned for, vaccines were not affordable or accessible in a timely manner for a majority of the population, and the surrounding conditions gave way to fake vaccinations.

Many forces acted simultaneously to complicate the process of vaccinating India's population. Yet the CoWIN portal's limited functionality and the very decision to rely on an online platform to distribute vaccines did not take into account the gaps in digital literacy or the fact that many in India, including those residing in urban centers, do not have continuous data connections or electricity that can support internet services, sufficient data packages, or enough phone memory to host large applications. By distributing vaccines through CoWIN, equity was no longer the primary goal, and an effective hierarchy of who could receive vaccines was created—first would be those who are digitally

literate, conversant in English, and able to pay for their vaccines; after them would be poor people, women, migrants, persons with disabilities, and other vulnerable populations.²⁴ The government's attitude was exemplified in a statement to the Supreme Court of India noting that those without digital access could accept the help of nongovernmental organizations, friends, family members, and common service centers established by local self-governments in villages to book appointments. However, the efficacy of these centers in facilitating vaccine registrations is largely unclear.²⁵ Some reports suggested that as of May 2021, a network of 400,000 such centers in rural areas had integrated their back end with the CoWIN portal and had registered close to 430,000 people through registration drives. The government also claimed that it had strengthened security features on the platform to reduce the possibilities of bots booking slots, introduced the telephone booking of vaccine slots, and made it possible for multiple slots to be booked through one phone number to enable those with digital access and skills to assist others.²⁶ However, other conflicting reports from the same time period have shown that out of a total of 300,000 common service centers, only 54,460 were active and only 170,000 individuals had been registered.²⁷ The inconsistency in reported data on the service centers and reports of vaccinations being impeded due to logistical difficulties in accessing the centers amid lockdowns renders doubtful claims of their efficiency in boosting vaccine registrations and their sufficiency as an alternative to the CoWIN platform.

National Digital Health Mission: A digital solution to a governance challenge

India's experience with CoWIN provides an indication of the limitations of relying exclusively on digital technologies. However, the NDHM also ushers in a digital revolution in health care without addressing the many deficiencies of the Indian health care system that were revealed during the first two waves of the pandemic. Considering that the COVID-19 threat has not yet passed and the

second wave is fresh in India's collective memory, NDHM's promises and ability to alter the landscape of health care are worth interrogating.

The NDHM is a federated digital architecture comprising electronic health registries, personal health records, and a health analytics platform, atop which other components and health care services may be built. The stated objective is to make available efficient, accessible, inclusive, affordable, timely, and safe universal health coverage by leveraging data and digital infrastructure built using open, interoperable, and standards-based systems that ensure the security, confidentiality, and privacy of health-related personal information.²⁸

A brief timeline of the NDHM's development offers insight into the motivations behind its conceptualization, the different government agencies involved, and its key aims and functions. Its origins can be traced back to 2011, when the idea of using Aadhaar numbers to create a database of all patients "for seamless use by various health chains [t]hat could also be used for insurance claims" was first floated.²⁹ This found expression in the National Health Policy of 2017, which proposed a digital health technology ecosystem and a national digital health authority to "regulate, develop and deploy digital health across the continuum of care." The aim was to create an integrated but federated health information infrastructure that would link systems across private and public health care service providers and allow for the creation of massive registries and databases to facilitate big data analytics.³⁰ At the time, the policy anticipated the use of Aadhaar for this purpose, especially as Aadhaar was envisaged as the single identity system for all Indian residents.

Shortly after, in 2018, the National Institution for Transforming India released a consultation document on the National Health Stack, which is a digital infrastructure that constitutes the building blocks of all the digital health initiatives envisaged under the NDHM and comprises electronic health registries, an insurance claims platform, a personal health records framework, health analytics, and other components. The preface to the consultation document affords an indication of the government's

approach to health care management and governance more broadly; it understands “a strong health system as inconceivable without a resilient digital backbone.”³¹ The National Health Stack will provide a shared digital infrastructure for use across central and state governments and by public and private actors, as well as the services required to manage the data for all programs. Private players can build cloud-based applications and tools that will sit atop this shared infrastructure to fill the gaps in the delivery of health services by the public sector. A close comparator of the National Health Stack is the India Stack, with its four-pronged consent layer, cashless layer, paperless layer, and presence-less layer (removal of barriers to participation through remote authentication mechanisms). The National Health Stack document also envisages a key role for the India Stack, which will support the digital health ecosystem by enabling the linkage of bank accounts and phone numbers.³² The government’s primary role vis-à-vis the National Health Stack is to create the necessary digital, rather than health, infrastructure that can foster a “more robust private sector ecosystem.”³³

This digital health ecosystem is predicated on issuing a health ID to every individual. The health IDs, which are being created based on an existing national ID and mediate interactions with the National Health Stack, are expected to reduce the risk of preventable medical error, limit costs and inefficiencies, increase quality of care, and provide users with a longitudinal view of health care records.

The consultation document identifies the lack of accessible master data on health as the core problem of India’s health care system, impeding the development of a holistic picture of care, and the health ID is only a part of the solution. The base layer contemplated for the National Health Stack will include information on patients, health care providers, doctors, insurers, accredited social health workers, pharmacies, clinics, labs, and beneficiaries, collectively called the National Health Registries. The document lays out the principles that would define the registries, such as self-maintainability (listed entities should be able to view and update information), flexible schemes that can incorporate

feedback, consented data sharing, non-repudiable data (viewers should be able to tell who has edited or added data), and data provenance (audit trail for changes). Other services such as insurance coverage and claim processing will be built on top of this layer and will interact with the health registries through simple open APIs that are compatible with global standards.³⁴ While APIs can enable and provide authorization for sharing data between different actors in the National Health Stack based on predetermined standards or permissions, they cannot fully restrict how the data are used once an entity gains access, which would once again have to be defined by law. Therefore, the use and sharing of data are in turn guided by the National Health Data Management Policy mentioned above. But in effect, the National Health Stack enables private actors to access vast amounts of data for a variety of purposes.

In 2019, this digital health ecosystem was formally presented by the Ministry of Health and Family Welfare through the National Digital Health Blueprint.³⁵ As a document produced by the ministry, this blueprint is significant for defining the country’s health agenda. The fundamental goal of the National Digital Health Blueprint is universal health coverage, primarily through insurance. The document notes that the government seeks to achieve the highest possible level of health and provide universal access to good quality health care services for all without imposing financial hardships. Digital tools are offered as the most promising method to achieve these goals by ensuring citizen empowerment, improving public health care delivery, and addressing the fragmentation of health care data.

In 2020, the NDHM’s strategy overview was released. It identifies the citizen as the owner of the data and claims that the integrated data system will help patients securely store and access their medical records; gain accurate information on health facilities and service providers; and achieve faster processing of insurance claims. Under the NDHM, health information providers such as hospitals will create a personal record linked to a user’s health ID, which will be anonymized for the data

feed forming part of the national health analytics architecture. Here, the strategy overview distinguishes between personal data and nonpersonal, or anonymized, health data that are likely to be used in health planning.³⁶ In terms of personal data, a user will be able to give consent, using their health ID, to anyone who requests permission to view and use their data. This process will be coordinated by a consent manager, and every individual can choose the consent manager to whom their health ID will be linked.

The precise intended or expected benefits of the NDHM as outlined in the National Health Stack consultation document uses the language of international human rights law on the right to health—it identifies availability, accessibility, affordability, and acceptability as the four major challenges of health care delivery in India and as the corresponding benefits of the National Health Stack.³⁷ With regard to the first two challenges, health care will be made more accessible and available since individuals will be able to avail insurance at any point in the year and have more options for service providers enabled by faster claims processing. With regard to the third, technology will improve affordability due to the increased participation of service providers on account of justified pricing and the instantaneous and cashless adjudication of claims. Finally, the National Health Stack is expected to improve acceptability by encouraging hospitals to improve quality of care through reward programs using information generated by the National Health Stack. An associated benefit for the government will be the ability to reach migrants and provide health care and protection to anyone, anywhere in India due to the feature of portability.

Thus, on paper, the NDHM appears to be a comprehensive plan to boost the health care system and address its considerable weaknesses. Yet medical professionals and digital rights activists in India have expressed misgivings about its many promises, which have assumed prominence since the onset of the pandemic.³⁸

Why create a digital health ID?

The obvious question to ask of the NDHM

is why the need for a new health ID when there is near universal coverage under Aadhaar. The reason for this may lie in the prominent role envisaged for private enterprises by the NDHM. By 2018, the Supreme Court of India had recognized a fundamental right to privacy, and a decision on the constitutionality of the Aadhaar project was imminent. In October 2018, it held that the Aadhaar project was constitutional but added that it could not be made the sole basis for accessing welfare schemes and that private players could not use it for authentication.³⁹ While the latter ban has been slowly eroded in practice, one reason for developing the health ID may be to sidestep any similar potential objections on its use by private players.⁴⁰

Despite the health ID, Aadhaar is still likely to play an important role in the NDHM. As one of the proofs of identification for creation of the health ID and as an element of the India Stack mentioned above, it will enable linkages between different databases that also operate using Aadhaar. Although the various strategy documents claim that failure to provide one's Aadhaar for the creation of the health ID and the denial of permission to share one's health ID would reportedly not result in denials of service, once the Aadhaar is integrated into the NDHM, individuals will find it difficult to refuse to provide their details.⁴¹

The similarities in at least some of the goals of the health ID and Aadhaar as mechanisms to enable unique identification, prevent fraud, and plug leakages should alert us to common concerns. For one, in the past, Aadhaar numbers have been leaked despite the government's claims that the information was stored securely.⁴² With the health ID, a number of private actors—such as medical practitioners, clinicians, labs, insurance companies, private hospitals, and tech start-ups—that build applications atop the National Health Stack will have access to the data contained in the health registries. Moreover, the National Health Data Management Policy also contemplates that sensitive personal data such as sexual orientation, financial information, mental health conditions, and biometric information is likely to be collected under the NDHM.⁴³ Leaks and misuse of personal health data and other sensitive

information such as sexual orientation are serious and could have grave implications for individuals.

Second, if obtaining the health ID and registration with the NDHM are not compulsory for individuals or health care service providers, as the government has claimed, it is unclear how the NDHM will bridge the data gap. Health data for the analytics engine of the NDHM are valuable only if they are available in the aggregate, which requires different actors in the health care system to participate and generate sufficient data.⁴⁴ But the creation of a health ID and digitalization will present major challenges for health care providers. While the NDHM may offer incentives for insurance companies and large private hospitals, health care in India is still substantially provided by independent medical practitioners in local clinics and primary health centers. The NDHM's administrative and cost burdens of digitalization and converting from a legacy system to a digital health model will undoubtedly require a significant shift in practices. The transition is likely to take away important time and resources from the caregiving duties of medical professionals who are not provided with adequate financial and administrative support to ensure accurate data entry that can guarantee robust data for the NDHM and mitigate the serious repercussions of incorrect entries for patients.⁴⁵

The guarantee of universal health coverage

India's insurance market comprises a few state-run players and a host of private insurance providers that cater to a large proportion of the middle class. While the central government recently introduced a state-funded insurance scheme for rural and poor families with the aim of reducing high out-of-pocket expenditures on health, the majority of enlisted hospitals that provide health care are private and account for a substantial part of the claim value. Since the program was implemented, there have been reports of individuals having to incur out-of-pocket expenses and of hospitals threatening to or in fact pulling out of the scheme on account of the nonpayment of claims by insurance companies.⁴⁶

This is essential context for the issue of insurance coverage, since an important goal of the

NDHM is universal health coverage and since all of the strategy documents refer to the ease of processing insurance claims and identify benefits for private insurance providers. The National Health Stack is intended to be the primary coverage and claims platform, and the government claims that it will solve the problem of a lack of health data; enable the standardization of processes such as preauthorization and claims processing; facilitate on-time payments for service providers; prevent fraud by service providers by rewarding honest claims through instant adjudication; and filter poor-quality service providers through the interplay of strong data sets and market-based mechanisms.⁴⁷

Specifically for insurance providers, the National Health Stack document identifies market expansion and "targeted product offering with availability of supply side data" as a benefit. However, the ability of insurance providers to access detailed and highly personalized information on individuals' health conditions has raised alarms. A major concern is that insurance providers might engage in the suppression of scheme utilization and target product offerings or increase premiums based on geography or income levels or by specifically accounting for preexisting conditions.⁴⁸ This is a significant issue because for a substantial portion of India's population, including its middle class, health care is expensive, requires out-of-pocket spending, and is not always cashless. Therefore, in the absence of a strong public health care system, apprehensions about how insurance companies will respond in terms of health care coverage and its potential impact on achieving the goal of universal health coverage are not misplaced.

Is informed consent sufficient to protect health data?

Informed consent is offered at multiple points as the primary method of ensuring the confidentiality of personal information. The National Health Data Management Policy identifies consent as valid only if it is free, informed, specific, clearly given, and capable of being withdrawn at any time.⁴⁹ However, the presence of informed consent as the primary safeguard may not be sufficient.

First, there are already numerous reports of health IDs having been generated automatically for individuals who registered for vaccinations on the CoWIN platform using their Aadhaar numbers and of instances where registration to obtain a health ID was made mandatory.⁵⁰ Officials who were operating the system at many of the vaccination centers did not explicitly seek consent and assumed that one's sharing of their Aadhaar equaled authorization to create a health ID.⁵¹ Recently, the government claimed that nearly 96% of the health IDs issued so far are linked with Aadhaar.⁵²

Second, to safeguard personal data, the policy attempts to instill a "privacy by design" approach among the NDHM's different actors through consent managers, but this is unlikely to protect personal health information to the extent necessary. Consent managers are electronic systems that will interact with the data principal and obtain consent for access to personal data but will not be able to access the information themselves. Fresh consent is required from the data principal through the consent managers only if data are used for a previously unidentified purpose—in other words, it does not appear that individuals can object to specific data points being digitized; consent to be part of the NDHM and for processing personal data applies to all kinds of personal information.⁵³

Through consent managers, the NDHM seeks to solve the problem of loss of health records or poor maintenance at the hospital level and address the coercive conditions around informed consent at the point of care. However, the ability to provide informed consent presupposes that an individual has all the relevant information to make a rational determination and that this information was communicated to them in an understandable language; and in the case of the NDHM, it also presupposes that an individual has easy access to a screen and internet. Considering that the NDHM will be catering to individuals of varying educational backgrounds, the requirements of free, informed, and explicit consent are unlikely to be fulfilled if the process of securing consent is standardized and highly technical.⁵⁴ Consent fatigue as a result of repeatedly encountering complex documents is

an additional well-documented challenge and, in the case of NDHM, could impede comprehensive protection of personal data by leading to automatic consent decisions.⁵⁵ Further, given the gaps in digital literacy, access to the internet, and access to smartphones, the process of obtaining informed consent for many is likely to take place in the presence of medical staff, which does not address the coercive conditions around which consent is typically sought in India. When the alternative to refusing consent to share information is the possibility of being refused medical care or the settlement of claims, informed consent becomes a mere formality.⁵⁶

Should health data be treated as a public good?

The National Health Registries characterize the idea of data as a public good. At least some kinds of data are considered public goods if they have two essential characteristics—they are non-rivalrous (not a limited resource) and non-excludable (accessible by all).⁵⁷ In the context of health, anonymized disaggregated data collected by the government can have these qualities, although personal data that are de-anonymized are not completely non-excludable.

The *Economic Survey of 2018* released by the Ministry of Finance makes a case for treating data as a public good on account of the difference between the marginal costs of data compared to the benefit they yield.⁵⁸ It argues that since the private sector might be hesitant to invest in building data in sectors such as health care due to limited returns, government intervention is required to ensure that an optimum amount of long-term data of a critical mass of persons and firms is harvested and integrated with other databases. In essence, health data gathered in the social interest are claimed to be by the people, of the people, and for the people.⁵⁹ Further, the survey states that data as a public good can be monetized and used by private actors to generate profit, claiming that there is "no reason to preclude commercial use of [these] data." It emphasizes that datasets may be sold to the corporate sector, which can generate insights, tap into markets, develop new products, while also ensuring data privacy and confidentiality.⁶⁰

Under the NDHM, many private enterprises offering services across the digital health ecosystem are likely have access to vast quantities of disaggregated and anonymized patient data through the apps built atop the National Health Stack, and the range of opportunities that such data present to these entities and other private medical and tech firms are yet unknown. Though the NDHM contemplates sharing only nonpersonal health data that are anonymized for the purpose of health data analytics, anonymization is not considered to be sufficiently privacy protective given that re-identification is not impossible or particularly complicated, especially when combined with other datasets.⁶¹ The absence of fool-proof anonymization only reiterates the need for other regulatory frameworks where informed consent is not sufficient to protect personal information. Therefore, handling and making available large amounts of sensitive data requires data management practices that are ethical and equitable, as well as strict accountability under data protection laws, which does not yet exist in India.⁶²

Although the latest draft of the Data Protection Bill of 2021, which is likely to be passed into law, now covers nonpersonal data that will also come under the remit of the proposed Data Protection Authority, an earlier report of the Committee of Experts on Non-Personal Data Governance Framework provides a window into the discomfort and concerns around treating health data as a public good. The report identified anonymized health data as public nonpersonal data that have the characteristics of a natural resource and proposed a Non-Personal Data Authority whose primary goal would be to unlock the value in nonpersonal data for the economy. While it stated that consent for the collection of personal data would not automatically imply consent to anonymize, it contemplated consent as being provided only once, both for anonymization and subsequent use.⁶³

An additional level of analysis leads us to the technologies and infrastructures that enable the collection of health data.⁶⁴ For example, the government announced that the CoWIN platform is a global public good and has made it available to

countries around the world to build on and use for vaccine distribution and management. If a digital technology is a public good, are all data collected and processed through it a public good? As a shared digital infrastructure across different actors, the NDHM too has been described as a digital public good, and, taken together with the *Economic Survey's* description of how data as a public good can be leveraged, individuals are likely to have little factual control over their anonymized personal and health information in the absence of any binding regulatory statute or institution.

Digitalization of health in India and implications for the right to health

Under international human rights law, the right to health is indispensable and every person is entitled to the enjoyment of the highest attainable standard of health, guaranteed by article 12 of the International Covenant on Economic, Social and Cultural Rights. General Comment 14 of the Committee on Economic, Social and Cultural Rights identifies two aspects of the right of health—freedom and entitlements—and notes that entitlements include the “right to a system of health protection which provides equality of opportunity for people to enjoy the highest attainable level of health.” Securing the right to health requires ensuring the basic social and economic determinants of health, such as access to a clean environment, housing, nutrition, and sanitation, as well as the provision of health care facilities.⁶⁵

Human rights law does not mandate that all health care be public but requires the presence of four key elements in the provision of public and private health care services and facilities: availability, accessibility, acceptability, and quality.⁶⁶ Availability refers to a functioning public health system available in sufficient quantity, including hospitals, clinics, trained professionals, competitive salaries, and other infrastructure. Accessibility covers physical accessibility, including for the most vulnerable groups such as children, persons with disabilities, elderly persons, economic migrants, and Indigenous communities. It must be affordable

and available to all irrespective of their identities. Acceptability and quality ensure that health facilities are scientifically, culturally, and medically appropriate. Significantly, while states have an obligation to achieve the progressive realization of the right to health, they must take steps that are concrete, deliberate, and targeted toward full realization in the interim.⁶⁷

The NDHM, however, diverts attention and resources away from making available affordable health facilities and services to strengthening the delivery of private health care, despite the fact that during the pandemic many private hospitals were unable to manage the caseload, charged exorbitant prices for beds and COVID-19 care, or refused to take in patients. Public hospitals undertook the burden of addressing the vast majority of health care needs even as the state stepped in to set caps on private hospital charges.⁶⁸ While noting the benefits and advantages of digital health interventions in health care management, the World Health Organization's recent guidance on the rights-based and ethical use of digital technologies also cautions that digital interventions developed for systems with underlying flaws or inadequacies can replicate inefficiencies and exacerbate inequity.⁶⁹ Therefore, the implications of technological solutionism for securing the right to health and the steady erosion of state investment in health infrastructure and health care delivery as a public service are urgent. Even as surveillance and data protection become externalities that can be addressed via a solutionist approach, the impact of rapid digitalization on the right to health will persist.

On the other hand are serious concerns of exclusion on account of varying rates of digital access and literacy for many anticipated users of the NDHM, including patients and health care providers.⁷⁰ Access to a smartphone or computer and the internet are necessary preconditions for managing patient records and for accessing other tools that are expected to be integrated with the NDHM, such as e-Sanjeevani, the telemedicine platform that has been proposed as a key innovation to connect rural areas with quality health care providers. While India is one of the fastest-growing digital markets in

the world, it has far from the kind of universal access to the internet required for the NDHM. Based on 2017–2018 national data, internet penetration in India stands at 42% in urban areas and only 15% in rural areas, while more recent data peg average internet penetration at around 43% of the total population. Only 4.4% of households own a computer in rural areas, compared to 23.4% in urban areas; and average digital literacy is around 38%, with a wide split between urban and rural areas.⁷¹ Given this backdrop, it is unclear how telemedicine, rather than brick-and-mortar hospitals, will address the problem of access to health care in the remotest parts of India and in conflict areas such as Kashmir, where internet shutdowns are routine.⁷²

Considering the significant impact of digital inclusion on access to digital health interventions, digital access is rightly being recognized as an emerging social determinant of health.⁷³ In the context of the NDHM, the role of digital access and literacy as a social determinant of health in facilitating or impeding informed consent is likely to be especially crucial. Informed consent is a key ethical principle both in health care delivery and in the use of personal information. However, for a project as ambitious and large scale as the NDHM, it could well be a nominal or formalistic protection against the unauthorized use of personal health information and the inferences derived from it for which consent has been obtained. As discussed above, this could have significant implications for access to health coverage.⁷⁴ A rights-based approach to informed consent would necessarily require taking into account structural inequalities such as economic status, digital access, and relationships with health care providers to truly allow for individuals to make considered decisions on the use of their personal data.⁷⁵ Therefore, in addition to its centrality to the right to privacy and autonomy in relation to personal data, in the context of the NDHM, informed consent could be key to realizing the right to health.

Conclusion

The COVID-19 crisis and the extraordinary focus

on digital solutions for a public health problem in India betrays a tendency to “manage social problems as they bubble up into crises rather than intervening in their causes.”⁷⁶ The Indian government has repeatedly pushed the use of digital tools to drive the economy, plug leakages, and increase the ease of doing business—all untested claims in the context of public health governance—even in the absence of state capacity for dealing with and responding to the consequences of rapid digitalization.

The two technologies surveyed in this paper have functioned as embellishments over a weak public health system, and they illustrate the conception of health data as a public good rather than health care as a public good. Public health in India is no doubt a complex space, intensified by a range of documentary-, institutional-, insurance-, and physician-related challenges, and it will be near impossible to provide sufficient state-funded health care at this stage. However, by prioritizing digitalization despite the experience of the second wave of the pandemic, the central government is placing the proverbial cart before the horse. Of the many objectives behind introducing digital tools in public health, universal health coverage and access to health care are key. If the NDHM cannot fulfill this objective, it will once again reveal the limitations of resorting to digital technology as a solution to a crisis with deeper roots at the expense of the people’s right to health.

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Developing Data Governance Agreements with Indigenous Communities in Canada: Toward Equitable Tuberculosis Programming, Research, and Reconciliation

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Abstract

Indigenous rights to self-determination and data sovereignty support Indigenous-led data governance, which, when adequately resourced, can act as a catalyst for Indigenous-led strategic planning and decision-making in public health research and programming. Respecting Indigenous data sovereignty and governance requires time, resources, education, and planning. Here we share our experiences and lessons learned when developing and implementing data governance agreements with select First Nations and Métis partnering communities in Canada in the context of tuberculosis prevention and care. We define the process undertaken to create a decision space, supported by data governance agreements, where researchers, program (government) stakeholders, and Indigenous community partners are equally and equitably informed to co-develop public health interventions. The decision space has implications for tackling all manner of public health concerns and can inform policy for nation-to-nation public health relationships to advance public health goals.

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Competing interests: None declared.

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Introduction

Indigenous rights to self-determination and data sovereignty support Indigenous-led data governance, which, when adequately resourced, can act as a catalyst for Indigenous-led strategic planning and decision-making in public health research and programming. For Indigenous peoples, self-determination is central to reversing the impact of colonialism, an Indigenous-specific social inequity impeding the right to health. In the Canadian context, Indigenous refers to the first inhabitants of Canada—First Nations, Métis, and Inuit—each with their own distinct culture, history, language, and spiritual beliefs.¹ The calls to action in the Truth and Reconciliation Commission of Canada's (TRC) Report summarize steps toward reconciliation with Indigenous peoples in Canada.² The United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP), recently ratified by the government of Canada, alongside research guidelines (e.g., Tri-Council Policy Statement 2) and First Nations ethical principles (e.g., ownership, control, access, and possession, or OCAP[®]), further outline rights and corresponding duties for the conduct of equitable and beneficial research and health programming with and for Indigenous peoples in Canada.³ Together, these authoritative statements have prompted many universities and public institutions in Canada to work toward meaningful engagement with First Nations, Inuit, and Métis organizations and their respective communities. Key to these engagement and equitable relationships is the recognition, by universities and public institutions, of Indigenous data sovereignty and the Indigenous right to self-determination.

Indigenous sovereignty in Canada, albeit affirmed in the Indian Act, has been a long-standing area of neglect among government officials and other decision-makers.⁴ The Canadian government plays a paternalistic role in the health and welfare of Indigenous peoples, with jurisdictional disputes revealing reluctant responsibility (e.g., Jordan's Principle).⁵ Acts to defend sovereignty, particularly land-based sovereignty, such as Oka in 1998 and more recently in Fairy Creek, highlight disconnects

between those maintaining a colonial agenda and those who continue to experience ongoing colonization.⁶ Indigenous sovereignty broadly refers to the right to self-governance. Self-governance requires full and unfettered access to information relating to the state of one's affairs. In Canada, health data are collected and disseminated according to relevant federal, provincial, and territorial legislation and policies. As with other areas of Indigenous sovereignty, these policies and laws do not always include Indigenous communities as equal partners in the process. As a result, Indigenous communities have limited input on how health data about their respective communities are collected and shared. The effect of these approaches is to reduce the ability of Indigenous communities to make informed and evidence-based decisions, thereby infringing on their rights. With respect to communicable diseases such as tuberculosis (TB), a community's lack of access to health information is indirectly affects access to care.

Data sovereignty as a component of Indigenous sovereignty is not limited to data held by governments; it encompasses all Indigenous knowledges, whether health related or cultural. These may include history, stories, art, health knowledge, science, and practices. Indigenous knowledges and data are the subject of much interest within the research community and consequently form the basis of a number of studies. However, Indigenous knowledges and data, when taken out of context, can be abused, appropriated, and exploited in ways that fail to benefit Indigenous communities, most of whom continue to experience significant health inequities when compared to non-Indigenous people. As recently as 2004, the Havasupai Tribe filed a lawsuit against Arizona State University for allowing a researcher to use blood samples drawn from community members to describe genetic factors pertaining to diabetes. These samples were later used to study many other health-related issues without the donors' consent.⁷

Indigenous data sovereignty and governance are essential rights protected by articles 18 and 23 of the UNDRIP.⁸ In most of Canada, however, public

health research and programming are resourced and controlled primarily by non-Indigenous researchers and government agencies, even when Indigenous peoples are the subjects of those activities. As a result, Indigenous communities are often required to negotiate with researchers and government agencies to gain access to the resultant data or the resources necessary to collect or access their own data.⁹ Data governance agreements (DGAs), as legally binding documents, provide a mechanism to support community interests. Well-designed DGAs support equitable relationships by increasing both transparency and accountability toward Indigenous partners. In this way, a well-designed DGA can contribute to shifting the inherent imbalances of power that typically characterize the relationship between researchers and researched, or government agency and community. DGAs should therefore outline the purpose, roles, available resources, and time frames for interaction and accordingly demonstrate commitment by partners to the agreement. They may also include stipulations on the ownership, analysis, and interpretation of data, including the appropriate communication of findings. These stipulations should maximize beneficial community returns and lead to relevant and meaningful conclusions.

The Pathways TB Project

The Canadian Institutes of Health Research's signature initiative, the Pathways to Health Equity for Aboriginal Peoples, funds projects aimed at addressing four priority areas: mental wellness; diabetes and obesity; oral health; and TB.¹⁰ The Pathways TB Project is one such funded project. This project partners with Indigenous community co-investigators who work together to develop interventions to close gaps in local TB surveillance and improve the provision of public health outreach.¹¹ It also brings together practitioners and government agencies to meet and respond to community-identified priorities. In this now well-established network, where all input is considered to be equally significant, Indigenous community partners have direct in-

put into the provision of TB prevention and care services adapted to their own realities. Progress toward more equitable and respectful public health surveillance relationships is modeled in Figure 1.¹²

Early on, community partners identified a lack of TB surveillance data describing their local TB epidemic. Government and programmatic stakeholders passively gather TB surveillance data, which is then stored in difficult-to-access forms for under-resourced communities (Figure 1A). At the behest of community partners, the Pathways team began repatriating TB surveillance data to communities (Figure 1B). Informed by the TB surveillance data, communities were able to contextualize local TB epidemics and define additional surveillance or action. As this environment of data flow and response developed, Pathways and community partners formalized the process through DGAs thereby creating a model for future government/programmatic stakeholder-community relations regarding public health data where an intermediary like Pathways would not be necessary (Figure 1C).

TB persists in many middle and far northern Indigenous communities across Canada.¹³ In general, the persistence of TB is multifactorial and includes geographic challenges, systemic neglect, ignorance, imposition of multiple forms of exclusion, and segregation.¹⁴ In Canada, the high burden of disease in Indigenous populations, relative to that in the non-Indigenous population, is long-standing (49-fold higher rates in Indigenous versus non-Indigenous Canadians in 2017), and to date, solutions identified or implemented by researchers and programmers have failed to advance the TB elimination agenda.¹⁵ To achieve TB elimination among Indigenous peoples in Canada—a target that is well within sight for non-Indigenous peoples—a new way forward, with solutions identified and implemented by and with First Nations, Inuit, and Métis communities, is required.¹⁶ TB is a notifiable disease of public health concern, meaning that public health TB surveillance data is collected at the provincial and national levels.¹⁷ These data, although public, are reported in aggregate and generally do not recognize the principles of Indigenous

data sovereignty (e.g., ownership, control, access, and possession), limiting their utility to individual Indigenous communities.

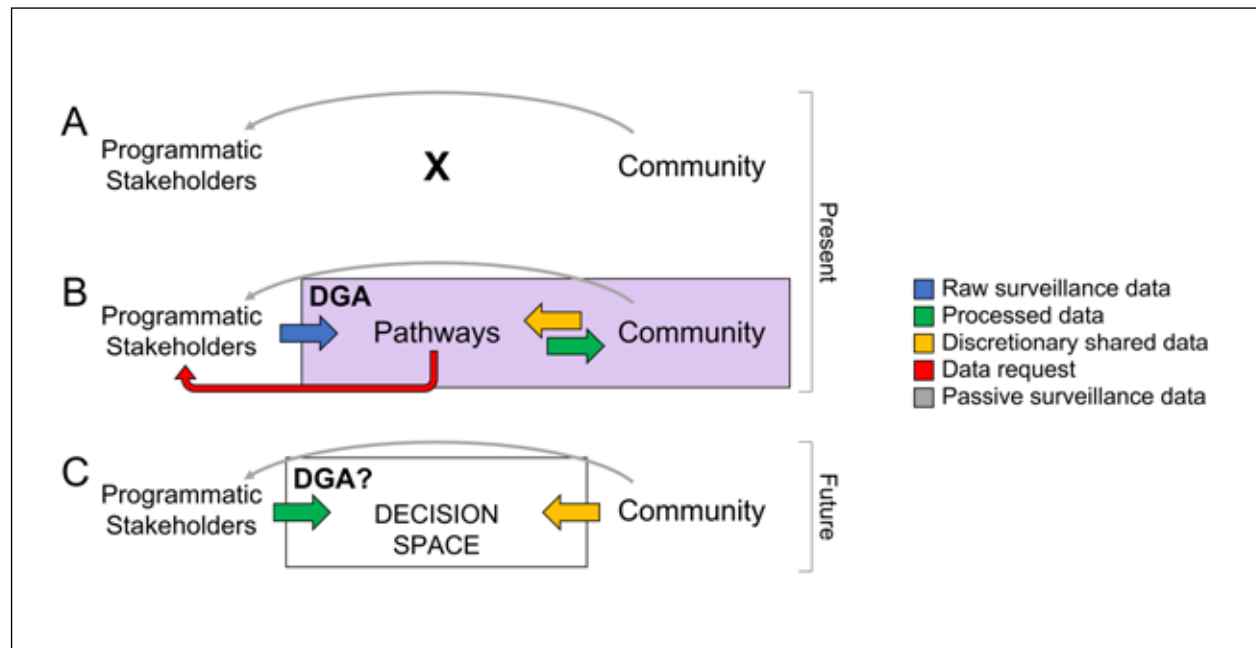
The Pathways TB Project was designed to show that a community-centered, multijurisdictional collaboration is entirely possible and that this approach can help reduce regional TB incidence. It is expected that collaboration will lead to greater awareness, community-initiated and -led programs, and improved health outcomes for Indigenous peoples in the participating region.

The Indigenous communities and regional partners of the Pathways TB Project are in Treaty 8 territory across Alberta and Saskatchewan, two of the three prairie provinces of Canada. They include four communities: two First Nations, one small northern city, and a northern village inhabited predominantly by Métis people. The four communities are connected through culture, kinship, commerce, and employment. The continuity of TB patient care

and any public health issue can be interrupted by extensive travel between communities and across multiple health jurisdictions. As colonial by-products, jurisdictional silos confound TB prevention and care programs wherever they overlap.

The Pathways TB Project comprises three sequential components spanning a teambuilding phase, an implementation science component, and a scale-up or ripple-out component.¹⁸ Initially, a set of shared values was developed in Component I to guide the partnership, focusing on trust building to foster strong relationships. A community co-investigator was recruited from each community. Component II identified specific interventions of the communities' choosing and laid the groundwork for their implementation, which, in turn, revealed the need to develop a formal DGA. Finally, Component III, which is currently underway, sees expansion of the program to other regions among culturally distinct Indigenous groups, beyond Tre-

FIGURE 1. Models of TB surveillance relationships



Part A—community interactions with health services—results in the passive collection of public health data with no specific data returned to the community. Part B—the Pathways project—acts as an intermediary between programmatic stakeholders and the community. Pathways requests (red) data from programmatic stakeholders and then processes it and repatriates (green) it to the community, who determines action, narrative, and potential additional data to generate (yellow). Data created as a response to processed data is shared at the discretion of the community. The relationship between Pathways and communities is framed by DGAs (lavender). Part C—acknowledgement by programmatic stakeholders of community self-determination, autonomy, and public health competency—would ideally lead to policy changes where TB surveillance data automatically flow bidirectionally and both partners make decisions in a decision space where intermediaries such as Pathways are no longer necessary. The decision space may or may not use DGAs.

ty 8 territory. This component will demonstrate the generalizability, feasibility, and portability of the Pathways concept.

Process of data governance agreement development

Phase 1: Introduction to data governance agreements

The Pathways TB Project developed a network of community co-investigators, academics, TB program nurses and physicians, medical officers, policymakers, and Indigenous research centers who shared the common goal of advancing TB elimination. Well Living House, an Indigenous-led action research center and Pathways affiliate, helped the network initiate research agreements with Indigenous community partners through presentations and the provision of templates and background materials. Discussion within the network began with a presentation on research, publication, and DGAs by Well Living House at an annual meeting of the Pathways TB Project in year one of Component II. These meetings include participation from all members and had been underway prior to the discussion of agreements. The purpose of the presentation was to highlight current wise practices in Indigenous health data governance and management, affirming the need to actively involve Indigenous governing agencies or organizations in the management and governance of their health data through collaborative research agreements. The nominated principal investigator from the University of Alberta proposed the following as a starting point for discussion:

The purpose of our eventual agreement will be to ensure that the project is respectful to the cultures, language, knowledge, values, and rights to self-determination for the peoples in [the four groups identified]. This agreement also provides a framework for the use of data collected during the Research Project. This agreement supports principles of Indigenous collective and self-determined data management and governance. These are not financial agreements. The agreement supports the information needs of the community partners, as well as acknowledging the desire

of Dr. Richard Long and his research team to conduct this collaborative research. It defines the opportunity(ies) to develop research questions and responses alongside our community partners. Our community partners should anticipate this research project will assist in programming, service delivery, policy making, planning, and evaluation.

The above text was derived from conventional research agreements. It was concluded that a more broad definition of data was needed. The community co-investigators were requesting access to public health data—a task that Pathways could facilitate. Research data, if co-generated by the project and the community, would indeed be covered by the DGA; however, it was the flow of public health data that precipitated the DGA.

A number of different principles were proposed and discussed. These included maintaining mutual respect and accountability between the parties; recognizing the complementary and distinct expertise, responsibilities, mandates, and accountability structures of each party; ensuring the highest standards of research ethics, including the acknowledgement of community-partner-specific principles of self-determined data management; respecting the individual and collective privacy rights of community-partner personnel; recognizing the value and potential of research that is scientifically and culturally validated and programmatic data sharing that is mutually beneficial; data storage and stewardship; potential publications; disagreement resolution; who would be tasked with enforcing the agreement; and recognizing the value of supporting community-partner processes, including the analysis and dissemination of results and timing of any research activities.

Phase 2: Drafting the data governance agreements

Several months later, the Pathways team reviewed the template agreements that had been provided by Well Living House and worked with the Indigenous community partners to prepare a draft DGA. This draft addressed roles, responsibilities, data-sharing protocols, funding transparency,

the publication process, and intellectual property. Community partners raised the issues of storage and stewardship of data, information technology limitations, privacy, and human resource gaps within the community (e.g., students, volunteers, etc.) as significant concerns; these considerations were included. Agreements were developed to explicitly address community priorities, as well as community co-ownership of program surveillance data and co-authorship of research publications.

DGAs are legal agreements that identify the parties and outline how the data are collected and used, with the intention of shifting the balance of power back to community signatories. These agreements were central to achieving the goals of sustainability and scalability identified in Components I and II. Discussions with the home institution from which Pathways originated—in this case, the University of Alberta—regarding the nature of the agreements was also critical given the legal implications engendered by these agreements. The principles of UNDRIP and First Nations OCAP[®] were used to underpin the legal proceedings.

Phase 3: Definition of data

Community partners worked together to identify and define the data of interest at the local level. Co-investigators highlighted the need for routine access to relevant TB surveillance data that could be used to develop community-defined strategies to achieve elimination.

Public TB surveillance data are collected and held by provincial health authorities, but aggregation dilutes the relevance of these data to TB-affected communities. They are not research data per se but data that were requested as an “intervention” within the context of a research project. In response to this community-identified need, the Pathways team repatriated these surveillance data to the community and provided support by way of presentation, dissemination, and interpretation. Implicit in the entire exercise was the intention that routinely collected surveillance data (from high-incidence communities) could, in the future, be repatriated in such a manner, perhaps as policy,

beyond the life of the Pathways TB Project, and with an agreement to respond to the data collaboratively.

These repatriated TB surveillance data further equip the community to ask their own questions and identify gaps in understanding and managing local epidemics. These questions could then develop, or not, into data-generating initiatives, with the Pathways team acting as facilitator. For example, some TB surveillance data not collected by the province but which community partners considered relevant include the experience and effects of trauma and grief; addictions and mental health; maternal and child health; available health services and programs and their perceived usefulness; and community-based strengths and resources. In the event that data are collected on any of these factors, they could, in turn, be shared with the Pathways network to the extent that members therein are well positioned to enhance and improve TB prevention and care services in response to this new knowledge. This final step—the sharing of community-collected data—is at the discretion of the community and defined as such in the DGA.

Phase 4: Site visits

Over the next several months, numerous site visits and teleconferences were undertaken with partner communities. Additional community data collection was identified in relation to kinship, cultural healing, and well-being to complement the TB surveillance data. These valuable considerations were realized following careful thought and rumination by community partners and would have been missed had the process been hastily undertaken.

It was proposed that discrete DGAs be established with each community to fit their unique needs. All four communities performed their own negotiation. It was established from the outset, at all-participant meetings, that all negotiations and drafts would be shared across the network to foster increased discussion and cross-learning. The research team had little experience initiating DGAs. Moreover, community research partners differed in negotiation experience with respect to DGAs. Openly discussing strengths and challenges point-

ed both directly to solutions and to the need to look outside the network for additional support. As an example of this, the First Nation partner community in Alberta requested support from the Alberta First Nations Information Governance Centre (AFNIGC), the regional satellite center of the National FNIGC, which then provided basic training and advice on the process.

Indigenous governance organizations such as the AFNIGC offer support to communities and should be considered essential brokers in fair negotiations. First Nations and Métis are distinct and consist of many nations and regions, each of which may or may not have organizations that can be invited to perform this role. Indigenous governance organizations are found around the world in support of distinct communities (see Table 1 and Box 1).

Phase 5: Meeting with the AFNIGC

A teleconference was held with all community partners, the Pathways team, Well Living House, and the AFNIGC (see Box 1) to decide the role of

each in the DGA development process.

Some of the research team and community research partners noted their unfamiliarity with OCAP® principles; as a result, it was agreed that investing in the training available through the AFNIGC would provide value to the ongoing negotiations. The AFNIGC thus provided a training session on ethical space and OCAP®. The fees for training were waived as an in-kind contribution by the AFNIGC to the researchers and Indigenous partners.

Following the training sessions, community co-investigators once again reflected on the type of research they would like to see conducted at the community level, as well as how any resultant data might be stewarded and stored. An adapted framework with key elements of the agreements was established with each community research partner and included the following: a definition of the parties; establishment of each party’s authority to share and receive the data; provisions regulating the use and restrictions of data disclosure; security and privacy requirements; policies and procedures and

TABLE 1. Examples of Indigenous governance organizations¹⁹

Organization	Country
Alberta First Nations Information Governance Centre	Canada
Centre for First Nations Governance	Canada
First Nations Information Governance Centre (National)	Canada
Institute on Governance	Canada
Inuit Tapiriit Kanatami	Canada
Well Living House	Canada
Te Mana Raraunga – Māori Data Sovereignty Network	New Zealand
National Congress of American Indians	USA
Native Governance Center	USA

This list is not exhaustive.

Box 1. The Alberta First Nations Information Governance Centre

AFNIGC has been working with First Nation communities across Alberta to develop a First Nations health governance agreement and registry system. As part of this initiative, it has been providing training to First Nations communities on data stewardship, privacy laws, privacy policies and protocols, data analysis, and statistical software so that they can tell their own stories and develop health indicators rooted in their own traditional world views. During DGA development, AFNIGC shared its experience and provided recommendations regarding data collection tools and the importance of incorporating Indigenous language. It also shared information on available training through its organization that Pathways members could access, including ethical space, parallel world view, and OCAP®.

oversight committee; a determination of whether data are project or program specific; provisions for the publication of results; and provisions on how a party can terminate the agreement and how data will be destroyed or archived. The new agreements incorporated the AFNIGC framework and the principles of ownership, control, access, and possession relevant to each community. AFNIGC provided additional core support to the negotiations to the First Nation in Alberta.

Phase 6: Data governance agreement negotiations

Nearly 18 months after initial the discussions of DGAs, negotiations began between the Pathways TB Team, the Board of Governors of the University of Alberta, and the AFNIGC. Concerns were raised by the university regarding publication rights given the equal authority provided to community co-investigators. While, initially, the terms put forth by each side were non-negotiable, the university eventually acquiesced to the DGAs co-developed by the Pathways team and community partners, and met its stated commitments to the TRC's calls to action and related obligations to Indigenous partners. By so doing, a legal precedent was established by the team in which Indigenous partners were made equal participants in the full scope of the research project and co-authors on relevant outputs. The most significant takeaway from these negotiations was that in the face of opposition to this kind of relationship or agreement, there is a moral imperative to insist on the protection of the rights of Indigenous community partners, or else be complicit in the colonial agenda that has historically propped up institutions of exclusion—an antithetical proposition to reconciliation within the academe. This imperative has been affirmed and reaffirmed in UNDRIP, the TRC's calls to action, and other rights-based documents.

One First Nations partner community was simultaneously negotiating three or four additional research agreements independent of Pathways. This community actively used what was learned in those negotiations when approaching the Path-

ways agreement. This active iteration increased the period necessary for negotiation but also both the confidence the community had with the final Pathways agreement and the quality of the document.

Finally, the two provincial communities (the northern city and the northern village) opted to pursue less formal DGAs. Each of these communities had multiple governing bodies and research interests, and they did not want to create the perception that one would have power or be prioritized over the others. Moreover, in both of these communities, the primary source of data for the surveillance component of our work is provincial governments—in other words, both communities reside within the jurisdictions of regional health authorities governed by provincial legislation and mandates for the provision of services. As a result, a formal DGA in these contexts would have been between the province and itself, with the university acting as shepherd through the bureaucracy. Letters of acknowledgement (LOAs) for the receipt and responsible use of data were agreed on by these parties instead.

Outcome

Discussions related to the development of DGAs began in May 2017, and negotiations were complete by 2019. Two DGAs were negotiated and signed with two First Nations, one in Alberta and one in Saskatchewan. LOAs for the receipt of data were signed by appropriate signatories (research partners and knowledge users) in the city and northern village (Métis).

Since signing the DGAs, the Pathways team has presented surveillance data to the communities on several occasions. The community has convened committees to respond to the data and pitch ideas for additional surveillance and action.

Discussion

In the creation of DGAs or LOAs with the four partnering communities, we set the stage for a decision space where stakeholders in health come together, equally informed, to devise interventions

and action against TB (part C of Figure 1). This was possible because Pathways recognizes the sovereignty of Indigenous peoples and communities, respecting their right to self-determination in the development of partnerships. The decision space described here builds on the ethical space of engagement described by Willie Ermine.²⁰ Indeed, Indigenous self-determination vis-à-vis public health will require the sharing and processing of surveillance data and respect for community decisions that result from their interpretation. The creation of decision-making spaces for other public health concerns may not require the explicit development of DGAs; however, the exercise undertaken with Pathways demonstrates the time and care required for all parties.

An ethical decision space framework can be applied to all public health concerns, as it reflects the spirit of nation-to-nation relationships inherent to questions of sovereignty and self-determination. A commitment to equitability and respect for others' right to autonomy leads to better outcomes and greater efficiency. In the Canadian context, many well-intentioned public health programs aimed at tackling addiction, mental health, and communicable infectious diseases are created without the consideration of local priorities of Indigenous communities and, as a result, are not as effective or outright fail.²¹

Several lessons were learned during the DGA process (Table 2). All members of the Pathways research team required training and education on Indigenous data sovereignty. Each communi-

ty research partner came with a different level of experience, and some required additional support and resources to enter these negotiations. Additional funding support may be required to supply both research teams and partners with training.²² Fully informed negotiating parties can contribute to addressing power imbalances and lead to more equitable arrangements.

The work and agreements were between researchers representing a Canadian institution—the University of Alberta—and First Nations and Métis communities. Some of the process and developmental details reported herein may be specific to Canada, but colonized and post-colonized Indigenous peoples are found throughout the world. As a result, the act of DGAs is sound policy for respecting Indigenous rights to self-determination and data sovereignty worldwide.

The University of Alberta has only recently begun to implement the recommendations made by the TRC's calls to action, hiring an Indigenous vice provost to develop and implement an Indigenous strategic initiative in 2019. As a result, establishing legally binding agreements with explicit intentions to share power and research (via co-authorship) with Indigenous communities was still relatively novel at the administration level. These novel asks posed a challenge with respect to the timeliness of negotiation and required some capacity-building to reach consensus on the requirements of UNDRIP, OCAP®, and the TRC. For instance, the contract office lacked a basic template and was mostly hands-off during the initial development

TABLE 2. Lessons learned developing data governance agreements

Research teams may require additional education and training on Indigenous sovereignty and data governance.
Indigenous community research partners may require additional supports to enter into negotiations for data governance agreements; a different level of experience can be expected.
Research sponsors or institutions should provide support or funding for research teams and Indigenous communities in the negotiation of data governance agreements.
Establishing data agreements with Indigenous communities under provincial jurisdiction can be challenging, specifically in terms of identifying a signatory or steward for the agreement.
Institutions and researchers may require information and additional training regarding OCAP®, UNDRIP, and the TRC.
For parties to undergo equitable discussion, time must be spent building trust. Community engagement and feedback will usher projects into unexpected, richer, and higher-impact directions.

of the agreements. These gaps in knowledge reflect similarities with past research that identified the need for practical instructions for financial administrators and researchers to better understand how to implement the Tri-Council Policy Statement 2 guidelines to improve the research interface with Indigenous communities.²³ It is recommended that universities proactively address these gaps in knowledge through capacity-building and training of their staff and faculty and that researchers engage their institutions well in advance of agreement negotiations.

Establishing DGAs with non-First Nations Indigenous communities can be challenging, specifically in terms of identifying an agreed-upon, responsible, and interested signatory or steward for the agreement. In our project, non-First Nations communities were not able to identify a preferred signatory or steward and so, by consensus, opted for an LOA. An LOA does not provide the same legal supports as a DGA and, as a result, may not achieve the same goals (e.g., shifting power dynamics and reciprocity between researchers and community). An LOA is not an agreement between an academic research team and an Indigenous community; it simply provides unidirectional data accountability. However, given the underlying statement of values, co-generated by all signatories in the early stages of Component I, we do not believe this will negatively affect a mutually beneficial relationship. Furthermore, the shifting of power dynamics and encouragement of reciprocity between researchers and community should be prioritized when working in partnership with Indigenous communities, regardless of intention or presence of a DGA or LOA.

Indigenous peoples have been, at times, “re-searched to death.”²⁴ A long history of disclosure abuse, privacy violations, misinterpretations, and misappropriation exists.²⁵ Conversely, data collected by government bodies may be locked away, becoming inaccessible or uninterpretable. These fears also fuel worries about deductive disclosure since communities are small.²⁶ Working together with communities to develop DGAs that describe expectations, timelines, and outcomes is an important step in addressing the aforementioned pitfalls.

Forming equitable partnerships and then negotiating formal DGAs relates to five important Indigenous data sovereignty considerations. First, the right questions are asked. Phenomena seen from outside communities may appear and feel very different to those with lived experience. The group knowledge and history of a problem will generate hypotheses and actions unavailable to an outsider.²⁷ Additionally, Indigenous groups are best equipped to define their membership.²⁸ Jurisdictional division and technical definitions of group membership are often the result of colonial rulings and, at times, fail to reflect real communities.

Second, privacy is respected. The community is the only party fit to interpret and disclose sensitive descriptive data about themselves. There are currently no laws in Canada recognizing community rights to self-descriptive data.²⁹ Outside parties disclose data for singular goals; these goals may be well intentioned, but they are seldom permanent. The community must, then, “live” with disclosure decisions. The continuity of the community will vastly outrun the continuity of research teams. The community participating in collecting their own data are not impeded by deductive disclosure, though moratoria may be put in place to protect individuals.

Third, agreements ensure that data are converted to knowledge, ensuring their social value to Indigenous communities. Data exist that are unavailable to decision-makers in Indigenous communities because of barriers to access and interpretation. Data are often exported without a return of knowledge. Data analysis requires resources that are, at times, lacking in Indigenous communities.³⁰ Further, data generation and analysis without community input should be deemed meaningless, potentially harmful, and likely to contribute to research hesitancy.³¹ Agreements should include stipulations on reporting actionable information.

Fourth, communities retain the publishing rights of data. Including Indigenous partners in writing and publishing efforts ensures open dialogue and prevents the reckless sensationalizing of negative aspects of study results. Community

publishing rights ensure that the role of ongoing colonialization is squarely considered in the Indigenous experience.

Fifth, data are described as the sovereign property of the community. Harvesting and publishing data without community consent is theft.

Throughout the process of negotiating these DGAs, we have learned that it is critical to be flexible, to respond to context and the priorities and needs of community members, and to remember that their input guides the process (Figure 2). It requires conviction to create policy changes in institutions. The case we have outlined herein took time, but the process is key to fair dealings in research and reconciliation. Our own DGA is available upon request to the corresponding author as an example of the process described throughout this paper and as a potential template for other researchers and community teams.

Acknowledgments

We are grateful to all the members of the Pathways coalition, especially the community co-investiga-

tors, for their contributions to the success of this project. We also thank the Canadian Institutes of Health Research, Alberta Innovates, Saskatchewan Health Research Foundation, and Indigenous Services Canada Alberta and Saskatchewan Regions for their generous financial support.

Funding

Funding for this study was provided by the Canadian Institutes of Health Research, Saskatchewan Health Research Foundation, and Alberta Innovates.

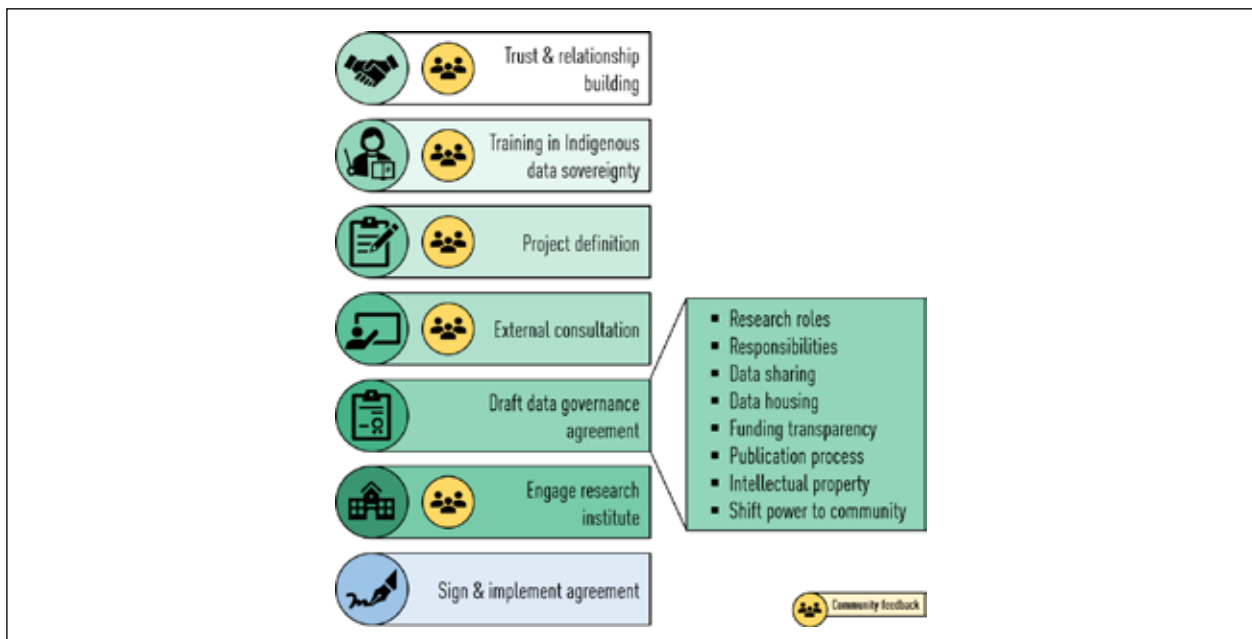
Ethics statement

This work did not involve human subjects or data.

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FIGURE 2. Process of developing data governance agreements



The development of data governance agreements proceeds through distinct stages. Community feedback and consultation (yellow) occurs throughout the process.

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(Re)Claiming Health: The Human Rights of Young LGBTIQ+ Indigenous People in Australia

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Abstract

The human rights of both LGBTIQ+ and Indigenous peoples are far from realized. When conjoined, intersecting identities reveal how racism and queer phobia affect well-being, negating the right to health and resulting in devastating impacts on people's social, cultural, and emotional well-being. This paper documents the lived experiences of a sample of young gender- and sexuality-diverse Aboriginal and Torres Strait Islander peoples from a research project conducted in New South Wales, Australia. Their perspectives reveal how, for this cohort, discrimination and privation is manifest at the family, community, and institutional levels. This paper informs an understanding of human rights as experienced by Aboriginal and Torres Strait Islander LGBTIQ+-identified peoples, where racism and queer phobia are evident in the spheres of education, employment, and service provision. Adopting a critical human rights stance, our analysis illustrates how settler colonialism manifests through the processes and outcomes of settler colonial institutions and structures.

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Competing interests: None declared.

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“These are structural colonial problems that aren’t gonna be fixed by services.”

—survey participant

Introduction

The human rights of First Nations peoples around the world have been eroded through settler colonialism. “Modern” formulations of human rights, with their legal dominance, fail to be attentive to settler colonial history and violations that occurred before human rights were formally deliberated.

Despite ongoing neglect within settler colonial societies, there have been attempts in Australia to restore rights to First Nations peoples. Current endeavors include programs to “close the gap.” This First Nations-led effort aims to pressure the Australian government to achieve health equity for First Nations peoples by 2030.¹ The gap is far from closed, as social and economic disparities between Indigenous and non-Indigenous populations deny Indigenous peoples their full humanity.

For people identifying as LGBTIQ+, rights denial has occurred through prohibition, criminalization, and queer phobia. Laws in Australia have gradually become inclusive of sexuality-diverse people.² The most recent transformation in the public domain was a majority “yes” vote on a survey on marriage equality and its subsequent introduction into Australian same-sex marriage legislation in 2017. Despite hard-fought gains, the experiences of young LGBTIQ+ people, including the Indigenous cohort in our study, reveal that further progress is warranted that does not rest solely on legislative change.

Growing scholarship on intersectionality supports this claim, evolving from the landmark work of Kimberly Crenshaw from the late 1980s.³ Although this is a broad concept yet to be influential in the field of human rights, particularly normative human rights, it offers insights when examining multiple axes of oppression that have their roots in historical subjugation stemming from settler colonialism that manifest in poor institutional practices outlined in this paper. For Collins, emergent and diverse intersectionality theorizing and

praxis can address social problems and the social changes required to solve them. Categories such as gender, sexuality, race, and age are not merely academic but constitute resistant knowledges for people who oppose the injustices that they have experienced.⁴ Unlike research that is frequently confined to two categories alone, our project explores three identities as they intersect—namely, Indigenous and LGBTIQ+ and young, as noted below.⁵ In doing so, we recognize that incorporating intersectionality into human rights frameworks has lagged, although some scholars see this as an area that requires attention so that issues of class, gender, and race are taken into account.⁶ Similarly, Johanna Bond argues for an expansive definition of human rights to encompass harm caused by multiple, intersecting forms of subordination.⁷

The paper is informed by young Aboriginal and Torres Strait Islander LGBTIQ+ peoples who spoke out about their experiences and aspirations in a project based in New South Wales, Australia. The project, entitled Dalarinji (the Gadigal word meaning “your story”), reveals the complex journey for participants in endeavors to surmount their “intersectional disadvantage,” providing leads for human rights-restoring measures. In order to center and privilege the voices of Aboriginal and Torres Strait Islander LGBTIQ+ youth, all components of the research process were co-designed and co-led by First Nations LGBTIQ+ people. Service proposals to be developed at the end of the research process will similarly be co-designed. These measures resist the dominance of settler colonial heteropatriarchal paradigms within human rights frameworks. In the well-being sphere, physical and mental well-being is dominated by psychological and medical frameworks that fail to achieve the full potential of young Indigenous LGBTIQ+ cohorts.⁸ There is a tendency to impose Western ideas of mental health that fail to recognize the legacy and endurance of settler colonialism.

As a backdrop to participant testimonies in the findings section, we begin with critical reference to normative human rights understandings, followed by a probing of the intersection between colonization and the right to health. As argued by Corrinne

Sullivan, the privileging of Indigenous LGBTIQ+ voices “is intended to un-silence and demarginalize our position as queer, Indigenous Australians and our voices are raised to bolster knowledges of our own sexual landscapes.”⁹

The terminology used reflects current norms and is used interchangeably according to the perspectives from which they are drawn. Terms include “Indigenous,” “First Nations,” and “Aboriginal and Torres Strait Islander” peoples, while recognizing that many Indigenous peoples and our participants use identifiers from their own nations. We also recognize that for international readers, terminology can have multiple meanings of inclusion and exclusion, and we emphasize that the terminology in this paper reflects the current Australian context. The term “LGBTIQ+” denotes lesbian, gay, bisexual, trans, intersex, queer or questioning, and other diverse identities.

Globally, scholarly research on the social and emotional well-being and mental health needs of Indigenous gender- and sexuality-diverse youth is limited, rendering this population an invisible minority within a minority group.¹⁰ Our scoping review found only one published report that included young First Nations LGBTIQ+ people in Australia.¹¹ This invisibility extends beyond academic research and literature. As our research reveals, absences are reflected in everyday community practices in institutional settings such as schools and places of employment. Such deficiencies contribute to a trajectory of mental health and well-being concerns that lead those experiencing multiple forms of discrimination to seek out professional services. When entering service structures, similar barriers are frequently encountered that limit the capacity for restorative health and well-being and reinforce biomedical and psychological Western constructs of “treatment.” For young people identifying as Indigenous and LGBTIQ+, their identities and experiences tend to be perceived as deficits by some service providers.

This paper focuses primarily on in-depth qualitative interviews drawn from a selection of 15 participants. Although the interviews produce information across a gamut of topics published

elsewhere, including family and community obstacles and strengths, the conceptual framework of our paper derives from a human rights lens by expounding the intersection between settler colonialism and the right to health and well-being, emphasizing institutional and structural barriers to the achievement of this right.¹² The implications of not addressing existing gaps are threefold: perpetuating absences in scholarly domains and communities of practice; minimizing voices and perpetuating service responses that fail to recognize the rights of this cohort; and limiting opportunities for restorative and equitable lived outcomes.

The Dalarinji project is funded by the Australian National Health and Medical Research Council, under its 2018 targeted call on Indigenous social and emotional well-being (grant ID 1157377).

Human rights and the right to health

Globally, the human rights of Indigenous peoples are advanced through Indigenous leadership and allied work. In Australia, the realization of such rights has been hampered by the Australian government’s failure to adhere to international instruments to which it subscribes, which is partly attributed to an absence of national human rights legislation. As a federated nation, some jurisdictions have introduced human rights laws, but this has not occurred in the site of our research—New South Wales.

A significant achievement for Indigenous peoples was the United Nations’ adoption of the 2007 International Declaration on the Rights of Indigenous Peoples. The passage of the declaration through United Nations processes took two decades, with resistance coming from Australia, Canada, New Zealand, and the United States. For Indigenous communities, it trumps the more universal declarations such as the Universal Declaration on Human Rights (1948), the International Covenant on Civil and Political Rights (1976), and the International Covenant on Economic, Social and Cultural Rights (1976), which although worthy as universal statements do not cover the specificity of Indigenous LGBTIQ+ rights.

For LGBTIQ+ peoples, both Indigenous and non-Indigenous, there is no treaty or convention that focuses specifically on their rights. Nonetheless, there have been mentions of LGBTIQ+ peoples within the United Nations committees that oversee the different treaties, with language becoming more inclusive of sexuality and gender diversity.¹³ Support for the idea that human rights apply to sexuality- and gender-diverse people can be found in several statements from the United Nations, the most important being the Human Rights Council's Joint Statement on Sexual Orientation and Gender Identity.

An applicable federal law for First Nations peoples in Australia is the federal Racial Discrimination Act of 1975. The act purports to promote equality before the law for all people, regardless of their race, color, or national or ethnic origin, and to make discrimination against people on the basis of their race, color, descent, or national or ethnic origin unlawful. Actions that constitute statutory racial discrimination are nonetheless of limited applicability to the LGBTIQ+ cohort of our research. The act is unlikely to remedy the discrimination that they experience, as such discrimination is frequently covert and insidious and unlikely to find remedy through legislation that has not kept pace with their rights.

Rights negotiation in Indigenous human rights is heightened when advocating for collective rights, known as “third-generation rights,” that extend beyond individualism. Unlike codified rights, collective rights are not enshrined in any United Nations instrument. They are particularly important to Indigenous societies in the quest for self-determination and as a challenge to settler colonial practices.¹⁴ They receive little support in mainstream Western societies, which privilege civil and political (first-generation) rights and, to a lesser degree, economic, social, and cultural (second-generation) rights. Resistance to collective rights is illustrative of the problems of legal discourse whereby human rights understandings are “top-down” in their reliance on human rights declarations, conventions, charters, and laws, which are inevitably drafted by powerful people, such as

politicians and lawyers, resulting in the hegemonic diffusion and narrowing of human rights outcomes experienced at the margins.¹⁵

It is not merely collective rights that are of significance when discussing Indigenous rights but the way in which these ideas are voiced. Narratives such as those expressed in our research reveal, for example, that Indigenous peoples see health, mental health and well-being in a more holistic way than dominant Western societies.¹⁶ With medical models of health dominating, Indigenous peoples' more holistic world views and knowledges are trounced by an uneven balance of power that is reflected in traditional human rights formulations.

Hegemonic and universal application of human rights frameworks underpin the 1948 Universal Declaration of Human Rights. Article 25(1) states that “everyone has the right to a standard of living adequate for the health and well-being of himself and of his family.” This codification has been reiterated in subsequent treaties and declarations and has taken hold in the global health sphere.¹⁷ Yet more than 70 years on, these health and well-being ideals are largely unachieved and continue to reflect Western heterosexual normativities.

In the context of our research, the right to health refers not only to health care provision but to the conditions that promote Indigenous LGBTIQ+ human rights. This includes overt recognition of colonial processes and the provision of measures required to transcend them. For health to be seen as a human rights issue, acknowledgment of past and continuing settler colonialism's subjugation of Indigenous peoples must occur. The Human Rights Council argues that “forced assimilation, political and economic marginalization, discrimination and prejudice, poverty and other legacies of colonialism have also led to a lack of control over individual and collective health.”¹⁸

The World Health Organization notes that a human rights approach to health provides clear principles for setting and evaluating health policy and service delivery, through targeting discriminatory practices and unjust power relations that underly inequitable health outcomes.¹⁹ Ill-health and chronic conditions experienced by Indige-

nous peoples in settler colonial nation states are traceable to settler colonialism, as is the situation in Australia.²⁰

Robert Parker and Helen Milroy point out that British colonization had devastating impacts on both the physical and mental health of Indigenous peoples.²¹ Tom Calma and Pat Dudgeon say that building on culture and social and emotional well-being is core to responsiveness to Indigenous mental health and disturbing suicide rates, warranting renewed prominence of the right to health.²² A national Australian roundtable held in 2015 emphasized that sexuality- and gender-diverse populations are a group at higher risk of suicide and that Aboriginal and Torres Strait Islander sexuality- and gender-diverse populations remain invisible.²³ In recognition of the paucity of research on the intersection between Indigeneity and gender and sexuality diversity, a 2021 Western Australian project captured the experiences of Aboriginal LGBTIQ+ people living in that state.²⁴ The methods adopted in the Dalarinji project, outlined below, contribute to growing scholarship in this area, with a focus on young people.

Methods

The Dalarinji project research was undertaken in three consecutive stages:

1. In-depth interviews with 15 young Aboriginal and Torres Strait Islander LGBTIQ+ people.
2. An online survey of Aboriginal and Torres Strait Islander LGBTIQ+ people, with 16 respondents, co-designed with our research partner BlaQ Aboriginal Corporation. Interview participants were asked to suggest survey questions, which were incorporated into the design.
3. A series of workshops led in conjunction with BlaQ Aboriginal Corporation to obtain guidance from community members and service providers on the interview findings and survey results.

Recruitment of interview participants occurred through First Nations networks, social media posts, and service provider networks. Later, in-

terviews took place via Zoom due to COVID-19 restrictions. The research participants identified across LGBTIQ+ communities included bisexual, fluid, gay, lesbian, non-binary, queer, and trans individuals. They all identified as proud First Nations peoples from New South Wales. Qualitative interviews were thematically analyzed using an inductive approach whereby analysis arose from participant narratives rather than preconceived themes.²⁵ All phases of the research process have been guided by an advisory group of First Nations LGBTIQ+ young people and service provider representatives from our community partners—namely, BlaQ Aboriginal Corporation and the Aids Council of New South Wales.

Participant voices provided rich material on family and community barriers and strengths, which have been described elsewhere.²⁶ This paper focuses on institutionalized hurdles to human rights realization, offering proposals for a way to ensure that human rights are centered. Although we focus on the manifestations of institutional responses, we analyze these within the context of settler colonialism, arguing that on-the-ground responses need to be located within a collective, as narrated by respondents.

Findings

First Nations peoples worldwide have been impacted by policies and practices that followed colonization, including “protection” and assimilation. In Australia, the approaches adopted to meet the country’s ideologically driven policy goals included the displacement of Indigenous peoples to sites such as missions and reserves.²⁷ One of the most profoundly disturbing practices, which resonates throughout subsequent generations, was the forcible removal of children from their families and communities and their placement into children’s homes, foster care settings, and adoptive white families.²⁸ In this way, assimilationist policies targeted children of “mixed race” in order to “breed out” their Aboriginality through miscegenation. Karen Menzies posits that collective, historical, and intergenerational trauma are important for understanding the health and

social challenges within Indigenous communities.²⁹ This was reinforced by one interview participant:

I think a lot of queer people or multiple minority people do carry some form of trauma with themselves, whether that's struggling with accepting your identity, aspects of community, anything. I think there's some elements of trauma that we all hold and have a responsibility to ourselves to work through.

The impact of growing up and being told that both Indigenous and LGBTIQ+ identities were invalid was recounted by one participant:

So, I wasn't black 'cause I was white and being gay is bad. So, it kind of had adverse effects on your mental health, which I'm still coping and struggling with, but thriving today. But I guess you could say that's how my cultural identity and my sexual identity intersect like that.

Another participant noted:

I find being Aboriginal within Australia is its own issue but then being gay within Australia has its own issue. But then to be Aboriginal and gay within Australia is like a whole other ball game.

Findings outlined below fall within the realm of public human rights that are vested in societal institutions and ought to be protected by the state and non-state actors, as opposed to those manifested in the private realm. Although most participants did not confine their comments to categories and spoke of well-being in an integrated way, it has been possible to extricate features in education systems, workplaces, and service organizations that converge to paint a picture of the erosion of Indigenous and LGBTIQ+ human rights.

Schools

The worth of schooling and education is encapsulated in the statement of a participant who said:

It's so important. It's a very vital and pivotal part and you're so vulnerable at that age. Like for a start, your brain is still forming, and you're very easily influenced and it's crazy.

Another participant spoke of the racism experienced at school, including being called (the highly offensive slur) “half-caste” and then having to deal with sexual discrimination:

Then a few weeks later they went around that they thought I was gay and all this stuff, so they were saying, “Now you are a gay half-caste” and all that kind of stuff, and so stupid gestures. All the girls in the change room would come up to me and try and touch me. So, I was very depressed. I think no matter how much racism I got, I was born Aboriginal, I can't help it. So, it never really affected me to a point where they were calling me half-caste, like a gay half-caste. That's when it affected me 'cause it was both and it was both things I couldn't really control, but I think it was more so being queer and stuff like going through that transition, not being able to tell. I felt okay at home to go and say “Mum, they've been racist.” I wasn't comfortable about what they're saying all this stuff about me being gay. So, I think because it was years and years of trying to suppress it and I felt disgusting. Felt like no one would love me anymore, just horrible things.

Feeling safe at school was not always possible for another participant:

Absolutely it was not safe, I believe, back when I was 14, to hold my girlfriend's hand walking to school—no way. We were definitely closeted. I think what made me so certain that I needed to be closeted and take advantage of that passing privilege, although I wouldn't have the language to put to it back then.

White passing was a protective measure for one participant:

But I am white passing, and you could say that my Aboriginality, like my sexuality, was invisible, therefore it was easy to suppress growing up ... I've always known being black and being gay—always knew I was different, couldn't really put a finger on it until I was older. But being able to pass as a white person and growing up in high school realizing that people are pretty conservative and that gay was a bad thing. It was very easy to suppress that as well, to pass as a white hetero-cis man, but eventually that just got too much physically and emotionally to keep suppressing. It's definitely about performing masculinity. It was just about performing that to

fit in, to say safe, to make—have people like me, so I wasn't alone. I grew up in high school with a bunch of lads, if you will, and I felt fine and stuff, but obviously as I got older and matured, I realized that this can't go on and I drifted apart and found my own people.

Finding support within the school system was fraught for one participant:

I saw the school psych, once or twice, because of my depression and anxiety being so bad. They were terrible. They were so bad. I just remember leaving crying, and I'm like, "Why am I feeling worse."

Sex education at school was problematic, as expressed by a participant:

It was compulsory sexual health education. That was mostly focused on male and female, cis male and female partners. So, when I started having sex with cis-women or people with vaginas instead, that was a lot more different.

Having a child from a former relationship presented a barrier for a participant in revealing their sexual orientation in a school setting:

I probably just would keep that to myself 'cause they get around and they'll talk about their husbands, and the houses they own and whatnot, and I'm just the odd one out, the young gay mum ... Yeah, a major fear of being judged.

Exacerbating these feelings, their son's father believed that their boy would be bullied "if all his friends know that his mum is gay."

One participant experienced post-school discrimination after coming out on social media and subsequently being unfriended by some high school friends. They also referred to having "dark times at school, but university was a more positive experience, and I was comfortable with self."

Workplaces

The right to work is recognized in the Universal Declaration of Human Rights, whose article 23 states, "Everyone has the right to work, to free choice of employment, to just and favorable conditions of

work and protection against unemployment." For the study participants, questions of free choice, work conditions, and protections against unemployment were compromised by discriminatory practices.

Working in a hospital resulted in one participant adopting avoidance strategies:

I learned to avoid wards and things like that ... the patients, just some shit they're saying, like "Oh God, I don't wanna hear you," they will say stuff about gay people and Aboriginals.

Referring to their workplace, another participant stated:

I started a job and I found it really hard because the job that I was doing was as a support worker, and I couldn't tell any clients about like my gender or stuff ... I don't know how to have that conversation with other Aboriginal people, especially if I hear them making homophobic comments, just while I'm with them. It was like, I'm not going to bring that up to them, like I'm there for them, they're not there for me. So, it just made me uncomfortable because it was like, "Oh this is just not working yet."

And another said:

And with employment now, I don't even tell them I'm trans. I just go without because young men, they need young men in the industry I'm working in. So, I'm just gonna be a young man, let's not complicate it.

Service provision

To foster the realization of human rights, external institutions such as schools and workplaces play a formative role. By the time individuals reach the stage of seeking well-being and health services, challenges are apparent. While medical services are pivotal to well-being, it is evident from our research that the right to health is not evenly implemented for the young Indigenous LGBTIQ+ demographic.

Participant narratives reveal mixed responses in their detail, but relationships with health providers were seen as central to well-being. Particularly important were relationships with general practitioners (GPs), who are usually the first contact point of medical service provision in Australia. GPs

are influential in both providing primary health care and making referrals to specialists. Views were expressed by participants about mainstream mental health services, queer services, and Indigenous health services. The snapshot below reveals diversity and commonality. Arising from participant stories were implicit and explicit suggestions for developing and implementing services that advance social, cultural, and emotional well-being.

One participant spoke positively about receiving help from a mainstream youth mental health service, Headspace. In the regional location where the branch was located, they became part of a youth reference group:

They were pretty helpful. I just did everything with them just because they were the only place in [name removed] that I knew supported LGBT people and Aboriginal people. Like I was like, "This fits so well." So yeah, I spent so much time there. I gave them a lot of my time which like no regrets, it was really fun.

For this participant, there were identifiable reasons for their positive comments, both in the form of services and visibility, with the latter indicating cultural awareness:

The first time I go in there, they ask me if I need like a translator. If English was my first language or if they needed to find someone with that same language group. I'm like, "No I speak English." But the fact that they offered, I was like, "That's really cool that you have that option there." I think another thing was, you know they do have the flags and stuff as well, and then they have Aboriginal art in the waiting room. It was just simple things, but I think that makes a difference.

Another participant had positive experiences with a Headspace service in the Greater Sydney metropolitan area, where they were introduced to a helpful yarning circle. Headspace instilled confidence for them, enabling them to seek hormones. Specifically, this service was affirming because

you are not streamed. When I walked into Headspace I didn't feel judged. I was perceived as a person. They asked what they should call me and then only asked for the name on my Medicare card.

Another survey participant reinforced the importance of visibility:

I feel a lot safer when there is an Acknowledgment of Country in a prominent place in a health service.

Varied responses were received from participants in discussing how sensitive services were about culture, with one participant stating that you could tell when staff were trained to be culturally sensitive.

Participants described problematic responses by practitioners, including the following:

"Oh, you're feeling depressed, you take this anti-depressant, get out of my office, it's too hard."

A lot of doctors don't know what a pronoun is.

They also noted that sexuality diversity could be viewed as deleterious by service providers:

If I said I had depression and anxiety, they were like, "So you're trans?" And I'm like, "Yes," and they're like, "Hmmm," and I'm, "What, treat me if I have depression and anxiety" like they would just, they were acting like my problem was that I was trans and that was very frustrating.

The education of practitioners played a role:

Yes, there was one doctor that I do like. I think they could probably—I don't know, she's not very knowledgeable but she's learning about it, but it also feels that I shouldn't be the one educating her.

One participant minimized the cultural aspect based on their experience with a therapist they were seeing at college:

She's very accommodating to black and queer people so I felt safe. I don't think she has any cultural training though, but my problems weren't with culture. It was mainly just emotional well-being. So, I felt safe with her and we got to the root of the problem and I'm on medication now and I'm thriving.

Another expressed their negative experience:

Definitely the service is what is important. I have a GP just down the road to me that I don't go anymore

'cause I feel like he maybe doesn't understand the queer side of sexual health.

A participant who identified as bisexual spoke about how sexual health checks “can be really tricky because they ask a lot of questions and they're usually pretty heteronormative”:

I can feel a bit nervous about what the GP is going to do if I asked for a sexual health check-up. What questions are they going to ask? Am I gonna feel comfortable? So, I guess I'm just preparing myself and going through mentally in my head like, okay, for me I try and do my own check in my brain of what the doctor should ask and then answer the questions based on that if I'm not comfortable.

Actually, I think I prefer it when they don't ask any questions at all ... I've been to the doctor's once and she was so confused, 'cause she's like, “Tell me about your partner” and I have to be like, “I don't know what that means in this context. I think you have to be more specific than that.” So, when I go to a doctor, I either want them to ask no questions at all or be much more open about different gender identities and not being so heteronormative in the questions that they have been asking me.

This participant was able to find a way to resolve this discomfort:

Going to the ACON [Aids Council of New South Wales] clinic and asking questions there where I felt more comfortable, and then from there, I felt like I could go to any GP and ask for the tests that I needed.

An affirming experience with a GP was recounted by a participant who said:

So, I went to the GP and just spoke to him. I just laid it all out on the floor and I said, “I need help. I'm suicidal, I need help right now.” So, he offered me a few things—he offered me like Aboriginal counseling services as well, but I didn't want to go there because my family is from around this area as well, mum's family, my aunties and all that. So, I went to a service near his office ... I check in every now and then with him as well. He's a good doctor. He always does my mental health plans for me. They're very big on Aboriginal culture too. They have Close the Gap.

When probed about services that would make a difference, responses included the following:

Maybe like a support group or something for queers. A more modernized Aboriginal health center with young workers, like younger health workers to help with the coming out process and bringing in family interventions. I think that's what I needed at the time.

For another:

So, I can only imagine what that would have been if there was a lesbian, an Aboriginal person or an Indigenous mental health professional that I was receiving that support from 'cause it was incredible to have those conversations with someone who genuinely did get it rather than talking to a professional who they just say they do. But I have found it difficult to find particularly mental health services that are Indigenous and queer. But in the queer space, I found people are much more aware of Indigenous aspects of it than in the heteronormative space.

One participant proposed:

Aboriginal medical services could be more comfortable for queer people by being more front facing and queer facing.

They added:

There is a lack of services for young queer people. Something needed is a service to target parents and siblings of young queer people to build up family support and provide guidance for families. There is also a lack of services for trans men, compared with those available for sistergirls.

Also for this participant:

Services that bring out the positives are important instead of seeing LGBTIQ experiences as negative.

The detailed narrative from the following participant, who describes themselves as “picky,” encapsulates a range of dimensions related to service, including the relational, professional, and respectful dimensions:

So, when it comes to me venting and telling someone my problems, I don't necessarily want it just to be a random. I obviously want it to be somewhat of a professional. So, for me, it does take a bit of time just to find that right person. The general services are there, don't get me wrong, they're obviously there, there's someone to talk to, but whether or not it's a good quality and it's a good person to talk to, and sometimes the services you're offered like counseling and stuff, sometimes they don't necessarily understand cultural issues and cultural backgrounds as well. So, it's great to say we have a service here, look into it, but then I think there needs to be a bit more look into it to make sure that it's the right person that they're talking to and not just someone who's there just wanting to give a chat and gets paid for it. There actually needs to be a bit more emphasis behind the importance of that.

I find going to just my normal, with my home family GP better for me just 'cause I've got a bit of a relationship with them but I do understand not wanting to go to the AMS [Aboriginal Medical Service] and wanting to go to more a queer-based one, just because you feel more comfortable that they understand you. Obviously in our society two men together is not normal. So there hasn't been a lot of education around safe sex with two men or two women and stuff like that. So I do understand that there is a bit of a sense of shame going to the AMS. I know I felt like that, just purely because although I'm a proud Aboriginal man, I do know within our Indigenous community, there's a lot of homophobia and transphobia that still does go on, and so going into it and being, "Oh, yeah," to me, it's a little disrespectful as well, that's just my opinion. So, I do definitely get the whole being more comfortable going to a queer-based one because they're people like you, they share the same stories, so I definitely get that. But for me, personally, I feel more comfortable going to my own family GP just 'cause I've known him for years, but if I wasn't to, in regards to sexual health and stuff, I would probably go to more of a queer-based one. I know when I went into AMS once to try it, I just didn't ask, I just went in and walked straight back out.

Discussion

Qualitative, narrative-guided research presented an opportunity for individual stories to emerge, providing leads for a subsequent quantitative survey and workshops. By capturing individual

stories, the project demonstrates the differing levels of agency. Some participants were emboldened by equitable service provision and found strength in being "out and proud" First Nations people through such relationships. Some responses highlighted the ways in which young Aboriginal and Torres Strait Islander LGBTIQ+ people continue to navigate a mire of discrimination, imposition, and inadequate responses that ignored their humanness and the right to a dignified life. Such factors do not align with the right to health, including mental health, despite global and localized norms and pronouncements. For schools and workplaces in particular, the right to health, including mental health and well-being, as opposed to the right to education or the right to employment, is minimized. It is in the services arena where fractures between the right to health and everyday practices are most apparent.

Interview participants demonstrated that First Nations LGBTIQ+ people were far from positive about places they were expected to frequent in the public domain. Schooling produced challenges, with bullying, discrimination, racism, and queer phobia reported as being prevalent and therefore creating unsafe environments. In some instances, workplace culture and practices meant that people weren't always able to be out and proud. Some individuals developed strategies to conceal their identities and thus feel safe in the workplace, but this meant hiding an important part of themselves. Participant stories about service providers were mixed. Finding a good mental, sexual, or physical health provider was generally though trial and error. Participants shopped around for GPs, counselors, and organizations, testing out whether they were allies to First Nations peoples who could provide Indigenous- and LGBTIQ+-appropriate services. Once they had done so, participants exhibited a strong capacity to use available services, asserting their rights to high-quality mental, physical, and sexual health service provision that met their demands as both First Nations and LGBTIQ+ people.³⁰

In singling out schools, workplaces, and professional services as institutional barriers to attaining rights, the 1986 Ottawa Charter for Health

Promotion provides guidance. The charter states that the foundational prerequisites for improvements to health include education, income, and social justice and equity.

The agony of racism and queer phobia has lifelong impacts on health and well-being, pointing to the urgency of transforming schools, places of employment, and services to be affirming of Indigenous LGBTIQ+ human rights and specifically the right to achieving parity in health, including mental health, which combines universal provision with attention to the unique experiences of this community. Restorative measures require sensitivity and thoughtfulness and are not necessarily demanding of resources. Research participants valued symbols that created visibility of their existence. This could occur, for example, by displaying Aboriginal and Torres Strait Islander and Rainbow flags; such displays would signal that service providers are more open and socially and culturally aware. A participant spoke of the importance of “acknowledgment of country.” This presents an opportunity for service providers, as formal acknowledgments are now well established in many organizations and settings throughout Australia. Acknowledgments recognize that services are located on unceded Aboriginal land. They affirm that the notion of country has particular meaning, with land “as a living entity, the essence of Aboriginality and includes the human and non-human; people, culture, spirituality, history, land, waterways, animals, plants, insects, habitats and ecosystems.”³¹

When respondents discussed inadequate service provision, there was clear direction as to what elements promising services should contain. In this regard, relational aspects were important, as was positive recognition of both culture and sexuality. One aspect that stood out was the ignorance of many service providers. The comment by one participant who said it was not their role to educate practitioners leads to the question of whether human rights education programs would minimize the challenges experienced by research participants. Such programs could overhaul existing training approaches, such as inclusive cultural awareness, by aligning good practices with human

rights from below; these programs could be run by young Indigenous LGBTIQ+ people and could move away from legalistic constructs while benchmarking against the Declaration on the Rights of Indigenous Peoples. They could be crafted around the rights of self-determination, the rights of young people to express themselves without judgment, and the rights afforded to people experiencing “double challenges,” such as those in our cohort. Bringing these individuals’ knowledges and experiences to the forefront would challenge the ethnocentric, normative hegemony of traditional human rights education delivery and center Indigenous pedagogies.³²

Given that most of the criticism was leveled directly at practitioners, the role of professional associations, peak bodies, trade unions, and educational institutions—particularly medical schools and general practitioner peak bodies—requires consideration. The codes of ethics of professional organizations could be amended to affirm the rights of young, queer Indigenous people. Indeed, professional practices would benefit from an overhaul of underlying assumptions. For social workers seeking to understand how to serve LGBTIQ+ Aboriginal communities in Australia, Bindi Bennett and Trevor Gates adopt the term “cultural humility.” They see this as a way of overturning monolithic educational practices that reinforce an imbalance of privilege and power enshrined in notions of cultural competency and associated training.³³ Human rights education is not a top-down endeavor, and it requires critical reflection and critical consciousness for it to be meaningful. Because of intersecting realities for Indigenous LGBTIQ+ people, a grounded approach would recognize the struggles of participants in environments that should be foundational to well-being. As posited by Fuad Al-Daraweesh and Dale Snauwaert, for human rights to achieve equality for all, it is the people who should have the right to decide on their own interests.³⁴ This is reinforced by the 1986 Ottawa Charter, which states that “health promotion is the process of enabling people to increase control over, and to improve, their health.”

It can be deduced from participant stories that

a legacy of settler colonialism remains present in the lives of First Nations peoples. Racism and queer phobia continue, despite existing international human rights instruments designed to eliminate discrimination through universality. Failure to eliminate injustices in health care has been detrimental to the research participants, signaling a societal failure to foreground human rights in Indigenous LGBTIQ+ health care.

Conclusion

The research presented in this paper investigated factors that presented health and well-being challenges for young Indigenous LGBTIQ+ people in New South Wales, Australia. We analyzed the challenges through a human rights lens by examining the institutional settings of schools, workplaces, and service providers.

Participant narratives make clear that health and mental health services must be attentive to Indigenous LGBTIQ+ specificities, with service provision located within a historical and cultural context that recognizes the effects of settler colonialism and the resultant trauma for First Nations LGBTIQ+ peoples. Recognition of the rights of young LGBTIQ+ First Nations communities has yet to make its way into institutional policies and practices, and the nexus between intersectionality and human rights has not had a significant impact. Contributing to the lag is uneven academic work on intersectionality across disciplines, such as education, psychology, and social work, revealing the need for ongoing transformative research.

The human right to health, including mental health, is enshrined in international norms, although universal instruments and global statements fall short of application to groups that have been historically oppressed and subject to racism and queer phobia. The concerns outlined in our paper necessitate active measures to be taken by human rights educators, educational institutions, places of work, and a range of health and well-being service providers. In order to “reclaim” the rights of those whose stories have been told and to minimize harms

arising from multiple oppression, ongoing research and activism from below is an urgent quest.

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Advancing a Human Rights-Based Approach to Access to Medicines: Lessons Learned from the Constitutional Court of Peru

LOWRI DAVIES

Abstract

Access to medicines and the right to health continues to be widely discussed in academic literature. United Nations human rights bodies have done much work to elaborate on the normative content of the right to health and the obligations of states to uphold this right, although translating this into tangible benefits to the public at national level remains a challenge. This paper explores the case of Peru to evaluate prominent decisions of the Constitutional Court that have been instructive in clarifying the state's obligations in relation to health. I argue that the court's rights-based approach offers lessons that other states can draw on to meet their obligations to ensure the right to health by securing access to essential medicines.

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Competing interests: None declared.

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Introduction

The close link between the right to health in article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR) and access to medicines is widely acknowledged in academic literature. United Nations human rights bodies have produced guidance on the normative content of the right and the obligations of states, establishing that access to essential medicines is a core component of the right to health.¹ It is clear that states have human rights obligations with regard to access to medicines, although the access to medicines agenda is less precise with regard to how this should translate into national law. The obligations of states to progressively realize the right to health raises the question of how this right might be realized for patients struggling to access—or being denied access to—medicines. Exploring a rights-based approach to securing access to medicines at the national level can provide greater understanding to states seeking to meet their international human rights obligations to ensure the right to health, including access to essential medicines. In addition to their obligations under the ICESCR, states have committed to the 2030 Agenda for Sustainable Development, which includes achieving the goal of healthy lives.² Providing access to essential medicines is central to this goal.

This paper explores right to health litigation in Peru and evaluates the extent to which the Peruvian state has complied with its human rights obligations in relation to the right to health and access to medicines. Peru has adopted a range of measures to give effect to the right to health at the national level, including by enshrining the right to health in its Constitution.³ By examining several prominent decisions of the Constitutional Court concerning the right to health, this paper reflects on whether Peru offers examples of good practice that other states can model in meeting their obligations to ensure the right to health by securing access to essential medicines.

Background

Peru is a lower-middle-income South American country with a population of approximately 33

million.⁴ The country has established democratic institutions, although in recent years the democratic process has been undermined by several high-profile corruption allegations.⁵ Health expenditure was 5.2% of the gross domestic product in 2018, which was among the lowest in Latin America, and 29.15% of health expenditures were out-of-pocket expenditures.⁶ Life expectancy in Peru is 76 years, one of the highest in Latin America, and the country's Human Development Index score is 0.777 (79th in the world), which increased from 0.613 in 1990, reflecting improvements in overall standards of living, including health.⁷

Peru ratified the ICESCR in 1978 and therefore has international obligations to realize the right to health as enshrined in article 12. Peru's health system is segmented, with the Ministry of Health providing health services for approximately 60% of the population, and EsSalud (the social security system) serving approximately 30% of the population.⁸ The military and police have their own health services, which, together with private sector entities, provide health services to the remaining population.⁹ This fragmented system has led to some inefficiencies in the provision of health care and to the inequitable distribution of services in remote regions.¹⁰

Since the turn of the century, the state has been making efforts to expand health coverage, including by introducing comprehensive health insurance and mandatory health insurance coverage for the population.¹¹ However, problems still exist in relation to the quality of services, as well as access to health care for the country's significant Indigenous population.¹² Moreover, problems in the provision of health care services is a key barrier to access to medicines for many people in the country; although there are publicly funded health services and health insurance coverage available, underfunding has led to many patients purchasing medicines themselves.¹³

National constitutional measures affecting access to medicines

The Constitution of Peru and its interpretation by

the Constitutional Court provides an important example of the state's political commitment to enhancing access to medicines and its engagement in measures to promote this.¹⁴ The current Constitution came into force in 1993 and sets out the rights and duties of citizens. The right to the protection of health is recognized in article 7, which states:

*Everyone has the right to protection of his health, his family environment, and his community, just as it is his duty to contribute to their development and defense. Any individual unable to care for himself due to physical or mental disability has the right to respect for his dignity and to a regime of protection, care, rehabilitation, and security.*¹⁵

A literal interpretation of this provision indicates that the right does not amount to a right to good health but a right to achieve the highest level of health possible and to have access to the appropriate services to do so. This is comparable with the guidance on the normative content of article 12 of the ICESCR, set out in General Comment 14, indicating that the Peruvian state has understood the nature and content of the right to health under the ICESCR and has reflected such an understanding in its Constitution.¹⁶ Therefore, the national right to health is in line with international standards. Article 9 of the Constitution provides that the state is responsible for determining national health policy to provide equal access to all health services, and article 11 provides that free access to health benefits is guaranteed by the state through public, private, or mixed entities.¹⁷ These articles do not explicitly include a reference to medicines, although they do refer to health services, which include the provision of medicines.

The state has constitutional obligations to ensure that the right to health of the population is fulfilled. María Sánchez-Moreno argues that the rights within the Constitution have not been embedded into public practices and that due to the unstable political landscape of the state, the Constitution does not occupy a stable and authoritative position.¹⁸ Meanwhile, Clara Sandoval and Carlos F. Cáceres argue that the right to health is treated as a national aspiration rather than an entitlement

that can be enforced vis-à-vis the state.¹⁹ The right to health is contained not in the first chapter (on fundamental rights) but in the second chapter (on social and economic rights), which highlights that the status of the right to health within the Constitution does not amount to a fundamental right.²⁰ Therefore, this suggests that this principle is not legally enforceable but is instead a directive principle of state policy. However, the manner in which these provisions have been interpreted by the national courts provides authoritative guidance on the status of the right to health, including access to medicines, in the country. The Constitutional Court has a duty to hear writs of unconstitutionality.²¹ Several key decisions of this court in relation to the right to health have been instructive in clarifying the state's constitutional obligations concerning the health of the population.

*Azanca Alhelí Meza García*²²

In *Azanca Alhelí Meza García*, the Constitutional Court considered whether the state had an obligation under articles 7 and 9 of the Constitution to provide comprehensive medical care for the protection of health.²³ The case involved a patient diagnosed with HIV in 1996 who argued that since being diagnosed, she had not received comprehensive medical care, including medicines. She could not afford the necessary medicines for her treatment and sought protection of her constitutional rights to life and health, claiming that the Ministry of Health was obligated to provide comprehensive medical care—including a permanent supply of antiretroviral medicines—in accordance with article 7. The Ministry of Health, in its defense, argued that the right to health is a social right that is programmatic in nature, representing only an action plan of the state rather than a concrete right, and that the petitioner did not fall within the category of patients eligible to receive comprehensive medical treatment for HIV/AIDS under national health policy.²⁴

The significance of this case lies in the court's discussion of the nature of social rights and its evaluation of the reasonableness of the state's measures

to maximize available resources.²⁵ The Constitutional Court took the approach of protecting the right to health by way of its connection to the fundamental right to life. In reaching its decision, the court stated that although the right to health is not a fundamental right, when the violation of the right to health compromises other fundamental rights, such as the right to life, it acquires the character of a fundamental right.²⁶ The court stated that the right to health has an inseparable relationship with the right to life and that the state must protect this right by strengthening health services; moreover, it noted that the right to health as enshrined in article 7 includes medical assistance to the level allowed by public resources.²⁷ Therefore, the court accepted that treating life-limiting or serious diseases such as HIV and AIDS, including through the provision of antiretroviral drugs, is an example of the situations where it will consider that an infringement of the non-fundamental right to health provides an indicator that a fundamental right has been breached.

The court also set out the parameters of the state's obligations under the right to health. It emphasized that the economic and social rights included in the Constitution are not to be considered merely a declaration of good intentions but rather a commitment to clear and realistic goals.²⁸ Therefore, although the right to health, including access to medicines, is not enforceable as a fundamental right under the Constitution, it is not enough to treat it as a mere aspiration—the state must set genuine and achievable objectives for the fulfillment of this right. This is consistent with states' obligations under international law; although social rights are to be progressively realized, states are required to take concrete and quantifiable steps to implement public policies that ensure their realization.²⁹ The court explained that social and economic rights are how individuals can achieve full self-determination and that the realization of socioeconomic rights and civil and political rights are interrelated and interdependent.³⁰ Therefore, the court noted, the state must establish basic public services as a minimum of action.³¹ Further, social rights must be interpreted as genuine claims of the citizen against

the state if the legal effectiveness of the constitutional mandates, and therefore the validity of the Constitution, is to be recognized.³²

The court went further to illustrate how courts should implement social rights, explaining that a judicial claim of a social right will depend on the “severity and reasonableness of the case, its link or effects on other rights, and the available state budget, provided that concrete actions can be proven for the implementation of social policies.”³³ The court recognized that social rights cannot be demanded in the same way in all cases due to budget constraints. It recognized the difficulty of Peru—as a developing country—enacting immediate policies for the benefit of the whole population, given that social rights depend on the means and resources available to the state.³⁴ However, it also noted that this is a valid justification only when the state takes positive actions to fulfill these rights as much as possible and that prolonged inaction cannot be justified and would result in a constitutional omission.³⁵

The Constitutional Court recommended that the state take tangible, concrete actions to achieve the petitioner's right to health and ordered that the petitioner be considered part of the group of patients receiving comprehensive HIV/AIDS treatment, including essential medicines. It also required that the treating hospital report back every six months on the petitioner's treatment.³⁶ Following this ruling, Peru adjusted its public health spending.³⁷ In addition, in 2004, the state obtained financial support to scale up the provision of free antiretroviral medicines for those who need them.³⁸ Illari Noriega argues that *Azanca* is a significant ruling because the court protected the right to health by linking it to other fundamental rights and, in doing so, established an important precedent for the legal protection of the right to health.³⁹ The decision also clarified that the right to health includes the provision of essential medicines, meaning that it opened the door for the legal enforceability of access to essential medicines as part of the constitutional right to health.

*RJSA Vda. de R.*⁴⁰

In *RJSA Vda. de R.*, the parent of a patient diagnosed with paranoid schizophrenia filed an *amparo* lawsuit against EsSalud, Peru's social security program, requesting that an order for the patient's discharge from the hospital be canceled because the patient was not sufficiently recovered to leave hospital care. EsSalud argued that the medical criteria for discharge had been met. The petitioner's claim related to the protection of the mental health of her daughter. In its ruling, the court stated that the constitutional right to health does not amount to a right to be healthy but does guarantee access to adequate, quality health services to the extent that public resources allow.⁴¹ This interpretation is consistent with the court's interpretation in *Azanca*. Furthermore, as in *Azanca*, the court highlighted that the right to health deserved protection because of its intrinsic connection with the right to life in the situation at hand.⁴² It is important to appreciate that the right to life is distinct from a patient's quality of life, which, although important to the patient, is a subjective standard of well-being and cannot be described as a fundamental right. Therefore, since the right to health is not interpreted as fundamental in Peru, it can be protected only in specific cases that have a strong right to life element, underlining the fragility of the protection of the right to health determined by the court.

A notable outcome of this case is how the court evolved its assessment of the enforceability of social rights to a three-step test. The court stated that enforceability depends on three factors: the seriousness and reasonableness of the case; its connection with other fundamental rights; and budget availability.⁴³ This suggests that there are qualifications to the framing of the right to health as a fundamental right and that the seriousness of each particular case would have to be demonstrated in order to be able to enforce the right to health. This test stemmed from the *Azanca* case, outlined above.

Felipe Florian is critical of this approach, arguing that there are ambiguities regarding the determination of how social rights can be claimed in judicial proceedings.⁴⁴ Florian argues that

challenges could arise where there is no specific protection of a social right, or where such a right has not been recognized in any budget.⁴⁵ These cases did not elaborate on how this test should be applied, and the court in *RJSA* also did not elaborate on its reasoning for adopting the factors set out in *Azanca* as a legal test.⁴⁶ Therefore, it could be said that the Constitutional Court has not addressed all of the issues that could arise when applying this test. However, these cases do show that the court has taken positive steps toward embracing more comprehensive protection of health challenges, including those relating to access to medicines and cases where vulnerable individuals are affected.

In addition to outlining the state's responsibilities under the right to health, the court's *RJSA* ruling undertook an evaluation of state actions to maximize available resources. It noted that Ministry of Health Resolution 0943-2006-MINSA identifies people's limited access to health services and medicines as one of the main problems affecting mental health care.⁴⁷ The court stated that the Ministry of Health should consider an expansion to the free delivery of medicines to ensure equitable access to medicines, while taking into account the state's limited resources.⁴⁸ It also stated that the Ministry of Health must develop a policy that ensures access to affordable medicines for low-income individuals, as well as sufficient regulation of medicines to guarantee effective and quality medicines.⁴⁹ The court's assessment that the delivery of medicines should be a priority in the national budget provides an example of how the court applied the third factor of the enforceability test outlined above—budget availability—in relation to medicines.

The outcome of *RJSA* was that the patient was granted indefinite medical care, including the provision of necessary medication for the treatment of her mental health condition. This is a significant decision, as the patient's constitutional right to health was enforced against the state, requiring the state to take positive measures to fulfill its obligations to her. Also, the court held that the patient, as part of her constitutional right to health, had a right to access medicines necessary to her care. Her medication, clozapine, was not on the World

Health Organization's essential medicines list in 2007 (although it has since been added), and so it did not fall within the definition of an "essential" medicine outlined in General Comment 14.⁵⁰ Therefore, in this case the state was not precluded from citing progressive realization as justification for not providing the medication necessary to the patient.⁵¹ The court's interpretation of the principle of progressive realization acknowledged that the state may experience difficulties due to resource availability but that this justification is acceptable only where the state can demonstrate ongoing and concrete actions to fulfill the patient's rights. The court's interpretation assists our understanding of states' duties in relation to progressive realization, although the issue of resource constraints, particularly in relation to medicines that are high priced, means it is conceivable to make such assessments in individual cases but less certain whether this would increase or decrease equality of access on a collective basis.

Although the wider impacts of this decision are less clear, the decision provides helpful insights on the enforceability of the right to health as a social right. It also demonstrates the tangible patient-level benefits of Peru's approach to interpreting the right to health. The decision resulted in the necessary medicines being secured for the patient's care, and the test for enforceability of a social right applied by the court was therefore effective in enhancing access to medicines. Therefore, this test could be a useful tool for courts in other jurisdictions to utilize when adjudicating on access to medicines and the competing obligations of the state with regard to the right to health.

Other related decisions of the Constitutional Court

Subsequent cases of the Constitutional Court have also emphasized the significance of the link between the right to health and other fundamental rights. In *Teofanes Ronquillo Cornelio*, where the appellant was not transferred to the favored hospital to receive the optimum treatment for his diagnosed condition, the court referred to *Azanca*, highlighting that

the right to health is inseparable from the right to life and is thus a fundamental right.⁵² The court also held that the state has a duty to guarantee the right to health, including by taking positive actions to promote the right.⁵³ This position was also stated in *Carlos Gonzales La Torre*, a case where—although relating to the hospitalization of a prisoner and not presenting a direct right to life or right to health issue—the court outlined that the right to health is necessary for the exercise of the right to life and has an inherent connection to the right to life, right to personal integrity, and other fundamental rights.⁵⁴ These decisions emphasize the importance of the right to health in terms of fulfilling the right to life and indicate that the close connection between the two rights elevates the right to health to the status of a fundamental right. This interpretation is also consistent with the *Azanca* ruling, suggesting that a body of jurisprudence on this issue has emerged in relation to the content of the state's obligations regarding the constitutional right to health.⁵⁵ This indicates that citizens can enforce their right to health against the state in circumstances where they can show that there is a risk to their right to life if their right to health is not fulfilled.

The Constitutional Court has sought to ensure the close alignment of national constitutional rights with international human rights norms in cases involving human rights arguments. This has been observed by the Committee on Economic, Social and Cultural Rights, which has noted that Peru has "made huge advances in the constitutional interpretation of human rights."⁵⁶ The committee's concluding observations from 2012 note that the Constitutional Court has issued several innovative judgements enriching constitutional law and recognizing that international human rights treaties are of immediate application.⁵⁷ The concluding observations further note that the Constitutional Court has on several occasions applied an expanded interpretation of the right to health set out in General Comment 14.⁵⁸ This is evident in several of the cases discussed above, and it highlights that the Constitutional Court is engaging with the guidance of United Nations human rights bodies on the state's obligation in relation to the right to health,

including access to medicines.

Implications for health care systems

The above cases raise the question of whether health rights litigation upholding the right to medicines leads to more fairness in access. As noted above, Peru's expenditure on health is low compared to other Latin American countries, and there are concerns over inequitable health provision for the poor. An individual approach to access to essential medicines, such as antiretrovirals in the *Azanca* case, is inadequate where others who also have the same right to those medicines continue to face barriers to access.⁵⁹ Thus, while the cases have produced some success in relation to access to medicines, their wider impact in terms of inducing health policy changes to enhance accessibility for the population in general is less evident. This presents the question of whether collective action would be more effective in ensuring equitable access to essential medicines, as it would help overcome inequality for those who cannot afford to litigate. The effect of collective lawsuits in other Latin American jurisdictions has produced some success, although it has not been without problems. For example, such actions in Argentina have had a limited impact on changing systemic problems in medicines access, while in Costa Rica the most successful cases have concerned low-priority, non-essential medicines.⁶⁰ Meanwhile, collective action in Colombia has led to problems relating to the availability of medicines, cost burdens on the health system, and priority setting.⁶¹

It cannot be said conclusively that collective action is more effective than individual action, although it is important to recognize that not all courts are the same, and single case studies cannot produce concrete conclusions for all.⁶² The judicialization of health rights in Latin America has opened health policy decision-making to public scrutiny and stimulated public debate on health care.⁶³ However, judicialization can also have a disruptive impact on health systems, including on which medicines are available and accessible.⁶⁴ A related concern is the additional pressure generated

on national health care systems if access to medicines is awarded regardless of the cost.⁶⁵ Increased burdens on health budgets could have a detrimental impact on the provision of other health services, which could also undermine health equity.

It must be appreciated that the courts can go only so far before impinging on public policy decisions regarding health and the principle of separation of powers. However, Amy Kapczynski argues that judicial decisions upholding the right to health and granting access to medicines have had important indirect effects, including the triggering of responses from other government departments that have improved health care systems, such as stronger price control measures.⁶⁶ Such litigation can also promote a dialogic approach between the courts and the government on finding solutions to the issue of protecting human rights in cases of limited state resources, as seen in *Azanca*, where the Peruvian Constitutional Court invited the government to consider utilizing tools such as compulsory licensing.⁶⁷

Peru's Constitutional Court has contributed useful jurisprudence in relation to the enforceability of the right to health, and the test outlined in *Azanca* and developed in *RJSA* offers a framework to evaluate the country's measures to protect the right to health in line with its national and international obligations.⁶⁸ The court's approach reflects the value of using a human rights framework to enhance access to medicines, and it could be a useful example for other states that are seeking to meet their human rights obligations under article 12 of the ICESCR.

Conclusion

The jurisprudence of the Peruvian Constitutional Court shows that the court is taking full account of the right to health under the Constitution in cases relating to access to medicines and that its interpretation of the right is in line with the state's obligations under article 12 of the ICESCR. The value of a human rights approach is evident in the cases discussed in this paper, as it strengthened individual patients' access to medicines. However, it

is less clear whether the judicialization of the right to health in Peru has improved health outcomes for the wider population. It is thus difficult to assess whether the inclusion of the right to health in the Constitution has strengthened the country's protection of the right to health. That said, some have argued that the constitutionalization of the right to health in Latin American countries provides an avenue for citizens to enforce their rights at the national level and therefore offers an important motivation for states to comply with their obligations.⁶⁹

These key decisions in Peru have been instructive in clarifying the state's obligations in relation to the right to health, as well as navigating challenges such as resource constraints. Strengthening health provision is connected to resources, and the decisions make clear that the Constitutional Court acknowledges the progressive nature of health as a social right. However, the court has also explained that the state must take immediate and concrete steps to realize the right. The three-part test developed in *Azanca* provides an example of good practice that can be used by other states. This test can be applied to evaluate states' actions to progressively realize the right to health. It also provides flexibility in terms of enforcing a social right to help patients requiring access to medicines, while also taking into account the arguments relating to resource constraints. While this approach will not resolve all of the challenges arising from a highly complex issue, it could be a potentially useful tool to consider as part of the continually evolving discourse on how states' obligations in relation to access to medicines can be effectively upheld.

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A Human Rights Framework for Advancing the Standard of Medical Care for Incarcerated People in the United States in the Time of COVID-19

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Abstract

The COVID-19 pandemic has underscored the lack of resources and oversight that hinders medical care for incarcerated people in the United States. The US Supreme Court has held that “deliberate indifference” to “serious medical needs” violates the Constitution. But this legal standard does not assure the consistent provision of health care services. This leads the United States to fall behind European nations that define universal standards of care grounded in principles of human rights and the ideal of equivalence that incarcerated and non-incarcerated people are entitled to the same health care. In this paper, we review a diverse legal and policy literature and undertake a conceptual analysis of policy issues related to the standard of care in correctional health; we then describe a framework for moving incrementally closer toward a universal standard. The expansion of Medicaid funding and benefits to corrections facilities, alongside a system of comprehensive and enforceable external oversight, would meaningfully raise the standard of care. Although these changes on their own will not resolve all of the thorny health problems posed by mass incarceration, they present a tangible opportunity to move closer to the human rights ideal.

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Competing interests: Gabriel B. Eber is a member of the Centurion Health Advisory Board, which meets four times annually and for which he receives remuneration.

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Introduction

The COVID-19 pandemic has brought into sharp relief the health risks of incarceration. As the virus first swept across the United States in the spring of 2020, the disease ravaged people in places of detention.¹ By the summer of 2020, there were more than fivefold higher COVID-19 cases in prisons than in the general population and threefold higher mortality when accounting for differences in age.² Two years into the pandemic, the cumulative incidence of COVID-19 remained more than threefold higher in prisons.³

While some carceral facilities undertook remarkable efforts to protect residents and staff, these efforts have frequently been hampered by a lack of resources, diversion of care away from routine chronic disease care, disjointed implementation of public health preventive measures, and fragmented planning. In other facilities, there was a marked pattern that led to avoidable suffering. In one Texas facility that housed primarily elderly and medically vulnerable residents, an astonishing 6% of the population died of COVID-19. A federal district court found a marked pattern of neglect and a lack of precautions.⁴ In the egregious example of Cummins Correctional Facility in Arkansas—a prison where virtually all residents were eventually infected with COVID-19—the custodial and medical staff reportedly ignored all requests for care from the residents and required all but the sickest residents to report to work shifts. As one resident recalled, “I watched nurses put the paper sick calls [written requests for health care] in the shredder and never blink an eye.”⁵

The COVID-19 crisis has no contemporary precedent in modern carceral health in the United States, yet many of the harms were predictable and avoidable. Conditions of close confinement due to overcrowding in often poorly ventilated, antiquated facilities provided a ready environment for the virus to spread.⁶ The daily movement of staff between their communities and carceral places of work, along with the arrival of newly incarcerated individuals, enabled the virus to travel between carceral facilities and surrounding communities.⁷

Conditions that allowed COVID-19 to proliferate inside were exacerbated by the understaffing of medical providers in many facilities, inconsistent testing, and a lack of access by staff and residents to basic prevention measures early in the pandemic, including face masks and hygiene supplies.⁸ Fully confronting these structural problems will require addressing mass incarceration and the attendant overcrowding present in many facilities. This overcrowding is the result of decades of growth in a punitive system that disproportionately affects poor people of color.⁹

In this paper, we argue that the COVID-19 pandemic has presented an opportunity to systematize standards and oversight of health care for incarcerated people in the United States, not only in the context of disease outbreaks but also more generally. By standard of care, we refer to the covered services, guidelines, and practices and procedures that govern the delivery of care in carceral settings. We argue that standards of care must carry flexibility in their implementation, while also helping define a transparent and measurable benchmark for quality of care and ultimately helping clinicians deliver care consistent with the best medical interests of patients.

We urge two reforms that would raise the standard of care. First, we advocate for expanding Medicaid financing and required benefits to correctional facilities, while tailoring this coverage to the context of jails and prisons. Second, we argue for federal and state oversight modeled on the oversight required in long-term care and other congregate settings to ensure compliance with standards. We argue that these standards must be enforceable, something that has been a major challenge under the status quo. These steps, taken together, would move carceral health care closer to equity between incarcerated and non-incarcerated people, an ideal grounded in the principle of fairness and expressed in human rights frameworks for carceral facilities. We acknowledge that this approach would still leave much work to improve the health of incarcerated people, most fundamentally by still needing to shift US society’s overreliance on incarceration in the first place, but it is nevertheless an essential step

forward for people confined in these facilities. We close by describing some of the tasks that lie ahead.

COVID-19 and the long-standing failures of US carceral health care

COVID-19 put on full display the harms of mass incarceration in the United States. As Benjamin Barsky and colleagues argue in relation to the pandemic, “perhaps no collective preexisting condition has been more acute and preventable than that associated with the U.S. system of mass incarceration.”¹⁰ As of May 2022, there were almost 810,000 confirmed cases and 3,412 deaths in US prisons and jails.¹¹ These cases are almost surely an undercount of the true burden, due to inconsistent testing and reporting from carceral authorities.¹² Nor do these numbers fully convey the morbidity of trauma and isolation, combined with fear of infection, that has afflicted incarcerated people.¹³ To quote a resident of a Michigan prison, “It’s inevitable. So we’re basically just sitting back and biding our time until we get sick.”¹⁴

Most carceral health care systems were not equipped to deal with a public health emergency such as the COVID-19 pandemic. Facilities that were already underperforming in their delivery of care for acute and chronic health conditions and which often lacked adequate dental, mental health, and other components of health care, were called on to address a monumental, resource-intensive challenge. In many facilities, resource constraints intersected with inconsistent infection control practices, including measures to implement testing and contact tracing and to reduce vectors of community spread, which were not effectively implemented in most facilities. Outbreaks among staff frequently have preceded outbreaks among residents, suggesting that staff were a common vector for COVID-19.¹⁵ However, few steps were taken to reduce transmission from staff to people in custody. For example, while some facilities have had strong compliance with face-mask wearing among staff, others had (and continue to have) widespread flouting of these requirements.¹⁶

During the height of the pandemic, supplies

were sometimes slow to flow from state agencies to prisons. In some of the most egregious documented cases, carceral authorities flagrantly ignored the severe and worsening conditions of patients with COVID-19, leading to likely avoidable deaths of patients in custody.¹⁷ This lack of urgency also plagued vaccination efforts in some facilities. Most state vaccination allocation policies enabled prison guards and other frontline staff to access vaccines well before incarcerated people, ignoring recommendations from expert groups that incarcerated people be given vaccine access at the same time as carceral staff.¹⁸ Vaccination rates in prisons have varied widely.¹⁹ Moreover, there have been continual challenges addressing vaccine hesitancy among incarcerated people, which itself can indicate low trust in carceral health providers and inadequate outreach and education.²⁰

In short, the COVID-19 experience crystallizes three critical points that we expand on in this paper. First, in carceral facilities, health care providers should be empowered to implement strong public health prevention measures, including better sanitary conditions and de-crowding efforts. These elements are among the “structural determinants of health.”²¹ Second, financing must be allocated to enable facilities to provide access to health care services at least equivalent to the quality afforded to the community. This goal can be achieved by building capacity within facilities, though in smaller facilities or for more specialized treatments, care for incarcerated people must be rendered in the community. Third, there must be a robust system for monitoring and enforcement. Such a system would encompass clear metrics for oversight, transparency to the public, and plans for remediation of shortcomings.

The Mandela Rules and equivalence

The “North Star” in defining a standard of care should be international rules on the rights of the incarcerated, particularly the United Nations (UN) Standard Minimum Rules for the Treatment of Prisoners, the most recent version of which is referred to as the Mandela Rules, in honor of Nelson

Mandela.²² Although not a comprehensive set of standards or guidelines, they set forth that “prisoners should enjoy the same standards of health care that are available in the community, and should have access to necessary health-care services free of charge without discrimination on the grounds of their legal status.” The Mandela Rules are an outgrowth of long-standing principles for the treatment of prisoners that date back to the 1955 UN Congress on Crime Prevention and Criminal Justice.²³ The 2015 update includes 122 rules covering all aspects of prisoners’ rights. Among these, 23 deal explicitly with medical and health services (rules 24–46). The Mandela Rules provide a strong basis for defining a carceral standard of care, including these elements:

- A set of required medical services and conditions that warrant evaluation and treatment
- Standards for adequate staffing
- Standards for medical records
- Provisions that cover prevention, hygiene, and public health preparedness
- Due process and coverage appeals
- Adequate care during reentry
- Medical ethics.²⁴

A commitment to the principle of equivalence reflects the ideal that a person’s incarcerated status does not diminish their basic entitlement to the same care that similarly situated people in the outside world would receive. In the European Union, the principles of equivalence are foundational to carceral health care and were written into law even before the adoption of the Mandela Rules.²⁵ In 2006, the Council of Europe amended its European Rules on Prisons to require health services under the conditions and with a frequency consistent with health care standards in the community. The European Court of Human Rights has cited the equivalence standard in its decisions.²⁶

Although many jurisdictions strive to provide care equivalent to that provided in the community, US courts will not uniformly enforce equivalence.

Some courts have held to the effect that the Constitution “does not require medical care that comports with the community standard of care.”²⁷ Within the European Union there exists a European network of national preventive mechanisms that monitors the health care and sanitary conditions for incarcerated people and measures compliance with the specific rules that have been adopted in each country (for example, countries have rules that encompass staffing and timely assessment in custody).²⁸ Similarly, in the United Kingdom, the standard is “to give prisoners access to the same quality and range of health care services as the general public receive from the National Health Service.”²⁹

The precise translation of these rules into practice is challenging and varies across the European Union, and even within that bloc there is some heterogeneity in the scope and delivery of carceral health care.³⁰ As Gérard Niveau argues, translating equivalence into carceral settings is challenging for at least two reasons. First, incarcerated people often have greater health needs than non-incarcerated people and require relatively more health interventions than the community.³¹ To make valid comparisons, it is therefore important to adequately account for the underlying differences in health needs between incarcerated and non-incarcerated people, meaning that measures that compare spending and other health care parameters must adjust for the greater burden of illness among incarcerated people. The goal of equivalence is to ensure that comparable needs receive comparable care in both quality and scope. We return to this issue in the context of oversight later in this paper.

A second challenge with an equivalence standard is that the elements of choice and autonomy are intentionally limited for incarcerated people. Even if health care practitioners have the same qualifications and training in carceral settings as in the community, incarcerated people rarely can select from a list of practitioners, for example, to find someone who matches their cultural background or care preferences. Furthermore, even if the practitioners and range of services are of comparable

quality, it has been argued that the special vulnerability of incarcerated people to adverse health outcomes requires going beyond equivalence and giving priorities to incarcerated people that do not typically exist in the community.³² For example, certain medical treatments may need to be “fast tracked” for incarcerated people in ways that are not normally required for non-incarcerated people to ensure that the special health risks of incarceration and the precarious period after release are addressed.³³

A third challenge is that the purview of correctional health extends beyond conventional health care services to encompass aspects of daily life that are medicalized in secure facilities. Access to resources such as bottom bunks, dietary accommodations, and even mundane items such as ice chips based on health needs often require medical approval. The peculiarity of medicalization of everyday life in correctional facilities has no parallel in community settings and is therefore beyond the reach of a uniform equivalence standard.

Whatever the limitations of an equivalence standard, however, it captures a fundamental ideal of justice that health needs in society should be met in relation to the urgency and health vulnerability of the people who have those needs. At its core, equivalence is rooted in a commitment to the moral equality of people, expressing the same rights to have health needs met between incarcerated and non-incarcerated people. Additionally, health care in carceral institutions must be decoupled from punishment since people do not forfeit all human rights (including the right to health care) when they become incarcerated. It is illegitimate to effectively add to the sentences of detained individuals by withholding resources or treatments that should otherwise be available to them outside of carceral settings.³⁴

In the next section, we describe how a US framework for equivalence has gone largely un-built and neglected. With an eye toward the goal of equivalence, we then show how to build on this structure to begin to improve the standard of carceral health care.

The US (non) approach to the standard of care

The United States does not come close to the Mandela Rules requirement of equivalence. Indeed, several political and legal realities in the United States explicitly rule out the direct application of the Mandela Rules. Foremost, the United States does not consider UN interpretations of treaties binding. However, there may be scope for indirect influences. For example, the State Department often cites these interpretations—especially those of the UN Convention against Torture, which the United States has ratified, albeit with reservations—in its annual human rights reports. The Mandela Rules have also achieved widespread legitimacy, and like other international human rights standards can be employed to press states and the federal government to move toward adherence with them. Because there are so many detention and imprisonment systems in the United States, it is likely that some systems will be more open to adhering to these rules than others. It is therefore reasonable to anticipate incremental, system-by-system moves toward following the Mandela Rules as administrators, the carceral health community, and reformers recognize their value.

Implementing the Mandela Rules would be a vast improvement over current law. Most prominently, constitutional standards under the Eighth Amendment require only that carceral staff not be “deliberate[ly] indifferen[t] to serious medical needs of prisoners,” or, as more recently refined, that prison staff who essentially know of a “substantial risk of serious harm” take reasonable steps to abate that risk.³⁵ These judicial standards leave much room for discretion from carceral administrators as they determine what health care services their facility will provide. These standards are also interpreted diversely between courts.³⁶ Certainly, there have been instances in which the courts have taken stronger measures to affirm access to health and health care resources for incarcerated people. For example, the Supreme Court has allowed lower courts to uphold the regulation of environmental tobacco smoke and other risks, even if the adverse outcome has not yet come to fruition.³⁷ In 2011, the

Supreme Court upheld a massive prisoner release order in California upon proof that overcrowding was leading to seriously adverse health conditions and that years of efforts had failed to provide relief.³⁸

However, due process as conceived under the Mandela Rules is continually thwarted in correctional health care. A key hindrance is the Prison Litigation Reform Act, enacted by Congress in 1996 and signed into law by President Bill Clinton.³⁹ The act, among other measures designed to deter and nullify legal actions brought by incarcerated persons, requires that incarcerated persons “exhaust” their facilities’ grievance processes before seeking relief in court, meaning that several weeks or months must pass between the injury or risk and when they can file a lawsuit.⁴⁰ There is generally no exception for emergencies, and it was this provision that prevented residents from obtaining COVID-19 protective measures in the judicial system.⁴¹ Even when a person is successful and, for example, convinces a court to require a facility to make changes to prevent the spread of COVID-19, these changes expire after a period of 90 days to two years, depending on the nature of the judicial order issued and actions of the defendant, after which the plaintiff must essentially prove his or her case again to continue the relief won.⁴²

The absence of a standard with clearly defined covered services sheds light on stymied or delayed work to improve health care in carceral settings, such as initial resistance to antiretroviral treatments for HIV/AIDS and antiviral medications for hepatitis C.⁴³ Similar struggles have played out in efforts to address needs in sexual and reproductive health, including hormone and surgical therapy for gender-affirming care for transgender patients and access to abortion and contraception.⁴⁴ Moreover, medications for opioid use disorder such as buprenorphine and methadone are not in many correctional facilities despite clear evidence that they would be lifesaving in the midst of a national opioid overdose crisis.⁴⁵

These examples typify some of the wide-ranging variation in correctional health care services, but existing data on carceral health care are scarce

as there is no national database on health status, per capita health spending for incarcerated people, or service utilization. The national incidence of medical and psychiatric conditions among incarcerated people is uncertain. A now-dated survey of prison administrators reveals widespread differences in types of services offered onsite (and no comparable data exist for jails or other places of detention).⁴⁶ Spending on correctional health care is likewise known to vary widely. Annual per capita health care spending in a 2015 survey of state departments of correction ranged from almost US\$20,000 in California to about US\$2,000 in Louisiana, with a median of US\$5,720.⁴⁷

In the absence of national standards, several disparate sources have influenced the prevailing norms of care in correctional health care. We review three sources of health care norms: contracted health care services, guidelines from expert bodies, and voluntary accreditation standards. These influences are not nearly strong enough to achieve a comprehensive standard but are worth considering because of their reach, power, and authority in correctional health care.

Many correctional facilities contract their services to private for-profit health care companies and, to a lesser extent, local government or academic medical centers.⁴⁸ According to a 2018 survey by Reuters, 62% of US jails contract with a private company to deliver some or all of their health services.⁴⁹ Currently, the correctional health care landscape is dominated by a few large and many smaller firms, and their business is valued at US\$9.3 billion.⁵⁰ In state prisons in 2015, 17 systems used a direct provision model, 20 contracted with vendors, 8 used a hybrid (direct and contracted) model, and 4 had a state university partnership.⁵¹ The practice of contracting health care to private vendors could push toward some uniform standards through requirements for services, cost, and quality. In particular, health care vendors have the ability to negotiate contracts that cover a consistent set of services and can impose organization-wide quality-control measures enforced and made transparent through various auditing and quality-control techniques.

However, uniformity is by no means guaranteed. The specific manner that medical services are provided depends on the terms of the contract for health services in each facility. Thus, each company can offer widely varying experiences for patients depending on what the jurisdictions are willing to cover.

While there have been successful examples of private firms providing contracted services, helping lower costs without compromising quality of care, many firms have escaped accountability for lapses.⁵² However, the Supreme Court has held that health providers acting under contract with public correctional authorities cannot escape liability by virtue of their privatized relationship.⁵³ News reports highlight some egregious cases where privatized health care vendors engaged in deliberate understaffing, widespread denials of care, and unnecessarily burdensome utilization management to deter access to health care.⁵⁴ While, in theory, state correctional agencies have leverage through the request for proposal (RFP) process and may even fine companies for failure to maintain quality, many RFPs result in few bids, often in a market of just a few large companies. A 2017 review of 81 jail health care RFPs by the Pew Charitable Trusts concluded that “few RFPs laid out performance requirements and financial penalties or incentives that would hold contractors accountable for meeting service requirements.”⁵⁵

A different type of norm comes from the guidelines and advocacy positions of expert bodies. Various medical specialties provide specific guidelines for the care of incarcerated people. For example, the American College of Obstetrics and Gynecology has advocacy positions and standards for caring for pregnant people during incarceration.⁵⁶ Similarly, major international health organizations such as the World Health Organization define guidelines for the care of people with HIV who are incarcerated.⁵⁷ In the United States, the Centers for Disease Control and Prevention has put forward specific standards for incarcerated people and, most recently, guidelines for infection control during the COVID-19 pandemic.⁵⁸ However, in all cases, these guidelines are voluntary and do not generally constrain the de-

isions made by individual correctional authorities or medical care providers, or courts adjudicating prison health care cases.

A third, and sometimes overlapping, factor shaping the norms of care is third-party accreditation. The two most prominent accrediting bodies are the National Commission on Correctional Health Care (NCCCHC) and the American Correctional Association. NCCCHC is the most prominent health accrediting body and publishes manuals of standards related to jails, prisons, and juvenile detention facilities that are revised every five years.⁵⁹ To become accredited, facilities must meet these standards and undergo periodic reaccreditation review by NCCCHC. Accreditation has the potential to establish minimum benchmarks for the standard of care by enumerating different functions and indicators for compliance that would need to be fulfilled by inspectors. For example, NCCCHC manuals define the essential and important elements that must be met for functions such as governance, medical records, delivery of care, and staffing.⁶⁰ These standards are sometimes incorporated into the RFP process, requiring vendors to either obtain (or maintain) accreditation.

However, accreditation has severe limitations regarding standards of care. Because accreditation is fee based, the entire accreditation process can be costly and difficult to navigate. It is also voluntary. Further, with one or two limited exceptions related to triage, NCCCHC focuses on the existence of policies and procedures rather than the attainment of specific quality metrics. Also, while surveyors may examine some aspects of quality of care, providing quality care is not a general requirement for accreditation, and facilities with poor access or poor quality of care as judged by either the experience of patients (including the often degrading treatment that patients endure from staff) or outcomes for patients may still qualify for accreditation. Indeed, facilities accredited by both organizations have been found unconstitutional by courts nonetheless.⁶¹ Furthermore, most facilities, particularly jails, are not accredited. Accreditation is notoriously expensive, raising conflicts of interest, since the accreditator depends on the goodwill and continued

business of the correctional health industry. As a result, accreditors may need to accommodate the industry's priorities and to moderate the content of standards and the scope of auditing.⁶² Finally, accreditation standards require that facilities implement policies and practices but do not require that a specific level of quality of care be provided. It is possible to satisfy accreditation standards and provide substandard clinical care to patients.

In sum, the United States overlays a vague constitutional standard on a patchwork system that has no central standards, metrics, or authority. Accountability for care is often further circumscribed by vague contracts that are difficult to enforce. While third-party accreditation is perceived to set national standards, the reach and scope of accreditation remains limited.

Moving closer to equivalence: Medicaid

To improve medical care, a more stable source of funding is needed alongside clear standards. Medicaid funding could create needed resources and a transparent, comprehensive, and consistent set of covered services grounded in an achievable community standard, but adapted to the complexities of the carceral environment. As in Europe, the equivalence standard would benchmark care to the national health care system.⁶³ In a recent article, Marin Olson and colleagues argue that “the services that Medicaid covers could serve as a model for a reasonable set of mandated health services within correctional facilities to ensure care in these institutions is commensurate with care available in the community.”⁶⁴

Because of its program rules, Medicaid has been hemmed in from playing a wider role in correctional health care, at least until now. In 1965, when the program was first established, it was limited to covering the health care needs of specific groups of non-institutionalized people living in poverty—people with severe disabilities and women and children on welfare.⁶⁵ Congress did not want to assume costs that states were paying for people in institutions other than residents of long-term care facilities and explicitly excluded incarcerated indi-

viduals through the “Inmate Exclusion” clause.⁶⁶

Since 1965, however, Medicaid has grown in scope considerably. In half a century, it has grown from a relatively niche program to a program that now covers 56 million people living in the United States, including most people below the poverty level.⁶⁷ Most significantly, the 2010 Affordable Care Act provided a Medicaid expansion intended to cover virtually all non-institutionalized people below 138% of the federal poverty level and provided expansive subsidies to states.⁶⁸ The US Supreme Court ruled in 2012 that states could not be forced to expand Medicaid, which triggered a fiercely partisan fight over the law.⁶⁹ By 2022, 38 states and the District of Columbia had a Medicaid expansion.⁷⁰ There is ample evidence showing that Medicaid expansion improves access to care, reduces chronic disease, and saves lives among new enrollees.⁷¹

The growth of Medicaid has created more opportunities to coordinate care for people leaving correctional facilities. Under current statute, this takes the form of ensuring that incarcerated people have prompt access to a Medicaid card as soon as they are released.⁷² Indeed, 43 states have opted to suspend Medicaid benefits during incarceration, rather than terminating coverage and requiring individuals to re-enroll in the program.⁷³ In many states, caseworkers from Medicaid will help individuals complete the necessary paperwork to regain their benefits prior to reentry to ensure that individuals have a working Medicaid card on their day of release. These efforts have been shown to have substantial benefits to post-release coverage and access to care.⁷⁴

Further opportunities to use Medicaid during reentry could be on the horizon. The Medicaid Reentry Act was included as part of the Build Back Better legislation being considered in 2022.⁷⁵ If passed, the act would allow Medicaid funds to cover services for individuals in the 30 days prior to release from a prison or jail. This would be a major change, the first significant step toward paring back the Medicaid Inmate Exclusion. Indeed, in many jails where many people serve sentences of less than a month, the act would effectively cover the full duration of stays. As of this writing (May 2022),

the Build Back Better legislation appears unlikely to advance as proposed, but it is possible that a compromise bill may move forward. The Medicaid Reentry Act is believed to enjoy some bipartisan support and could potentially pass as a stand-alone piece of legislation in a future Congress.

Even if the Medicaid Reentry Act does not pass, there may be some promising advances made through the Medicaid waiver process. The idea of partially repealing the Inmate Exclusion has a history; states such as New York have previously applied for Section 1115 waivers that allow Medicaid to cover some health care costs, including COVID-19-related costs, for people in jails and prisons.⁷⁶ Provisions of the SUPPORT Act also created a pathway for states to obtain waivers from the federal government to use Medicaid to cover services for individuals with substance disorders in the 30 days prior to release, but guidance on how states could implement these provisions did not initially get provided.⁷⁷ Six states (Arizona, California, Kentucky, Montana, Utah, and Vermont) have waivers that were under consideration as of this writing to seek greater flexibility around the Medicaid Inmate Exclusion in the period prior to release.⁷⁸

The extension of Medicaid coverage requirements to jails and prisons as envisioned in the Medicaid Reentry Act has several benefits and provides a foundation for a longer-term expansion of Medicaid into correctional health. First, it would allow for consistent funding for carceral health and continuity of coverage for people who were already eligible for the program on the day before entering the facility. Ideally, this would mean that during a period of incarceration people would have assurance that their ongoing treatments and health needs would be met in a manner consistent with the services they received prior to incarceration. Second, for many incarcerated people, it would also raise the average standard of care, offering broader choice and more benefits than exist now. The 10 essential health benefits that are standard in Medicaid coverage and protected under statute would reach beyond the kinds of services typically offered to incarcerated people.⁷⁹ This would include coverage of contraceptive services, substance use

treatment, and the full array of prescription medications provided under Medicaid. Third, it would create more timely and seamless transitions around ongoing health needs, allow for more portability of health records, and provide assurance that medications and other services would be covered during the period of reentry.

For these reasons, Medicaid coverage would be a major step toward the Mandela Rules equivalence standard and even beyond it. As the program grows to cover most poor Americans, and particularly people leaving correctional facilities, it defines a viable community standard—no small feat for a country that has long abjured universal coverage. For people covered by Medicaid, the program has moved closer to a consistent set of benefits. Medicaid benefits are typically covered at no cost for enrollees, although those closer to the poverty line may be asked to provide nominal co-payments for services such as visits to the emergency department or prescription drugs. Beyond the required benefits, many states opt to cover additional services in Medicaid. For example, 47 states and the District of Columbia provide at least emergency dental coverage in Medicaid, and 35 cover some diagnostic, preventive, and restorative treatments.⁸⁰ Similarly, most states opt to include services such as optometry and podiatry, though the scope of these benefits varies.⁸¹

It must be acknowledged that the full expansion of Medicaid into correctional health requires grappling with substantial implementation considerations. The first issue is that not all Medicaid benefits can be easily grafted onto correctional health. Correctional care encompasses services that make it qualitatively different in many respects. While some benefits—such as coverage of the prescription drug formulary or requirements to offer vaccinations and preventive health exams—would be relatively straightforward to implement, other benefits would be much more complicated to implement given the unique staffing and clinical environment of jails and prisons. For example, there is no translatable Medicaid benefit for intake screening. Another critical issue relates to staffing and access to specialists. Medicaid programs

typically create network adequacy standards that must be met by managed care plans. These standards would need to be wholly reconceptualized in correctional settings and would likely need to be adapted to myriad factors, including the size of the facility and whether there is an outside specialist who can be readily brought on site (or to whom patients can be transported) to provide care. This issue is critical, since poor specialist availability is often a major bottleneck in correctional health care. Access may also be practically overcome with greater use of telehealth, a service modality that already exists in many facilities and is reimbursed to some extent by all Medicaid programs.⁸²

While we believe that correctional facilities would generally be motivated to meet Medicaid standards to take advantage of federal funding (which typically covers more than two-thirds of the total cost of care), working through the specification of a correctional Medicaid benefit will be a complex and necessary undertaking. It requires a wider process of federal and state regulation and stakeholder engagement. A full process of inclusive rule-making and a phase-in period for full compliance can help surface specific issues and develop workable approaches. Broadly, the critical task will be to develop regulations that encompass a certain amount of generality and uniformity (that any correctional entity would need to meet), while still creating adequate flexibility to allow services and coverage to adapt to the unique constraints and resources of each facility. This concern goes in two directions—it is important that a Medicaid standard does not create an unattainable target for facilities that have very low capacity, and equally important (for the small number of facilities that go beyond what state Medicaid programs offer) that the introduction of Medicaid does not “level down” the quality of services. For high-performing facilities, it may be beneficial to create aspirational standards that are markers of excellence or high quality and which could be linked to special incentives.

It can be useful to consider other prior areas where Medicaid has been expanded, particularly into institutional settings. For example, Medicaid created a single national standard for long-term

care facilities under the Nursing Home Reform Act. It states that nursing homes “must provide services and activities to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident in accordance with a written plan of care.”⁸³ A similar standard, along with detailed requirements for services and access, could be established for carceral facilities. Doing so could dramatically reduce inequalities that currently exist for people incarcerated within the same state—for example, by reducing the perpetuation of unequal care that exists between neighboring jails or between jails and prisons. A critical element of any national standard will be consistent oversight and quality assurance.

Oversight and quality assurance

Coverage and standards require oversight to ensure that benefits are consistently and equitably provided. Unlike the constitutional deliberate indifference standard, the focus should be not just on egregious violations of the limited rights recognized as constitutionally based but on quality of care.⁸⁴ Currently, there is no national oversight system, and even the term “oversight” has broad, inconsistent uses in corrections. We think that the core concern is to ensure that there is transparency and impartial documentation of how health care is actually being provided through on-the-ground fact-finding. Michele Deitch recently defined correctional oversight as

*an independent, external mechanism designed, at a minimum, to ensure the collection, dissemination, and use of unbiased, accurate, and first-hand information about correctional conditions of confinement or the treatment of incarcerated individuals, primarily through on-site access to the facilities.*⁸⁵

As Deitch and her team document, oversight practices vary widely across different authorities and have different levels of independence, authority, resources to conduct their investigations, and ability to make their findings public. Furthermore, some oversight bodies have the ability to set stan-

dards (i.e., to enact regulations) while others are tasked with monitoring compliance with existing guidelines but do not define standards to be met. In general, oversight bodies in the United States are weak where they exist and nonexistent in many jurisdictions. Nevertheless, Deitch's team found that from 2010 to 2020, there was a substantial growth in the number of jail and prison systems that came under external oversight in the United States. There are many forms of such external oversight, such as the New York City Board of Corrections, an independent body that inspects and reports on conditions in the city's jails in conjunction with the city's minimum standards set by its Jail Regulations, and ombuds models for state prisons in New Jersey and Washington State.⁸⁶ External oversight is also sometimes provided through monitors appointed through court-ordered consent decrees, though their work arises only after considerable harms have been endured.⁸⁷ Although far from perfect, they have had some successes in identifying and forcing remediation of conditions of confinement.⁸⁸

In most US cases, oversight is more limited in scope and access than the more robust and wide-ranging oversight models that exist, for example, in the United Kingdom (through Her Majesty's Inspectorate of Prisons, which publishes comprehensive facility-based reports) and in the Committee for the Prevention of Torture in Europe, whose inspectors regularly make unannounced inspections of prisons and write comprehensive fact-finding reports.⁸⁹ These reports, moreover, have been relied on by the European Court of Human Rights to make binding decisions on the health rights of incarcerated people.⁹⁰ The United States could adopt a similar approach and could advance oversight by agreeing to a protocol of the Convention against Torture that establishes the framework for this kind of mechanism.

Outside of a human rights framework, the US Congress could take steps to create an oversight body that ensures that facilities are meeting minimal standards. The presence of Medicaid funding for health care programs increases the leverage of federal authorities to regulate conditions in facilities. The comparison with long-term care fa-

cilities is instructive, where standards are enforced through state inspections. As Nina Kohn explains, historically, long-term care regulations have had mixed effects, particularly as the thoroughness and quality of inspections delegated to state agencies are often weak or inadequate, and accountability has been all too often absent even when penalties are available.⁹¹ Even violations of easily measurable metrics such as staff ratios have been overlooked. Thus, a federal framework for independent inspection by teams of inspectors as free of dual loyalty conflicts as possible would need to have clear guidelines for the training of the inspectors and rigor of the inspections. Inspectors should be authorized to have access to speak confidentially with health care staff, incarcerated persons, correctional personnel, and administrators, as well as given unfettered access to health care records and other documents.⁹² They should also have "golden key" access, allowing inspectors to enter a facility without prior notice and to go anywhere in the facility. Findings should be made public, and compliance with resulting recommendations should be assessed with binding remediation plans implemented if necessary. These recommendations are consistent with the guidelines offered by the American Bar Association.

To the greatest extent possible, it is important to insulate oversight efforts from "capture" in the political process. This is best accomplished by establishing independence of the regulators—that is, situating oversight bodies outside of the control and influence of correctional agencies, private vendors, and other such stakeholders. This reduces the potential conflict of interest that currently exists in voluntary accreditation, whereby the accreditor is dependent on the agencies and therefore may be reluctant to find faults or to impose strong conditions for remediation. In general, it is better to take the regulator outside of the normal political chain of command. Even placing the oversight body under the control of governors can raise potential challenges, since regulators may be reluctant to challenge elected officials or their appointees. However, we also recognize that there is a tension between making the regulator entirely arms-length from government authorities and giving it the

power to engage political authorities where needed. Oversight should also encompass a direct role for advocacy and inclusion from people who are currently or formerly incarcerated. The input of incarcerated people is infrequently solicited and often selectively ignored. We therefore recommend the creation of residents' councils that are consulted as part of the oversight process.

Finally, it is important that a system of oversight be oriented toward enforceable corrective actions and systemic remedial plans, when called for. The two elements of the system can work together: a quality-improvement paradigm can spur cultural changes that encourage learning across correctional health systems, disclosures of errors, and creativity in developing better solutions. The ultimate goal would be to break down the secretive culture that has pervaded correctional health care and to encourage friendly competition toward better care. Indeed, one of the tragedies of the COVID-19 pandemic in correctional health care is that learning across facilities was piecemeal and often emphasized failures of care rather than problem-solving that could be shared widely. However, corrective action also must be possible through the regulatory process. This may include developing new avenues for the legal enforcement of care standards through the courts, including allowing for private enforcement of the regulatory standards and repeal or relaxation of the Prison Litigation Reform Act. Ultimately, the test of the oversight system must be the progressive achievement of better, more reliable, and safe health care for incarcerated people.

Conclusion

Access to comprehensive health care for incarcerated people is a requirement of international human rights doctrines. The standard of equivalence, which is core to correctional health care in Europe, has long proven elusive in the United States despite the legal basis to have some health needs met under the Eighth Amendment. We have argued in this paper, however, that moving toward equivalence is now a more realistic goal and could concretely

be achieved by expanding the benefits and financing of Medicaid to correctional facilities, while ensuring that correctional health care is subject to external oversight to ensure that care is provided equitably and with transparency. We conclude with some practical observations about the challenges and opportunities that lie ahead.

Perhaps the clearest challenge is finally repealing the Medicaid exclusion for incarcerated people. The bipartisan principles of the Medicaid Reentry Act provide the most significant momentum toward repeal by allowing for Medicaid funding to cover incarcerated people 30 days prior to their release. While this still keeps most funding responsibility for prisons at the state level, it is a potentially transformative change. Even if the Medicaid Reentry Act is not immediately passed, we believe that proposed 1115 waivers could meaningfully advance the goals of broadening Medicaid funding in jails and prisons. Beyond the immediate potential to shift more financing to Medicaid, the introduction of Medicaid funding creates pressure for correctional facilities to begin aligning services with existing Medicaid benefits while adapting to the unique circumstances of correctional facilities and to introduce external oversight from Medicaid as a payer that is necessarily invested in ensuring that correctional facilities meet the program's standards.

More generally, we foresee challenges to creating broader national oversight of correctional health care. We believe that an incremental campaign focused first on transparency is important. As noted, there is a glaring gap in data on the health needs of incarcerated people and their access to care. Federal laws could increase data collection and introduce health care measures into facilities. For example, the federal government could lay the groundwork for expanding data collection of health surveys into correctional facilities. Currently, other data collection efforts such as the American Community Survey Group Quarters component are already successfully being implemented in correctional facilities.⁹³ There are also opportunities to create better models of oversight. For example, the federal Bureau of Prisons could commit to new

standards of transparency, such as reporting on health care quality metrics such as those found in the Healthcare Effectiveness Data and Information Set core measures promulgated by the National Center for Quality Assurance. These measures span six domains that reach beyond the current criteria used by correctional health care accreditation.⁹⁴

A third challenge that must be acknowledged is that efforts to reform correctional health care must coexist alongside a campaign to reform correctional institutions as a whole, as well as the wider campaign to end mass incarceration. It might be argued that bolstering correctional health care and spending more federal dollars in this arena reduces pressure to slow the growth of incarceration. According to this theory, the greater availability of Medicaid funding could reduce budgetary pressure that typically leads jurisdictions to seek ways to reduce correctional budgets, including efforts to decarcerate more rapidly. However, we do not see the two goals in tension. For example, it is possible to create decarceral goals as a condition for federal grants (e.g., providing grants for reducing population size), an idea that was seriously considered by the Biden administration.⁹⁵

Fourth, and related, correctional health care cannot be narrowly construed to draw limits at the boundaries of medical care; it should also encompass the public health metrics that reflect overcrowding and environmental exposures. This includes violence, sanitation, corrections, and custody, each of which has an important interaction with health in places of detention. That is, creating comprehensive health care standards are necessary but not sufficient to boost the health of incarcerated people. As noted earlier, correctional health already has a toehold in the oversight of living conditions, but mainly in the context of requests for accommodations such as bunking. However, we believe that greater external monitoring and measurement of changes in health status can draw attention to environmental conditions that affect health and health care. For example, public health prevention goals could be incorporated into the standard Medicaid plan, similar to patient safety standards that currently govern long-term care facilities.

Despite their high walls and steel doors, prisons and jails remain part of the community and are fully integrated with a community's epidemiological environment. A move toward equivalence acknowledges this reality on two levels—first by upholding that incarceration does not nullify human rights claims to have basic health needs met by the state and second by clarifying that what happens in prisons matters to everyone in society. COVID-19 has proven that there is no magic barrier that prevents correctional facilities from diseases circulating rapidly in the population and, in turn, from becoming a source of transmission back into the community. The point has a more general significance as people who leave correctional facilities contribute to the collective health and well-being of society. In the final calculation, greater attention to the health of incarcerated people underscores the fundamental reality that we are all in this together.

Acknowledgments

We gratefully acknowledge a Making a Difference grant from the Greenwall Foundation, entitled "Rationing Behind Bars: Resource Allocation in Jails and Prisons During COVID-19." We also thank Minna Song for assistance preparing the manuscript.

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PERSPECTIVE

State Accountability for the Good Health of Palestinians Has Failed: What Can the Global Health Community Do Next?

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Introduction

In early June 2021, *Scientific American* published a statement by health care workers, calling on health care systems, academic institutions, and health care professionals in the United States to “unequivocally condemn Israel’s long-standing oppression of the Palestinian people” and the ongoing decimation of their health.¹ Similar statements were issued by other health professional groups.² These statements of solidarity with the Palestinian people came following the May 2021 deadly bombings in the Gaza Strip and violence in the West Bank and East Jerusalem, and amid a shifting global recognition of the realities of systemic discrimination, racism, and settler colonialism against Palestinians in the occupied Palestinian territories (oPt) and Israel. Around the world, awareness has been growing of the illegal and immoral crimes committed against Palestinians by Israeli government policies, soldiers, and settlers, and of the impacts on health resulting from persistent oppression amid this profound power disparity.

The *Scientific American* solidarity statement has since been retracted, replaced with an editor’s note that the article “fell outside the scope of *Scientific American*.” The same day this statement was initially published, *BMJ Opinion* featured an article highlighting the dangerous new precedent for political censorship on Palestine in academic journals.³ This opinion piece described the publishing and subsequent retraction by the *Lancet* from its website and print journal of a letter on the potential devastation of COVID-19 in Gaza. While the letter remains accessible through other sites, it has been removed from the *Lancet* journal itself.⁴

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Competing interests: None declared.

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As public health academics and practitioners working around the world who believe in the right to health as a basic human right, closing the health equity gap and the attainment of universal health coverage, the importance of evidence-based health care, and the ethical principles of ensuring good health and well-being that underpin our health education and training, we fully support the call to action from health care colleagues originally published by *Scientific American*, and we are appalled that their voices have been silenced post-publication.⁵ Further, we appeal to *all* health care scientists and professionals, health care organizations, global health academic institutions, and global health academic journals to take steps to hold to account the states and institutions that deprive people anywhere, including Palestinians, of their right to health, and to reproach any attempts to censor calls for the realization of this right. Building on recent global momentum, we propose the establishment of an independent observatory of prominent and powerful health professionals and institutions to ensure a more effective accountability mechanism for the health of Palestinians.⁶

Health as a universal human right, “without distinction of race, religion, political belief, economic or social condition,” was first agreed on by states in the Constitution of the World Health Organization and the Universal Declaration of Human Rights, and enumerated in many international agreements since.⁷ Ironically, the Universal Declaration of Human Rights was adopted the same year that Palestinian people were initially dispossessed—1948, the year of the Nakba—and Palestinians living under Israeli settler colonial rule have since endured seven decades of violence, gross human rights violations, and poor health outcomes.⁸

Why, then, is there continued disregard by states and the wider global health community toward accountability for the good health of Palestinians, regardless of race, religion, or political belief? Bluntly put, state accountability for the health of Palestinians has failed. How can we, as a global health community, ensure such accountability and overcome the impunity afforded to Israel for

its role in exiling Palestinians from their right to health? “Silence,” the health care workers wrote in their (paradoxically now-retracted statement), “is complicity.”⁹ We are at a critical new juncture—and silence is no longer an acceptable response.

The failure of global health accountability to protect the health of Palestinians

Accountability for health is rooted in international legal obligations and human rights. Israel has continued to ignore duties under international human rights law and the right to health—as well as its obligations under international humanitarian law as an occupying power—by denying Palestinians essential health resources, actively obstructing access to health care, and deliberately attacking health infrastructure.¹⁰ This denial and obstruction includes a stifling blockade of the Gaza Strip; a separation wall, expanding settlement infrastructure, and an extensive checkpoint system in the West Bank; and a medical permit system, controlled by Israel, for travel out of the West Bank or Gaza Strip to receive health care unavailable in the territories due to these same Israeli restrictions. Israeli authorities’ denial of permits, often without explanation, for Palestinians wishing to access urgent and often lifesaving health care outside Gaza and the West Bank has led to the unnecessary deaths and suffering of many patients, especially those with cancer.¹¹ Moreover, the May 2021 period of heavy Israeli bombardment on Gaza led to the direct targeting of key roads and access routes, preventing ambulances from reaching hospitals and health clinics.¹²

While countries have scrambled to vaccinate their populations against COVID-19, Israel has unashamedly withheld vaccines from the Palestinian population.¹³ As of November 18, 2021, just over 53% of Palestinians across the West Bank and Gaza had been vaccinated, while Israel has been lauded for the success of its mass vaccination campaign of its own citizens.¹⁴ Last year’s escalation of violence increased the risk of likelihood of COVID-19 transmission, and damage to health facilities—including Gaza’s only COVID-19 diagnostic testing facility—hindered the ability to properly respond

to the pandemic, as did the killing of Abu al-Ouf, the physician leading the pandemic response at the largest hospital in Gaza.¹⁵ In intensive care units, 36% of those admitted during the escalations were patients with COVID-19-related complications.¹⁶

In March 2020, Michael Lynk, the United Nations (UN) Special Rapporteur on the situation of human rights in the Palestinian territory occupied since 1967, appealed to Israel's legal duty, anchored in article 56 of the Fourth Geneva Convention, to ensure all necessary preventive means available to combat the spread of contagious diseases and epidemics and ensure that Palestinians receive essential health services.¹⁷ In October 2020, Lynk reported to the UN General Assembly that "Israel as the occupying power has the primary responsibility to ensure respect, protection and fulfilment of the right to health of Palestinians in Gaza to the full extent of their actual control" and that the ongoing Israeli-imposed blockade on Gaza contravenes international law, specifically article 33 of the Fourth Geneva Convention, amounting to "the collective punishment of the entire civilian population in Gaza" and an experiment "in human despair."¹⁸

Global health accountability mechanisms are supposed to exist to ensure that governments, health policy makers, and health systems follow through on their legal and moral duties to improve the health and well-being of all people, especially the most vulnerable.¹⁹ Accountability processes are supposed to play a vital role in driving progress toward health equity commitments that governments, institutions, and organizations have made.²⁰ "Without accountability," says Lynk on Palestine, "the possibility of political reconciliation, let alone its flourishing, is unattainable. And without accountability, social wounds metastasize, leaving unchecked retaliation, rather than measured restitution, as the likely response to the injustices of the past and present."²¹

A number of multilateral mechanisms exist to keep Israel's adherence to duties, including health, in check. The Office of the UN High Commissioner for Human Rights in the occupied Palestinian territory is responsible for monitoring and reporting publicly on the human rights situation there.²² The

Special Rapporteur on the situation on human rights in the oPt, the Special Committee to Investigate Israeli Practices Affecting the Human Rights of the Palestinian People and Other Arabs of the Occupied Territories, and the UN Secretary-General himself regularly investigate and report on the situation in Palestine. The Security Council is the custodian for ensuring international peace and security and has the authority to impose international sanctions when peace and security are threatened. The World Health Organization's Right to Health Advocacy program in the oPt works specifically to strengthen the monitoring of barriers to the right to health, including obstacles to health access and attacks on health care.²³ Reports on progress toward Palestinians' right to health are provided to member states at each World Health Assembly by the Director-General of the World Health Organization.²⁴

But what have these mechanisms achieved to improve the health of Palestinian people? Israel continues to act with impunity under the world's watch, other global powers allow this impunity without consequence, and private corporations continue to play a significant role in propping up and profiting from the illegal Israeli occupation and settlements. The veto powers of the permanent members of the Security Council undermine the very accountability mechanism that exists to maintain peace and security and perpetuate an agenda with colonial roots.²⁵ Appeals—over decades—to Israel's legal, human rights, and moral duties have fallen on deaf ears; and international condemnations for grave breaches to health rights and humanitarian law have failed to make Israel accountable in practical terms. Even the decision to report on progress toward Palestinians' health at the World Health Assembly has caused division among member states.²⁶ The international community of nation-states and key UN bodies have failed the Palestinian people. As Rashid Khalidi recently voiced to the UN Security Council:

Since the founding of the United Nations, the Security Council has passed multiple resolutions on the Palestine problem and the Israeli-Arab conflict. These issues that have taken up more of the time and energy of this body than any other

*global problem. Most of these resolutions have not been implemented or respected. They are dead letters. This systematic disrespect for Security Council resolutions, encouraged by the impunity I have described, has left this Council, and the United Nations itself, in justifiable disrepute. More seriously, this impunity has been a major obstacle to establishing peace, justice and security for all who live in Palestine and Israel.*²⁷

First steps toward accountability for the good health of Palestinians

In 2019, *Lancet* editor Richard Horton published an article titled “The urgent need to protect global health accountability.”²⁸ What can be done? What can we do?

Achieving accountability for the good health of Palestinians will require that we as individuals and the organizations we work with and for do not allow a sense of helplessness to overcome us. The big-picture situation in terms of ending the occupation of Palestine undoubtedly needs resolution, but we as a global health community can take some immediate, smaller steps—including steps to hold accountable those who perpetuate the poor health outcomes and unnecessary suffering of Palestinians, and calling out those complicit in censorship.

Accountability means raising our united voices as health-focused institutions, organizations, and individuals to challenge settler colonization, racism, and asymmetries of power and demand that the health needs of Palestinians be met.

History has universally demonstrated that the cost of colonization and systemic racism is the good health of the colonized and subjugated. In the case of the Palestinian population, colonization, systemic racism, and conflict are root causes of adverse health outcomes, unnecessary suffering, and preventable deaths.²⁹ There can be no accountability for good health if governments, institutions, and organizations continue to perpetuate imbalances of power by excusing policies and practices that support structural violence and oppression.

Discourse on the decolonization of global health has gained momentum in the past year,

amid racial reckoning following the Black Lives Matter movement. The *decolonizing global health* movement fights against ingrained systems of dominance and power to improve the health of populations.³⁰ We have a greater understanding of the impacts of systematic oppression and occupation on health; and now is the time to challenge and correct asymmetries of power and dominant discourse by promoting decolonial narratives with regard to the health of Palestinians.

For decades, improving the health of Palestinians has been framed as a “humanitarian issue” under the responsibility of the international community.³¹ Though humanitarian assistance to Palestinians is well intentioned, this framing relieves Israel of its duty as a belligerent occupying power to assure the good health of Palestinians. It also has the effect of categorizing Palestinians as a class of victims to be saved with donations, aid, and service provision by humanitarian actors. A more just and historically rooted approach would be to frame the situation as it is—an Indigenous population resisting a settler colonial regime in order to achieve sovereignty and rebuild its own health care system.

We have been encouraged by recent calls for the decolonization of journalistic reporting and academic scholarship on Palestine, as well as by academic solidarity in support of the self-determination and liberation of the Palestinian people against Israeli colonialism.³² We are also heartened by growing public support for Palestinians in all corners of the globe. Health professionals are increasingly rallying against health violations targeting the Palestinian people.³³ The *Lancet* Palestinian Health Alliance, established in 2009 as a network of Palestinian and international researchers, has provided an important platform for research, advocacy, and action on health in Palestine.³⁴ We are uplifted by the recent statements of health workers and professionals in the United States in support of Palestine, including the retracted solidarity statement.³⁵

Now is the time to expand such statements and build on the work of the *Lancet* Palestinian Health Alliance and other collective efforts. Global health

institutions and bodies, health academics, practitioners, and policy makers are “uniquely positioned to respond to the social, political, and economic structures affecting our patients’ health” and to act on evidence-based truths.³⁶ It is incumbent on us to do so, and to do so collectively.

The first important step is to keep pressing forward with the decolonizing health discourse through formal statements and calls to action across all health systems, global health academic institutions and journals, and health care colleagues. We need a critical mass of health professionals and institutions campaigning for the right to health in Palestine.

In the immediate term, we must collectively call on Israel to do the following:

- take responsibility for repairing and restoring the health care infrastructure decimated by the May 2021 bombings;
- commit to a cessation of military and civilian violence directed toward the Palestinian people;
- end attacks on health care workers and health care infrastructure;
- permit free, easy, timely, and sustainable access to essential health services and goods in Gaza and the West Bank; and
- permit free, easy, timely, and sustainable access for people requiring essential medical care outside of Gaza and the West Bank.

We must publicly reproach efforts to censor Palestinian voices and stories in favor of “balance” or the “cruel false equivalence.”³⁷ It is incumbent on us as individuals and organizations in global health to hold accountable any person or organization that attempts to silence the voices of those who advocate for the good health of Palestinians.

Accountability means bolstering independent processes for monitoring and reporting on violations to the right to health, with sanctions imposed when the right is not met.

Israel continues to shrug in the face of immunity

from consequences for violating legal duties and societal norms, a path smoothed by other dominant global powers and large private corporations. Despite credible monitoring and documentation on progress (or lack thereof) toward Palestinians’ health and human rights by institutions such as the World Health Organization and the Office of the United Nations High Commissioner for Human Rights, existing accountability mechanisms have failed. We propose bolstering independent mechanisms for health accountability toward Palestinians in the oPt, with representation, input, and lobbying from a formalized independent observatory of prominent and powerful health professionals and institutions.

There is precedent for such independent mechanisms. In 2012, the independent Expert Review Group on Information and Accountability for Women’s and Children’s Health was created in response to the failure of UN agencies, donors, and countries to achieve improvements in the health of women and children, and in recognition of the need to better track progress on and resources for women’s and children’s health. The group was made up of leading global health academics and practitioners, including Horton, editor of the *Lancet*, serving in an independent capacity. In their first progress report, the independent reviewers wrote that

our shared view is that independent accountability is, and will increasingly become, a powerful force to accelerate progress towards both national and international health and development targets ... We want to see independent accountability not only become a new norm in global health, but also demonstrably improve the lives of women and children worldwide.³⁸

Monitoring and reporting alone are not sufficient for successful accountability. A new and formalized alliance of powerful global health scientists and professionals, health care organizations, global health academic institutions, and global health academic journals committed to achieving the right to health, starting with Palestinians’ health, could achieve the following:

- form a secretariat and seek registration as a non-state observer to the World Health Organization;
- use existing evidence to call on states to take action to enforce health and human rights norms; and
- demand the enactment of sanctions when right to health violations are reported and key health outcomes are not met. This would include seeking an end to all partnerships with private corporations that uphold Israel's occupation and oppression of the Palestinian people and revisiting all government aid that may perpetuate the occupation.

To have an impact that shifts the balance beyond politics as usual, such an observatory would require the support of powerful and respected public and private health institutions. Health advocates and institutions must be prepared to stand firm in the face of fear of reprisal, harassment, or silencing from any government, institution, or funding body.³⁹

This observatory would help communicate to the world in a relatable manner the impacts of structural racism and oppression—for example, vaccination rates of the population of Israel versus vaccination rates for Palestinians; access to lifesaving cancer treatments for Israeli patients versus access to lifesaving cancer treatments for Palestinian patients; and advancements in health care resources, infrastructure, and technology in Israel versus the destruction of health care facilities in Palestine.

If proven effective in improving health-focused accountability for Palestine, such an independent observatory could also seek to achieve improved health across other contexts of occupation or conflict around the world where the right to health of people living in conflict is ignored or undermined, such as Syria, Yemen, and Myanmar—in this way aligning with and reinforcing the World Health Organization's Health and Peace Initiative, which promotes a health care lens to address the underlying causes of conflict.⁴⁰

Conclusion

There must be accountability for the acute and longer-term impacts on Palestinian health that flow from the bombings in Gaza and violence in the West Bank and East Jerusalem. Israel has not been held to account for the recent escalation of violence or for the willful obstruction of the passage of essential care and resources that would protect the Palestinian people from COVID-19. Israel has also not been held to account for creating and perpetuating the conditions that have led to the chronic degradation of the Palestinian health system and the poor health of Palestinians.

States that act to degrade the health of whole populations must not be permitted to continue doing so with impunity. It is time to end our tolerance for companies and institutions that are complicit with or support the structural violence of colonization and racism that is denying the good health of Palestinians—a right that all Palestinians are entitled to enjoy. Strengthening health accountability toward people living in conflict settings can open new avenues for assuring good health, ending oppression and violence, and building peace. As a global health community, we must raise our collective voices and reproach censorship and attempts to silence us.

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PERSPECTIVE

Mandatory COVID-19 Vaccination: Lessons from Tuberculosis and HIV

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There is little doubt that vaccines represent one of the most significant medical advancements in human history, eradicating smallpox and averting millions of deaths from infectious diseases annually.¹ Nevertheless, they are currently undermined by the convergence of three pandemics: COVID-19, vaccine hesitancy, and internet-facilitated misinformation. This convergence has had a catastrophic cost across multiple dimensions: human lives, society and the economy, civil rights, individual rights, livelihoods, and access to essential health care services. At the same time, science has made tremendous progress. Within 12 months, pharmaceutical companies managed to develop, manufacture, and scale up access to COVID-19 vaccines, leading to the global distribution of several vaccines with proven safety and efficacy. However, as each new wave of infection approaches, vaccine uptake appears to be plateauing in many countries. In most settings, there is evidence that a significant proportion of people have so far chosen to remain unvaccinated despite the accessible and free delivery of vaccines. While many countries rapidly declared a state of disaster early in the pandemic, we are now seeing burgeoning national debates around mandatory COVID-19 vaccination and other COVID-19 precautions in democratic societies, where an argument is being made that autonomy, civil liberties, and individual rights are in conflict with the protection of public health and efforts to achieve population immunity.

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Competing interests: None declared.

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The enforcement of individual obligations to the community and restrictions on individual freedoms are not novel; service on juries, the use of seatbelts, and the prohibition of firearms have been integrated in different countries to varying degrees and are widely accepted as benefitting the greater good.² Furthermore, in many settings, mandatory vaccination policies for children, tied to schooling, and mandatory influenza vaccines for health care workers are already in existence.³ By extension, could mandatory COVID-19 vaccination be similarly justified? Indeed, the introduction of mandatory COVID-19 vaccination would increase uptake, but its implementation could also increase public mistrust in governments and vaccine hesitancy. Further, the consideration of appropriate penalties for individuals who reject such vaccination raises complex human rights considerations.

Although governments could, in theory, consider the implementation of mandatory COVID-19 vaccination across their populations, selective approaches intended to yield the greatest protection for those at highest risk are more typical.⁴ In addition to any government requirements, many employers have also already instituted mandatory vaccination. For several reasons, the mandatory vaccination of health care workers has been the focus of much debate. The main reasons that led to the earliest vaccine mandates implemented among health care workers globally included (1) the protection of a scarce and skilled workforce on the frontlines; (2) the prevention of health-worker-associated outbreaks; and (3) the building of public confidence in vaccination.⁵ But today, more than a year after the COVID-19 vaccines became available, it is clear that this approach will not successfully contain the pandemic in such an interconnected world and that COVID-19 is likely to be with us for the foreseeable future. For example, workers in the retail, hospitality, travel, and beauty industries are also high-risk groups who have close human interactions daily. Moreover, corporate workers—who may be appropriately physically distanced in the office—may utilize crowded public transport systems for their daily commute.

Therefore, global efforts to control and con-

tain the COVID-19 pandemic require a paradigm shift. Even in selected populations, mandatory vaccination is logistically challenging to enforce, particularly with an anti-vaccination movement at its peak, and also ethically challenging to justify, especially when accompanied by punitive measures for noncompliance.

The human-rights-versus-public-health arguments require further exploration where testing and mandatory vaccinations are concerned. Currently, mandatory testing is in place for COVID-19 in countries such as Austria, Ecuador, Greece, Indonesia, and Micronesia. During a major surge in COVID-19 cases in Austria in early 2022, Austria introduced mandatory vaccination for all eligible adults, with a fine of €3,600 for noncompliance. Although the mandate has subsequently been suspended alongside the waning of COVID-19 cases, the regulatory framework remains in place should the epidemic trajectory change. Ecuador became the first Latin American country to introduce mandatory COVID-19 vaccination for all eligible adults in December 2021. There, although private individuals face no punishment for noncompliance, venue operators of non-essential activities (such as restaurants and shopping malls) can be fined or shut down for allowing unvaccinated individuals to access their venues. In Greece, COVID-19 vaccination is mandatory for individuals over the age of 60 and for health care workers, who face escalating fines or dismissal, respectively. Indonesia introduced mandatory COVID-19 vaccination for all eligible adults in February 2021 via a presidential regulation, with a fine of US\$355 for noncompliance. Micronesia introduced mandatory vaccination for all eligible adults in August 2021, with a penalty of the loss of all forms of federal funding for noncompliance.

Before we had vaccines, many individuals understood the necessity of mandatory testing in order for certain liberties to be afforded to them. This included travel and visiting certain spaces, whether private or public. Now that some countries have access to vaccines, the discourse of mandatory vaccination has taken center stage. From an international and comparative constitutional law perspective, there is growing consensus that vaccine

mandates may be legal and ethically justifiable. The Lex-Atlas COVID-19 (LAC19) project, comprising a global network of 50 jurists, has concluded that mandatory vaccination and human rights law are compatible in principle.⁶ However, in-principle compatibility does not reduce the burden of establishing when vaccine mandates may be necessary, justifiable, and ethical. Further, implementing vaccine mandates in the face of government mistrust, high levels of misinformation, and vaccine hesitancy requires great care. Indeed, the LAC19 principles call for constructive public engagement, especially in dealing with reasonable vaccine hesitancy. Thankfully, various lessons can be learned from the global experience of other diseases, especially in the last three decades.

If the world has learned nothing about the ineffectiveness of coercive strategies where public health measures are concerned, one only has to look at the HIV and tuberculosis (TB) epidemics. For the former, the scientific community, which initially promoted bio-medicalized approaches, learned quickly that there would be no epidemic control without the leadership of HIV-affected communities. The introduction and scale-up of life-saving antiretroviral therapy was borne out of one of the strongest health movements the globe has ever seen. People living with HIV spearheaded interventions that were community led and owned. Those lessons continue to be a backbone for some of the world's largest and most sustainable HIV responses.⁷

This has come as a result of bottom-up responses, a focus on HIV treatment literacy, and a commitment to keeping people living with HIV well informed about the benefits of antiretroviral therapy. At the same time, people living with HIV continue to face stigma and discrimination. This includes restrictive measures such as travel bans from a number of countries.⁸ The HIV movement has instilled, across the globe, the necessity for rights-based, people-centered responses for any public health response to be effective. This has also gone a long way in ensuring the meaningful engagement of people living with HIV and the widespread acceptability of treatment, including

introducing a long-acting injectable regimen, which will revolutionize antiretroviral therapy. Notably, HIV advocacy groups are key proponents of the ongoing search for a successful HIV vaccine.⁹

Important lessons have been learned from the TB response too. TB is a disease of antiquity and continues to be highly bio-medicalized. Learning from the HIV movement, yet appreciating the nuances that differentiate the two diseases, the global TB response has required a complete paradigm shift from the biomedical paternalism of the past. From a public health standpoint, TB has remained a legally notifiable disease in many countries. As a result, persons with TB have been subjected to coercive measures in some countries, leading to forced isolation and involuntary detention as part of public health strategies for limiting disease transmission. In countries as diverse as Canada and Kenya, individuals have been imprisoned for non-adherence to their TB treatment.¹⁰ In the Kenyan case, this led to a class-action lawsuit by imprisoned men. Petition 329 (as the case is famously called) focused on the lack of rights-based responses to treatment and the abrogation of duty by the government to follow due process in terms of the isolation protocols required by the Kenyan Public Health Act. The court in the case found that involuntary confinement in a prison setting did not amount to isolation.¹¹ Although the petitioners won the case, they were not rewarded due to their non-adherence to TB care. The judgment instructed the Ministry of Health to develop a rights-based people-centered isolation policy. Kenya's reformed Tuberculosis Isolation Policy was launched in Nairobi in June 2018 by the Ministry of Health and the National Tuberculosis Program.¹² The policy outlines the procedures to be followed in the isolation and admission of TB patients who interrupt TB treatment or refuse to take anti-TB medicine.

Even with urgency to invest in and advance community-centered and client-centric rights-based responses to TB, the World Health Organization's *Global Tuberculosis Report 2020* estimates that 10 million people developed TB in 2019. Broken down, 7.1 million (71%) were diagnosed and reported to national TB programs worldwide, leav-

ing a gap of 2.9 million undiagnosed people (29%).¹³ The TB community continues to grapple with finding people with TB, bringing them into care, and retaining them in follow-up care. The failure to prioritize and invest in rights-based approaches contributes significantly to why people affected by TB do not feel comfortable accessing TB services or completing their treatment.

Alongside COVID-19, multidrug-resistant TB (MDR-TB) remains another area of concern. A large proportion of people with MDR-TB are missing or not brought into sustainable care. According to the World Health Organization, out of an estimated 500,000 people with rifampicin-resistant or multidrug-resistant TB, 293,970 (59%) were missed due to inadequate testing for drug susceptibility, especially among people with new episodes of TB. Since 2020, the diagnosis, notification, and treatment of MDR-TB have been on a downward trajectory.¹⁴ While the reported cases of MDR-TB are falling, the true incidence of MDR-TB continues to increase due to various factors. The scientific community opines that this is a result of inadequate testing; however, several questions remain. Why are people not coming forth to be tested? Why do those who receive their results not want to be initiated on MDR-TB treatment? Why are so many people dying from a curable infectious disease? These are not philosophical questions. The answer is found in the way in which people are treated or in their perceptions of how they might be treated. Lengthy treatments aside, the lack of prioritization of human rights responses and the continuation of biomedical and coercive public health-based approaches remain the key problems. Today, there is a growing community movement of MDR-TB affected communities who have survived the disease. The MDR-TB community engagement tells us what works: the installation of rights-based, patient-centered responses to MDR-TB.¹⁵

The COVID-19 response since the start of the pandemic tells an unfortunate tale in terms of global solidarity and equitable access to COVID-19 therapeutics. While some countries (mostly high-income ones) have had access to the vaccines since late 2020 and are now implementing booster

shot strategies to fight the more virulent strains of COVID-19, other countries had not had the opportunity to provide a second dose of the vaccine to their populations by early 2022. Some middle-income and most low-income countries had been unable to access vaccines until as recently as early 2022. Thus, while countries such as the United Arab Emirates report a 96% vaccination rate of their population, less than 10% of Africa's 54 nations hit the 2021 year-end target of fully vaccinating 40% of eligible people.¹⁶

Global health inequities aside, the introduction of mandatory vaccination protocols is rising across the globe.¹⁷ Many countries started with staggered approaches, focusing on frontline workforces, public-facing service delivery workers, and other at-risk populations. What started as a trickle effect has now become a tidal wave of vaccine mandates, differing in form and intensity from country to country.

Importantly, a growing movement of individuals identify as part of an "anti-vaccination movement." This movement argues that vaccine programs are coercive and are government attempts to control the bodily autonomy of individuals and freedom of movement; as such, they amount to a violation of people's fundamental human rights. This conundrum raises two critical questions. One is whether these arguments of so-called anti-vaxxers are justifiable. The second is whether governments are looking for avenues to abrogate their duty of care by bluntly enforcing these mandatory vaccine measures and punishing people for refusing to comply. In many countries that have already started enforcing mandatory testing measures, there has been increasing resistance to the manner in which they are carried out. For instance, in November 2021, when 64% of the Austrian population was fully vaccinated (below the European Union average), the government implemented new restrictions, including the restriction of movement of those who refused to be vaccinated, while countries such as Australia and Latvia banned unvaccinated legislators from parliament. The list of countries adopting vaccine mandates continues to grow but includes few African countries. In this region, the

mandatory vaccination discourse is led by countries such as South Africa, Kenya, and Nigeria, where vaccines are accessible. Arguments for this restriction of freedom of movement include the fact that individuals who have not been vaccinated are more likely to transmit COVID-19 and contribute disproportionately to the burden of hospitalization. Governments argue that the intensification of mandatory vaccination protocols is due to the spike in hospitalization of unvaccinated people and that their intensive-care wards could rather be utilized for people who suffer from illnesses other than COVID-19. It remains undisputed that while vaccines do not completely stop the transmission of the more transmissible variants, they do circumvent hospitalization and death as a result of COVID-19-related complications.¹⁸ But to squarely blame those who have not been vaccinated and who have solid reasons why they do not want these vaccines seems a bit harsh and could be subject to legal scrutiny.

As restrictive measures intensify, the question arises whether restrictions on the freedom of movement of unvaccinated individuals has the potential to become not only a disincentive but also punitive, where access to essential services, for example, are available to vaccinated people only. A case in point is the Singaporean approach of barring the unvaccinated from free health care.¹⁹ Experts believe that the stricter the measures, the more they should be balanced against governments' own duty of care. In countries where vaccines are easily accessible and where governments are introducing mandatory vaccinations in stages, some companies and organizations have installed mandatory vaccination protocols for their employees. This has been to limit the further spread of COVID-19 among employees who engage with one another in close proximity. Where employees have refused to be vaccinated, mandatory protocols have been installed, resulting in cases coming under the scrutiny of labor arbitrators and courts. In some of these cases, the law has largely been on the side of the employers, where employees have been found culpable.²⁰ As to whether this will withstand constitutional scrutiny, we have yet to see a test case under the ambit of

constitutional law. Legal experts argue that mandatory workplace vaccination policies will most likely survive a constitutional challenge.²¹ Further, they argue that mandatory vaccines for COVID-19 will not infringe constitutional rights, and that even if it did, it would be found to be justifiable.²² In Brazil, the Supreme Court found that vaccine mandates are constitutional in principle, provided that they respect human rights and satisfy the reasonableness and proportionality tests.²³ Ultimately, any vaccine mandate's ethical and legal soundness may be fluid and specific to the set of prevailing circumstances: the magnitude of the threat posed by the virus during a particular phase of the pandemic, the characteristics of the available vaccines, and the availability of alternative interventions.²⁴

In the Kenyan case, Petition 329 raised the constitutional mandate of vetting individual rights against those of the general population. It considered the case of *Midi Television (Pty) Ltd t/a E-TV v. Director of Public Prosecutions (Western Cape)*.²⁵ The South African Supreme Court of Appeal case considered the exercise of balancing competing rights. It ruled that "where constitutional rights have the potential to be mutually limiting, in that full enjoyment of one right necessarily curtails the full enjoyment of another, a court must reconcile them." These rights should not be reconciled by weighing the value of one right against another, since all protected rights have equal value. It is not so much the values of the rights themselves that are to be weighed but rather the benefit flowing from the intrusion to be weighed against the loss that the intrusion would entail.²⁶ A recent petition to the Kenyan High Court to suspend the government's plans to restrict unvaccinated individuals' access to governmental services was successful.²⁷ Although the case has not yet been decided, the court order suspending the government's plan to limit access to such services demonstrates the cautious approach that courts are likely to take in determining the lawfulness of such actions.

There is a balance to be struck. "Vaccine hesitancy" is the coined term for those who wish to delay their acceptance or refusal of vaccines. A key factor in vaccine hesitancy has been mistrust

in governments, wherein some countries' officials and health care workers themselves have expressed hesitancy toward getting vaccinated.²⁸ The second-largest contributor has been internet- and social-media-facilitated misinformation, leading to the World Health Organization calling for the "WhatsApp aunties" phenomenon to be addressed to rebuild community trust.²⁹ The mandatory vaccination debate remains highly contested. Current approaches equate to public health protection trumping individual rights without a serious and deserved interrogation of governments' duty of care to their citizens. Indeed, more work can be done to increase access to reliable and credible information on vaccine safety and efficacy, including access for people with disabilities.

There are arguments to be made for a more sensible, human rights-based, people-centered approach. We have international human rights instruments for guidance, including the Siracusa Principles, which state that restrictions on human rights protected by the International Covenant on Civil and Political Rights must meet standards of legality, evidence-based necessity, proportionality, and gradualism.³⁰ There is no doubt that the burden of COVID-19 is immeasurable and that its impact has rearranged every facet of human life. In our haste to return to "normal," we risk alienating populations and inadvertently intensifying vaccine hesitancy. Mandatory vaccination is the most intrusive form of vaccine implementation. However, voluntary vaccination based on science and altruism faces ongoing challenges. The COVID-19 pandemic exists in an era when access to information—and, unfortunately, misinformation—is at its greatest. Pharmacovigilance, transparency around adverse events, and safety data may help build trust while uptake and acceptability among those who are vaccine "hesitant" may increase in time as more individuals around them are vaccinated. The acceptability and lawfulness of mandatory vaccination policies will likely be context specific and may further depend on the set of prevailing circumstances within each context. Given the scale of the pandemic, the enormous social, health, and economic costs associated with COVID-19, and the

availability of safe and effective vaccines, mandatory vaccination is a viable, reasonable, and ethical policy position to mitigate further pandemic-related losses.

Funding

Nesri Padayatchi is funded through EDCTP grant TMA2018SF.

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STUDENT ESSAY

Algorithmic Discrimination in Health Care: An EU Law Perspective

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Introduction

Pursuant to article 168(7) of the Treaty on the Functioning of the European Union (TFEU), the organization of national health care systems and the definition of national health policy remain the exclusive competences of member states. In spite of clear differences in funding and management, European health care systems share common values of universality, access to good-quality care, equity, and solidarity, which presume a commitment to combating discrimination.¹ Nevertheless, in practice, significant divergences in access to and quality of health care persist within the European Union (EU), and vulnerable groups are often subject to discriminatory practices.² This problem is likely to be exacerbated by the growing deployment of artificial intelligence (AI) in medical diagnosis, prognosis, and benefit allocation. In spite of the presumed neutrality of technology, algorithmic decision-making is capable of perpetuating social inequalities and creating new patterns of discrimination.

This essay explores whether the EU's current anti-discrimination legal framework offers adequate protection to patients who face automated discrimination. In order to answer this question, I analyze the problem of discrimination in health care from three perspectives: social, legal, and technological. I argue that EU anti-discrimination law, in its current state, is not well suited to address the challenges raised by algorithmic bias. Thus, there is an urgent need for reform.

The essay proceeds as follows. The first section explores the social perspective by mapping out discriminatory practices in health care. The next section addresses the legal perspective, introducing EU anti-discrimination law and discussing its pitfalls. This is followed by a discussion of the technological perspective that explores the use of AI in health care, its potential to remedy existing discriminatory practices, and its potential to reinforce discrimination. The following section analyzes the EU's anti-discrimination legal framework in light of the algorithmic challenges and proposes reforms that could strengthen its resilience. The final section briefly examines the additional protection against algorithmic discrimination offered by the EU's proposal for a regulation laying down harmonized rules on AI.

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Competing interests: None declared.

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The social perspective: Discrimination in the provision of health care in the EU

In 2013, the Fundamental Rights Agency published a report surveying inequalities in access to and the quality of health care in selected member states.³ The study focused on three particularly vulnerable groups within the migrant and ethnic minority population: women, older people, and young people with intellectual disabilities. It revealed that patients coming from these groups often face multiple discrimination, which means that they are discriminated against on more than one ground. In particular, two leading patterns of multiple discrimination emerged among the respondents: additive discrimination and intersectional discrimination.⁴ Additive discrimination occurs when patients are simultaneously discriminated against on several grounds—such as race, ethnicity, religion or belief, sex, sexual orientation, age, or disability—and when each type of discrimination can be proven independently. For example, a disabled gay person can face discriminatory treatment in accessing health care because of both their disability and their sexual orientation. Intersectional discrimination, on the other hand, is not based on the additive character of discrimination grounds but rather on their unique synergy. For example, the experience of ethnic minority women who access reproductive health care is qualitatively different both from the experience of ethnic minority men and from the experience of white women.

According to the report, discrimination experienced by migrant and ethnic minority patients was either direct, when respondents were denied equal access to health care because of their characteristics, or indirect, when the respondents were treated equally but the treatment failed to account for their specific needs. For example, migrants often faced indirect discrimination because of linguistic, socioeconomic, and cultural barriers.⁵ Vulnerable minority patients also experienced direct discrimination, such as delay or refusal of treatment, humiliating treatment, harassment, and forced treatment. The study found that in some cases the delay in treatment was caused by health care professionals' lack of knowledge about conditions

specific to specific ethnic minority groups, such as female genital mutilation.⁶ Roma and Muslim women, as well as women with disabilities, were particularly likely to suffer undignified treatment as a result of intersectional discrimination, often in connection with violations of their reproductive rights; forced gynecological examinations, sterilizations, and abortions are some of the examples in the report.⁷

Many respondents claimed that they did not report the discrimination they suffered. This decision was caused mainly by their lack of knowledge of redress procedures, difficulties in proving the allegations, general mistrust in the effectiveness of the complaint process, and a fear of retaliation from health care or immigration authorities.⁸ Moreover, the report indicated that a significant number of health care professionals have an insufficient understanding of the concept of discrimination. Interestingly, although many professionals were aware of the linguistic and structural barriers in accessing health care and found them problematic, they were hesitant to label them as discrimination.⁹ Among the professionals who acknowledged discrimination, only a few were able to explain the problem of multiple discrimination and offer solutions.¹⁰

A recent study conducted by Equinet, the European Network of Equality Bodies, has shown that the existing patterns of discrimination in health care have been exacerbated due to the COVID-19 pandemic.¹¹ Multiple—and, in particular, intersectional—discrimination remains a problem, with socioeconomic status being the key intersecting ground.¹²

The legal perspective: EU anti-discrimination law

The issues of equality and nondiscrimination are addressed in both primary and secondary sources of EU law. The former include the founding treaties—that is, the Treaty on the European Union, the TFEU, and the European Charter of Fundamental Rights—and general principles of EU law, while the latter encompass legislative acts adopted by EU institutions pursuant to article 288 of the TFEU. For

the purposes of this essay, the two most relevant types of secondary law instruments are directives and regulations. A directive is binding as to the result to be achieved, but it leaves member states with discretion over the mode of implementation. A regulation is directly applicable and binding in all member states.

According to article 2 of the Treaty on the European Union, equality is one of the founding values of the EU. Pursuant to article 3 of the treaty, equality, nondiscrimination, and social justice also remain the EU's objectives. Furthermore, in *Mangold*, the European Court of Justice confirmed that nondiscrimination constitutes a general principle of EU law.¹³ The European Charter, which applies to EU institutions and to member states when they implement EU law (art. 51(1)), protects everybody's rights to access preventive health care and medical treatment (art. 35). It also contains an open-ended anti-discrimination provision, which provides a non-exhaustive list of discrimination grounds (art. 21). Finally, pursuant to article 19 of the TFEU, the European Council, acting with the European Parliament's consent, "may take appropriate action to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation." While many secondary sources of EU law address the issue of discrimination based on these grounds, their scope of application differs.

In relation to individuals accessing health care services, only two EU directives apply: Directive 2000/43/EC (Racial Equality Directive) and Directive 2004/113/EC (Goods and Services Directive). The former prohibits discrimination based on race and ethnic origin, *inter alia*, in the context of health care; the latter prohibits discrimination based on sex when accessing goods and services, including health care.¹⁴ Both directives apply to direct and indirect discrimination in the private and public sector. None of the instruments explicitly protects against multiple discrimination. However, the Race Equality Directive makes reference to it in the preamble.¹⁵ Both instruments operate on a reversed burden of proof. This means that if the claimant is able to present *prima facie* evidence of discrimination, the respondent must prove that his

or her action did not constitute discrimination. The directives also foresee the establishment of equality bodies that are responsible for monitoring discrimination and protecting victims.¹⁶

Giacomo Di Federico points out three problems with EU anti-discrimination law in relation to health care.¹⁷ First of all, the applicable directives do not prohibit discrimination based on religion or belief, disability, age, or sexual orientation in accessing health care. This is highly problematic because, as indicated in the previous section, patients are often subject to discrimination based on these characteristics. Second, individuals' ability to bring a claim of discrimination on more than one ground is severely limited because the directives applicable in the field of health care neither define nor explicitly prohibit multiple discrimination. This is unsatisfactory because patients are rarely subject to discrimination on a single ground. Limited number of protected grounds allows patients to bring multiple additive discrimination claim based only on sex and race or ethnic origin. However, for the same grounds, particular hurdles exist in case of intersectional discrimination because of the difficulties in finding a legitimate comparator for the disadvantaged group, as required by the law.¹⁸ Third, the implementation of the directives varies among member states, especially when it comes to the structure and mandate of equality bodies; some states designate a single equality body while others favor multiple bodies specialized in a specific ground of discrimination.¹⁹ Unfortunately, these complexities often contribute to the aforementioned phenomenon of underreporting and poor outcomes for complainants. In the context of health care, equality bodies experience particular difficulties due to the low number of complaints, problems with gathering evidence, lack of expertise to deal with the complexity of health care systems, lack of competences to make legally binding decisions, insufficient resources, inadequate understanding of the problem of discrimination among health care providers, and failure to implement equality bodies' recommendations.²⁰

Finally, it is worth underlining that individuals can rely on the anti-discrimination provisions of the directives and article 21 of the European

Charter only when the situation falls within the scope of EU law.²¹ Therefore, because of limited competences of the EU in the area of health care, the situations when patients can directly invoke EU anti-discrimination law are limited.²² The EU retains shared competence in the regulation of free movement of medical goods and services on the internal market (art. 4(2)(a) of the TFEU) and common safety concerns in public health matters (art. 4(2)(k) and art. 168(4) of the TFEU). The EU can also support, coordinate, or supplement the actions of member states in the protection and improvement of public health (art. 6(a) of the TFEU). However, as mentioned in the introduction, the organization of national health care systems remains the exclusive competence of member states, and thus no harmonization is possible in this regard (art. 168(7) of the TFEU). Therefore, it is mainly for the member states themselves to address the problem of discrimination in the field of health care. Unfortunately, this often leads to unequal levels of protection against discrimination in health care across the EU.

The technological perspective: Artificial intelligence and health care

Given that EU anti-discrimination law does not adequately address the nature of discrimination faced by patients in Europe, adding AI to this already complex picture raises new concerns. On the one hand, AI offers solutions that can help tackle existing discriminatory practices. On the other, it can also create new patterns of discrimination, some of which are difficult to detect and address. This section explains the use of AI in health care and explores its benefits and risks.

The use of artificial intelligence in health care

AI can be described as “computers’ ability to mimic human behavior and learn.”²³ The process of learning takes place through algorithms. An algorithm is a series of computational instructions that transforms the input value into the output value.²⁴ An important field of AI is machine learning, which allows the computer to detect patterns in data

and use them to make predictions or decisions.²⁵ Machine learning algorithms are usually trained using “big data,” a collection of information of high volume, variety, and velocity.²⁶

In medicine, machine learning systems can be used for “prognostics, diagnostics, image analysis, resource allocation, and treatment recommendations.”²⁷ During the COVID-19 pandemic, the deployment of AI in health care has intensified. For example, experts have been working on developing algorithms that can diagnose COVID-19 through chest scan analysis or predict the severity of infection.²⁸

However, a crucial concern regarding some machine learning algorithms is that the output they generate is not fully predictable, and sometimes it is not possible to explain why and how they have reached a decision. That is why some scholars refer to algorithmic decision-making in health care as “black-box medicine.”²⁹ An interesting example of an opaque system is IBM Watson, which is currently being tested as an evidence-based decision-support system for medical use.³⁰ Watson uses advanced machine learning techniques that allow the system to infer rules, develop classification models, make predictions, and make decisions based on the analysis of a large set of both structured and unstructured data, such as doctor’s notes.³¹ Unfortunately, its data-driven approach makes Watson “unpredictable by design.”³²

The benefits of artificial intelligence in combating discrimination in the field of health care

As noted above, health care providers discriminate against patients for two main reasons: they are biased (either openly or subconsciously) or they lack knowledge about health problems specific to minority groups. Both of these issues could be addressed by the use of AI.

First, algorithmic decision-making has the potential to avoid stereotypes inherent in human decision-making. For example, it is possible to train algorithms to be fairness-aware “through incorporating anti-discriminatory constraints during data processing or removing the sources of bias prior to

processing.³³ However, in order for these algorithms to be successfully designed and deployed, we need comprehensive data surveying the discrimination experience in the field of health care. This is necessary in order to identify vulnerable groups and correlations that can lead to discriminatory outcomes. Since there exists a tension between different mathematical notions of fairness, data concerning discrimination are essential to establish the most appropriate fairness criteria. As stated in the preceding sections, the lack of data on inequality remains a problem in the EU, especially as many discrimination cases in health care are unreported.

Second, AI clinical-decision-support systems that are trained on a sufficiently large and diverse set of data could help health care practitioners fill in possible gaps in medical knowledge, especially when it comes to minority-specific health conditions. The added value of systems such as IBM Watson is that they can overcome the human cognitive limitations in collecting and processing information and are capable of outperforming human doctors in diagnosis.³⁴ Moreover, AI allows for the progress of personalized medicine that is individually tailored to the needs of patients.³⁵

Third, it is also possible to adjust the algorithm's output to account for the needs of specific ethnic or racial groups. For example, Alvin Rajkomar et al. suggest how distributive justice could guide the development and implementation of AI in the field of health care, actively advancing health equity for protected groups.³⁶ Recently, a group-specific approach to data analysis has been widely discussed in the context of ensuring a more equitable pandemic response. Some European scientists and activists have urged that collecting epidemiologic and mortality data by race and ethnic origin is necessary to address the impact of COVID-19 on specific communities.³⁷ For example, as reported in the Fundamental Rights Agency's bulletin, during the present COVID-19 pandemic, Roma, whose underlying health problems make them more susceptible to severe symptoms of infection, keep experiencing discrimination when accessing health care.³⁸ On the other hand, certain commentators

have warned against the use of racially tailored algorithms in health care, arguing, *inter alia*, that racial differences can in fact be genetic or socio-economic and that race or ethnicity are elusive concepts that depend largely on self-identity.³⁹

Fourth, the wide deployment of AI in health care, coupled with its comprehensive regulation at the European level, offers a chance to reinforce anti-discrimination protections for patients. As stated earlier, the scope of EU anti-discrimination law is limited in the field of health care because the organization of domestic social security systems is the sole competence of member states. On the other hand, the EU has competence to regulate AI technologies pursuant to articles 114 and 168(4)(c) of the TFEU (the internal market and the quality and safety of medical devices, respectively). Indeed, the EU is currently in the process of developing a complex regulatory framework for AI that has the potential to ensure a high degree of oversight over algorithms in health care, both before and after their implementation. The new regulation aims to minimize the risk of algorithmic discrimination and to help detect and rectify it.

Algorithmic discrimination in health care

Although AI can offer potential solutions to combat human bias, it can also widen existing divisions in the provision of health care. The most obvious concern is the inequitable deployment of new technologies, which are "disproportionately available to well-off, educated, young, and urban patients and to urban and academic medical centers."⁴⁰ Innovative solutions such as personalized medicine are usually very costly and thus are likely to remain unavailable to poor and vulnerable groups, exacerbating inequalities in access to and the quality of health care.⁴¹

Apart from the question of availability, issues with the fairness of AI itself also arise. Sharona Hoffman and Andy Podgurski distinguish three main problems with algorithmic decision-making: measurement errors, selection bias, and feedback-loop bias.⁴² Measurement errors relate to the quality of data. The "garbage in, garbage out" principle states

that incomplete or misleading data inevitably lead to unsatisfactory algorithmic performance. The quality and interoperability of health data in the EU leave much to be desired. For example, during the COVID-19 pandemic, the inability to swiftly exchange and compare epidemiologic data halted a coordinated response.⁴³ Moreover, due to the structural, linguistic, and socioeconomic barriers to accessing health care, vulnerable groups are likely to be significantly underrepresented in the main sources of health data, such as electronic health records. When big data on which the algorithm is trained are not representative of the target patient population, selection bias occurs. In this case, AI can produce unintended results, such as interpreting the lack of data as the lack of disease. For example, when an algorithm used to distinguish malignant and benign moles is trained on fair-skinned patients, it might fail to properly diagnose moles on people of color.⁴⁴ Similarly, algorithms deployed to detect cardiovascular diseases might underperform on women because most of the medical training data concerns men.⁴⁵ Moreover, if the data reflect systemic bias toward different groups, existing patterns of discrimination can be entrenched in the algorithm; this is called feedback-loop bias. For example, according to the Fundamental Rights Agency, health care professionals often suspect immigrants, older people, and people with disabilities of exaggerating their health problems in order to claim benefits.⁴⁶ This harmful stereotype can, for instance, cause doctors to routinely administer incorrect doses of medicine to patients belonging to one of these groups. If these data are later fed to an algorithm, the output is likely to reaffirm human bias. This problem is especially difficult to detect, since even seemingly neutral data (such as place of residence) can be a proxy for a protected ground of discrimination (such as race or ethnic origin). An illustrative example of proxy discrimination is provided by an algorithm used to identify patients who are likely to miss their medical appointment. In this case, the system caused the overbooking of people of color because prior no-shows were a proxy for socioeconomic background, which in turn was a proxy for race.⁴⁷

Facing the algorithmic challenge: The future of EU anti-discrimination law

The challenges raised by AI further question the effectiveness of EU anti-discrimination law in the field of health care, reinforcing already existing problems: limited grounds of discrimination, the absence of protection in case of multiple discrimination, and structural and evidentiary difficulties with pursuing a complaint.

First, the problem of proxy discrimination escapes the legal framework, which is based on specific protected grounds.⁴⁸ The European Court of Justice has not developed coherent criteria for assessing whether a proxy falls within the scope of protected categories. For example, in *Dekker*, the court accepted that discrimination based on pregnancy is a form of discrimination based on sex.⁴⁹ However, in *Jyske Finans*, the court ruled that unequal treatment based on the claimant's country of origin and patronym could not constitute discrimination based on ethnic origin.⁵⁰ The problems with discrimination by proxy are exacerbated when it comes to health care, where protected grounds are limited to just three: race, ethnic origin, and gender. Moreover, because discovering previously unknown correlations lies in the very nature of algorithms, they are capable of discriminating in new, abstract ways, making the established categories redundant. The anti-discrimination directives appear inherently unsuitable to address this problem, as they are designed with a human perpetrator in mind. As humans, we use common sense to recognize discriminatory patterns in one another's behavior. Thus, in law, discrimination and fairness are "contextual" concepts, and their determination is guided by judicial logic and intuition.⁵¹ Unfortunately, the same tools are not equally effective against algorithmic discrimination, which is more subtle and unintuitive.

Second, as Raphaële Xenidis underlines, algorithms are likely to reinforce intersectional discrimination, which is already "a blind spot" in EU law.⁵² She argues that the risk is particularly high in algorithmic profiling, which uses very precise identity data to classify subjects into distinctive subgroups.⁵³ Intersectional minorities are most

likely to be underrepresented and misrepresented in datasets, which are infused with historic bias. Thus, if such a technology were used to allocate health care benefits, it would risk deepening intersectional discrimination, which is already pervasive in health care. At the same time, neither the anti-discrimination directives nor the case law of the European Court of Justice explicitly address the problem of intersectional discrimination.⁵⁴

Third, the nature of algorithmic bias makes it difficult to establish that *prima facie* discrimination exists. In fact, it is highly possible that the victims of algorithmic bias will never know that they were discriminated against.⁵⁵ Again, these concerns are particularly strong in health care, where general awareness of discrimination is low among both patients and health care providers. As stated in the previous sections, patients coming from vulnerable groups often refrain from reporting discrimination precisely because it is difficult to meet the high burden of evidence to prove it.

Last but not least, unless it can be proven that the developers of discriminatory algorithms were explicitly or implicitly biased, most of the cases of algorithmic discrimination would qualify as indirect discrimination. Thus, according to EU law, these discrimination claims could be quite easily rebutted by proving that the application of algorithm is “objectively justified by a legitimate aim and the means of achieving that aim are appropriate and necessary.”⁵⁶ As noted by Daniel Schönberger, many algorithms used in health care are likely to fulfill legitimate aim, suitability, and necessity requirements, and thus the outcome of the challenge is likely to depend on the proportionality test.⁵⁷ There is a risk that courts will find the deployment of algorithms of overall high accuracy proportionate, even if they disadvantage certain protected groups.

Two approaches can be taken to address the discrepancies between EU anti-discrimination law and algorithmic discrimination. On the one hand, a captivating paper by Sandra Wachter, Brent Mittelstadt, and Chris Russell combines legal, ethical, and technological perspectives in an attempt to propose a technical standard in AI development

that will allow technology developers to detect discrimination early on and provide judges with the resources needed to reach a well-informed decision in cases of automated discrimination.⁵⁸ The authors argue that the “golden standard” of review developed by the European Court of Justice in *Seymour-Smith*, which defines disparity by assessing the effects on both the disadvantaged and advantaged group, can be translated into the statistical method of conditional demographic disparity.⁵⁹ Importantly, this method does not offer a clear-cut answer as to whether unlawful discrimination has occurred. Instead, its purpose is to provide support for judicial assessment of automated discrimination by allowing the judiciary to identify possible group comparators and compare the distribution of outcomes among various protected groups. Conditional demographic disparity could help adopt a common standard of assessment in algorithmic discrimination cases, while leaving judges with interpretative discretion when it comes to the final result. Accordingly, it could contribute to bridging the gap between technical and legal notions of fairness, embracing the contextual approach to equality favored by the European Court of Justice.

On the other hand, Xenidis proposes how existing concepts and doctrines of EU anti-discrimination law can be “tuned” to address the new challenges raised by AI.⁶⁰ In particular, she focuses on demarginalizing the concept of multiple discrimination, which is acknowledged in the preamble of the Race Equality Directive. Xenidis draws the reader’s attention toward doctrinal developments that favor the recognition of multiple discrimination as an established legal concept.⁶¹ For example, the opinion of Advocate General Kokott in *Parris*, albeit not followed by the court, emphasizes that in order to reflect the nature of discrimination in real life, the court must analyze the discrimination factors in combination rather than isolation.⁶² Another promising development in the anti-discrimination jurisprudence is the relaxation of a link between the identity of the victim and the protected grounds.⁶³ The court is also increasingly willing to find direct discrimination without proof of actual harm to particular victims, when pro-

tected groups are directly targeted.⁶⁴ According to Xenidis, these approaches are particularly useful in dealing with the problem of proxy discrimination by algorithms, as they relax the burden of proof and introduce flexibility to the rigid framework of protected grounds.⁶⁵ Lastly, she argues that further flexibility can be achieved by fully exploiting the possibilities offered by the open-ended nature of article 21 of the European Charter and the general principle of nondiscrimination.⁶⁶ It is worth noting that article 21 was recently successfully invoked in a case of discrimination based on religion in the cross-border treatment context.⁶⁷

Clearly, the resilience of EU anti-discrimination law against the challenges raised by automated discrimination is particularly low in the field of health care. The legal framework—which is already patchy and fails to address the nature of discrimination faced by many patients—is not likely to offer the desired level of protection. Hence, reforms are urgently needed to strengthen its resilience. Most importantly, the gap in protected grounds needs to be bridged. In this context, it is worth revisiting the proposal for a Horizontal Anti-Discrimination Directive, which would add the new protected grounds of religion or belief, disability, age, sex, and sexual orientation to the areas covered by the Racial Equality Directive.⁶⁸ Another much-needed reform proposed by the European Parliament's amendment to the Horizontal Anti-Discrimination Directive is the prohibition of direct and indirect discrimination on multiple grounds.⁶⁹ The implementation of these proposals should be coupled with a coherent approach of the European Court of Justice, which should develop its future jurisprudence by embracing flexibilities described by Xenidis. Lastly, efforts to find a common grammar between the legal and mathematical notions of fairness should continue in order to enable detecting and assessing AI discrimination.

The new Regulation on Artificial Intelligence: A source of additional protection?

EU anti-discrimination law can be adjusted to

better address the challenges raised by algorithmic decision-making. Nevertheless, when it comes to health care, the applicability of anti-discrimination legislation remains limited because the EU's competences in the area are mainly shared and supportive. Thus, EU anti-discrimination law alone does not provide sufficient protection to patients facing automated bias. In this context, it is interesting to consider how discrimination in health care is tackled by the recent proposal for an EU regulation harmonizing the rules on AI.⁷⁰

The explanatory memorandum for the proposal states that the regulation would complement the anti-discrimination law by minimizing the risk of algorithmic discrimination.⁷¹ Moreover, the proposal acknowledges the need to ensure good quality of data (recital 44) and “non-discriminatory access to health data” (recital 45). The regulation foresees different treatment of AI systems based on their risk assessment, from unacceptable to minimal. AI systems causing unacceptable risk, such as the violation of fundamental rights through the exploitation of social vulnerabilities and manipulation of human behavior, are prohibited.⁷² Recital 27 defines high-risk systems as those that “have a significant harmful impact on the health, safety and fundamental rights of persons.” They are subject to strict obligations both before and after being placed on the market. According to article 6, there are two main categories of high-risk systems.

The first category is AI systems intended to be used as safety component of products that are subject to third-party *ex ante* conformity assessment or AI systems that are themselves a product subject to third-party *ex ante* conformity assessment under EU harmonization legislation listed in annex II. AI that is either an independent software or an accessory to a medical device (e.g., software for a wearable device) can fall within the scope of the new Medical Device Regulation 2017/745, which is listed in annex II of the AI regulation proposal.⁷³ The Medical Device Regulation covers more AI-based systems than its predecessor, Medical Device Directive 93/42/EEC, as it expands the scope of medical purposes by including “prediction” and “prognosis” of a disease.⁷⁴ The conformity assessment procedure for

medical devices depends on their classification into four categories: I (low risk), IIa (moderate risk), IIb (medium risk), and III (high risk). The class is ascertained on the basis of the device's intended purpose and inherent risks associated with it.⁷⁵ While class I requires only a self-assessment by the manufacturers, classes IIa, IIb, and III require a varying degree of intervention by a notified body.⁷⁶ According to rule 11 of annex VIII to the Medical Device Regulation, software is classified as low risk unless it is used for medical diagnosis, therapy, or to monitor physiological processes. In these cases, it falls under class IIa (moderate risk), IIb (medium risk), or III (high risk), depending on its possible impact on the state of health. This means that AI systems that are classified as medical devices of moderate, medium, or high risk would need to comply both with the Medical Devices Regulation and the additional *ex ante* and *ex post* risk assessments and safety requirements for high-risk systems under the proposed AI regulation. However, AI systems that are classified as low-risk medical devices, and thus are not subject to third-party *ex ante* assessment under the Medical Devices Regulation, would not be considered high-risk systems for the purpose of the AI regulation proposal.

The second category of high-risk systems are stand-alone systems listed in annex III, which mentions, *inter alia*, "access and enjoyment of essential private and public services." Under this section, the annex explicitly includes determining eligibility for public assistance benefits and services and allocating emergency services, such as medical aid.⁷⁷ Thus, algorithms deployed to assess health care benefits or dispatch ambulances would likely fall within this category and attract a high level of protection. Nevertheless, it is less clear if an algorithm identifying patients who are likely to miss appointments would be classified as high risk. It could be argued that this is simply an administrative tool used to avoid under-booking, not to assess the eligibility or priority of benefits. Yet, as described above, a system of this kind can trigger discriminatory results for patients.

The proposed AI regulation provides additional safeguards against algorithmic discrimination

by high-risk systems, setting obligations relating to risk management, quality of data requirements, technical documentation, transparency and provision of information to users, quality management systems, human oversight, robustness, accuracy, and cybersecurity.⁷⁸ However, certain improvements could be introduced to the proposal in order to tackle the problem of discrimination in health care more effectively. For example, the regulation could include a direct cause of action for people suffering discrimination by algorithms. It would also be desirable to broaden the list of high-risk systems in annex III to ensure that algorithms that cannot be classified as moderate-, medium-, or high-risk medical devices under the Medical Devices Regulation, but are nevertheless used in the context of health care, do not escape the higher level of scrutiny.

Conclusion

Apart from perpetuating social inequalities and violating fundamental rights, algorithmic discrimination questions the very usefulness of AI. In the case of health care, the stakes are particularly high, as the life and health of marginalized and vulnerable minority groups could be endangered. The potential success or failure of AI in the diagnosis of minority-specific health conditions and the equitable distribution of benefits ultimately depends on the availability of health data concerning these groups, who constantly face obstacles in access to health care.

Unfortunately, current EU anti-discrimination law does not offer adequate protection to patients facing discrimination, much less to those facing algorithmic discrimination. Addressing this problem will be possible only if the social, legal, and technological perspectives on discrimination are analyzed together. Thus, the anti-discrimination law in the field of health care should be reformed to more adequately address the social experience of discrimination, which must be extensively surveyed by the qualified equality bodies. Moreover, even if automating the notion of fairness is neither possible nor desirable, law and technology must

look for ways to develop common standards of assessing discrimination. Apart from the anti-discrimination law, additional protections under the proposed regulation on AI are also welcome in order to ensure that fairness is monitored in the design and implementation phases.

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STUDENT ESSAY

A Human Rights Case Study on Access to Pre-exposure Prophylaxis for Female Sex Workers in South Africa

STEVEN WINKELMAN

Abstract

This paper examines the extent to which access to HIV preventive medicines such as pre-exposure prophylaxis (PrEP) are ensured under the International Covenant on Economic, Social and Cultural Rights. There is a lack of human rights-focused research on access to HIV preventive medicines for vulnerable populations such as female sex workers in HIV-endemic countries. To help fill this gap, I utilized a case study approach to critically examine the rollout of PrEP for female sex workers in South Africa, drawing on the country's Bill of Rights, health care policies, and PrEP implementation. My analysis found that (1) PrEP rollout was largely physically and economically *inaccessible* for female sex workers outside of urban centers; (2) the dissemination of PrEP information specific to female sex workers was limited both virtually and in clinics, reducing the medicine's *acceptability*; and (3) South Africa's overburdened public health care system and continued criminalization of sex work limited the *accessibility* and *quality* of HIV prevention services, contributing to weak uptake of PrEP among female sex workers. To remedy these issues, state leaders should prioritize PrEP counseling and socially acceptable information dissemination; expand comprehensive, coherent, and coordinated sexual health services for female sex workers; increase the financial resources available for programs specific to female sex workers; and decriminalize sex work.

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Competing interests: None declared.

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Introduction

A human rights lens, particularly regarding the universal right to health, is useful to understand and address complex global public health problems. A human rights-based approach to health is one that acknowledges and aligns with the universality of human rights, recognizes and facilitates the agency of vulnerable populations, and holds states and other institutional powers accountable for the achievement and protection of human rights.¹ Article 25 of the Universal Declaration of Human Rights (UDHR) states that “everyone has the right to a standard of living adequate for the health and wellbeing of himself and of his family.”² Similarly, article 12(1) of the International Covenant on Economic, Social and Cultural Rights (ICESCR) asserts the universal right of all people to the “highest attainable standard of physical and mental health.”³ States that have ratified this international covenant have committed to taking deliberate steps to progressively realize the right to health for people both within their country using maximum available resources, and globally through international cooperation.⁴ However, states must also contend with limited resources, conflicting sociopolitical agendas, and ongoing epidemics, all of which threaten the progressive realization of the right to health.

HIV is an ongoing epidemic that continues to pose significant health and human rights risks globally, particularly for members of disempowered and marginalized populations in HIV-endemic and hyperendemic countries, where the virus maintains a consistently high presence among the adult population.⁵ Female sex workers are an especially vulnerable population for HIV as a result of factors such as gender-based violence, substance use, fear of discrimination from health care providers, and difficulties negotiating condom use with sexual partners for fear of violence or disincentivizing business, as well as structural issues such as poverty, the criminalization of sex work, and police harassment.⁶ The criminalization of sex work in particular prevents female sex workers from accessing health and social services for fear of imprisonment or assault, thereby worsening health outcomes and infringing on their right to

health.⁷ As a result, the United Nations has called on states to protect and ensure access to sexual and reproductive services for sex workers.⁸ Some states, including South Africa, have specifically identified female sex workers as a priority population for HIV prevention and treatment services through national policies and strategic plans.⁹ Human rights-based analysis, which rigorously examines the impact of state policies and systems on the health of members of vulnerable populations, is an important tool in challenging the HIV epidemic.¹⁰

Human rights-based approaches to HIV are historically rooted in ensuring access to HIV treatment, clinical services, and education on behavioral prevention strategies such as condom use through civil engagement and legal action.¹¹ New biomedical HIV prevention tools, particularly oral pre-exposure prophylaxis (PrEP), evidence a shift in the global response to the HIV epidemic. PrEP is a combination of antiretroviral medications, most commonly taken as a once-daily pill containing emtricitabine and tenofovir disoproxil, which can prevent the sexual transmission of HIV by up to 99% when taken with high adherence by a person who is HIV negative.¹² Alternatives to oral PrEP, such as long-lasting injectable cabotegravir and the dapivirine vaginal ring, are under review or have been approved for use in South Africa, although their rollout is still being piloted.¹³ PrEP is an increasingly significant HIV prevention tool globally; however, given its relative recency, there is an absence of human rights-based research regarding access to PrEP. This lack of rights-based analysis is particularly concerning given the precarity of priority populations at risk of HIV who could benefit from increased access to PrEP, including female sex workers.

To address this gap in knowledge, I use a case-study approach to examine the extent to which access to HIV preventive medicines such as PrEP is ensured under international human rights law for priority populations in HIV-endemic countries. This analysis focuses on access to PrEP for female sex workers in South Africa, given the country’s rich history of human rights-driven HIV prevention and treatment policies.¹⁴ Female sex workers

were selected as the primary population for this case study because they face significant barriers to health care access and have been explicitly identified as a priority population for PrEP in existing literature and government documents.¹⁵

This analysis examines the current status of female sex workers in South Africa, details the right to health in South Africa and the country's national PrEP policies and strategic plans, and concludes with a critical analysis of the de facto rollout of PrEP for female sex workers in South Africa to answer the following questions:

1. To what extent does the right to the highest attainable standard of health, as enshrined in article 12(1) of the ICESCR, include preventive health measures such as PrEP for HIV-negative female sex workers in HIV-endemic countries?
2. How are human rights frameworks currently guiding the implementation of PrEP delivery for female sex workers in South Africa?

The status of female sex workers in South Africa

South Africa faces one of the world's highest HIV burdens, with a reported HIV prevalence rate of approximately 19% among adults, an HIV incidence rate of approximately 6.9 per 1,000 adults, and approximately 7.5 million people living with HIV in 2019.¹⁶ As of 2019, South Africa had a population of approximately 59 million people across nine provinces. Over 67% of the population lives in urban areas and cities.¹⁷ The health system in South Africa is organized under a unified National Department of Health, which manages the nine provincial departments of health and municipal and local health authorities.¹⁸ Approximately 14% of South Africa's government spending was on the health care sector in 2020 and 2021; however, the country continues to experience lagging health outcomes resulting from poor infrastructure and an overstrained health care system.¹⁹

Health care in South Africa is delivered through both public health facilities and the private sector. The public system is funded primarily

by the South African government and international funding bodies such as the US President's Emergency Plan for AIDS Relief and the Global Fund to Fight AIDS, Tuberculosis and Malaria and provides services to uninsured patients, while the private system is funded through out-of-pocket payments and insurance premiums.²⁰ The public health care system in South Africa is being increasingly decentralized, with authority being transferred to local clinics, hospitals, ward-based outreach teams, and rural home-based care organizations.²¹ Approximately 84% of South African citizens access their health care through public clinics and hospitals.²² However, an overwhelming majority of doctors in South Africa work in the private sector and provide services to the 16% of South Africans with private health insurance.²³ Approximately 50% of national health care expenditures is spent on those with private health insurance.²⁴ This inequitable public-private split presents a concerning dichotomy of health care access, leading to many South Africans struggling to receive necessary care and treatment within an overburdened public health system.

Sex workers are recognized by the South African government as a key and vulnerable population for HIV prevention services.²⁵ Sex work in South Africa is immensely complicated, and not all people who engage in sex work may consider themselves to be sex workers.²⁶ Human Rights Watch reports that the majority of sex workers in South Africa are female, black, and living in poverty.²⁷ Sex work can take place in both urban and rural settings, though the majority of health care services targeted toward female sex workers are based in major cities such as Johannesburg. Such services are provided through sex worker clinics, mobile clinical outreach vans, and targeted clinical services delivered in hotels and brothels where sex workers operate.²⁸ Access to clinical services in rural areas is limited, including access to HIV prevention and treatment services specific to female sex workers. As a result, women who engage in sex work in rural areas may be at higher risk of HIV infection due to a lack of available services.²⁹ This lack of rural access to clinical services may also negatively affect young women engaging in transactional sex or "blesser-blessee"

relationships, in which an older, typically male, partner provides money, goods, or services to a younger partner in exchange for sex.³⁰ While transactional sex is considered distinct from sex work, both practices present significant HIV risk, and young women who rely on transactional sex may be more likely to engage in sex work in the future.³¹

The right to health and the right to the benefits of science in South Africa

The Republic of South Africa was readmitted to the United Nations General Assembly in 1994, following the end of Apartheid. This readmittance was followed by an amalgamation and domestication of human rights elements enshrined in the UDHR into the country's Bill of Rights in 1996, under the leadership of the newly elected African National Congress.³² The country later ratified the ICESCR in 2015.

Articles 25 and 27 of the UDHR and articles 12 and 15 of the ICESCR encompass the universal and inalienable right to health and the right to participate in and benefit from scientific progress. Article 25(1) of the UDHR declares that “everyone has the right to a standard of living adequate for the health and wellbeing of himself and of his family, including food, clothing, housing, and medical care and necessary social services.”³³ Article 27(1) notes that everyone has the right “to share in scientific advancements and its benefits.”³⁴ Meanwhile, article 12 of the ICESCR recognizes the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, while also noting that steps to achieve the highest attainable standard of health must include the prevention, treatment, and control of epidemic, endemic, occupational, and other diseases.³⁵ Article 15(1)(b) of the ICESCR recognizes the rights of everyone to enjoy the benefits of scientific progress and its applications.³⁶

The Committee on Economic, Social and Cultural Rights oversees state parties' implementation of the ICESCR by monitoring the progressive realization of rights and by releasing general comments. General comments are recommendations to guide the implementation, interpretation, and monitoring

of specific provisions within international treaties. The committee's General Comment 14 notes that the realization of the right to health is dependent on a public health system or program meeting the required conditions of *availability, accessibility, acceptability, and quality*.³⁷ *Availability* refers to the presence and quantity of health care-related facilities, goods, and services, and also takes into consideration underlying determinants of health such as safe drinking water and housing.³⁸ *Accessibility* refers to nondiscrimination, which means ensuring that health programs are physically and economically accessible and that related information is presented in a way that can be understood by all.³⁹ *Acceptability* relates to the cultural appropriateness of health care programs, alignment with medical ethics, and level of respect and sensitivity provided to the needs of marginalized communities.⁴⁰ *Quality* refers to the quality and medical soundness of a health care program and requires the presence of skilled health care staff, safe drugs, and adequate and sanitary health care facilities.⁴¹ The presence of these qualities is dependent on the available resources of the state, but they are necessary to achieve the progressive realization of the right to health.

General Comment 14 notes that the realization of article 12(2)(c) of the ICESCR requires “the establishment of prevention and education programmes,” particularly relating to epidemics such as HIV/AIDS.⁴² The control of diseases is also dependent on the individual and joint efforts of state parties to ensure the availability of relevant technologies.⁴³ The realization of article 12(2)(d)—the right to health facilities, goods, and services—requires access to basic preventive, curative, and rehabilitative health services, as well as the provision of essential drugs. PrEP has been included in the World Health Organization's (WHO) Model List of Essential Medicines since 2017.⁴⁴

General Comment 22 on the right to sexual and reproductive health notes that essential medicines should be made available for the prevention and treatment of sexually transmitted infections (STIs) and HIV.⁴⁵ It also emphasizes that state parties should take measures to fully protect persons

working in the sex industry against all forms of violence, coercion, and discrimination and to ensure that such persons have access to the full range of sexual and reproductive health care services.⁴⁶ States should act to ensure universal access to nondiscriminatory sexual and reproductive health services, particularly for members of disadvantaged and marginalized groups. Finally, General Comment 22 notes the importance of ensuring access to quality technologies, personnel, equipment, and medicines, including generic medicines based on the WHO Model List of Essential Medicines.⁴⁷

General Comment 25 on the right to enjoy the benefits of scientific progress and its applications declares that the right to benefit from scientific progress is instrumental in realizing the right to health.⁴⁸ New medicines and health care services should be made available to everyone, especially members of the most vulnerable populations, and particularly as “means for the prevention, control and treatment of epidemic, endemic, occupational and other diseases.”⁴⁹ States should also promote scientific research and ensure that everyone benefits from the findings of this research.⁵⁰ Elements of the right to participate in and enjoy the benefits of scientific progress and its applications include *availability*, *accessibility*, *quality*, and *acceptability*. *Availability* refers to the enactment and dissemination of scientific progress; *accessibility* refers to equal access to participate in and benefit from scientific progress; *quality* refers to advanced and verifiable science; and *acceptability* refers to the dissemination of scientific findings and technologies in different social and cultural contexts.⁵¹

The right to health is enshrined in the South African Constitution and Bill of Rights, and policies that seek to increase equitable access to health care for persons disadvantaged by unfair discrimination have been gradually adopted following the end of Apartheid in 1994.⁵² The domestication of policies that embrace the right to health and nondiscrimination suggests a strong commitment from the government of South Africa to apply and enforce international human rights law within the country’s borders.⁵³ Notable articles in the South

African Bill of Rights relating to the right to health include the following:

- article 10: the right to human dignity
- article 11: the right to life
- article 27(1)(a): the right to have access to health care services, including reproductive health care
- article 27(2): the state’s duty to take legislative and other measures within available resources to achieve the progressive realization of these rights⁵⁴

As recognized by the Constitutional Court of South Africa, the progressive realization of rights requires the state to strive to the maximum extent possible within available resources, increasing access for vulnerable populations over time.⁵⁵

South Africa’s health care policies and national strategies

Oral PrEP was approved for use in South Africa in 2015. Both brand-name and generic versions of PrEP can be purchased at cost from the private sector. South Africa has historically gone to great lengths to ensure affordable or free access to generic medicines through policies such as the 1996 National Drug Policy, which established a nondiscriminatory pricing system, and the implementation of the 2004 Single Exit Price Policy, which further regulated the cost of imported pharmaceuticals.⁵⁶ Since June 2016, PrEP has been offered free to female sex workers through select public health clinics, mobile outreach vans, and fixed facilities in select urban centers such as Cape Town, Durban, Johannesburg, and Hillbrow, eventually expanding to clinics across the country.⁵⁷ In order to access services specific to female sex workers, however, the women must disclose their sexual activity, which may prevent many eligible PrEP users from accessing the medication for fear of stigma or arrest.⁵⁸

The South African Guidelines for the Provision of PrEP to Persons at Substantial Risk of HIV Infection notes that PrEP provision must be com-

bined with existing sexual and reproductive health services, with PrEP clients receiving a minimum package of services, including HIV testing and antiretroviral therapy initiation for those diagnosed with HIV, syndromic STI diagnosis and treatment, tuberculosis screening, pregnancy screening, mental health counseling, contraception, and condoms and lubricants.⁵⁹ The guidelines advise that PrEP users undergo an HIV test, STI screening, and counseling one month after PrEP initiation, and every three months after.⁶⁰

South Africa's PrEP policies for female sex workers

South Africa has recognized the need to expand HIV prevention and treatment services for female sex workers. The country's 2016 National Policy on HIV Pre-exposure Prophylaxis (PrEP) and Test and Treat (T&T) follows WHO guidelines recommending the provision of daily PrEP to members of priority populations at substantial risk of HIV infection in order to reduce HIV incidence over time.⁶¹ The objectives of this policy are to expand prevention options such as PrEP, increase access to treatment, integrate PrEP and T&T into existing health care systems, and ensure high-quality and well-communicated community-based strategies.⁶² The National Department of Health has further clarified the implementation of PrEP and T&T for female sex workers through the publication of the *Guidelines for Expanding Combination Prevention and Treatment Options for Sex Workers: Oral PrEP and Test and Treat (T&T)*. This document advises that PrEP should be offered to female sex workers at high risk of HIV, along with a combination prevention package, including the provision of condoms, risk reduction counseling, and immediate initiation of antiretroviral therapy if a patient tests positive for HIV.⁶³ The guidelines also call for the integration of PrEP programs into existing sexual and reproductive health programs and family planning services and for capacity-building and sensitivity training for health care providers.⁶⁴

Female sex workers are identified as a key population for PrEP under South Africa's 2017–2022

National Strategic Plan on HIV, TB and STIs, particularly under goal 1, which concerns prevention to reduce new HIV and tuberculosis infections and STIs.⁶⁵ Objective 1.14 of this strategic plan calls for the provision of PrEP to identified risk populations, including sex workers. It also calls for the expansion of combination HIV prevention, which combines human rights-based and evidence-informed behavioral, biomedical, and structural strategies, including PrEP.⁶⁶

Implementation of PrEP policies in South Africa

Following the passage of the National Policy on HIV Pre-exposure Prophylaxis (PrEP) and Test and Treat (T&T), the government began a phased rollout of PrEP. The rollout initially targeted female sex workers at select public health care centers across the country and was then expanded to include facilities providing services to men who have sex with men, and finally to students at select university campuses, before being offered at primary clinics in 2018.⁶⁷ Although female sex workers were the first population to be targeted for PrEP rollout, their uptake compared to other populations has been relatively low.⁶⁸ As of 2018, approximately 4,109 female sex workers had initiated PrEP, representing only 13% of those who had been offered PrEP clinically.⁶⁹ Further, only 66% of female sex workers who tested negative at a clinic were offered PrEP.⁷⁰ Female sex workers were initiating PrEP at significantly lower rates than men who have sex with men, approximately 54% of whom initiated PrEP upon offer.⁷¹ In a study on clients attending clinics for female sex workers and men who have sex with men in South Africa, over half of the clients who had never initiated PrEP attributed this to having never been offered PrEP.⁷² This evidences a serious gap in PrEP implementation and information accessibility. Many clients also expressed that they stopped adhering to PrEP as a result of early side effects of the medication, suggesting that counseling on side-effect management was not regularly provided.⁷³

To increase the dissemination of information

about PrEP, the government of South Africa has created a publicly accessible website, www.myprep.co.za. However, the website makes no mention of PrEP services for sex workers, asks no questions about sex work in the self-assessment survey, and does not provide information on free or publicly funded PrEP. Female sex workers in South Africa face difficulties accessing sexual health information due to stigma and judgment within clinic settings.⁷⁴ A non-stigmatizing website containing PrEP information and resources would help close this information gap.

Clinical trials and demonstration projects were also implemented in parallel to the passage of the National Policy on HIV Pre-exposure Prophylaxis (PrEP) and Test and Treat (T&T) to assess the acceptability and effectiveness of PrEP for various priority populations. Only one demonstration project specifically targeted female sex workers: the Treatment and Prevention for Female Sex Workers (TAPS) project, which ran from 2015 to 2017.⁷⁵ The primary aim of the TAPS project was to assess whether female sex workers would accept and adhere to a combination prevention and care approach that included PrEP, and whether the South African health care system could handle the additional strain. The study found that female sex workers place significant emphasis on the role of social networks in their acceptance of PrEP. Many workers in the study reported mistrusting PrEP or health care providers.⁷⁶ This mistrust was strengthened by participants in the clinical trial not being able to share PrEP with those in their social network who were not enrolled in the TAPS study. However, PrEP was viewed to be a valuable HIV prevention option. The TAPS study recommended that information about PrEP be disseminated widely to increase support among diverse communities, in line with the recommendations of accessibility in General Comments 14 and 25.⁷⁷

Critical analysis of South Africa's PrEP implementation for female sex workers

The government of South Africa has shown that it is willing to take steps to progressively realize the

right to health and the right to benefit from scientific progress through the expansion of PrEP services for female sex workers. However, the implementation of PrEP for this population falls short with regard to the realization of both the right to health and the right to benefit from scientific progress.

The right to health

PrEP implementation for female sex workers has not met the standard of *availability* as outlined in General Comment 14.⁷⁸ PrEP is available in sufficient quantities in South Africa; however, health care facilities and demonstration sites that disburse the medication and provide counseling on adherence and side-effect management to female sex workers are limited. The location of such services in primarily urban centers limits the *physical accessibility* for female sex workers in rural areas and reduces the *economic accessibility and affordability* of PrEP for female sex workers who cannot access these select public health care clinics. The creation of a PrEP website by the South African government suggests increased *information accessibility*, though the site makes no mention of services for female sex workers. Studies involving South African female sex workers suggest that PrEP information has not been effectively conveyed to this population, nor are health care providers initiating PrEP conversations with female sex workers during clinic visits, further limiting *information accessibility*. There are also limitations to the *acceptability* of PrEP, largely as a result of medical mistrust, poor communication about PrEP, and concerns about the medications' efficacy.⁷⁹ However, the *quality* of PrEP has been confirmed by numerous clinical and demonstration trials across the globe.⁸⁰ South Africa's PrEP guidelines follow established clinical protocols where resources allow. There are concerns that South Africa's overburdened public health care system may not be capable of providing appropriate or good-quality health care services for female sex workers. This is worsened by the lack of access to social determinants of health such as secure housing and safe and potable water for female sex workers in South Africa as a result of poverty.⁸¹

Through progressive drug coverage policies

such as the single exit price, which establishes a maximum price at which a medicine can be charged, South Africa has *protected* the right to health for some female sex workers by controlling the financial cost of generic PrEP in the public health sector, but this is not accessible to all female sex workers. South Africa has also committed to *fulfilling* the right to health for these workers through their inclusion in policies and national strategies such as South Africa's National Strategic Plan on HIV, STIs, and TB.⁸² The rollout of PrEP has been progressively improving in South Africa. Nonetheless, the government is falling short in the realization of the right to health for female sex workers as a result of harmful policies that criminalize sex work, and the inequitable distribution of public-private and urban-rural health care resources. In particular, the criminalization of sex work in South Africa continues to place female sex workers at risk of violence, harassment, and poor health outcomes. This conflicts with the text of General Comment 22, which calls for full protection for sex workers from violence and discrimination.⁸³

The right to the benefits of science

The lack of availability of PrEP for female sex workers across the country fails to meet the call for increased availability of new medicines for vulnerable populations found in General Comments 14, 22, and 25.⁸⁴ Regarding ICESCR article 15—the right of everyone to enjoy the benefits of scientific progress and its applications—it appears that the findings of clinical and demonstration trials have not been widely disseminated to female sex workers, reducing *availability*. Further, findings that have been disseminated appear to not be culturally *acceptable* for many female sex workers, largely as a result of a lack of community education about PrEP.⁸⁵ *Accessibility* for female sex workers to participate in PrEP-related science has been limited, as there has been only one demonstration trial targeting this group. The unequal distribution of PrEP services for female sex workers across the country has also reduced the *accessibility* of PrEP. However, the *quality* of PrEP-related scientific progress is high and remains verifiable.

Greater efforts must be made to achieve the progressive realization of the right to health and the right to benefit from scientific progress for female sex workers in South Africa, including by expanding comprehensive, coherent, and coordinated sexual health services specific to female sex workers across the country; increasing the financial resources available for programs specific to these workers; and releasing accessible information and educational resources specific to this population.⁸⁶

Limitations

This analysis focused on access to HIV preventive medications such as PrEP under the right to health for female sex workers in South Africa. Future human rights-based research should examine access to HIV preventive medicines for male, transgender, and non-binary sex workers.

Conclusion and recommendations

It is clear that the provision of PrEP for female sex workers in South Africa has been guided by human rights, most clearly evidenced within South Africa's National Strategic Plan on HIV, TB, and STIs.⁸⁷ However, the rollout of PrEP has led to some significant gaps in initiation and uptake among female sex workers and has failed to meet the recommended elements and core obligations outlined in General Comments 14 (right to health), 22 (right to sexual and reproductive health), and 25 (right to the benefits of science). Greater work must be undertaken to ensure that PrEP is *accessible, available, acceptable*, and of high *quality* for female sex workers in South Africa. In adopting the ICESCR, the South African government has committed to providing access to health care, safe and healthy working conditions, and socioeconomic factors that can promote a healthy life. The state has committed to expanding PrEP services for female sex workers across the country, suggesting that it will take active steps to ensure the progressive realization of the right to health through a variety of facilities, goods, and preventive health services. The inclusion of female sex workers in South Africa's National Policy on

HIV Pre-exposure Prophylaxis (PrEP) and Test and Treat (T&T), as well as its National Strategic Plan on HIV, TB and STIs, is promising, but more work must be done to ensure an equitable and human rights-driven PrEP rollout for female sex workers.

This analysis clearly shows that the right to the highest attainable standard of health, as enshrined in article 12(1) of the ICESCR, includes preventive health measures such as PrEP for HIV-negative female sex workers in HIV-endemic countries. In order to prevent, treat, and control epidemic and endemic diseases, a wide variety of medical services must be offered. PrEP is a high-quality medical technology that is included in the WHO List of Essential Medicines and can be incorporated into existing health services to help prevent the spread of HIV. Integrating PrEP delivery into existing sexual health and family planning programs bolsters prevention and education services and increases access to relevant HIV-prevention technologies, strengthening that ability of HIV-endemic states to fulfill article 12 of the ICESCR. PrEP has been shown to be a highly effective and acceptable form of HIV prevention for female sex workers in HIV-endemic countries when coupled with counseling services. The use of generic alternatives to PrEP minimizes the cost of PrEP implementation, ensuring that HIV-endemic countries can provide PrEP to vulnerable communities such as female sex workers even in times of resource constraints.

In order to increase the acceptability and availability of PrEP, PrEP programs should prioritize counseling, disseminate information in culturally and socially acceptable ways, and utilize existing social networks among female sex workers to disseminate information and reduce stigma. States should adopt specific legal instruments to ensure access to PrEP for female sex workers, including regulated training for health care providers. By addressing these implementation challenges, the governments of HIV-endemic countries can increase access to HIV prevention measures, essential medicines, sexual and reproductive health resources, and health-related education and information, thereby ensuring entitlements for female sex workers and other vulnerable populations outlined

under the right to health. Recognizing that many HIV-endemic countries face resource challenges, the use of generic PrEP and international pharmaceutical assistance is recommended to minimize financial burden and to ensure PrEP access in both urban and rural settings, through both private and public health care systems. Finally, in order to increase the overall health of female sex workers and reduce the rate of HIV infection, it is recommended that HIV-endemic countries address determinants of health for female sex workers, such as ensuring access to health care services and decriminalizing sex work. In particular, the decriminalization of sex work would allow female sex workers to benefit from protection from workplace discrimination and harassment as outlined in General Comment 22 and would increase the *acceptability, accessibility, availability, and quality* of HIV preventive services by reducing harassment and the threat of imprisonment.⁸⁸ PrEP is an important tool in the fight against HIV, and PrEP expansion must be aligned with a human rights framework in order to reach the most vulnerable populations equitably and effectively.

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VIEWPOINT

Pandemic Treaty Should Include Reporting in Prisons

KYLE KNIGHT, JULIA BLECKNER, EDWIN CAMERON, AND JOSEPH J. AMON

On December 1, 2021, the World Health Assembly, meeting in only the second special session since the World Health Organization's (WHO) founding in 1948, agreed to develop a "convention, agreement, or other international instrument" to strengthen pandemic prevention, preparedness, and response.¹ Tedros Ghebreyesus, WHO's director, explained that this decision was made as a result of the "many flaws in the global system to protect people from pandemics," which, although unstated in the WHO press release, necessarily must include the failure to protect those most vulnerable from SARS-CoV-2 infection and ensure their access to care.

At the onset of the COVID-19 pandemic, it was not hard to anticipate that transmission would be exacerbated in places where individuals were in close contact, ventilation systems were inadequate, and the availability of health care and prevention measures was limited. These conditions are all found in locations such as cruise ships, college dormitories, and prisons. Yet, while great effort was taken to prevent transmission in the first two of these settings, the third—prisons—was often overlooked. Despite overcrowding, communal meals, and frequent turnover among detainees and staff, governments' responses to COVID-19 in detention facilities—including jails, prisons, and immigration detention centers—were often limited, and actions taken to reduce risk and cases and deaths in detention were often unreported.

In the United States, since the start of the pandemic, efforts to monitor the impact in prison suggest that, at a minimum, over 600,00 people in detention have been infected.² Efforts to monitor COVID-19 infections and deaths globally have had limited funding and been largely unable to overcome the lack of reporting and transparency.³ But headlines about COVID-19 in detention can be found from around the world: "Prisons Face COVID-19 Catastrophe" in the Democratic Republic of the Congo, "Coronavirus Stalks Cells of Cameroon's Crowded Prisons," "Coronavirus Spreads in Egypt's Al-Qanater Prison," "New COVID-19 Outbreak in Iran's Prisons, Regime's Inaction, and a Looming Catastrophe," and on and on.⁴

WHO presents daily updates of COVID-19 cases in every country in the world.⁵ Information on COVID-19 in prisons, by contrast, is voluntarily reported to WHO, and between April 2020 and August

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Competing interests: None declared.

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2021, only 18 member states submitted reports.⁶ These reports are unpublished. Although WHO's regional office in Europe proactively sought to establish routine reporting of COVID-19 cases in prisons in the 53 countries in the region, reporting was limited.⁷ It is only as we enter the third year of the pandemic that the office is publishing a report on "good practices" in managing COVID-19 in prisons, highlighting examples from mid-2020.⁸

The United Nations Office on Drugs and Crime, which has a mandate to help countries in "building and reforming their prison systems ... in compliance with human rights principles," provides states with a voluntary checklist to assess prison conditions and the treatment of prisoners but has no information on the number of cases or deaths due to COVID-19 in detention worldwide, and scant guidance on the prevention of transmission.⁹ By contrast, it has research briefs related to the impact of COVID-19 on organized crime and on trafficking in opiates and methamphetamine.¹⁰

States have an obligation to ensure medical care for prisoners at least equivalent to that available to the general population.¹¹ According to the United Nations (UN) Committee on Economic, Social and Cultural Rights, "States are under the obligation to respect the right to health by, *inter alia*, refraining from denying or limiting equal access for all persons, including prisoners or detainees, minorities, asylum seekers and illegal immigrants, to preventive, curative and palliative health services."¹² The UN Human Rights Committee has stated that governments have a "heightened duty of care to take any necessary measures to protect the lives of individuals deprived of their liberty" because by detaining people, governments "assume responsibility to care for their lives."¹³ In the context of the COVID-19 pandemic, UN human rights experts have drawn attention to prison conditions, arguing that "loss of life occurring in custody in unnatural circumstances creates a presumption of arbitrary deprivation of life" and that "the duty to protect life also requires regular monitoring of prisoners' health."¹⁴

States also have obligations related to transparency, including the publication of information

that can steer policy decision-making on priority steps needed to protect the right to health.

But global implementation of this basic reporting practice has been piecemeal at best. Thailand's Department of Corrections, for example, reported on COVID-19 cases in prisons across the country and in specific facilities—but only after pressure from civil society.¹⁵

It was foreseeable that detention facilities would be hard hit by COVID-19. It is equally foreseeable that detention facilities will be hard hit the next time there is an airborne pandemic. The critical first step toward holding detention systems accountable and improving detainee health is to ensure visibility of the problem, but international agencies currently do little to encourage such reporting.

As negotiations toward a "pandemic treaty" advance, there will certainly be discussions on disease surveillance and reporting. There should also be discussion on the human rights obligations of states to collect and report data related to cases among those most vulnerable and those in state custody. Data transparency and accuracy are the first steps toward effective responses and fundamental rights protections. UN agencies such as the United Nations Office on Drugs and Crime and WHO, which have the promotion of health and human rights within their mandates, should provide technical assistance and make reporting mandatory and public to ensure transparency and accountability.

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VIEWPOINT

Health Workers on the Political Frontlines

GIDEON LASCO, RAUDAH MOHD YUNUS, EDWARD CHRISTOPHER DEE, AND MARTIN MCKEE

Health workers have been on the clinical frontlines of the struggle against COVID-19, enduring conditions they could never have anticipated. But many have also been engaged on the political frontlines. In brief interludes between caring for sick and dying patients, they have become advocates for health, demanding action on practical concerns, such as inadequate supplies of personal protective equipment, and on policies, including incoherent or dangerous responses and failures of political leadership.

Those speaking out are following a long and honorable tradition. Florence Nightingale was a powerful advocate for her patients, writing thousands of letters about the terrible conditions they often had to endure.¹ Rudolf Virchow, an eminent pathologist sent to investigate an outbreak of typhus in Silesia, then part of Prussia, decried the power of the aristocracy underpinned by the church. He famously said that doctors are “the natural attorneys of the poor.”²

In the decades since then, many others, less well known, have used their knowledge of the communities they serve, their professional knowledge of the determinants of disease, and their standing in society to speak truth to power. To do so takes courage, illustrated by the story of Ibsen’s fictitious hero Dr. Stockmann in his play *An Enemy of the People*.³ The doctor was chased out of town when he exposed contamination of the water that drew people to spend money in the local spas. But many still live up to this noble tradition, both individually and collectively through organizations like the People’s Health Movement.⁴

Those who do so can face enormous barriers. Some governments have used the impact of the pandemic, unprecedented in recent years, to justify exceptional measures, stifling venues for dissent.

This is illustrated starkly in Myanmar, where many health workers have opposed the military coup. “Our duty as doctors is to prioritise care for our patients—but how can we do this under an unlawful, undemocratic, and oppressive military system?,” asked several of the country’s prominent physicians in correspondence to the *Lancet*.⁵ Far from heeding their demands, the government resorted to further harassment, with armed soldiers abducting many people, including Maw Maw Oo.⁶

While the situation in Myanmar has caught the world’s attention, it has parallels around the world. In

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Competing interests: None declared.

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Egypt and Pakistan, health care workers have faced arrest for criticizing their governments' pandemic responses, and others have been detained in Belarus, where President Lukashenko has been in denial about COVID-19.⁷

Even without such threats of violence, health workers around the world face personal and professional risks. In the Philippines, for instance, protests by health workers in August 2020 were met with disdain by President Rodrigo Duterte, who accused them of fomenting revolution.⁸

Health workers in the United States have also been threatened for speaking out, with hospital staff being disciplined, fired, or declared persona non grata for raising COVID-19-related concerns.⁹

In Malaysia, the Hartal Doktor Kontrak became a nationwide movement when contract doctors who had been on the forefront in battling COVID-19 went on strikes and publicly demanded action by the government to end their years of job insecurity. As a result, many were harassed, "investigated" by police, and threatened with de-registration.¹⁰ The call for doctors to "comply" and "maintain discipline" was a complete double standard when considering the multiple political sagas staged by politicians since the advent of the pandemic. This includes the local Sabah election that was believed to have contributed to more than 60% of COVID-19 cases during the third wave in Malaysia.¹¹

In all these situations, health workers who support the government or stay silent are either ignored or, in some cases, lionized, but those who criticize the government are condemned. Worse, some politicians, governments, and media reports have tried to associate criticisms against poor COVID-19 measures as being unpatriotic or against the spirit of national solidarity. Yet acquiescence when things are going wrong is the last thing that is needed in a pandemic. Mistakes are inevitable, but we only progress if we learn from them.¹² This demands transparency and mechanisms for participation. Health workers have enough to fear from an invisible virus and the mental stress of working long hours in desperate situations. The last thing they need is to be attacked by those in authority.¹³

The situation is even worse for those who are seen, in some way, as different, for example on grounds of gender, social background, or ethnicity, where standing up to be counted invites hostility, especially on social media, where attackers are able to hide their identity. This is inimical to global health, which can thrive only in an atmosphere of freedom of expression and the protection of civil and political rights.

As Virchow taught us, health is political. This is true because power is exercised over it and its social determinants are amenable to political interventions.¹⁴ The decisions that politicians make and the ideologies they pursue are the difference between life and death. Many health workers will not want to put their head above the political parapet. That is their right. But those who do speak out also have rights that, in too many cases, are being ignored.

Our professional bodies, including the World Medical Association and International Council of Nurses, have a clear duty to demand that those who speak out are protected from harassment and persecution. This will not be easy. Some governments will condemn what they portray as interference in their domestic affairs, to which we can only reply that their silencing of those who call attention to their failure to control a virus that crosses borders with ease is a concern to us all.

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BOOK REVIEW

How to Resuscitate an Ailing Norm

ABBY STODDARD

Perilous Medicine: The Struggle to Protect Health Care from the Violence of War, by Leonard Rubenstein (Columbia University Press, 2021).

In the mid-19th century, a brief and little-known contretemps transpired between two icons of humanity and public health: Henri Dunant, founder of the Red Cross and progenitor of the Geneva Conventions, and Florence Nightingale, military nursing innovator and statistician. While both had experienced firsthand the ghastly aftermath of war, they each held different views on how to organize an effective and humane response for its victims. As recounted in Leonard Rubenstein's *Perilous Medicine: The Struggle to Protect Health Care from the Violence of War*, Nightingale disagreed with Dunant's vision for mobilizing societies of trained volunteers in each country to care for the wounded. This was essentially letting governments off the hook, she argued, for what was rightly their own militaries' responsibility. Dunant, who had sent Nightingale his proposal presumably hoping for an endorsement from the famed figure, shook off her critique, reasoning that "voluntary societies were essential because reform of military medical services was impossible." This question of the rightful locus of responsibility and target for reform recurs like a background drumbeat throughout Rubenstein's book.

On its face, the norm of allowing and protecting health care amid war makes unimpeachable sense from the standpoint of both morality and practical incentives. Combatants have strong interests in ensuring that their own wounded receive care and humane treatment, and in avoiding public moral outrage if they should, say, bomb a hospital. Yet this norm continues to be routinely violated by all manner of military actors, from small rebel militias to global superpowers, in violent acts that they readily justify on the grounds of strategic necessity or mere expedience.

Rubenstein, who directs the Human Rights and Health in Conflict program at the Johns Hopkins Bloomberg School of Public Health and was formerly president of the organization Physicians for Human Rights, has devoted much of his long career to making governments and international institutions pay attention to attacks on health care in armed conflict and to advocating for policies to better protect the wounded, the sick, and the people who care for them. In *Perilous Medicine*, he alternately employs the various lenses of his mixed professional background—advocate, academic, human rights lawyer—and engages the topic from these various angles. For readers seeking an in-depth and comprehensive understanding of the issue, it is an effective approach.

The narrative accounts of the violence experienced by medical providers and patients woven through the book give one the sense of being shaken by the collar by someone who has seen too much of this and insists we wake up to the enormity of the problem. Rubenstein describes in unflinching detail a great

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many documented cases of attacks on health care workers and facilities by warring forces who strike them intentionally or inadvertently. While noting that the violence is not at all new, the author underscores that the toll extends far beyond the visible damage. The individual tragedies of a bombing of a hospital in Yemen, of a massacre in a maternity ward in Afghanistan, or of doctors arrested and tortured for treating Arab Spring protestors are always compounded by the indirect harms to lives and health stemming from the loss in health care capacity. Once Rubenstein points it out, it is easy to see how many multiples of the original victim counts will follow after facilities close, programs are halted, and potential health care workers choose not to take on these dangerous roles. One example particularly illustrates the vastness of the ripple effects: “Insecurity in Pakistan, where more than seventy attacks on vaccinators have been committed, pushed back by years, perhaps decades, the realization of the comprehensive global plan to eradicate polio from the planet.”

How can such things happen, and so distressingly frequently, despite what most would believe to be a universal moral consensus condemning it, backed up by international legal instruments and codes? To examine this “paradox of inaction,” Rubenstein uses historical and legal analyses to argue that it comes down to competing interests and opposing views of morality in war (*jus in bello*) and of war (*jus ad bellum*). To illustrate what he posits as the fundamental tension, Rubenstein contrasts proto-humanitarian Henri Dunant with yet another of his historical contemporaries—the lesser-known Francis Lieber, a German American political theorist writing during the American Civil War.

Just as Dunant’s writing and advocacy helped shape the Geneva Conventions, Lieber’s work resulted in a major and enduring contribution to “laws defining the moral boundaries of the conduct of war, including obligations of the combatants toward the wounded and the sick.” In Lieber’s case, however, the laws were US military codes, which for many years bore his name and still bear the stamp of his ideas. The two different contexts of war shaped

both men’s thought. For Dunant, having witnessed the bloody results of the Battle of Solferino, the latest installment of centuries of European conflict, left the Swiss businessman with a sense of the senselessness, as well as the inevitability, of war. His project was to limit the worst excesses of brutality and bring some humanity to the battlefield. Lieber, in contrast, was faced with what he saw as the epitome of a just and urgent war—a fight against the evil of slavery. The moral ends of winning such a war trumped all other concerns and justified a wider range of means. His consequentialist moral reasoning can be summarized in the attitude that brutal acts “are moral if they quickly bring a just war to an end.”

The tension between the two views continues to play out in armed conflicts, with military decisions often defaulting to the consequentialist logic of Lieber to justify or excuse harms against health care, whether through direct targeting or recklessness, physical obstruction, or legal constraints. Despite the Geneva Conventions’ rejection of Lieber’s consequentialist approach, and most combatants today likely having never heard Lieber’s name, the logic he codified in an order for the Union Army in the American Civil War pervades much of military (and radical fundamentalist) thinking and moral intuitions, embodying what Hugo Slim termed the “ruthless pragmatism” of war. Even in today’s hybrid wars against terrorist insurgencies, fought more with special operations forces and drones than with infantry battalions, enabled what Rubenstein calls “a vast extension of the logic of denying health care to enemies and punishing their caregivers.”

Rubenstein, who has been documenting and reporting on these incidents since the early 1990s, does not hide his frustration with governments and international political bodies, including the World Health Organization, which has proceeded “gingerly” in holding its member states to account for misconduct. The US-enabled Saudi military campaign, whose airstrikes have indiscriminately battered Yemen without taking the slightest care to avoid medical facilities, receives especially strong condemnation: “At every turn, the leader-

ship engaged in manipulation, dissembling, spin, and intimidation. It kept its arms suppliers at bay through rhetoric that would please them and accepting technical support that made little difference to their conduct.”

Perilous Medicine is a significant milestone for a body of work that spans decades, continents, and professional métiers. Approaching the subject from multiple ethical, legal, and historical angles as Rubenstein has done (and more than this review has space to describe adequately) does due justice to a complex, longstanding, and morally thorny subject. Like most studies of chronic and complex issues, however, the book is more satisfying in its diagnosis of the issue than in its prescription for treatment. The principal contribution of this book is in laying bare and dissecting the problem and providing coherent explanations for why it persists. In terms of what to do about it, the author calls on the global community to

reinforce norms that protect health care that have been chipped away, often without acknowledgement, [on] governments, state militaries, and armed groups ... to follow through on commitments they have made to undertake the actions needed to prevent attacks on health care and end impunity, [and on] new sources of leadership and solidarity [to] demand action and support those dedicated to protecting health care in war and in circumstances of political violence.

These sensible and necessary (if broad) calls to action are undercut to some degree by the author's account, immediately following, of a promising report and series of robust recommendations by the United Nations Secretary-General never meaningfully taken forward by the member states of the Security Council: “[I]n the years that followed, the Security Council annually discussed violence against health care but never acted on the recommendations.” The answer to the question of who is ultimately responsible and where is the leverage point for addressing the current state of impunity seems every bit as elusive as it was in the 1860s.

If *Perilous Medicine* sounds a less than hopeful note, it nonetheless serves as a needed alarm

bell, alerting us to the fragility of this most vital of humanitarian norms.

EDITORIAL

A Slow Paradigm Shift: Prioritizing Transparency, Community Empowerment, and Sustained Advocacy to End Compulsory Drug Treatment

CLAUDIA STOICESCU, KAREN PETERS, AND QUINTEN LATAIRE

For the past two years, we, the editors of this special section, have worked in close collaboration in various ways to reenergize discussions at the international, regional, and national levels on the closure of compulsory drug detention facilities and the transition to rights-based approaches to drug treatment.¹ In August 2020, we convened the joint UNAIDS-UNODC Asia-Pacific Expert Advisory Group on Compulsory Facilities for People Who Use Drugs, comprising 11 academic, government, and civil society experts from the region working across disciplines and sectors to share strategic advice with the United Nations (UN) and strengthen advocacy for human rights-based alternatives to compulsory treatment in their respective national contexts.² Then, in January 2022, we published a new report taking stock of the last decade of compulsory drug treatment implementation and highlighting promising case studies of voluntary rights- and community-based responses in East and Southeast Asia.³ In the report, we documented continued political and financial support for compulsory facilities, with little change in the past decade in the number of people detained, which remains at almost half a million people annually in seven countries in East and Southeast Asia. Detention in compulsory centers has been associated with an elevated risk of acquiring HIV and not receiving antiretroviral therapy, with repeat detainment associated with a greater risk of HIV infection. Only two countries reported that referral to, or continuation of, antiretroviral therapy was provided for people living with HIV in such facilities. Free condoms and sterile injecting equipment were unavailable inside compulsory facilities in all the countries. Instead, many compulsory treatment systems in the region continue to implement unscientific, and often harmful, practices in the name of enforcing abstinence from drug use, leading to severe human rights violations. These include compulsory physical exercise, lack of adequate nutrition, physical and sexual violence, denial or comparatively lower access to quality health care services, mandatory religious instruction, and forced labor as “therapy.”

Efforts to convene the expert advisory group and to conduct a formal regional consultation with government authorities in East and Southeast Asia and engage in meaningful national-level advocacy following the publication of the findings have been punctuated by mobility restrictions and myriad challenges posed by the COVID-19 pandemic. But the pandemic has also made the costs of inaction on ending

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compulsory drug detention unquestionably clear. Nearly 500,000 people are detained in the name of drug rehabilitation in East and Southeast Asia in massively overcrowded conditions, facing grave violations of human rights and serious risks to health, as highlighted in 2020 in a joint statement by 13 UN entities.⁴ Indeed, the pandemic has made evident the urgent need to continue having discussions and engaging in advocacy efforts at all levels to better understand why the closure of compulsory drug detention facilities has stalled in recent years and to put renewed pressure on states to end the inhumane practice of detaining individuals involuntarily in the name of drug treatment.

One result of this ongoing joint work is this special section. The issue was timed to coincide with the 10-year anniversary of the 2012 UN Joint Statement on Compulsory Drug Detention and Rehabilitation Centres, in which 12 UN entities called on governments worldwide to close compulsory drug detention and rehabilitation facilities.⁵ The joint statement not only stressed that compulsory centers violate human rights and threaten the health of detainees but also recognized “their lack of effectiveness in preventing relapse, their high costs,” and their “negative impact on efforts to ensure universal access to HIV prevention, treatment, care and support.” Still highly relevant to today’s world and to the aims of this special section, the joint statement encouraged states to examine and address the “root causes of vulnerability,” including poverty, gender inequality, lack of sufficient family and community support structures, and other social determinants of health and drug use.

Our call for submissions aimed to attract papers and viewpoints that went beyond describing already widely documented harms associated with compulsory drug treatment to identifying critical leverage points to address the most pressing challenges to ending compulsory treatment and expanding voluntary evidence- and rights-based services.⁶ We were hopeful that papers from around the world would showcase human rights-based approaches to drug treatment, interrogate the status quo on the continued use of involuntary commitment of people who use drugs, and illuminate

important lessons and recommendations for revitalizing advocacy efforts to eradicate compulsory and punitive modalities in favor of health-oriented, rights-based responses.

In their totality, the papers and viewpoints dissect and critique the prohibitionist status quo using a range of multidisciplinary lenses and identify strategies for expanding voluntary health- and human rights-based alternatives. There is presently both a necessity and an opportunity to consolidate advocacy efforts across the UN, academia, and civil society and escalate pressure on states to end compulsory and punitive treatment practices and instead strengthen transparency, accountability, and monitoring related to national drug treatment systems. The contributions to this special section provide helpful potential pathways for taking concerted action to achieve our ultimate common goal of health and human rights for all persons whose lives involve drugs.

Interrogating the paradigm of prohibition

A first cluster of papers and viewpoints examine national iterations of the prohibitionist paradigm across varied contexts, from China and the Philippines to Morocco and Brazil. For decades, the discourse of prohibition has positioned drugs and people who use them as enemies in a “war” to be won at all costs. This framing has been used to systematically deprive people who use drugs of their human rights in the name of abstinence and treatment. Punishments meted out through criminal and administrative laws, policing, and imprisonment and other forms of detention emerged as the prevailing tools to achieve the elusive “drug free” world at the center of this paradigm. Compulsory centers and other coercive forms of drug treatment are part and parcel of this continuum of punishment.

In “No Exit: China’s State Surveillance over People Who Use Drugs,” Mu Lin, Nina Sun, and Joseph J. Amon describe the human rights concerns related to the wide-reaching state surveillance system imposed by Chinese authorities on people who use drugs. In particular, the authors elucidate how the integration of compulsory detoxification and

community-based rehabilitation into information management and control systems such as the Dynamic Control System restricts the most basic daily activities of people who use drugs, including their ability to access health and support services and pursue education and employment. In their quest to enforce total abstinence and prevent relapse into drug use, China has created an unremitting policing and “supervision” system that negatively affects the rights and health of people who use drugs and exacerbates drug-related stigma and discrimination.

In “The Politics of Drug Rehabilitation in the Philippines,” Gideon Lasco and Lee Edson Yarcia argue that forced drug rehabilitation is popularly conceptualized as the humane and acceptable alternative to incarceration or—worse—extrajudicial killings in the Philippines. This long-standing perception is perpetuated by a history of penal populism, moral panic around drugs, and moralistic views of people who use them. In practice, however, the authors show that there is little difference between jails and drug rehabilitation centers. Lasco and Yarcia conclude with a call for rights-based responses to drugs that goes beyond the criminal and medical frameworks portraying people who use drugs either as “criminals” or “patients.” Real change, they argue, requires redressing the colonial roots of international drug control, particularly by creating spaces for and supporting civil society voices from the Global South to lead drug policy reform efforts.

In “The Right to Health as a Tool of Social Control: Compulsory Treatment Orders by Courts in Brazil,” Luciano Bottini Filho reviews a sample of court decisions to show how the constitutional right to health has been used to justify handing out compulsory treatment orders in a context of mounting punitive policies and discourse in Brazil, where therapeutic communities are historically seen as promoters of compulsory detention for people who use drugs. In particular, the author warns that easily enforceable compulsory drug detention in combination with weak patient rights is especially problematic in a country with a rampant detention culture.

In his viewpoint “Toward the Emergence of Compulsory Treatment for Drug Use in Morocco?,” Khalid Tinasti describes the first compulsory drug treatment order in the country since Morocco’s Narcotics Act came into force in 1974. The author considers whether the 2021 ruling of a lower court judge in Kenitra could act as a precedent for the future imposition of compulsory treatment within Morocco’s evolving national drug policy landscape. The viewpoint concludes with a call for scaling up harm reduction services, decriminalizing drug use and possession for personal consumption, and repealing legal provisions allowing for forced treatment toward the full realization of human rights for people who use drugs in Morocco.

Critical leverage points for disrupting the status quo

A second cluster of papers and viewpoints reflects on the critical leverage points that can drive change toward ending punitive forms of treatment and realizing human rights protections for people who use drugs. The alternative paradigm offered by this set of papers prioritizes drug decriminalization and accepts that a person must not necessarily give up drug use to access health care and claim their rights. Indeed, the UN system has now joined many policy makers and scholars in calling for decriminalization of drug possession for personal use alongside alternatives to conviction and punishment as an essential step to ending punitive forms of treatment.⁷ Such a policy shift should be accompanied by the expansion of a continuum of services provided in the community—from outreach services to low-threshold harm reduction services such as needle syringe programs and opioid agonist therapy, to residential rehabilitation and outpatient psychosocial and mental health support—to respond to individuals’ complex and intersectional needs.⁸

In their viewpoint “Not Enough Stick? Drug Detention and the Limits of United Nations Norm Setting,” Daniel Wolfe and Roxanne Saucier give their opinion on why national responses to drug detention in Asia have been plagued by inaction.

The authors argue that principal among these has been the lack of sustained advocacy targeted at governments by a range of international stakeholders, including international organizations, donors, civil society, and UN entities. Measurable change, they argue, necessitates a relentless effort and sustained by consistent funding to place ongoing pressure on governments and keep human rights-based alternatives on political agendas.

In the viewpoint “Transitions from Compulsory Detention to Community-Based Treatment: No Transparency without Data, No Accountability without Independent Evaluations,” Pascal Tanguay, Anand Chabungbam, and Gino Vumbaca expand on the inaction of governments to close compulsory centers in Asia. They posit that the lack of international sanctions for operating compulsory facilities and absence of incentives to accelerate the implementation of voluntary community-based models have contributed to political inertia on this issue. The paper recommends refining regional and international monitoring mechanisms to strengthen governments’ accountability to fulfilling the right to health for all, including people who use drugs. In particular, the authors call for more deliberate efforts to demand government transparency regarding the operation of compulsory centers, including by regularly collecting and publishing data on these facilities and demanding that they be subject to independent external evaluations to gauge their compliance with international human rights standards, in the same way as is expected of other places of detention.

Robert Ali and Matthew Stevens, in their viewpoint “Moving toward Voluntary Community-Based Treatment for Drug Use and Dependence,” probe the topic of the transition toward voluntary community-based treatment by exploring the financial, human, technical, and ideological barriers to this process. A key shift, they argue, must occur in the very way in which drugs are perceived. Compulsory treatment, the authors reflect, operates based on a moralistic view that drug use is a character flaw that can be “cured” through various forms of therapy. This view is not only false but also a slippery slope, since dehumanizing people who

use drugs can subsequently be used to justify depriving them of their basic human rights. Another area critical to the paradigm shift is the inclusion of structural interventions addressing the social determinants of health—employment, housing, and social connectedness—as part of the drug treatment continuum.

In “Capacity-Building in Community-Based Drug Treatment Services,” Michael J. Cole makes a case for strengthening good treatment practices through comprehensive and empowerment-based capacity-building in low-resource settings. Quality treatment provision is largely influenced by the capacity of service providers and has a direct influence on clients’ experience of those services. The author presents a step-by-step approach for improving monitoring, evaluation, and reporting service outcomes and promoting research to expand the scale and quality of voluntary evidence-based treatment interventions.

Finally, the virtual roundtable makes a critical contribution to this collection. As part of this roundtable, we brought together 11 global and regional experts from academia and civil society, including people with lived experience of drug use, to take a deep dive into issues surrounding compulsory treatment, health, and human rights. Apinun Aramrattana, Judy Chang, Ma. Inez Feria, Priya Gopalan, Francis Joseph, Karyn Kaplan, Sangeeth Kaur, Gloria Lai, Ajeng Larasati, Samuel Nugraha, and Krisanaphong Poothakool joined us in discussion of their experiences in addressing the issues of compulsory treatment and the mechanisms that sustain them. Their insights from the Asia region and beyond provide answers to some of the tough questions regarding the persistence of compulsory drug treatment modalities and the motivations for governments to maintain them. Discussions highlighted the need for changing the narrative of people who use drugs as “criminals” or “patients” toward humanizing their experiences and normalizing harm reduction measures, which are still lacking in many countries in the region. Civil society voices maintain that there is an urgent need to fund practical evidence-based alternatives with the potential to be culturally adapted and

scaled up across contexts. One such example is Rumah Singgah PEKA in Bogor, Indonesia, which was established in 2010 with a view to providing a drug treatment option that does not require individuals to be abstinent in order to improve their quality of life. Several roundtable participants underscore the importance of holding countries accountable to their international human rights obligations, something the UN Working Group on Arbitrary Detention implements in practice by conducting country visits. The working group also completed a study in 2021 on arbitrary detention that identifies “increasing instances of arbitrary detention as a consequence of drug control laws and policies,” which was presented to the Human Rights Council in July 2021.⁹

Conclusion

We hope that readers find this collection useful in their scholarship, practice, and advocacy. Civil society, especially movements of people with lived experience of drug use, and the UN have brought attention to the failure of compulsory treatment to meet the needs and secure the rights of people who use drugs. While the guest editors’ own work around ending compulsory treatment and promoting voluntary community-based treatment and care services has focused on the Asia region, we aimed for this issue to reflect a broader global focus. Nevertheless, the focus of most submissions remained on government-run centers in Asia, with some important exceptions. While continued pressure is needed to end compulsory treatment in Asia where such facilities have documented negative consequences, several roundtable participants note that compulsory and punitive treatment practices also occur in other geographical contexts around the world. These practices may be facilitated by governments and nonstate actors alike, including state-endorsed and often unregulated private and faith-based treatment centers. There is both a need and an opportunity for future research to investigate punitive and coercive drug treatment practices in varied geographical settings, including those implemented by nonstate actors. Ultimately, such

work will serve to inform more diverse conversations and targeted advocacy to transform harmful drug-related practices.

A shortcoming of this collection is the limited representation of voices of people who use drugs and those with lived experience of compulsory treatment, especially those whose first language is not English, in the pages of this special issue. The barriers for people who use drugs to share their experiences in academic forums such as this journal can be colossal. These barriers are representative of broader socioeconomic inequities, including language barriers, as well as systemic stigma and discrimination, and unequal power dynamics and resources. The voices of people who use drugs must be strengthened and supported toward contributing meaningfully to the development, analysis, and elucidation of rights-based community-led alternatives to compulsory treatment.

Ultimately, this collection demonstrates the centrality of human rights in all discourse around drugs and drug use. Punitive approaches to drug use and treatment, including compulsory detention, will not be eradicated without disrupting the dominant discourse that portrays abstinence as the only acceptable outcome of treatment and characterizes people who use drugs as individuals lacking agency who need to be “cured” in order to resume their social function. A rights-based approach must involve a paradigm shift away from demonizing and criminalizing people who use drugs. It requires dismantling interconnected structural inequalities and barriers such as economic disadvantage, stigma and discrimination, and laws that criminalize drug use or the possession for personal use, and empowering people with lived experience of drug use to shape policies and practices affecting their lives. To shift the paradigm, we must keep having global, regional, and national conversations, funding sustained advocacy efforts, and empowering people whose lives involve drugs.

Acknowledgments

This special issue has been made possible with funding from the Joint United Nations Programme

for HIV/AIDS (UNAIDS) Regional Support Team for Asia and the Pacific and the United Nations Office on Drugs and Crime (UNODC) Regional Office for Southeast Asia and the Pacific.

Disclaimer

The views and opinions expressed in this special section are those of the authors and do not necessarily reflect the views or positions of the guest editors or their affiliated organizations.

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No Exit: China's State Surveillance over People Who Use Drugs

MU LIN, NINA SUN, AND JOSEPH J. AMON

Abstract

In China, although drug use is an administrative and not criminal offense, individuals detained by public security authorities are subject to coercive or compulsory “treatment,” which can include community-based detoxification and rehabilitation and two years of compulsory isolation. Individuals are also entered into a system called the Drug User Internet Dynamic Control and Early Warning System, or simply the Dynamic Control System. The Dynamic Control System, run by the Ministry of Public Security, acts as an extension of China’s drug control efforts by monitoring the movement of people in the system and alerting police when individuals, for example, use their identity documents when registering at a hotel, conducting business at a government office or bank, registering a mobile phone, applying for tertiary education, or traveling. This alert typically results in an interrogation and a drug test by police. This paper seeks to summarize, using published government reports, news articles, and academic papers, what is known about the Dynamic Control System, focusing on the procedures of (1) registration; (2) management; and (3) exit. At each step, people subject to the Dynamic Control System face human rights concerns, especially related to the right to privacy, rights to education and work, and right to health.

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Competing interests: None declared.

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Introduction

In China, drug use is an administrative and not criminal offense; however, individuals detained by public security authorities are subject to coercive or compulsory “treatment.” This approach has been subject to widespread condemnation, including repeated calls over the past decade by United Nations (UN) agencies, UN human rights experts, and human rights organizations for the country to close compulsory drug detention centers and increase voluntary, community-based alternatives. Nonetheless, between 2012 and 2018, the number of people in compulsory drug detention centers in China remained virtually unchanged, and the number enrolled in compulsory community-based treatment rose sharply.¹

In addition to these approaches, the government enters all people detained by public security authorities for drug use in China into a system called the Drug User Internet Dynamic Control and Early Warning System, or Dynamic Control System (DCS). This is a reporting and monitoring system launched by the Ministry of Public Security in 2006.² Individuals are entered into the system regardless of whether they are dependent on drugs or subject to criminal or administrative detention; some individuals who may be stopped by public security but not formally detained may also be enrolled in the DCS.

Once entered into the DCS, registered individuals’ personal information is shared within the national public security apparatus.³ When individuals who are in DCS use their identity documents—for example, when registering at a hotel, conducting business at a government office or bank, registering a mobile phone, applying for tertiary education, or traveling—the DCS alerts the police, typically resulting in an interrogation and a drug test.⁴

The DCS first came to public notice in a government news story.⁵ In the article, the system was described as an important initiative to reduce demand for drugs, maximize education and access to treatment to “rescue” persons who use drugs, reduce criminal activity, and maintain social harmony and stability. In 2012, a State Council report

on anti-drug laws cited the DCS as an innovative measure that “enhances the detection and control of drug-users.”⁶ As a part of the launch of the DCS, public security authorities conducted a comprehensive sweep of individuals suspected of drug use; by the end of March 2007, 785,900 individuals had been entered into the system.⁷ According to data released by the Ministry of Public Security, as of 2019, there were 4.7 million people registered in the DCS, including 2.2 million identified as current drug users and 2.5 million identified as former drug users (\geq three years without drug use).⁸

Prior to the establishment of the DCS, China’s surveillance management of people suspected of drug use relied, like other forms of social management, on the household registration system (*hukou*). The *hukou* system was viewed by government authorities as inadequate, however, because it did not effectively restrict persons who use drugs from changing their residence, which many did because of the discrimination from having been arrested. To address this, the DCS combined online databases with new information technologies such as cell phone apps and facial recognition, with an emphasis on real-time updating of information and around-the-clock tracking of people’s movements.⁹

Five years after the launch of the DCS, in 2011 the State Council published the Regulation on Drug Rehabilitation, which gave the system legal authorization.¹⁰ Yet the legal provisions in the regulations regarding the DCS are simplistic and vague. For an administrative and policing system that affects millions of people who live and work in China, the legal provisions stipulate only the registration criteria and the implementing institutions for the DCS, as well as the general exit criteria. Specific operational procedures are not identified.

This paper provides an in-depth description of the DCS, drawing on published laws and policies, national and local government reports, and Chinese academic journal articles, and describes the system’s shortcomings and impact.

Registration, management, and exit

The DCS system can be best understood in terms

of how individuals are registered, how they are managed once enrolled, and the legal requirements—and realities—around being unregistered, or exiting, from the system.

Registration

All individuals identified by police as having used drugs (often via a positive urine test) are entered into a database of the National Drug Control Information System.¹¹ Article 4 of the Regulation on Drug Rehabilitation stipulates that public security departments at the county level or above are responsible for testing suspected drug users and registering persons who use drugs in accordance with the law.¹²

The DCS draws information from the National Drug Control Information System and includes basic demographic characteristics, as well as the types of drugs allegedly used, where and how individuals reportedly consume them, and individuals’ drug treatment history.¹³ However, the system reportedly takes time to update, and from time to time there are problems with it being unresponsive or inefficient in executing its functions, with a low processing capacity for large-scale data.¹⁴ These problems make the DCS inconvenient for users at the local level, and many localities have developed their own information management systems that may have specific components that go beyond the core DCS information.

For example, the Yunnan Provincial Drug Enforcement Headquarters commissioned Shandong University to develop a local DCS in Yunnan Province. The system’s functions include registration management, compulsory isolation detoxification management, and community-based detoxification management.¹⁵ Similarly, in 2016, Ningxia Hui Au-

tonomous Region launched the Ningxia Socialized Service Management System for Drug Users. The system includes information on community-based detoxification and rehabilitation, drug testing monitoring, home visit records, and risk assessment, and it integrates information from the Ningxia household registration system, Department of Justice drug treatment centers, and health and medical institutions. In addition, the system was designed to provide policy analysis and early warning alerts.¹⁶

Management

Specific management of individuals in the DCS is determined by risk levels.¹⁷ The main determinants of how individuals are classified are whether the person poses a danger to society and whether they have undergone drug rehabilitation. Risk levels can be adjusted at the local level by the antinarcotics office and public security authorities.¹⁸ Risk levels then determine the degree of surveillance and management activities. For example, Huizhou City, Yuanzhou Township, determines the frequency of counseling (“education and persuasion”) and drug testing according to risk level (Table 1).¹⁹ After implementing control measures for more than six months, authorities are required to reassess risk levels.²⁰

With this information, the DCS seeks to create a system of enhanced control and management, purporting to effectively identify “warning signs” of relapse and opportunities for family and health care and social workers to continuously track the behavior and movement of persons who use drugs. To achieve this, the DCS is complemented by *investigation work*, including obligatory meetings of persons who use drugs with security personnel and unscheduled inspections (including drug tests)

TABLE 1. Huizhou City, Yuanzhou Township, management measures for drug users

Risk level	Counseling	Urine test
Extreme risk	At least once every two weeks	At least once every two weeks
High risk	Once a month	Once a month
Medium risk	Once every three months	At least twice a year
Low risk	At least once every half year	At least once a year

at their home or place of employment. Alongside these efforts is ongoing *maintenance work*, which involves the real-time updating of online information about individuals registered in the system. Finally, there is *enforcement work*, which includes active surveillance to detect unlawful activity and reduce drug-related crime.²¹

A drawback to such extensive monitoring is that for local police officers, responding to DCS alerts occupies a great deal of time and energy. The use of identity documents by individuals registered in DCS will trigger an alarm, and police are expected to respond regardless of the specific situation. The police are required to investigate alerts within a specified time limit and log results of their response into the database. Often, police arrive after the person triggering the alert has left. One study calculated that within a period of 10 months, the district police had responded to 3,640 DCS alerts, an average of 12 per day. However, police were able to make contact with the subject of the alert only 26% of the time, and only 51 alerts were identified as being related to drug use.²²

Efforts to manage persons who use drugs are also impeded by data errors, encouraged by the DCS's strict requirements for prompt data entry and quotas for monthly meetings and investigations.²³ This can result in, for example, errors in identifying information (names or identity document information), resulting in people who have no history of drug use being entered into the DCS and requiring people affected to file complaints or lawsuits.²⁴ Errors may also be more common during specific periods of heightened security, which can include expanded, or mass, drug testing of registered drug users.²⁵

The level of scrutiny of individuals in the DCS is increased for those undergoing community-based detoxification. For example, Zibo, Shandong Province, has introduced a community-based detoxification mobile management and service platform that provides staff, persons who use drugs, and family members with a cellphone app. The app includes GPS tracking and provides for the real-time monitoring of routine drug screening tests and clinical notes by detoxification staff.

The app automatically sends alerts and pushes real-time location information to program staff if the individual misses appointments or deviates from approved routines.²⁶

Another example of a mobile app-based electronic management system for individuals in community-based rehabilitation was piloted in Hongkou and Pudong districts of Shanghai. Persons who are registered are required to log on to the app every day and take mood surveys. The app provides information on drugs and relaxation techniques and helps them locate a nearby hospital if necessary. The core features of the system include a "positioning fence" and "voice recognition login" to validate the identity and location of individuals enrolled in the system. Social workers have access to the information in the app, theoretically to improve the efficiency of their oversight and determination of relapse risk. However, studies have found that the system fails to make substantive changes in addiction levels.²⁷

Yet another electronic management system tested in Qingyang District, Chengdu, has been designed with an app with surveillance and management tools for social workers, family members, and doctors. Individuals undergoing detoxification are required to report their emotional state and provide their location and other information, including a photo and a voice recording. Social workers and family members can view the information uploaded by individuals in the system at any time to track their status. The system claims to use artificial intelligence to identify mood and provide early warning of the risk of relapse. It also purports to use blockchain technology to build a chain of evidence, integrating every event that occurs during the management process into the block chain to form a "scientific basis" for assessing rehabilitation.²⁸

Since 2015, increasing emphasis has been put on the integration of DCS at a community level. This approach is consistent with "grid management" initiatives promoted by the Chinese government, which divides urban and rural administrative jurisdictions into "grid" segments and, using digital and traditional surveillance (such as patrols and site

visits), conducts “granular, informed and dynamic community service management” of households, organizations, and businesses within the grid.²⁹ This integrated approach was first piloted in September 2015, when the Central Public Security Comprehensive Management Commission and the National Narcotics Control Commission selected three cities and prefectures and seven counties and urban districts in the provinces of Jilin, Hubei, Guangdong, and Yunnan to carry out a pilot project on grid-based service management of persons who use drugs. Based on the results of the pilot, the government adopted a goal of nationwide coverage by 2018.³⁰ The objectives of grid management and dynamic control are essentially the same: to maintain social order and stability and to prevent and curb unlawful and criminal behavior.³¹

Under the grid-management model, persons who use drugs are under surveillance by committees responsible for geographically defined grids, which are adjusted according to terrain, urban density, or management needs. For example, Jiangsu Province, with a population of over 80 million, reportedly has 300,000 grid workers overseeing 120,000 grids, with each grid composed of an average of 670 people.³² Grid workers include individuals specifically recruited as grid officers, as well as social workers, police officers, cadres, and others.

In practice, the grid-management approach is a fleshing-out and deepening of the DCS. In Huangfu, Shanxi Province, for example, the responsibilities of the town’s grid-management of persons who use drugs include the following:

- Assessment: develop rehabilitation plans for persons who use drugs.
- Inspection: conduct weekly visits to “drug associated” persons in the district.
- Promotion: implement anti-drug use publicity campaigns.
- Investigation and registration: investigate reports of drug use, log information into the DCS, and complete the corresponding paper ledger registration.

- Assistance and mediation: collate, analyze, discuss, and consult on drug-related issues.³³

In some locations, more advanced systems and training for grid-management personnel allow for even more sophisticated grid-based management. For example, the Wuhan Fengpu Technology Company has customized a grid-management system for people undergoing community-based detoxification (rehabilitation) for many cities and counties in Hubei Province, purportedly using “big data” and artificial intelligence to establish a comprehensive control platform that includes “real-time data, transmission of location, statistical analysis, and research and judgment guidance.”³⁴

Exit

According to article 7 of the Regulation on Drug Rehabilitation, “Dynamic control shall no longer be applied to persons who have abstained [from drug use] for three years without relapse.”³⁵ This is the only provision in the regulation that deals with an exit mechanism for the DCS.³⁶ The main basis for determining whether a person has abstained from drug use for three years is regular drug testing. Typically, individuals in community-based detoxification programs undergo no fewer than 22 drug tests, and those under community-based rehabilitation undergo no fewer than 12 drug tests in a three-year period. Those who have no positive urinalysis tests and no record of drug-related criminal cases are deemed abstinent or rehabilitated.³⁷

While the criteria for exiting dynamic control are relatively clear, there are no operational guidelines on how dynamic control is actually suspended or lifted. As a result, many people enrolled in DCS find it difficult to exit the system. Initially, exiting the DCS required high-level authorization.³⁸ However, even as DCS has become localized, the procedures for exit remain unclear for many local public security departments.³⁹ Despite nominal “control” over the system, local public security departments are often authorized only to enter information into the DCS but not to modify or delete it; only provincial-level public security departments have this

authority.⁴⁰ When some kind of system error or human error occurs, the local public security office has to write to a higher-level authority to apply for modification, which can be time consuming.⁴¹

As a result of the difficulty exiting the DCS, two nongovernmental organizations have applied to public security departments to release information on how to exit the DCS. In August 2011, the Beijing Aizhixing Health Education Institute submitted an information request to the Ministry of Public Security, asking it to release information about the specific operational methods for releasing individuals from the DCS, the specific departments handling the process, and the documents that need to be submitted.⁴² The ministry replied that no application needs to be submitted, as people who use drugs are automatically released from dynamic control after three years of abstinence.⁴³ In October 2020, the Kunming Chunyu Tongxin Studio requested that the Yunnan Provincial Public Security Bureau disclose similar information. The response was similar: no application is required to exit the DCS, and there are no local regulations in Yunnan on the subject.⁴⁴

In practice, it appears that the requirement of three years of abstinence without relapse and no record of drug-related criminal cases is insufficient for release from dynamic control in some (if not most) cases. According to some accounts, people who are in the DCS can be partially released, meaning that they are no longer subject to surveillance alerts but still subject to community-based control and risk assessment. In areas where the authorities determine the drug situation to be serious, no one is released from dynamic control; instead, dynamic control is ongoing regardless of one's period of abstinence. In other places, the continued implementation of dynamic control on people who meet the exit requirements is most likely because information has not been updated in a timely manner.⁴⁵

Other administrative problems also cause people to remain in dynamic control for long periods. For example, people who are apprehended by the police but are not deemed to be dependent on drugs will not be ordered to undergo community-based detoxification and will generally be sentenced only

to administrative detention and then released. Since they lack a record of regular drug tests, these people are likely to remain under dynamic control for a long time.⁴⁶

Ultimately, having achieved the criteria required to exit DCS does not mean that the person's information is deleted from the system: the system no longer sends out an alert when an individual uses his or her identity card, but the individual's record of drug use, and some degree of monitoring (or "dynamic control"), is apparently permanent.⁴⁷ According to data released by the Ministry of Public Security, the number of people who have abstained for three years without relapse has now surpassed the number of existing drug users. By the end of 2019, the government reported that there were 2.2 million drug users in China and 2.5 million people who had not been found to have relapsed after three years of abstinence.⁴⁸ The state does not provide public data on how many of these 2.5 million "rehabilitated" individuals are still under dynamic control.

The effect of China's Dynamic Control System on persons who use drugs

When China's policy makers established the DCS, their objective was to prevent relapse through ongoing monitoring. However, there is little evidence that the DCS prevents relapse and ample evidence of the system's negative effects on the health of individuals enrolled in DCS and their integration into society. Research shows that persons who use drugs in China receive little social support during the detoxification process and that the social ostracism they face is the chief cause of relapse into drug use.⁴⁹ What empirical evidence exists on the impact of DCS shows the constraints that the DCS imposes on nearly every aspect of life.

A study in 2011 found that the interrogations, identity checks, and urinalysis imposed under the DCS have a significant effect on all aspects of life for persons who use drugs. The survey found that DCS is felt most frequently when obtaining accommodations (92%), followed by processing various documents (88%), travel (85%), and renting a home

(72%).⁵⁰ Survey respondents reported that DCS surveillance made them reluctant to advocate for their rights in disputes (73.5%) and that it triggered bias against them (96.5%), a loss of privacy (93.5%), fear that taking medication will affect urinalysis (90%), and negative effects on work and marriage (88.5%). Respondents also said that it affected family relations, with the constant examinations under DCS making family members suspicious of relapse and also creating bias against family members (including children) and affecting opportunities for family members to work outside the home.

A survey conducted in 2018 similarly found that the DCS had a negative impact on family relationships and that household visits and unannounced home drug tests, combined with interviews with neighbors and neighborhood committee members, violated the privacy of those registered in the DCS.⁵¹ Other components of the DCS, involving interrogation and drug tests in public venues such as train stations, hotels, airports, banks, and highway toll booths, also are likely to result in the disclosure of personal information. The DCS can also affect the employment of persons who use drugs, as public security officers may subject individuals to drug testing at work or during business trips, if individuals registered in the DCS are even able to get approval for work-related travel. The study concluded that the DCS exacerbates both stigma and the marginalization of those who are registered.

Human rights concerns

The DCS and the impacts described above relate to several key human rights, including the rights to privacy, to education, to work, and to health.

Privacy

The International Covenant on Civil and Political Rights, which China signed but has not ratified, provides that no one shall be subjected to arbitrary or unlawful interference with their privacy, family, home, or correspondence and that everyone has the right to the protection of the law against such interference.⁵² Any interference with the right to

privacy, including the collection, retention, and use of an individual's personal data, must be necessary and proportionate for a legitimate aim, and subject to a clear and public legal framework.⁵³

Furthermore, China's domestic Civil Code stipulates that everyone enjoys the right of privacy. No organization or individual may infringe on the privacy of any other person by spying, invading, harassing, or disclosing one's personal information. It also notes that state institutions must keep private and confidential personal information that is collected during the performance of duties.⁵⁴

In 2021, China passed new legislation, modeled after the European Union's General Data Protection Regulation, regulating the protection of personal information. The law provides explicit requirements related to consent, data localization and deletion, the transfer of personal information, and compliance in general. While the law regulates both private and government agencies, it provides government authorities a broad exception when acting in accordance with administrative regulations. However, the 2011 Regulation on Drug Rehabilitation specifically requires keeping the personal information of persons who use drugs confidential and includes penalties for the disclosure of such information.⁵⁵

Though both international and domestic legal obligations are meant to set standards of protection for personal information, in practice there are significant privacy concerns that make the personal information of individuals registered in the DCS broadly available.⁵⁶ For example, provincial and municipal public security departments seek to strengthen control over individuals registered in the DCS by sharing information with a wide range of security, health, social work, and neighborhood cadre workers.⁵⁷ Records are shared not only within the national public security apparatus but also with other major data systems for cross-checking purposes, such as the motor vehicle databases, aviation industry, hotel industry management system, banking and financial system, and railway system.⁵⁸ This has led to interrogations and drug tests of individuals registered in the DCS in public venues such as train stations, hotels, banks, airports, and other

locations, which inevitably result in the disclosure of personal information.

Human rights bodies have also found that mandatory testing itself violates an individual's right to privacy.⁵⁹ However, compulsory drug testing is a key DCS tool, and China's Anti-Drug Law provides that a person may be forcibly tested with the approval of the head of a public security authority at or above the county level.⁶⁰

Education and work

China is a state party to the International Covenant on Economic, Social and Cultural Rights, which commits state parties to respect the right to education and the right to work.⁶¹ The realization of the right to education not only includes ensuring that education is available, accessible, acceptable, and adaptable but also encompasses a requirement of nondiscrimination.⁶² The right to work means that individuals are provided the opportunity to gain their living by work that they are able to freely choose.⁶³

The practices under the DCS, and the various education and employment policies within China, raise concerns around violations of these rights. On education, for example, in 2018, Chongqing Municipality announced that an administrative and criminal offense disqualifies the person concerned from admission to colleges and universities.⁶⁴ The 2020 national-level Regulations on Admission to General Colleges and Universities also state that candidates who have a record of a criminal penalty, public security administration penalty, or other disciplinary measures must provide full and accurate information on the infraction and actions taken to correct it. Failure to provide this information could affect an individual's eligibility to take the college entrance examination.⁶⁵

A history of drug use can also be a barrier to obtaining employment. Although only persons who have committed criminal offenses are restricted from applying for the national civil service exam, some provinces explicitly restrict people with records of drug use.⁶⁶ Moreover, even where someone with a history of drug use was eligible to apply for the national or local civil service, or

even where a family member had a history of drug use, China's strict political vetting system for civil service positions would likely prevent hiring.⁶⁷ For these reasons, while drug use itself is not a crime in China, a history of drug use presents a significant barrier to certain types of employment.

Health

The right to health is also enshrined in the obligations under the International Covenant on Economic, Social and Cultural Rights.⁶⁸ As a party to the treaty, China should ensure the availability, accessibility, acceptability, and quality of health services, as well as ensure that services are provided in a nondiscriminatory manner, especially for marginalized groups.⁶⁹

While the 2008 Anti-Drug Law is progressive in that it recognizes individuals who use drugs as patients and calls for treatment, in practice China's drug treatment system operates as a system of monitoring and punishment.⁷⁰ It does not operationally acknowledge drug use as a public health issue that requires evidence-based, community supported long-term treatment. In the current treatment regime, detection of a relapse leads to harsher restrictions on personal rights and freedoms, without meaningfully addressing the right to health.⁷¹ China suffers from a severe lack of specialized drug treatment resources and a reliance on ineffective detoxification approaches dominated by restrictions on personal freedom.⁷²

China's punitive approach to drug dependency treatment also affects the ability of individuals who use drugs to address other health problems. For example, many of China's current national and local laws and regulations exclude persons who use drugs from occupational injury insurance and medical insurance.⁷³ Moreover, some local governments, such as in the cities of Nanping, Lanzhou, Urumqi, and Liuzhou, have enacted legislation that excludes medical expenses incurred as a result of drug use from the scope of urban and rural medical assistance.⁷⁴ These exclusions raise serious concerns about violations of the obligation to provide nondiscriminatory health services.

Conclusion

China has a binary legal system that differentiates between criminal offenses and administrative violations. Drug-taking behavior has never been designated a criminal activity, is not regulated by criminal law, and is not subject to trial by the courts, but it is an unlawful act punishable by the public security authorities. The Anti-Drug Law enacted in 2008 established a system of drug treatment divided into four categories: voluntary detoxification, community-based detoxification, community-based rehabilitation, and compulsory detoxification. Although distinct in the 2008 law, community-based detoxification and rehabilitation are operationally identical.

Apart from compulsory detoxification, the other measures are noncustodial and purportedly nonpunitive measures. However, in practice, China's drug treatment system, which is dominated by community-based detoxification and rehabilitation and by compulsory detoxification, is coercive in nature and provides limited evidence-based treatment or social support. Within this system, the DCS reinforces, and extends, an approach to drug use that is fundamentally punitive.

From the moment a person is apprehended by the police and his or her information is entered into the system, the DCS penetrates the entire process of punishment, treatment, and control, with the aim of ensuring that they are unable to evade a comprehensive system of social control. The DCS is not just a database but has become the main approach to China's anti-drug efforts, channeling individuals into a system from which exit is nearly impossible.

Individuals entering the system because of illicit drug use may be punished by up to five days in detention or a fine of up to 500 yuan. More serious offenses may require up to 15 days detention or a fine of up to 2,000 yuan. Yet that is nowhere near the end of it. For example, in Zhahua District, Guangyuan City, Sichuan Province, persons who use drugs but are not considered dependent at the time of their initial arrest are nonetheless required to undergo urinalysis every two months.⁷⁵

Alternatively, persons who use drugs can voluntarily enter a drug detoxification facility for

treatment. According to the Anti-Drug Law, public security authorities will not punish individuals who enter voluntary detoxification facilities.⁷⁶ Yet this voluntary step will result in long-term monitoring by local public security authorities.⁷⁷ Subsequent positive drug tests can result in individuals being sent to compulsory detoxification for two years.

The DCS in China has not been developed in isolation. State surveillance and control has been a feature of China's response to COVID-19 and has long targeted ethnic and religious minorities.⁷⁸ China has also used its health system as a means of monitoring and detaining dissidents.⁷⁹ Dynamic control systems track not only persons who use drugs but also individuals suspected of online fraud or labeled as fugitives, using software developed by private companies that can access individuals' online accounts, information on people they are related to, and information on their ethnicity, occupation, and education level.

The integration of DCS into existing compulsory detoxification and rehabilitation extends surveillance and control of persons who use drugs from local to national levels. Although information management and control systems are not officially punitive, in practice systematic monitoring imposes limitations on the personal freedom of persons who use drugs and restricts a wide range of fundamental rights. Rather than investing in evidence- and rights-based treatment of drug dependency, the Chinese government has created a comprehensive detention and surveillance network that ultimately fails to provide the medical support, community engagement, and legal assistance that individuals in China with drug dependency need.

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The Politics of Drug Rehabilitation in the Philippines

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Abstract

The international consensus to end compulsory drug treatments and close forced rehabilitation facilities needs urgent transformation to country policies. In the Philippines, as with other countries in Asia, rehabilitation can be compulsory and is seen as the humane alternative to the “war on drugs.” In this paper, we present the landscape of rehabilitation and narrate the ways in which people who use drugs are forced to undergo treatment. We unpack the politics behind rehabilitation and explain the sociocultural foundations that support compulsory treatment. We argue that a transition to a human rights-based approach, including voluntary alternatives in community settings, is possible by capitalizing on the reforms that are, unwittingly, the result of the “war on drugs.”

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Competing interests: None declared.

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This paper analyzes the Philippines as a case study of how politics and populism have framed the understanding and implementation of drug rehabilitation, particularly in an unstable democracy with a long history of authoritarianism and oligarchic patrimonialism.¹ The Philippines has taken global center stage since the Duterte administration's launch of a "war on drugs" in 2016, with much attention and concern focused on extrajudicial killings—numbering at least several thousand—in connection with this campaign.²

Less critically examined, however, is how this period—during which drugs have been at the forefront of political and public discourse—has shaped compulsory drug interventions in the country. Compulsory treatment in the Philippines occurs inside spectacular "mega rehabilitation centers" and in the context of a growing number of public and private drug treatment facilities.³ During the height of the "war on drugs," the police conducted door-to-door searches in order to compel people who use drugs to "surrender"—effectively a form of forced apprehension—and undergo "voluntary" rehabilitation.⁴ Philippine drug courts continued ordering people who use drugs to undergo rehabilitation in government centers or inside jails, with rehabilitation considered a penalty under the national drug law.⁵ In recent years, promising community-based programs have operated in parallel with compulsory detention and involuntary treatment, but difficulties have arisen in implementing a fully autonomy-respecting system given the punitive legal environment for people whose lives include drugs.⁶

In this case study, we argue that long-standing perceptions on drugs in the Philippines have created an uncritical acceptance that people who use drugs require "rehab" and, consequently, a permissive political environment for compulsory detention and involuntary treatment. Moreover, we argue that the punitive drug regime has reinforced similarly pernicious attitudes by presenting forced "rehab" as the humane and acceptable alternative to extrajudicial killings. To support our findings, we present figurations of "rehab" in the country over the past six years, from the Duterte administration's

statements and programs to the policy pronouncements of those who are running to succeed him in the 2022 elections. We explain this fixation on treating people who use drugs as either criminals or patients—in both cases deemed as without full autonomy to make informed and moral personal decisions—as a product of exploited populism in a predominantly Catholic country. Drawing from international human rights obligations in relation to drug policy, we conclude by identifying critical leverage points and structural factors that drug policy reformists in unstable democracies can maneuver toward a public health-centered framework that respects full patient autonomy and human dignity.

The drug rehabilitation landscape in the Philippines

Duterte's election to the highest post in the country was premised on a relentless and sustained fight against criminality, illegal drugs, and corruption.⁷ On his first day in office, Duterte appointed his former city police chief Ronald dela Rosa to implement his "war on drugs" to fulfill his campaign promise of eliminating illegal drugs in three to six months.⁸ As noted by the Office of the United Nations High Commissioner for Human Rights, between July 1, 2016, and November 27, 2017, there was a staggering average of nearly 40 deaths per day as a result of drug operations by the police and from homicides perpetrated by unidentified persons.⁹ The prosecutor of the International Criminal Court subsequently requested authorization to open an investigation in the Philippines after finding reasonable basis to believe that the crime against humanity of murder was being committed in the context of the government's "war on drugs."¹⁰

Against the backdrop of extrajudicial killings apparently perpetrated pursuant to an official state policy of the Philippines, the drug rehabilitation landscape in the Philippines was changing in light of the threat to life and liberty of people who use drugs.¹¹ The 2016 statistics of the Philippine Dangerous Drugs Board (DDB) showed that 6,079 individuals were admitted to residential

and outpatient facilities nationwide for rehabilitation.¹² A year later, the data showed a decrease in admission to 4,045 individuals, equivalent to a 33% reduction.¹³ This substantial drop in admissions is understandable in light of the threat to life and liberty of people who are identified to be using drugs. In 2018, a significant 34.55% increase in admission was reported, largely due to a court-directed policy that allowed for plea bargaining by persons charged with criminal cases, which made up 24.89% of the 5,447 admissions for the year.¹⁴ The 2019 data showed increasing admissions due to plea bargaining agreements, but an overall slight decrease of 4.04% in total admissions was observed, attributed to individuals' "voluntary submission" to community-based drug rehabilitation.¹⁵ Figure 1 shows the number of persons who use drugs who were admitted to rehabilitation facilities from 2016 to 2019. Close to the end of Duterte's term, a total of 55 treatment and rehabilitation facilities were operating, up from 31 centers before the start of his presidency.¹⁶

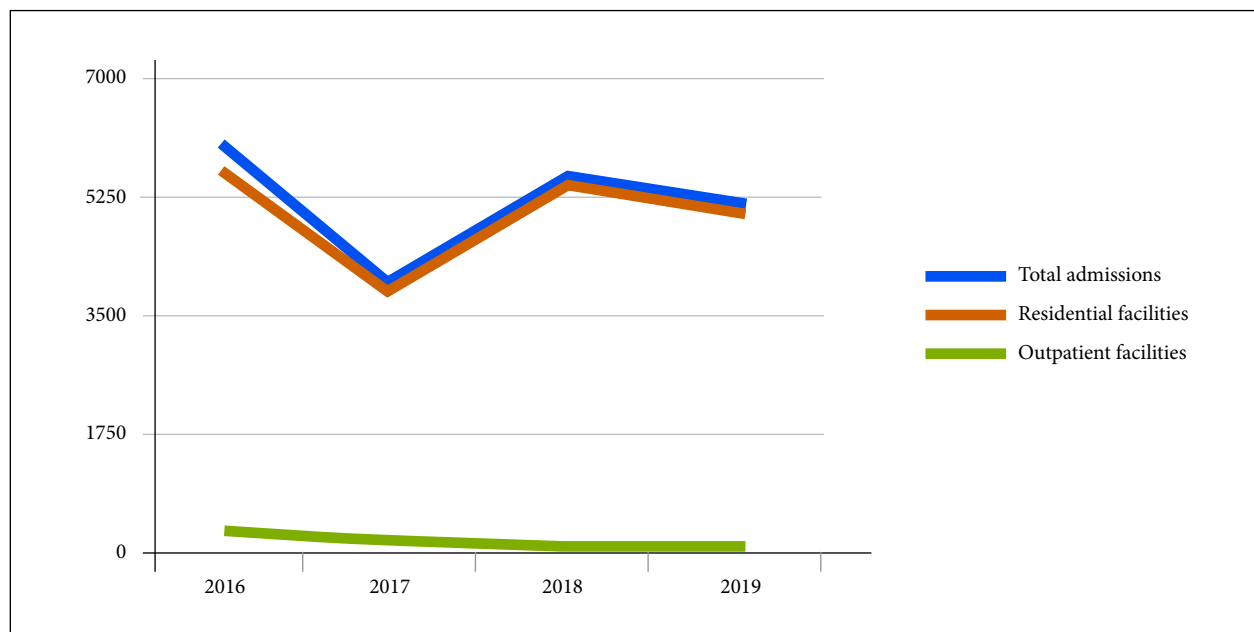
In November 2016, Duterte inaugurated a 10-hectare compound, dubbed a "mega rehab center," designed to house as many as 10,000 persons who "surrendered" and would undergo treatment.¹⁷

According to the compound's chief medical officer, Nelson Dancel, a typical day in the center starts at 5:30 a.m., when residents are required to do a series of physical exercises similar to those required in the army, followed by activities meant to teach the concepts of self-acceptance, self-development, and self-formation.¹⁸ For recreation, the mega rehab center boasts basketball and volleyball courts, chess boards, and musical instruments, with television reserved as a privilege for more senior residents.¹⁹ Dancel explains that escapes are a natural occurrence since some residents feel homesick or worry about their families; individuals who attempt to escape but fail are segregated from other residents, but Dancel is quick to clarify that they are not in solitary confinement.²⁰ If violations are severe, residents receive extra physical work, such as exercises or additional chores.²¹

A year after the center's inauguration, the DDB described it as a mistake.²² Only 400 people were treated in the 75,000-hectare property, leading the DDB chief to push for community-based interventions.²³

Nevertheless, the protocols in the mega rehab center reflect typical programs in drug treatment and rehabilitation centers nationwide. Guided by

FIGURE 1. Number of admissions in rehabilitation facilities (residential and outpatient) during the Duterte administration



the *Manual of Operations for Drug Abuse Treatment and Rehabilitation Centers*, which sets the minimum standards for this type of facility, the Department of Health accredits rehabilitation centers—both government and nongovernment owned or operated—based on their compliance with these prescribed uniform standards.²⁴ Notably, the manual enumerates the prescribed services, which are replicated here for a fuller appreciation of the mandated programs in rehabilitation centers:

1. Medical service provides comprehensive health care services ranging from routine physical examination and screening procedure for diagnosis, treatment and follow-up of illnesses and other medical problems.
2. Psychiatric service provides therapy to drug abusers with behavioural and psychiatric disorders through, among others, chemotherapy, individual and group psychotherapy, family therapy and occupational therapy conducted by a psychiatric team. A psychiatric team shall include a psychiatrist, psychologist and social worker. This may include an occupational therapist and para-professional worker.
3. Psychological service assists the team in the assessment, diagnosis and management of drug dependents through psychological testing and evaluation as well as in conducting therapy/counselling to patients and their families.
4. Social service assists the drug dependents help themselves cope [with] their problems, facilitate and/or promote their interpersonal relationship and adjustment to the demands of a treatment program with the end view of helping the drug dependents' physical, social, moral and spiritual development.
5. Spiritual and religious services include the development of moral and spiritual values of the drug dependent. It has been noted that the spiritual foundation of patients has been very weak that this could not provide support to them to enable them to cope with their problems and conflicts. Strengthening the spiritual foundation would involve, among others, reorientation of moral

values, spiritual renewal, bible study and other charismatic sessions. It aims to bring them closer to God and better relate to their fellowmen. Various religious and civic organizations can be contacted to provide services. Spiritual counselling shall be helpful in aiding and resolution of individual and family problems.

6. Referral service involves the process of identifying accurately the problems of the patient and sending him to the agency that can provide the appropriate services.
7. Sports and recreation services provide facilities for sports and recreation to offer patients the opportunity to engage in constructive activities and to establish peer relationship as an alternative to drug abuse. The emphasis in all activities should be on developing the discipline necessary to improve skills and on gaining respect for good physical health.
8. Residential/house care service includes provision of basic foods, clothing and shelter.
9. Aftercare and follow-up services provided to the patient after the primary rehabilitation program. Aftercare activities can be viewed as the first line of defence against relapse. The activities include attending self-help programs like Narcotics Anonymous (NA) / Alcoholic Anonymous (AA) meetings, regular follow-up at treatment Center, individual and group counsellings sponsor/sponsee meetings, alumni association meetings, etc. This is for a period not exceeding eighteen (18) months and should be undertaken by the appropriate Center personnel.²⁵

The manual further provides optional additional services, which may include placement service for work opportunities, volunteer service opportunities to assist the rehabilitation center, and educational opportunities.²⁶ Centers are mandated to contribute effectively to the goals of the Comprehensive Dangerous Drugs Act of 2002, which expresses the state policy of pursuing “an intensive and unrelenting campaign against the trafficking and use of dangerous drugs and other similar substances [including provision of] effective mechanisms or

measures to re-integrate into society individuals who have fallen victims to drug abuse or dangerous drugs through sustainable programs of treatment and rehabilitation.”²⁷

Presently, people who use drugs undergo drug treatment and rehabilitation programs and services following the guidelines set under Board Regulation No. 7 of 2019 by the DDB. Under this regulation, a verified application must be filed to the DDB to access a treatment and rehabilitation program. The application may be made by the person who uses drugs or by parents, spouses, guardians, or relatives within the fourth degree of consanguinity.²⁸ Upon recommendation by an accredited physician, “taking into consideration his/her level of drug dependency and the potential danger he/she may pose to himself/herself, his/her family and the community,” the DDB shall file a petition to the appropriate court for the confinement of the person for treatment and rehabilitation.²⁹ The court shall then order the person to undergo a drug dependency examination by an accredited physician, and, if certified to be drug dependent, “he/she shall be ordered by the court to undergo treatment and rehabilitation in a center designated by the Board for a period of not less than six (6) months.” Notably, the examination is conducted by physicians accredited by the Department of Health, with reference to the clinical parameters of drug dependency under the International Classification of Diseases, 10th revision.³⁰

Modes of compulsion in drug treatment and rehabilitation during Duterte’s administration

Under the Duterte administration, persons who use drugs may be compelled to undergo drug rehabilitation through three major modes: first, through a police and law enforcement-directed door-to-door search and “request to surrender” campaign known as Oplan Tokhang; second, through court-mandated rehabilitation of people arrested for drug use; and third, through family-initiated admission without the consent of the person who uses drugs. The second and third modes are not unique to the

Duterte administration, but a significant increase in arrests have been noted in the past six years, leading to congestion in jails.³¹

On the day of his appointment as chief of the Philippine National Police, dela Rosa issued a circular entitled PNP Anti-Illegal Drugs Campaign Plan – Project “Double Barrel,” where he ordered the police “to clear all drug affected barangays across the country.”³² The international community was shocked by this policy’s aftermath, with the Office of the United Nations High Commissioner for Human Rights reporting 5,601 killed based on information from the Philippine Drug Enforcement Agency; government data mentions 16,355 “homicide cases under investigation” as accomplishments in the fight against illegal drugs, while 20,322 deaths are reported from drug operations by police and homicides perpetrated by unidentified persons.³³ Less visible in the international public discourse is the plight of 223,780 persons arrested for drug-related cases, which led to massive congestion in jails—85% to 90% of those incarcerated are there for drug-related offenses.³⁴

The police have also conducted house-to-house visitations, which do not require search or arrest warrants, to “encourage voluntary surrender” to the government for drug-related acts.³⁵ Refusal leads to an immediate case build-up and “negation,” a term appearing in the aforementioned circular that could be interpreted by the police as permission to kill.³⁶ The DDB has noted “unprecedented responses from both law enforcement and the public,” including “voluntary surrender of self-confessed drug personalities nationwide.”³⁷ Under Board Regulation No. 3 of 2016, a “surrenderer” shall subscribe to an affidavit of undertaking and waiver that authorizes a medical examination and drug test; and if the individual in question is not engaged in trafficking or sale and is just using drugs, they shall state in the affidavit that “he/she shall undergo voluntary treatment and rehabilitation.”³⁸

According to the most recent data from the Bureau of Jail Management and Penology, there are now 80,162 persons deprived of liberty detained for violation of the national drug law.³⁹ On November 8, 2021, the bureau signed a memorandum of agree-

ment with the DDB so that such persons who have signed a plea bargain and who are classified as “low risk” or “moderate risk” for drug dependence may undergo court-mandated treatment and rehabilitation while in jail.⁴⁰

Long-standing perception on drug rehabilitation: “Save the user, jail the pusher”

The above policies and programs cannot be disentangled from the long-standing perception—characterized by some scholars as a “moral panic”—that people who use drugs are “addicts” and societal villains.⁴¹ This prohibitionist paradigm, which is perhaps best summed up by the popular slogan “save the user, jail the pusher,” has been reflected in various institutions throughout past half century, from the Catholic Church to broadcast and print media.⁴² Essentially, this part-moralistic, part-medicalized view forges divisions between “pushers” and “addicts” who are a menace to society and “users” (often depicted as young people) who need to be “saved.” As the Catholic Bishops’ Conference of the Philippines wrote in a pastoral letter that coincided with Ferdinand Marcos’ ascendancy:

*A country whose youths are mental and physical wrecks will be hopelessly doomed to ignominy unredeemable until, if that is possible, a new and strong breed will rise up from the ruins. These are the worst saboteurs and are worthy of the highest punishments. For they destroy the youth, the hope of the land.*⁴³

Rehabilitation centers figure in this narrative as sites where this “salvation” and “healing” can take place. In the words of a Catholic leader touting the church’s rehabilitation program, “Everybody needs healing. These drug addicts, they’ve been wounded very much and what they need is someone who can help them.”⁴⁴ Indeed, many such programs are affiliated with religious organizations; those who are not nonetheless orient themselves around the same themes of healing, redemption, and salvation.⁴⁵

Duterte’s punitive approach to drugs has arguably made rehabilitation an even more socially and politically viable position—an alternative to the extrajudicial killings that allows individuals and institutions to continue being seen as “tough” on drugs while also satisfying civil society’s clamor for human rights.

Notably, however, drug treatment and rehabilitation remains largely compulsory in the Philippines, with evidence-based initiatives in some communities seen as the exception to general forced treatments that often have little or no scientific basis. As reported by the United Nations Office on Drugs and Crime and UNAIDS, the Philippines continues to detain people who use drugs in closed settings, often against their will, without sufficient human rights safeguards and forces them to undergo rehabilitation for an average duration of ten months.⁴⁶ Government data show severe overcrowding and substandard compulsory facilities, as well as little evidence supporting the use of spiritual or religious interventions.⁴⁷ People who use drugs are coerced to undergo treatment in order to “cure” themselves of their addiction.

A number of episodes during the Duterte administration are illustrative. In response to the first few months of Duterte’s drug war, for instance, the Catholic bishops remonstrated in another pastoral letter:

*Our hearts reach out in love and compassion to our sons and daughters suffering from drug dependence and addiction. Drug addicts are children of God equal in dignity with the sober ones. Drug addicts are sick brethren in need of healing deserving of new life. They are patients begging for recovery. They may have behaved as scum and rubbish but the saving love of Jesus Christ is first and foremost for them. No man or woman is ever so unworthy of God’s love.*⁴⁸

As criticism mounted, including from the political opposition, Duterte at one point appointed Vice President Leni Robredo—the highest-ranking member of the opposition—as chair of the Inter-Agency Committee on Anti-Illegal Drugs.

Although her tenure was short-lived—17 days—her report, which she published months after, is reflective of her view.⁴⁹

Finally, the campaign for Duterte's successor in the May 2022 elections—still underway at the time of writing—is also reflective of the same view. Virtually all the major candidates have expressed support for an “intensified” anti-drug campaign while vowing to respect human rights and promote a “public health” approach. Invariably, however, their idea of what constitutes “public health” includes scaling up the same rehabilitation paradigm that dichotomizes between killing and “rehab.”

Tellingly, when the leading candidate—Ferdinand Marcos Jr.—was accused by Duterte as using cocaine, his opponents lost no time in calling out the contradictions in Duterte's drug war—while also calling on Marcos to be punished, as expressed in this tweet by Leody de Guzman, standard-bearer of the progressive left:

Tiyak, kilalang kilala ni Duterte kung sino ang supplier ng kandidatong ‘yan na nagpapasok ng cocaine sa bansa. ‘Yan dapat ang pokusan para mahuli at matigil na. Kaysa itsismis lang, ipahuli na ang kandidatong ‘yan para ipa-rehab. [For sure, Duterte knows who the supplier is of that candidate who trafficks cocaine in the country. That should be the focus so that he can be arrested and stopped. Instead of rumor-mongering, the candidate should be arrested and placed in rehab.]⁵⁰

For her part, Robredo has hewed close to the same discourse she raised as chair of the Inter-Agency Committee on Anti-Illegal Drugs:

In my belief, once DDB sits as the chair of DDB, its plan will not be just “kill, kill, kill” but the plan will be more comprehensive—heavy on prevention, heavy on rehabilitation.⁵¹

These political discourses reflect and reinforce the moral panic on drugs that sees rehabilitation as the humane (and only) way to “save the user,” precluding other initiatives such as harm reduction and decriminalization, which—notably—none of the candidates have mentioned.

Drug rehabilitation and populism

What can explain the subscription to the “save the user” narrative that has led to uncritical support for “rehabilitation” as it is (mis)understood by the Philippine public?

As discussed above, previous scholars have used the literature on “moral panic” to explain the long-standing vilification of drugs in the country. Drawing on the literature on penal and medical populisms, more recent scholarship has implicated political actors in reflecting and reinforcing public attitudes about drugs, portraying these actors as “moral entrepreneurs” who simplify, spectacularize, and forge divisions between “addicts” and the virtuous public.⁵²

Missing in these accounts, however, is the nuance regarding what people view as the rightful solution to the “problem.” Survey after survey has shown that Filipinos favor a strong approach to drugs—even approving of the “drug war”—despite the fact that they disapprove of the killings, suggestive that far from a monolithic dichotomy between supporting or opposing a draconian approach to drugs, people are divided on what particular draconian approach to take: either drug addicts deserve to be killed or drug addicts should be sent to compulsory rehabilitation.

Less emphasized in the scholarship is how Philippine drug policy has followed global drug policy flows; most notably, as Christopher Hobson notes, “among all the possible wrongdoing and bad things that exist in the world, it is slightly counter-intuitive that drugs are the only one to be labelled as ‘evil’ in international law.”⁵³ Indeed, the first drug war in the 1970s coincided with the Nixon-era war on drugs and global commitments to the “drug problem,” leading to the establishment of DDB in 1972 and inaugurating a trend of increasingly punitive drug laws. The parallels in high incarceration rates in the United States and the Philippines and similar institutional configurations (e.g., a Philippine Drug Enforcement Agency patterned after a similarly named agency in the United States) speak of how this international—and particularly American—influence continues to have an impact on drug policy in the country.⁵⁴

However, it must be pointed out that even as “Western democracies” and even international organizations are moving away from this approach, the Philippines and other countries in the region have steadfastly adhered to it (with notable exceptions such as Malaysia), suggesting that such an approach has been indigenized, likely enabled by a cultural environment that emphasizes “Asian values” such as conformity and social control, as well as the enduring valance of drugs as a populist trope in the region.⁵⁵

Because they do not specifically address the question of why a particular form of rehabilitation has gained uncritical popular and political acceptance, these explanations are at best partial and would require corroboration through cultural histories and contemporary ethnographic accounts of rehabilitation today. However, they suffice to furnish a historical context to the figurations of rehabilitation in today’s political discourse that in turn perpetuate popular perceptions.

Compulsory rehabilitation in the Philippines an urgent human rights issue

There is a dangerous tendency for reform advocates to condemn extrajudicial killings and due process rights violations as human rights concerns, while supporting rehabilitation as an acceptable alternative. As we have observed, the motivations behind gross human rights violations and forcing people to treatment are the same: the dehumanization of people who use drugs and the removal of their autonomy to decide on the treatment approaches that respond to their felt needs. Drug policies in the Philippines remain to be “substance-centric, moralistic, and medicalized.”⁵⁶ Present drug policy from the Department of Health does not recognize non-pathological use, as substance use is classified as mild, moderate, or severe and, in any case, as requiring medical or psychological interventions.⁵⁷ Because treatments are compulsory in nature, the right to health, which includes access to voluntary and evidence-based services, is breached.⁵⁸

Relatedly, drug testing has been transformed into a diagnostic and prosecutorial tool for treating

people who use drugs.⁵⁹ A positive random drug test is enough justification to remove students from school or to terminate employment of otherwise productive employees and to force them to undergo rehabilitation.⁶⁰ Notably, random drug testing in schools violate students’ right to privacy and is inconsistent with international guidelines on the rights of children in relation to obligations arising from the human rights of particular groups.⁶¹

As a result, in 2015, countries from Asia and the Pacific committed to facilitate the transition away from compulsory centers toward an “evidence-informed system of voluntary community-based treatment and services that are aligned with international guidelines and principles of drug dependence treatment, drug use and human rights.”⁶² Seven years after, however, the transition has yet to happen.

Moving forward: Transitioning to voluntary alternatives

Despite the problematics of drug rehabilitation in the Philippines being strongly determined by political and popular approaches to drug issues, recent developments suggest that a changing paradigm is not beyond the range of possibilities.

In the first place, the DDB has recognized the failures of closed settings in its approach to rehabilitation. The public admission that the mega rehab center was a mistake because it uproots people who use drugs from their families and the policy shift toward more community-based interventions are important concessions made as the country transitions to a more public health-based framework. More citations on community-based approaches appear in the DDB’s recent issuances that provide guidance to local government units on general interventions and programs.⁶³ Prior to Duterte’s time, rehabilitation programs were effectively available only in closed settings. Notably, the country has not closed down compulsory rehabilitation facilities and appears to be far from doing so. Nevertheless, at the close of Duterte’s term, we note a promising trend in the number of admissions in closed settings in favor of community-based programs.

This palpable shift in policy can be attributed largely to the work of civil society organizations, human rights groups, and academic institutions that are more sensitized to drug issues and more critical of the political discourses employed in the wake of Duterte's war on drugs. Many of these groups still embrace a decidedly "drug-free" paradigm, but they can nonetheless serve as entry points for interrogating rehabilitation as it is practiced and understood in the Philippines today. Policy officials, too, have learned important lessons from the drug war, leading them to revise the national guidelines on rehabilitation.

Similarly, as one of the authors notes in another work, "there has been a proliferation of drug war-related researches, from the documentation of its 'lived experiences' to policy analyses."⁶⁴ The academic interest in drug issues has included narratives of rehabilitation and case studies on community rehabilitation, all of which can contribute to a local evidence base for alternative interventions. Academic networks have been formed, and publications that problematize the drug war have allowed for dialogues nudging policy makers toward reform.

Second, although, as mentioned above, presidential politics have largely embraced the killings-versus-rehabilitation binary, lawmakers have in fact filed harm reduction bills and similar initiatives.⁶⁵ These legislative initiatives—though still unlikely to prosper at this stage—nonetheless represent a sea change from previous times and may signal more openness in the future. This is an important step to challenge the binary framework and to introduce a genuine option that promotes autonomy, human dignity, and health.

Nevertheless, legislative change is necessary. We can no longer avoid and delay the conversation on decriminalization of drug use, as it is apparent that the courts—supposedly the champions of human dignity—have become agents for compulsory rehabilitation. In the Philippines, people are ordered to undergo rehabilitation or face imprisonment. People arrested for drug-related offenses bargain for a lesser penalty, which includes rehabilitation. Jails are now formally considered centers for rehabilitation, putting into question the capac-

ity of these institutions to provide the standards necessary for genuine health programs.⁶⁶

Third, despite the defiant tone that government officials have struck in terms of Duterte's possible trial before the International Criminal Court, international pressure has been effective in forcing government officials to reform policies that address drug-related concerns. For example, the United Nations Joint Programme for Human Rights in the Philippines has become an important platform for introducing human rights-based approaches to drug control. Among other things, it calls for the improvement of prison conditions and development of community-based programs. If it is to make further progress in the country, however, the joint program must implement the international consensus on ending compulsory rehabilitation and invest in a transition toward voluntary services, following the consensus from the Third Regional Consultation on Compulsory Centres for Drug Users in Asia and the Pacific, and further accommodating the recommendations from the United Nations Office on Drugs and Crime and UNAIDS on adopting voluntary community-based services as the framework for drug-related programs and interventions.⁶⁷

One caveat about international pressure, though, is that it might perpetuate policies that can be framed by populist politicians as "colonial interventions," especially given the backdrop of how human rights and concerns over the drug war were cast by local politicians as "Western" or "colonial" impositions.⁶⁸ This goes to show that beyond "decolonizing drug policy," drug reform must also move toward decolonizing harm reduction.⁶⁹ It is important that attempts to reshape rehabilitation be based on the perspectives of people who use drugs. Thus, international support must not be merely a transplantation of practices from abroad but a genuine privileging of the voices of the communities whose lives involve drugs. Crucial to this project is empowering local actors (e.g., academics and advocates) who can then provide local scholarship and offer localized, culturally sensitive communications efforts that can be more difficult to delegitimize.⁷⁰

Finally, the long-standing support for forced rehabilitation ultimately rests on how people who use drugs are perceived by the public and leaders, both political and religious. Thus, any attempt to reform must involve careful thinking as to how public attitudes can be changed. The narratives that inform policies negatively portray people who use drugs, and moral leaders (predominantly Catholic) have provided the justifications for a draconian approach to drugs, including the removal of personal autonomy in decisions affecting one's life and health. Admittedly, this sociocultural foundation that supports compulsory rehabilitation is the hardest to break. However, cultural values such as the importance of family can be important themes in counter-narratives that can support family- and community-based approaches. Similarly, amplifying narratives from people who use drugs themselves can illuminate the lived realities of drug rehabilitation for the general public. More fundamentally, however, we need to deepen our understanding of the paradigms that inform the rigid binary to be able to transition to a framework that fully embraces human rights and public health.

Conclusion

In the Philippines, owing to a long history of penal populism, moral panic around drugs, and long-standing moralistic views of people who use them, “drug rehabilitation” is seen as a humane and acceptable alternative to the “drug problem,” and this has been reflected in (and reinforced by) contemporary political discourse. However, as we have shown in this paper, there is very little difference between jails and rehabilitation centers in terms of both philosophy and practice; in fact, jails are now centers for compulsory treatment. Those who seek to reform this untenable status quo need to capitalize on recent policy reforms, informed by a vibrant civil society and supported by the international community, to end the era of forced rehabilitation, with local actors and stakeholders empowered to take the lead.

As the Philippines undertakes a change of leadership, advocates in the country and elsewhere

must recognize the need to go beyond addressing killings and insist on a discussion about what kind of rehabilitation should exist—and for whom—and about how to genuinely expand our responses to drug-related issues in a way that goes beyond criminal and medical frameworks. Institutions that have been sensitized to what is at stake with drug policy in the country can be potential allies in this move, but it must be accompanied by international attention beyond the killings—as well as a recognition that “decolonizing drug policy” also entails decolonizing the ways we have sought to reform it.⁷¹ Lessons learned from the Philippines are likely relevant for neighboring countries and thus for drug policy and human rights advocacy around the world.

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The Right to Health as a Tool of Social Control: Compulsory Treatment Orders by Courts in Brazil

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Abstract

Brazilian citizens have a constitutional right to health. This right has also been a powerful instrument in the judicial enforcement of drug dependence treatment in Brazil. This study reviews a sample of decisions from the state of São Paulo and provides evidence that the right to health has been used to justify compulsory admission to treatment for people deemed to have a drug use disorder. These claims are filed against the state, mainly by families, who argue that the right to health of individuals is being violated. This model of litigation—oriented toward the satisfaction of a presumed health care need—does not engage sufficiently with individual informed consent and participation in the delivery of treatment, as a person-centered approach would demand. Further, the judgments reveal a low level of awareness among judges about the procedural rights of people ordered to undergo compulsory treatment, despite the large-scale implementation of the right to health via courts in Brazil. This problematic interpretation of the right to health, in the context of mounting punitive policies and ideology in Brazil, can be harmful to people who use drugs and bring about an environment of more limited patient safeguards.

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Competing interests: None declared.

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Introduction

For years, Brazil has been viewed as a controversial model for right to health litigation. The story of mass litigation in Brazil has been told through research suggesting the misspending of public resources and diversion of funds to the richer classes seeking the procurement of low-priority (and sometimes unproven) technologies.¹ The negative effects of courts in Brazil are still partially contested (even in this journal).² This paper describes one detrimental aspect, until now rarely explored: the misuse of the right to health as a normative tool to impose forced drug dependence treatment through court decisions.

In Brazil, compulsory drug dependence treatment is enforced via civil law rather than criminal law. Drug possession in Brazil remains a crime but is not widely prosecuted; more often it is subjected to non-detention sanctions, such as community service orders and educative programs.³ According to Brazil's mental health legislation, involuntary treatment can be imposed either administratively following a doctor's evaluation or judicially (compulsory admissions) through civil actions initiated by public defenders or relatives.⁴

In the Brazilian court system, relatives are able to judicially enforce the compulsory treatment of family members who use drugs by lodging civil claims against the state on the basis of the right to health, regardless of the individual's consent or the admitted person's involvement in their care plan.⁵ Considering this context, this study focuses on whether compulsory treatment in civil claims is proportionate and necessary: namely, whether it is essential to protect individuals from abusive practices and whether it can also be considered a justified interference with their liberties. Justifications include, at least as per the recommendations of the World Health Organization and the United Nations Office on Drugs and Crime, (1) a clinical evaluation and evidence-based treatment plan provided by a specialized medical doctor and confirmed by another doctor; (2) a short time limit for the forced treatment established in advance; and (3) judicial monitoring of the treatment progress and patient's recovery, personal well-being, and ongoing neces-

sity for continuation of the measures.⁶ As the cases in this study will demonstrate, the jurisprudence so far has not fully addressed the procedural rights of patients, and there is no indication that legislation from 2019 will change this judicial behavior, given that more claims are expected to be brought under the right to health in the future.

In relation to procedural guarantees for individuals ordered to compulsory treatment, Brazilian lawmakers have historically failed to implement monitoring mechanisms or to determine precise rules for a process of appeal.⁷ Some procedural guarantees for involuntary treatment and compulsory admissions are now provided in Law No 10.216 (2001), which provides for the protection and rights of people with mental disorders.⁸ For compulsory admissions, the statute requires that the judge pay due regard to the "safety conditions of the care facility, as to the protection of the person in treatment, other patients and staff."⁹ In 2019, lawmakers amended the country's drug law, which now explicitly includes procedural guarantees for nonjudicial admission (involuntary treatments) for people who use drugs, similar to the existing rights already conferred on all mental health patients.¹⁰ The new law requires a doctor's recommendation with a treatment plan, notification to the Public Prosecutor's Office within 72 hours, and a maximum duration of admission of 90 days (unless a request for an extension is made).¹¹ This is basically the same as the requirement for involuntary treatment previously adopted for the general mental health law, but it is unclear whether judges are bound by these procedures, as the law regulates only nonjudicial interventions.

The aim of this paper is to qualitatively analyze the nature of these civil claims and the discourse used by a select number of decisions from a regional court in the state of São Paulo. This review of jurisprudence seeks to explore how courts construe the right to health in relation to compulsory drug treatment in Brazil and, in the process, deny patient autonomy and fail to ensure access to less restrictive measures respectful of individual liberties. The results of this analysis are contextualized in relation to recent legislative developments and

the political climate in Brazil, which promotes compulsory treatment for people who use drugs.

The first section describes the methodological approach of this jurisprudence review. The second section outlines the findings based on the attributes of the cases and narratives presented by the judicial opinions. It also observes how the right to health is applied and in which ways guarantees of fair procedure are observed. The final section contextualizes the contemporary political and cultural backdrop in Brazil that influences the use of compulsory treatment orders in the name of the right to health.

Methods

This research tracked decisions concerning compulsory drug treatment orders in the state of São Paulo issued between January 1 and December 31, 2019. São Paulo is the most populous state of Brazil, with one of the highest levels of litigation. The jurisprudence available comes from appeal judgments published in the database of the State Court of São Paulo (Tribunal de Justiça de São Paulo), which acts as a second-instance court. Relevant decisions were identified by searching decision summaries for the term “compulsory admission” (*internação compulsória*), the common technical expression for this intervention. The law also prescribes “involuntary admissions,” but that is not the usual terminology used by judges (even though the law before 2019 distinguished compulsory treatments, made at the request of families, from compulsory ones, those determined by a judge). This search elicited 602 results, which were further refined to include only those containing the terms “drugs” or “alcohol,” resulting in 47 decisions included in this analysis.

Judgments in the sample differ from regular “community treatment orders” as they do not derive directly from a mental capacity assessment or proportionality test for an intervention within the patient’s community to avoid individual harm. Community treatment orders are defined as a course of treatment supervised by a doctor in a community, which in some jurisdictions can be monitored through court decisions (following a specific judicial procedure or an appeal).¹² In contrast,

judicial orders in the sample are issued on the basis of a medical diagnosis that needs to be complied with by virtue of a right to health obligation leading to compulsory admission in a hospital setting. While not all jurisdictions require a declaration of mental incapacity for a community treatment order, it is usual that, in any case, the intervention is the least restrictive among the possible solutions.¹³

Decisions were individually and manually screened to identify (1) litigant profile (family, public defender, or public prosecutor), (2) whether procedural patient rights guarantees were observed, (3) whether the right to health was applied as the basis of the decision, and (4) the merit of the decision (granting the forced treatment or not). Families were included because they are entitled to request that the court grant compulsory admission of a relative, and this has become a common practice.¹⁴ They appear in the court register as plaintiffs and are qualified as a family member (generally parents) when mentioned in the decision. The subsequent classification was tabled as a survey questionnaire divided by individual features (case number, party, right to health application, doctor prescription, procedural rights, and award decision). Arguments and legal references used in the decisions were analyzed as doctrinal research to examine discourse practices around the right to health and patient autonomy.¹⁵

Findings

The majority of the cases were filed by families (76%, or 36, of the 47 decisions screened). In comparison, public prosecutors lodged only eight procedures. Three cases out of the sample were excluded for being an appeal for reasons other than examining the merit of compulsory treatment for persons with substance use disorders. The right to health was the most commonly given legal basis (36 cases). In these cases, judges concluded that the state had a legal obligation to provide compulsory admission as a way of guaranteeing access to health care.

Almost all compulsory admissions were granted by judges, with only nine cases being refused. Most of the rulings in the sample did not

cover procedural aspects or consent as an individual guarantee (for instance, whether the patients could challenge the decision or were consulted about treatment preferences), save for five appeals (10.5% of the judgments). In general, those five appeals did not go into detail about possible interferences with patient freedoms or patients' right to influence their treatment.

Judicial reasoning is largely supported by doctor prescriptions and medical reports, illustrating how direct patient participation is not central to judicial scrutiny compared with expert opinion. Ten cases had no medical recommendations (in nine of which the order was declined), indicating that judges do not award admission without clinical reports.

The central role of family

The legal argument supporting compulsory admission is not only a question of providing care to patients but also protecting the family (an issue raised both by claimants and by judges). This view seems to conflate the rights of the person in detention with the threat that may potentially be caused to the family (by physical aggression or personal conflicts).

In accepting this argument, the balance of interests tilts toward compulsory treatment since the expected benefit of keeping the person secluded exceeds any loss of individual liberties. In one of the cases, the court warranted a search to take a patient (who was never notified of the process) for a medical examination as a matter of precaution in a claim brought by a mother.¹⁶

Despite this, family members' view of the compulsory treatment of their relatives has more complex aspects than just safety. As Cristiana Araujo and Clarissa Corradi-Webster observe, families can understand interventions as a necessary punishment, or as required abstinence for recovery, while at the same time still recognizing it as a traumatic experience for the affected family member.¹⁷

Rights language and legal reasoning

Legal analysis in these cases is rather superficial.

Judges hold that to realize the right to health for an individual, access to compulsory treatments must be awarded as a constitutional obligation. Jurisprudence refers either to the general right to health or to access to medicines, and in some instances specifically notes that the case concerns persons with substance disorders. No reference is made to any other set of individual rights that may clash with this type of measure. Judges merely reproduce a list of fundamental rights and state obligations in an exhortatory fashion, without pondering what impact the ruling might have on individual patient liberties, sense of control, and agency, as illustrated in the excerpt below (taken from the research sample):

*In avowal to the principle of dignity of all human beings, and aiming to protect the right to physical and mental health guaranteed by the Federal Constitution, I concur with the non-voluntary commission of the drug user for treatment and social rehabilitation, as well as for the protection of his family and the community around them.*¹⁸

Judges who hear such cases do not necessarily encounter mental health issues on a regular basis. Given that the lawsuits are lodged against the state, the cases go before judges specialized in disputes in relation to public law and government responsibilities, including the provision of health care services. Therefore, the judges concerned may overlook or be less predisposed to inquire into bioethical principles and patient rights in relation to compulsory treatments.

Procedural guarantees

Decisions in favor of compulsory treatments were not issued in line with international best practices concerning procedural guarantees (as described earlier), despite being made following a single doctor recommendation. First, implementation of the right to health does not presuppose, in the judge's reasoning, an investigation of a less restrictive order and the direct participation of the patient in the care plan. However, judges are cautious about the appropriate medical evaluation as a precondition for compulsory treatment (e.g., dismissing

claims without clinical evaluation, as shown by the findings), but a second doctor's opinion is never required. In the evidence assessed, no references were made to patient preferences (through interviews or a preliminary court hearing with the person undergoing forced treatment) to explore alternative treatments.

Judges do not impose the same strict criteria for review and control of patient well-being and progress (for instance, compulsory orders should have a 90-day limit under current legislation, but this is not uniformly applied). The legal standing held by the patient in the judicial process (e.g., as an interested third party or a defendant represented by a legal guardian) is not clear, and the opportunity for involvement by the patient in the process is obscure, with no direct reference to patient intervention during the trial. For instance, judges tend not to comment on submissions made by the patient's independent legal representation (challenging the allegations), though in some instances the patient's name can appear in the process register as an interested third party.¹⁹

Another problematic feature in these decisions is that mental capacity is generally presumed (or indirectly attested by a medical evaluation with no reference to a patient's continuing competencies). Judges do not recognize transitional or varying degrees of incapacity or in which ways patient values and preferences could be preserved throughout the treatment. Incapacity, in such cases, is declared or assumed incidentally but not fully explored separately as a formal declaration of incapacity through a specific process or evidence assessment, for instance, considering the patient's decision-making ability.

The context beyond courts

This research has provided a general picture of the way that the right to health is interpreted by judges in the state of São Paulo who order compulsory treatments for people with substance use disorders. This analysis may have some limitations. An important one is that some cases may deal with compulsory treatment without being indexed as

such. A similar term that could have been entered would be "involuntary admission" (mentioned above), but its occurrence is much less common during the period in question. As a comparison, for the period researched, 602 decisions were indexed as "compulsory admission," while only 52 had the term "involuntary admission." In addition, judges may not explicitly raise substance abuse in the facts, the database may be incomplete, and some decisions remain unpublished, especially if given "in camera."

Moreover, the necessity for judicial intervention for a compulsory treatment order was abolished in 2019, which may influence future litigation levels. Compulsory admission orders could arguably become less common, yet where public services are not accessible there is still scope for writs. Further, given the data set obtained from a single regional state jurisdiction, with its own demographic conditions and judicial behavior, these findings may not correspond to cases elsewhere in the country, where there is less litigation or where jurisprudence may have evolved differently.

Additionally, these findings cannot be understood in isolation from other important political factors influencing the rights of persons who use drugs. Forced treatments in Brazil are recognized among local scholars as a social cleansing strategy, a modality of biopolitics rooted in structural state violence, the police war on drugs, and prohibitionist policies.²⁰ Some structural issues affecting mental health policies in Brazil should be highlighted alongside the enforcement of the right to health devoid of procedural guarantees. Three main areas make this forceful employment of the right to health even more problematic: (1) pervasive legal and political incentives for compulsory treatment measures, (2) an underdeveloped legal culture of patient autonomy, and (3) risk of compulsory treatments as a means to solve urban problems of widespread substance use disorders.

Legal and political drivers of compulsory treatment

As in many countries, current drug legislation in Brazil embodies a punitive mindset, which gained

more prominence after the extreme right came to power in the 2018 elections.²¹ President Bolsonaro ratified a reform of mental health legislation to “abolish” (as it was described by the local media) the requirement of a judicial order for civil commitments of persons with substance disorders. The law was passed under the protest of jurists and public health experts who denounced the retrogression of patient rights.²²

This legal reform corresponds more to political rhetoric and a cosmetic review than a real policy departure. This is because the legislation in Brazil has been ambiguous about the compulsory admission of persons with substance disorders, while this practice has been largely tolerated in society. A 1934 federal decree permitting forced therapy for “toxic substances” was thought to have lost its effect after the 1985 Constitution took effect.²³ Yet, modern legislation has not eliminated this model despite attempts to move to patient-centered approaches. Administrative admission for drug users remained officially unregulated, but its use was commonly justified by another statute legalizing compulsory treatment for general psychiatric disorders.²⁴ Because compulsory drug treatment for persons with substance use disorders has been a long-established practice in Brazil, families (and public authorities) have developed the culture of resorting to writs to commit persons who use drugs, particularly where no institution was able to accept new patients.

In 2019, a Bolsonaro-backed bill was passed in the Congress establishing doctors’ ultimate authority to explicitly provide in legislation forced treatments without a judicial order in cases of substance use disorders.²⁵ This change may reduce the level of litigation in Brazil on this topic, but as mentioned above, it was more the codification of an existing practice in the legal framework than a substantial departure. The outlook, though, should be of growth in litigation as a whole. Since many municipalities do not provide mental health services, families would still have to resort to filing new claims even if they could request this administratively.

The architecture of the current legislation places the family and the doctor (not the individual

who uses drugs) at the center, just as judges have done in jurisprudence. No procedural rights are conferred to individuals for compulsory treatment, save the notification to the Public Prosecutor’s Office (Ministério Público). Involuntary admission (outside courts) can now be made by the decision of a doctor after the request of the patient’s family as if they were a legal tutor or guardian, but without a previous judicial order or declaration of incapacity. The doctor’s prescription must state that no alternative was available, and the restriction can last for 90 days only (though the law is silent about successive renewals).

Another justification for the recent legal reform in Brazil was to bolster and legitimize the activities of “therapeutic communities” (TCs) as a form of social control over addiction. Provided by legislation since the 1970s, these private entities are generally led by religious organizations and are not to be confused with progressive and humanistic community-based services introduced in other countries. Different from the best international guidance on drug rehabilitation, TC facilities offer services of rehabilitation that essentially could not be regarded as such—they are heavily reliant on coercion and segregation, with poor technical capacity and no extensive social services, including work and education.²⁶ Researchers, local authorities, and news outlets have exposed TCs’ brutal detention regime as a form of a “total institution” where individuals are cut off from society at the mercy of their hosting organizations.²⁷ Defying best practices around abstinence, TCs compel patients to live in long periods of isolation from family and friends, with no access to external communication or entertainment, including books and television.²⁸ Some inspections have found TCs operating with very poor standards of hygiene and food, as well as overcrowded accommodations.²⁹ Therapies are commonly religious and oriented toward spiritual salvation.³⁰

Again, families are an important factor in the promotion of a compulsory policy. TCs normally target advertisement and recruitment strategies at family members.³¹ As an operational arm of a compulsory policy, there are accounts of families

“disposing of” undesired members, sometimes for ulterior motives such as disapproval of sexual preferences or lifestyles (some TCs also offer sexuality conversion therapies).

The pressure of TCs on legislation and subsequent implementation of human rights standards cannot be ignored, nor can the lack of judicial intervention deterring these harmful services. With the political turn in Brazil in 2018 in favor of evangelical coalitions, TCs forged a connection between religious movements and Bolsonaro’s ideological mandate. While the legal reform by Bolsonaro does not permit compulsory treatment in TCs, some of those institutions have operated as if they were fully staffed clinics. Under these circumstances, a substantive right to health becomes a dangerous instrument in the hands of litigants if TCs are absorbed into the health system or licensed as a full health service. In the absence of public contracts with TCs, judicial orders may finance the expansion of those private entities in areas with deficient access to a public mental health system. Moreover, the growth of litigation in Brazil has shown to bear some relation to an increase in the usage of private providers of substance disorder treatments. For instance, in the state of Espírito Santo, expenditures on compulsory treatment orders between 2015 and 2019 have increased from R\$13 million to R\$39 million, of which almost all resources went to private institutions (41.6% of them being established after 2011).³²

Lack of a legal culture sensitive to persons with substance disorders

Not only is the legal framework in Brazil inadequate in recognizing patients’ autonomy, but it is also coupled with a widespread disinterest across the legal community about themes such as consent and ethics. One plausible reason for the limited recognition of patient guarantees in Brazilian judicial practice is that this matter has been largely overlooked by legal scholarship in Portuguese. Brazilian legal doctrine and course textbooks primarily address medical law as the sole study of liabilities in health care malpractice.³³ Only recently have authors promoted the concept of “human rights of the patient”

(as proposed by Albuquerque) or bioethics and law manuals to examine basic provisions of autonomy and consent not yet adopted by legislation.³⁴

To a degree, it is at least contradictory that a country with more than three decades of a Constitution establishing a right to health consistently enforced by courts has never fleshed out a comprehensive set of rules for patients’ freedoms. This demonstrates that the constitutional right to health in Brazil has been successful only in setting forth substantive care provisions (access to health) but not in stipulating minimal procedural conditions acknowledged in the legal community.

Additionally, there are signs of a lack of referential background beyond public law in Brazil to discuss appropriate guarantees in compulsory treatments. Some studies refer back to other constitutional provisions, but since the right to health as constitutionally defined does particularize individual guarantees, this level of analysis is insufficient to determine the nature of state obligations.³⁵ References to principles in international law are also vague, and even domestic human rights institutions do not specify the nature of those obligations.

This seeming unfamiliarity or unawareness can be also seen in Brazil’s highest courts. In 2016, the Brazilian Supreme Court heard a case on whether the prosecution authority had a legal standing to apply for court orders for compulsory treatment of a person with alcohol dependence on the grounds of the right to health.³⁶ The municipal government had challenged the legal competence of the Public Prosecutor’s Office to request compulsory treatment for this patient on behalf of the family, after the local authority failed to provide the compulsory admission.

The legal question referred to the court was whether the request at issue should have been filed instead by public defenders or the family. What ensued was a discussion of the nature of the rights in compulsory treatments—the individual, the family, or the society. This judgment is symptomatic of the hazy conception of individual rights versus public health powers, anti-drug policies, and access to health care.

Justice Carmen Lucia wondered how there

could be legitimacy in the public prosecutor taking legal action on behalf of society if that process would outstrip the person's "individuality" or human condition by imposing a treatment against their will. In her dissenting vote, she "cherished" the fact that today's patients are compulsorily treated based on individual rights. She noted, however, that "public prosecutors can find tomorrow that a certain disease causes certain harm, they lodge a case and one patient commitment follows."³⁷ "What is at play is not a patrimonial question, but a health as a major concern, to the extent that it harms the safety of third parties (the family)," replied Justice Marco Aurelio.³⁸ This comment conforms to the type of balancing reasoning that plays individual patient rights against the family's well-being.

Ultimately, the judgment was deliberated on procedural grounds, not patients' procedural rights. The order could have been requested solely by the family or a public defender, given that there was no "matter of public interest." Nothing was said about patients' procedural rights; the court's reasoning lay somewhere between the collective and individual, accepting the family and the public defenders as the legitimate parties. The circumstance was relegated to the private sphere, but the court never fully examined whether preserving patient autonomy and procedural rights were "a matter of public interest" in themselves (to warrant public prosecution intervention), as a fundamental constitutional obligation.

Judicialization as part of a repressive program

A potential risk to patients is public interest actions pursued by public authorities determined to eradicate persons with substance use disorders from public spaces. However, those claims are still rare and have been successful in bringing media attention to the need for minimum procedural guarantees for persons with substance use disorders.³⁹ In 2017, the São Paulo municipal administration sought a collective judicial warrant for the compulsory admission of an indeterminate number of persons with substance use disorders in the "Crackland" ("Cracolândia") region, an area of town used as an open-air drug space for hundreds

of people.⁴⁰ Focused more on restoring urban safety than the appropriate means for rehabilitation, the application was rejected by the São Paulo State Court. No right to health argument was made in the judgment dismissing the application.

However, one of the reasons to deny the motion was the lack of procedural guarantees, as the intervention did not ensure individual legal representation of all persons in custody. The court would need to serve several detention orders and force medical checks on homeless people and minors to then confirm the need for compulsory treatments.

A second noteworthy reason was that the municipal government lacked legal standing for that particular lawsuit. It is interesting to note that the initial lawsuit was an entirely different class action filed by the public prosecution seeking damages for police abuse in a raid of the area in 2012, where dozens of people were submitted to violence and illegal detentions.⁴¹ In the original claim, human rights were articulated but very generically and with no reference to the right to health or patient autonomy.

This approach confirms that public authorities in Brazil may struggle to bring together human rights standards, ethics, and patient procedural safeguards. Even by seeking to protect human rights principles, there is no direct mention of minimum standards for patients with substance use disorders, such as participation in their health care plan. Thus, right to health decisions in Brazil are more likely to be driven by families and oriented toward forced treatments than structural litigation to change public health policies and mental health practice at a population level. This pattern has been raised by Octavio Ferraz in his discussion of the judicial interpretation of the right to health in Brazilian courts, where private actions are more determinant than collective claims.⁴²

Conclusion: More dilemmas and future questions

The present findings suggest that the Brazilian constitutional right to health, as applied in the jurisdiction of the state of São Paulo, does not automatically contribute to a well-established

framework of procedural guarantees for persons with substance disorders who are ordered compulsory treatment. The current approach of judges, as demonstrated through recurrent and uniform decisions, has shown a large misinterpretation of the right to health, focused only on the provision of care as a substantive and automatic entitlement, without considering patient preferences or informed consent as part of the obligations of such a right in mental health practice. More importantly, the combination of an easily enforceable substantive right to health with weakly observed patient autonomy can be harmful to individual rights if wielded indiscriminately by families, as indicated by the decisions studied. For other countries, a lesson that may be heeded is that a domestic recognition of the right to health in law may not be sufficient to guide judicial standards for compulsory treatments of patients lacking capacity.

In Brazil, the neglect of procedural guarantees in the judicial discourse is particularly concerning in light of a repressive policy and intolerance toward persons with substance use disorders, which allow families to directly access services from treatment providers willing to perform a repressive role based on faith and ideology.

Although there are legitimate reasons and safety needs argued by some families, these circumstances may potentially turn courts into a compulsory apparatus artfully employed by bad-intentioned litigants in league with treatment providers moved by economic, religious, or political interests in a country with a rampant detention culture. Further qualitative research is needed to narrate the individual experience of patients in these judicial processes and describe the extent to which they were involved in the treatment decision, whether they could have had a less restrictive measure, or whether they could have refused their admission. As it currently stands, the documentation does not allow for assessing those facts.

The substantive enforcement of the right to health in Brazil and the potential negative effects of mental health policies for persons with substance disorders cannot be read beyond the scope of those decisions. The findings here are no reason to call

into question the effectiveness of the right to health in other jurisdictions or the effectiveness of socioeconomic rights' implementation by other courts. Legal reasoning and rights enforcement may vary in Brazil depending on the public health policy in question (see, for instance, the valuable invisible use of the right to health in courts to increase sanitation services).⁴³ More positive and comprehensive public health developments may have been promoted by judicialization in other areas, requiring independent studies and other methods to track the impact of the positive right to health.

That said, the litigation described here may very well cause substantial de-prioritization of the full provision of care beyond in-hospital or residential programs. At the outset, this study made clear that it would not aspire to perform a quantitative analysis, such as that used to determine the economic cost of access-to-medicine litigation. However, considering the stance taken by courts to grant compulsory treatments, there is reason to suggest that the basic formula of health care litigation (a readily accessible right to health in courts by families) may point to similar directions in public spending.

Yet, to prevent unnecessary compulsory treatments, public policies must address resource issues in the mental health system. Brazil's legal framework is strikingly mindful of the need for adequate resources to respect patient decisions. It sets out that compulsory treatment is permitted only if "extra-hospital resources are proven to be insufficient."⁴⁴ In reality, the rule means that forced therapy is a last-resort resource, but if there are not many public resources available for alternative treatments, the scope of the patient's decision and the burden to prove that a compulsory treatment is the last possibility is lower.

As mentioned earlier, therapeutic communities, particularly in the religious sector, are historical promoters of compulsory services and have limited capacity for integral care. Public health expenditure on other forms of community services in Brazil was reduced between 2010 and 2019, and much of the funding is now being directed to religiously led community groups that do not follow international

best practices or evidence-based treatments.⁴⁵ A reform of Brazil's mental health services would need a whole new direction, putting patient preferences and autonomy at the center.

Acknowledgments

I am thankful for the comments from the editors. I am also grateful to Judith Bueno de Mesquita and Professor Judy Laing for providing feedback on the manuscript. All errors and omission remain my own.

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VIEWPOINT

Toward the Emergence of Compulsory Treatment for Drug Use in Morocco?

KHALID TINASTI

In Morocco, people incarcerated for drug offenses make up 69% of those in pretrial detention (22,587 out of a total of 32,732 people).¹ As of 2018, 25% of people incarcerated were serving a drug-related sentence (21,004 out of a total of 83,732 people). Disaggregated data are not available on the number of prisoners serving sentences for use, possession, or trafficking charges.² Prison overcrowding can surpass 240% in some Moroccan prisons.³

For almost half a century, between 1974—when the Narcotics Act entered into force—and 2021, there were no reported judicial precedents for people charged with using drugs being sentenced to compulsory treatment. This changed in November 2021, when a judge sentenced an individual arrested for drug use to undergo compulsory treatment. This viewpoint essay contextualizes the recent compulsory drug treatment order within the evolving national drug policy ecosystem and explores how the 2021 court decision may influence the future imposition of compulsory treatment in Morocco.

Legal framework and drug policy situation

Reliable data on drug use in Morocco are challenging to source. The only comprehensive national survey to date, conducted in 2005, estimates the annual prevalence of illegal drug use in Morocco to be 4.1% among the adult general population, with cannabis prevalence alone representing 3.93% of this total.⁴ A 2007 study in 30 schools (primary, middle, and high schools) among 6,231 students found that 50% of those who use drugs consumed cannabis, while 12% used cocaine and 3% used heroin.⁵

In 1966, a decade after gaining independence, Morocco ratified the Single Convention on Narcotic Drugs of 1954; in 1979, it ratified the Convention on Psychotropic Substances of 1971; and in 2002, it ratified the United Nations Convention against Illicit Traffic of 1988.⁶ In 1977, Morocco established its National Narcotics Commission, an interdepartmental body tasked with coordinating the country's response to the illegal drug market.

One of the most important drug-related laws in Morocco is the *dahir* (Moroccan King's decree) that established the Narcotics Act of 1974. Under this law, people who use drugs (as confirmed by urine tests after being arrested by the police or denounced) are liable to prison sentences between two and twelve

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Competing interests: None declared.

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months, while those charged with possession for personal use risk prison sentences between five and ten years, regardless of whether the quantity carried is small.⁷

The legal framework also allows for dropping criminal charges if the individual is sentenced to compulsory treatment of one to three months. However, in practice, people arrested for using drugs rarely receive compulsory treatment sentences.⁸ People accused of committing a crime under the influence of illegal drugs, including alcohol, can be sentenced to compulsory treatment and be held under surveillance in one of the existing sixteen addiction units or clinics for a period of up to two years.⁹ For children and adolescents, mandatory treatment can be imposed without their consent if agreed to by their parents or legal guardians.¹⁰

Stigma and discrimination against people who use drugs are widespread. This includes psychological and physical mistreatment by police officers.¹¹ Lawyers report sexual harassment and abuse perpetrated against women who use drugs by police officers.¹²

In the last few years, there have been attempts to move the national approach toward a health-based management of illegal drug use. For example, the 2018–2022 National Strategic Plan for Prevention and Care of Addictive Disorders aims to increase investments in treatment (both abstinence-based and substitution therapies); however, it does not distinguish between occasional consumers and people with drug use disorders.¹³

The most recent drug policy reform is the medical and industrial cannabis use act (Cannabis Licit Uses Act), adopted in July 2021.¹⁴ The legalization of medical use of cannabis was adopted to respond to the social and economic issues of cannabis farmers. This latest reform is not expected to significantly influence Moroccan drug policy, since it does not include provisions to decriminalize recreational cannabis consumption.

Available rehabilitation and harm reduction services

The quality of treatment and management of

dependence and drug use in Morocco remains problematic. In 2010, the government introduced three pilot projects for methadone distribution (in Casablanca, Rabat, and Tangiers), which were later expanded to three sites in Tangiers and rolled out in two other cities (Tétouan and Nador) through residential facilities (locally called *services d'addictologie*), as well as within five prisons.¹⁵ These services are aimed at preventing the social and economic costs of HIV transmission and promoting abstinence among dependent consumers, rather than protecting the health and well-being of consumers. Nevertheless, existing services remain extremely limited and are struggling to respond to demand, leading to long waiting lists for enrollment.¹⁶ In 2012, there were a reported 293 people enrolled; this number reached 2,327 people in 2018, including only 180 women.¹⁷ Media reports refer to shortages in qualified health workers and geographic remoteness as reasons for waiting lists that can reach up to 1,000 people in the case of the city of Tétouan.¹⁸

At the same time, the number of drug dependence treatment facilities in public hospitals, including residential facilities where people in compulsory treatment are kept against their will and where consumers of all substances are forced to undergo abstinence, has grown in recent years, reaching 16 centers in 2021. These facilities function without specific guidelines, with each unit allowed to choose its methods and lengths of treatment.¹⁹ That said, the law requires that compulsory treatment sentenced for a period up to three months be controlled through a biweekly mandatory examination conducted by an expert medical doctor designated by the Public Prosecutor's Office.²⁰

Judicial precedent for compulsory treatment

In November 2021, a lower court judge in Kenitra, a city to the north of Rabat, the country's capital, rejected the prosecutor's charges on drug possession rather than use on the grounds that possession charges deny an individual the possibility to be sentenced to compulsory treatment and have his

criminal charges dropped. The judge decided that by denying compulsory treatment, and by not informing the person arrested of this existing provision in the law, the prosecution ignored article 8 of the Narcotics Act of 1974. The court concluded that all criminal charges should be dropped once the person undergoes mandatory treatment as punishment for drug use.²¹ The individual charged in this case has not appealed the judgment.

This judgment poses several legal and health-related concerns for people who use drugs, starting with the definition of the “agreement” to undergo treatment. According to the Narcotics Act’s article 8, people arrested on use (and not possession) grounds are coerced to undergo a urine drug test and subsequently subscribe to a treatment regimen in residential facilities, where they are retained for the period of the sentence (one to three months). The agreement therefore seems more related to avoiding incarceration and infringes the right to health since coercive medical treatments should be reserved as a last resort for the most serious mental health conditions or to control the spread of infectious diseases.²²

Conclusion

Evidence-based and human rights-informed drug policy reform has been slow in Morocco. The implementation of harm reduction services has been introduced to enhance the reduction of HIV transmission among people who inject drugs. A decade later, the country has legalized the medical use of cannabis to respond to the social and economic issues of cannabis farmers. Nevertheless, these reforms are limited and low-priority. Moroccan drug law and practice remain focused primarily on the prohibition of illegal drugs and the enforcement of abstinence from drug use, without specific attention to mitigating the negative consequences of prohibition on people who use drugs.

The country’s first court ruling requiring compulsory treatment for drug use represents a risk of increasing the numbers of people arrested for illegal drug use being sentenced to mandatory therapies as an option to avoid incarceration. In

order to avoid a judicial reliance on compulsory treatment, the scale-up and increased coverage of evidence-based harm reduction services, advocacy for the decriminalization of drug use and possession of small quantities carried for personal consumption, and the repeal of legal provisions allowing for coerced treatment must be brought back onto the political agenda.

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VIEWPOINT

Not Enough Stick? Drug Detention and the Limits of United Nations Norm Setting

DANIEL WOLFE AND ROXANNE SAUCIER

A January 2022 report by UNAIDS and the United Nations Office on Drugs and Crime is the first in years to gauge the state of detention in the name of drug treatment in Asia.¹ The report is also a sobering milestone: total numbers in drug detention centers remain essentially the same as 2012, when 12 United Nations (UN) agencies called for their closure.² Vietnam, which had announced a “renovation” of its approach and decreased detention by 25%, has almost returned to previous totals.³ Malaysia has returned to 2012 detention levels.⁴ Cambodia increased the number of people detained by 80% in the years following the UN’s 2012 call.⁵

Gathering data on this subject is a political and administrative challenge, and the analysis by UNAIDS and the UN Office on Drugs and Crime is critically important. Equally important is the need to ask why responses to drug use in Asia have bent toward inaction and regression on the part of governments, rather than toward human rights.

Not enough stick?

Medical anthropologist Richard Parker has observed that the more attention paid to the structural causes of HIV vulnerability, the less bold UN agencies have become in addressing them. He notes that UN agencies have turned instead to “administering the epidemic”—producing reports demonstrating the need for action but failing to rally action themselves.⁶ The same can arguably be said about drug detention—another threat to the health of populations that UN agencies are charged to protect. In 2010, UNAIDS head Michel Sidibe, addressing the International Harm Reduction Conference, declared that “the crimes which are being committed today in the name of drug detention must be denounced.”⁷ But despite establishing norms on voluntary treatment, issuing two strongly worded statements against drug detention, and hosting inter-governmental consultations at regular intervals, UN engagement has brought neither denunciation of bad state actors nor sustained results. No public UN comment came when Vietnam and Malaysia reversed progress and began again to expand drug detention. Despite member state commitments to transition to voluntary treatment at a 2015 UN consultation, failure to honor these commitments has brought neither

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Competing interests: None declared.

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censure nor penalty.⁸

Past actions taken by the UN and member states against drug detention did not arise spontaneously but emerged following concerted advocacy. At international conferences beginning in 2009, people who use drugs offered testimony of forced labor and inhuman and degrading treatment to audiences that included members of their governments and UN agencies. Activists at the 2009 International Harm Reduction Conference in Bangkok took the stage carrying banners calling for “treatment, not torture.” Human Rights Watch, the Open Society Foundations, and Harm Reduction International all issued reports documenting violations of human rights and international law in Asian drug detention centers.⁹

Importantly, advocacy also “followed the money,” using the withdrawal of financial support or its threat as a lever for change. Some reports turned the mirror to Western donors and the UN, documenting the use of UNICEF vans to transport children to detention, or of US aid to “build capacity” of detention center staff or construct centers themselves.¹⁰ By 2014, the UN Office on Drugs and Crime and the Global Fund to Fight AIDS, Tuberculosis and Malaria had both issued policies withdrawing support for detention centers.¹¹ In Vietnam, where “rehabilitation” included hours of unpaid labor in the service of private companies, campaigners raised the specter of the interruption of international trade. Human Rights Watch documented forced labor for the Vietnamese cashew industry, then accounting for US\$1.4 billion in annual exports.¹² The American Apparel and Footwear Association wrote to Vietnamese officials, expressing concern about forced labor in the supply chain of a major exporter to the United States.¹³ Concern about Vietnam’s drug detention centers was included in a 2013 US Department of Labor report.¹⁴ Marked decreases in detention followed.

There are lessons here not just for UN agencies but for civil society advocates and donors—including the authors, both of whom worked to end drug detention while employed by the Open Society Foundations. Principal among these is the importance of continued outside pressure to force change.

The multipolar advocacy on drug detention was not sustained. UN agencies continued intergovernmental consultations, but for seven years refrained from documenting numbers of people detained in the centers. The unit at Human Rights Watch that had rigorously followed the issue, producing seven investigations on drug detention in six years, shifted focus and was disbanded. We at the Open Society Foundations turned attention to abuses in privately run centers in Latin America. Perhaps most importantly, pressure on the key lever of labor, with implications for billions of dollars in international trade, was not maintained.

At the same time that advocates eased off the “stick,” the “carrot” was also lacking. Organizations documenting abuses in drug detention had no resources to fund alternatives. The Global Fund and the US President’s Emergency Plan for AIDS Relief prioritized investment in methadone prescription to reduce injection and HIV risk: treatment for stimulant users, who now account for the majority of Asian detainees, was not as robustly funded. As a Vietnamese official commented to the authors during a 2014 visit, “You people [Western donors] told us our house is so ugly we should tear it down. But now that it’s time to build another, you offer little help.” Governments in the region apparently found little incentive to reallocate their own resources: the new UN report finds that some spend up to 77% of their drug dependence treatment budget on detention.¹⁵

Doing better

UN representatives at the release of the 2022 report emphasized that the “time is now” to take action. While the time was arguably “then,” now is indeed a time to avoid setbacks of the past. Ongoing reporting on numbers of detainees, and pointed comment when negative trends emerge, is essential.

Monitors should continue to follow the money. As UN Office on Drugs and Crime representative Jeremy Douglas noted at the January 2022 report launch, drug detention commands substantial resources, which will not be easily relinquished by those who control them. Budget monitoring, and

mechanisms for government to support groups providing genuinely community-based treatment, will also be critical.

The case calls for continued public censure. International response to internment and forced labor imposed by China on the Uighurs—including bans on imports, and public condemnation from politicians and celebrities—is instructive. While the sweep of China’s rights violations against the Uighurs is particularly appalling, the tactics—including detention, forced labor, and compulsory reeducation—are the same China employs for people who use drugs.¹⁶

Finally, we must reckon the cost of failure to engage. As Martti Koskeniemi has warned, a political culture that “insists that rights are foundational ... but in practice constantly finds that they are not, becomes a culture of bad faith”—and one that alienates political engagement.¹⁷ This is terrible not just for the nearly 500,000 people detained in the name of drug rehabilitation in Asia but for the human rights field and the wider body politic.

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VIEWPOINT

Transitions from Compulsory Detention to Community-Based Treatment: No Transparency without Data, No Accountability without Independent Evaluations

PASCAL TANGUAY, ANAND CHABUNGBAM, AND GINO VUMBACA

In 2012, the cosponsors of the Joint United Nations Programme on HIV/AIDS (UNAIDS) issued a statement calling for the closure of compulsory drug detention and rehabilitation centers.¹ To accelerate this process, an expert working group—composed of eminent scholars and community leaders—was jointly established in 2014 by the United Nations Office on Drugs and Crime and the UNAIDS Regional Support Team in Bangkok.² Citing literature published by civil society, the expert working group reported in 2015 that such centers in Cambodia, China, Indonesia, Lao PDR, Malaysia, Myanmar, the Philippines, Thailand, and Vietnam were ineffective, unsafe for clients due to human rights violations and transmission of HIV and hepatitis (and more recently COVID-19), costly, insufficiently capacitated, filled with individuals who were not in need of clinical treatment for drug dependence, and operating as an extension of the criminal justice system rather than a mechanism to promote and protect the health and well-being of people who use drugs.³

Data on compulsory centers for people who use drugs are rare and difficult to obtain. Published data show that over 475,000 people who use drugs were being detained, often without due process or legal protections, in such facilities in 2018.⁴ Reports show that between 2012 and 2018, there was either an increase or no significant decrease in the number of people detained in compulsory centers in Cambodia, China, Lao PDR, Malaysia, the Philippines, Thailand, and Vietnam.⁵ Despite guidance and recommendations from the expert working group convened by the United Nations, governments in the region have not reduced their reliance on the compulsory detention of people who use drugs or transitioned toward community-based models.

Programmatic inertia, political and legal paralysis, and financial constraints have prevented the closure of compulsory centers and stalled the transition toward community-based and community-led models.⁶

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Compulsory centers have not closed because the governments that operate them simply do not have to—there has been no incentive to do so, and no negative consequences for keeping them open. This continues to exacerbate the meaningless suffering of people who use drugs and highlights the need for stronger measures to incentivize Asian governments to act decisively to close compulsory centers and to align their drug treatment mechanisms with evidence; with effective and cost-effective models, strategies, and interventions; and with international good practice.

Advocacy efforts must be strengthened, accelerated, and better funded by donors to create pressure that compels effective action. However, doing so will require additional evidence. It is therefore imperative that advocacy efforts urge governments, development partners, United Nations agencies, donors, and other key stakeholders to demand more transparency regarding the operations of compulsory centers. In its 2015 discussion paper, the expert working group specifically called for “improving data collection and monitoring and evaluation of the effectiveness and cost-effectiveness” of compulsory centers and provided sample indicators to do so, noting that “public dissemination of such data on a regular basis would further promote regional cooperation and transparency.”⁷ The proposed indicators should be updated, expanded, and integrated into existing national government and donor performance monitoring frameworks.

More importantly, the overarching policies, procedures, and interventions in compulsory centers should be subject to independent evaluations by external experts to generate an objective assessment of the situation in those facilities. To date, very few public documents present reliable evidence about the inner workings or the performance of compulsory centers, and when such reports are published, they are generally released by the agencies that are responsible for managing and maintaining those centers. Such potentially biased reporting cannot be considered appropriate given the clear conflict of interest and mounting international pressure to close such centers. Moreover, policies, procedures,

and interventions in compulsory centers must be regularly and independently evaluated against international guidelines and good practices.⁸ Data from regular monitoring and evaluations of compulsory centers should generate a more accurate assessment of the situation and inform advocacy efforts, galvanize action from key stakeholders, and mobilize additional support for a transition toward community-based models and community-led interventions. All relevant data should be reported on an annual basis to UNAIDS and the United Nations Office on Drugs and Crime to track progress and thereby help governments mobilize additional financial resources and technical support to accelerate the transition process.

A Human Rights Approach to Prison Management: Handbook for Prison Staff, an influential tool published by the Institute for Criminal Policy Research that promotes the human rights of people deprived of liberty, is explicit on the need for regular monitoring and evaluations of facilities where people deprived of liberty are detained by governments against their will: “Inspection procedures protect the rights of prisoners and their families. They are meant to ensure that proper procedures exist and that they are observed by staff at all times. Inspections should cover all the aspects of prison life.”⁹ By logical extension, the recommendations and guidance in the handbook could be considered invaluable for oversight over compulsory centers while they still exist given that people who use drugs in such custodial centers have been forcibly confined, detained, and deprived of liberty against their will by government authorities.

Specifically, several legal instruments—such as the Optional Protocol to the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (art. 1), the Convention against Torture (art. 16(1)), the Nelson Mandela Rules (rule 83), and the Body of Principles for the Protection of All Persons under Any Form of Detention or Imprisonment (principle 29)—recommend “that all prisons and places of detention should be subject to a system of inspection which is independent of the authority responsible for administering those prisons.”¹⁰ Given that these

instruments apply to all places of detention, they should also compel governments that continue to rely on compulsory centers to allow and ensure the implementation of regular and independent evaluations of their operations.

In 2015, the expert working group recommended that countries develop national transition plans—with clear objectives, expected outcomes, monitoring and evaluation indicators, measurable targets, and proposed timelines—to establish effective community-based drug treatment models. Yet as of 2019, since the formulation of the expert committee recommendations, not a single country in Asia has developed a national transition plan.¹¹ While efforts continue to be implemented to fully close compulsory centers, key stakeholders must ensure that the people who are trapped in these abominable institutions have some measure of protection—especially since most people detained in compulsory centers are more vulnerable than other persons deprived of liberty since they do not have access to legal protections (such as due process, parole, and legal representation) that are granted to persons deprived of liberty in other closed settings managed by the state. While there is growing recognition of the myriad problems created by compulsory centers and intensifying calls for their closure, they remain in operation across Asia. Accordingly, there is a clear need for evaluations, better data, and more transparency from Asian governments so that the agencies responsible for the health and well-being of people who use drugs can be held to account if they systematically fail to meet their own obligations.

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VIEWPOINT

Moving toward Voluntary Community-Based Treatment for Drug Use and Dependence

ROBERT ALI AND MATTHEW STEVENS

The supply of illicit drugs available in East and Southeast Asian markets is higher than ever before. Methamphetamine seizures across the region have increased yearly since 2011 due to the increased production and availability of crystal methamphetamine.¹ This has also coincided with an increase in the number of seizures from new and emerging psychostimulants, including those with opioid effects.² A wider scope of production and distribution of illicit drugs within the region has led authorities to establish more severe penalties for drug use in a misdirected attempt to curb the demand for drugs. These include the use of involuntary detainment approaches such as compulsory drug detention and rehabilitation centers (CDDCs).

CDDCs are part of a punitive treatment and rehabilitation system used by legal authorities to address drug use and dependence. But while many centers are designed for the purposes of treatment and rehabilitation, they are also commonly used for detainment across a range of issues beyond their scope. For example, individuals are often detained for, or under the suspicion of, a number of drug and non-drug-related behaviors, including the use or possession of illicit substances, engagement in sex work, and being (child) victims of sexual exploitation.³ Detainment in CDDCs typically involves elements of forced labor, physical and sexual violence, inadequate provision of nutrition, and limited access to quality health care services.⁴

A fundamental pillar of the compulsory detention model is that CDDCs work by reducing the supply of and demand for illicit drugs. However, the evidence in favor of these views is lacking. On the supply side, the rates of production and use of illicit drugs in the region are higher than ever.⁵ On the demand side, the high rate of relapse from involuntary treatment, and the lack of reduction in the number of people detained over the past decade seem to indicate similar failures.⁶ This may be partially explained by demand inelasticity among dependent individuals. In some cases, depending on the type of drug and the availability of substitutes, dependent individuals may be more willing to pay higher prices or to engage in criminal activity to obtain illicit drugs.⁷ Individual demand for illicit drugs is not likely to decrease without structured

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Competing interests: None declared.

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clinical interventions. Furthermore, lower prices in response to increased supply and rates of production may also contribute to sustained demand among marginal recreational users.⁸

Unless the situation changes, the call for more CDDCs is likely to continue to grow in line with the increased supply of illicit drugs in the region. Greater supply means a higher number of people detained, leading to more overcrowding and less capacity for effective service provision. The current system of forced detention, irrespective of detainees' level of dependence, has not worked and will not work in the way intended.

The hidden costs of compulsory detention and rehabilitation

There are significant financial costs associated with the compulsory treatment model. In an area where resources are extremely limited, the compulsory treatment model has been found to be costly and consumes considerable resources.⁹ But an underappreciated cost burden associated with the compulsory treatment model is the productive capacity lost through detainment. The majority of individuals detained in CDDCs are young, otherwise healthy individuals of productive working age.¹⁰ A great number of these young people are not drug dependent and are therefore not in need of intensive treatment for drug dependence. Removal of these individuals from the workplace and society, in socioeconomic terms, constitutes a loss of productivity and social capital.

Governments must also consider other significant economic and social costs associated with the spread of blood-borne illnesses such as HIV, as well as viral hepatitis. Given that the spread of HIV and other communicable diseases, including COVID-19, is higher in CDDCs than in voluntary community-based services, this represents another opportunity cost for governments.¹¹ Evidence from Indonesia suggests that governments can save an estimated US\$7,000 for each averted case of HIV, indicating that these resources could be better deployed elsewhere.¹² It is time to stop the cycle

of compulsory detention and move to a culturally adapted evidence-based system of voluntary community-based treatment that is less costly, more effective, and rights based.

Voluntary community-based treatments: A better alternative for all

There is mounting evidence that CDDCs are ineffective in the treatment of substance use disorders and dependence. In fact, on balance, CDDCs may actually contribute more harm than benefit to the health of both individuals and public.¹³ Several United Nations entities released a joint statement in 2012 calling for the closure of CDDCs, citing numerous health and human rights concerns.¹⁴ Since then, a number of calls have been made to transition from CDDCs to voluntary community-based treatment services.¹⁵ Recently, another joint statement was released by UN entities reiterating calls for the closure of CDDCs in light of the spread of COVID-19 and the risk it poses to people in prisons and other closed settings.¹⁶

There are several issues of concern relating to CDDCs, including higher rates of relapse compared to voluntary community-based treatment services; avoidance of health care in response to stigma and shame; higher rates of infectious disease and blood-borne virus transmission due to overcrowding; and inadequate medication and staffing.¹⁷ The last point is of particular concern in light of COVID-19 and the risk it poses to the community.

On the other hand, voluntary community-based treatment services present an effective, viable alternative. Voluntary community-based services are more cost-effective and more likely to lead to better drug-related outcomes, including sustained abstinence.¹⁸ They have also been shown to be more effective from a public health perspective in that they are less stigmatizing and discriminatory, lead to more prosocial behavior, and lead to a reduction in the spread of infectious diseases.¹⁹

Despite evidence in favor of the socioeconomic advantage of voluntary approaches, some jurisdictions continue to object to community-based

treatments, citing a lack of evidence. Proponents of the compulsory treatment model might argue that voluntary approaches have been shown to be effective only for sedative and opioid-type drugs, and in the absence of effective medicines to treat dependence on stimulant-type drugs the perception is that there is no alternative option for public security and safety other than retaining the centers to detain the drug user. Once again, however, the evidence to support such a claim is unfounded. Community-based psychosocial interventions for methamphetamine dependence have been shown to work and have good acceptability.²⁰ The absence of safe and effective medication to treat methamphetamine dependence is no justification for preventing the introduction and scaling-up of evidence-based psychosocial interventions in community-based settings.

Concluding remarks

Given the arguments in favor of voluntary community-based approaches, the natural question becomes, What is stopping governments from moving in that direction? The answer is less clear and requires a change in perspective.

First, moving to a community-based model requires a shift in paradigm away from viewing drug dependence as a moral failing toward viewing it as a treatable condition that can be addressed through evidence-informed, community-based treatment approaches. CDDCs operate within the moralistic view that drug use is a character flaw that can be “cured” through various forms of therapy. The CDDC model typically uses religious education, physical exercise, forced labor, and even unmedicated withdrawal as a form of punishment to coerce individuals into future abstinence. This is highly problematic given that CDDCs are often staffed with workers who have no formal training in treating substance use disorders. Also, the frequent lack of medical personnel means that staff are ill-equipped to supervise persons going through withdrawal.²¹

Aside from the commonly held view among government authorities regarding the “need” for CDDCs to cope with growing rate of methamphet-

amine use in the region, it has also been argued that there are limited financial, human, and technical resources available to aid transition.²² But these and other key issues have been considered and rebutted. Most notably, in 2015, an expert advisory group at the United Nations Office on Drugs and Crime laid out its vision of a roadmap to enable a transition toward voluntary community-based treatment approaches.²³

A final challenge preventing the move toward voluntary community-based approaches is the need for continuing support for recovery. Rehabilitation programs require continuing support to help individuals transition back into society following release. Employment, housing, and social connectedness with non-drug-using family and friends are key components to reduce the risk of relapse.²⁴ Unfortunately, the reality is that CDDCs are not providing meaningful treatment, and due to the stigma and shame associated with drug detention, many detainees struggle to assimilate back into the community, often ending up back in detention following relapse. The absence of a community support system greatly increases that risk.

In summary, not only is involuntary detention ineffective in the treatment of drug dependence, but there are more cost-effective and socially beneficial programs available. Drug dependence is not a moral failing, and moving toward a person-centered approach that views drug dependence as a treatable chronic relapsing disorder using interventions that are grounded in evidence and embrace a rights-based approach to health is the way forward. Ultimately, CDDCs are the enduring legacy of a system of coercive abstinence-based treatment that has been shown, time and again, to be both costly and ineffective—and more importantly, harmful. Governments that want to enable improvements in public health outcomes for their jurisdictions must move to close all CDDCs immediately and scale up voluntary community-based treatment. This is particularly important in light of the COVID-19 pandemic, in which overcrowding continues to represent a significant risk to both individuals and the community.

Funding

Both authors are funded by a grant awarded by the Australian Government Department of Health for the prevention of substance use disorders.

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Capacity-Building in Community-Based Drug Treatment Services

MICHAEL J. COLE

Abstract

Globally, there are not enough services to meet the enormous demand for evidence-based community-based drug treatment. Further, the effectiveness of available services varies as much as the diversity of their treatment regimens. Capacity-building can help increase the scale and improve the quality of those interventions. Maximizing the impact of capacity-building requires a comprehensive and systematic approach considering three levels—the individual worker, organization, and service sector—and it starts with assessment and planning. This paper describes the areas to consider and steps to follow when planning and implementing a comprehensive capacity-building approach in community-based drug treatment services. Utilizing an empowerment model for capacity-building can increase the stakeholders and resources engaged in the process. Better engagement with community stakeholders increases the likelihood that capacity-building outcomes will be sustainable. Further, the institutionalization of capacity-building can establish and promote an organizational culture of continuous learning.

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Competing interests: None declared.

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Introduction

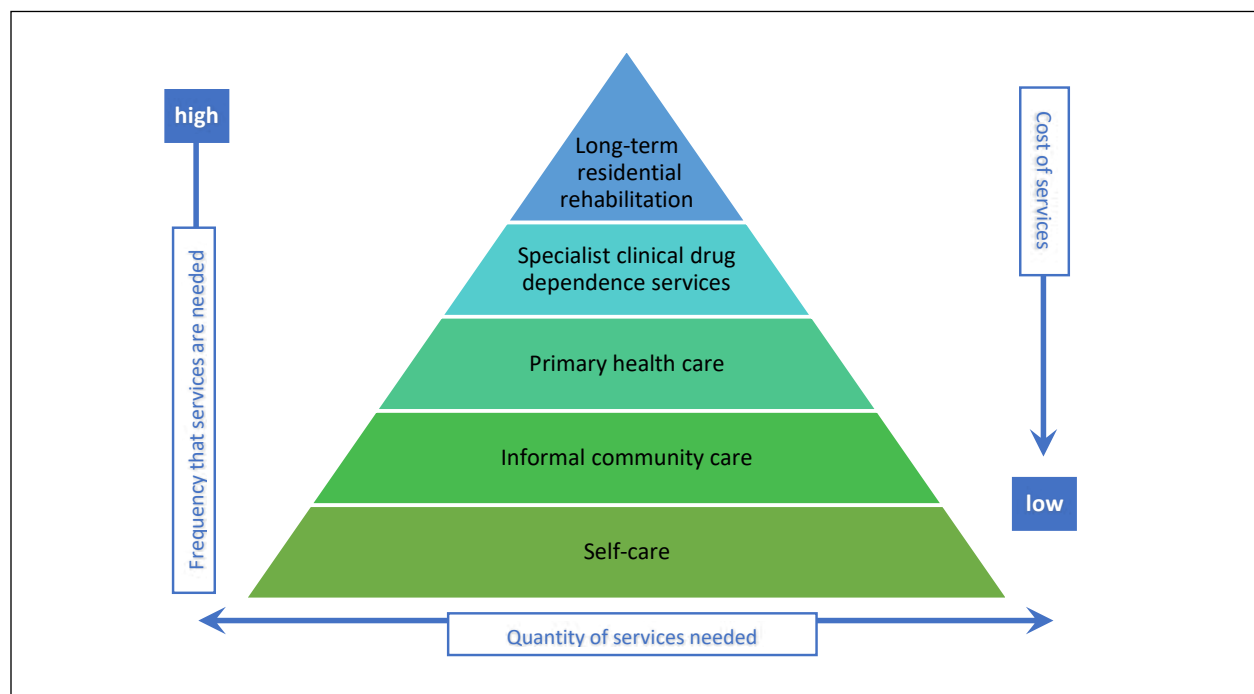
Global expenditure on drug law enforcement is well over US\$100 billion annually.¹ Despite this, the number of people who use illicit drugs continues to grow. In 2019, approximately 275 million people, or 5.5% of the world's population (15–64 years of age), had used illicit drugs in the previous year.² In the same year, approximately half a million people died from drug use, mainly from overdoses and liver disease.³ It was also estimated that just over 12%, or approximately 36.3 million, of those who had used illicit drugs in 2019 may experience drug use disorders for which they may need treatment.⁴ Treatment can dramatically reduce the costs associated with problematic drug use. For example, US estimates indicate that every US\$1 invested in treatment for drug use results in a savings of US\$12 in costs associated with health care, drug-related crime, and criminal justice.⁵ A significant obstacle to people who use drugs achieving positive health outcomes is the insufficient availability of community-based services to meet demand. According to the United Nations Office on Drugs and Crime (UNODC), only one in six people with a drug use

disorder received treatment during 2016, and this fraction has remained relatively constant.⁶

Community-based treatment and care (CBTC) services for people who use drugs are informed by the World Health Organization (WHO) and UNODC international treatment standards for drug use disorders and by UNODC principles and guidance.⁷ The CBTC model is based on evidence showing that approximately 90% of people who use drugs do not develop problematic or dependent drug use.⁸ Of those who do, most can be supported by informal services (self-care and community care) without entering a residential treatment setting. These informal services are the cheapest to fund and deliver. A much smaller number of people with severe dependence or complex needs may need a residential setting (e.g., clinical service or hospital) with specialist staff. This is the most expensive way to provide services.⁹ Integrated within existing health care systems, CBTC provides the opportunity for each client to choose the least restrictive and most appropriate type of service.

The CBTC service pyramid in Figure 1 shows that most people who have problematic drug use

FIGURE 1. Community-based treatment and care service pyramid



resolve it themselves with the support of friends and family or informal community services. Specialist longer-term residential services are needed for only a small percentage of people with severe dependence and complex needs.¹⁰

Despite advocacy for CBTC by entities such as WHO, UNODC, Human Rights Watch, and national civil society organizations, many countries still favor punitive compulsory drug detention centers rather than voluntary community-based therapeutic services. People who use drugs are incarcerated in compulsory centers long term, from several months to a few years. Compulsory drug detention centers are not evidence based, have high relapse rates, and frequently involve abuse, corporal punishment, and torture.¹¹ It should not need to be stated that vulnerable people with treatable health conditions should not be subjected to cruel, inhuman, or degrading actions. Treating a client with care, respect, and dignity is essential to achieving therapeutic outcomes. It is also cost-effective. For example, research comparing compulsory drug detention centers and community-based voluntary methadone maintenance treatment in Vietnam confirmed that community-based treatment is less expensive and more effective than compulsory

centers in achieving drug-free days among heroin-dependent individuals.¹²

Unfortunately, globally CBTC services are trying and failing to meet an enormous unmet need. The *World Drug Report 2021* estimates that of the 275 million people aged 15–64 who used drugs in the previous 12 months, about 13%, or 36.3 million, suffer from drug use disorders requiring treatment.¹³ Yet evidence-based drug treatment services in most countries are relatively new fields compared with other health and social services. As a result, they are frequently underdeveloped and under-resourced. Even in countries with well-developed and well-resourced health service infrastructure, CBTC services are under-resourced. Before accessing treatment and support, their clients often endure long waiting times, sometimes in desperate circumstances. An Australian study, for example, found that, against international benchmarks, Australia had high rates of treatment utilization and one of the lowest rates of unmet demand in the world.¹⁴ Despite this, Australian drug treatment services were meeting only 26%–48% of demand, with residential rehabilitation, residential withdrawal, pharmacotherapies, and counseling most frequently unable to meet demand.¹⁵

TABLE 1. The World Health Organization and United Nations Office on Drugs and Crime's 12 principles of community-based drug treatment and care services

1	Continuum of care from outreach, basic support, and harm reduction to social reintegration, with no “wrong door” for entry into the system
2	Delivery of services in the community—as close as possible to where people who use drugs live
3	Minimal disruption of social links and employment
4	Integration into existing health and social services
5	Involved with and built on community resources, including families
6	Participation of people who are affected by drug use and dependence, families, and the community at large in service planning and delivery
7	A comprehensive approach that takes into account different needs (e.g., health, family, education, employment, and housing)
8	Close collaboration between civil society, law enforcement, and the health sector
9	Provision of evidence-based interventions
10	Informed and voluntary participation in treatment
11	Respect for human rights and dignity, including confidentiality
12	Acceptance that relapse is part of the treatment process and will not stop an individual from re-accessing treatment services

Source: United Nations Office on Drugs and Crime, *Guidance for community-based treatment and care services for people affected by drug use and dependence in Southeast Asia* (Bangkok: UNODC, 2014).

UNODC and WHO have published a set of 12 principles to guide the design and delivery of drug treatment services (see Table 1).¹⁶ Each is a core characteristic of the CBTC model and an essential element to consider when strengthening capacity. In addition, depending on the organization's goals, context, and clientele, other principles may be considered—for example, principles requiring that service provision be culturally appropriate, equity-focused, and client-centered. Good-quality CBTC services are guided by international, national, or professional principles. They are also designed and delivered around their clients' and communities' unique contexts and needs.

Capacity gaps in existing services

One reason for the inadequate availability of evidence-based community services for people who use drugs is that there are gaps and shortages in the capacity of existing services and the capability of their workforce. Over the past two decades, the author's work on capacity-building and program evaluation of such services throughout Asia has identified a growing need for capacity-building to establish and strengthen the CBTC services sector. Many local drug treatment systems across a variety of settings lack sufficient staff with the appropriate type and level of knowledge and skills to establish and maintain community services that achieve reliable, good-quality client outcomes. Furthermore, the establishment of new services and their scale-up are often constrained by difficulties in recruiting enough qualified staff.¹⁷

In addition, capacity-building is important to ensure the health and safety of staff working in CBTC services. It can make the difference between staff feeling empowered and capable or becoming despondent and burnt out and leaving the field altogether. Jianhua Li and colleagues found that high rates of staff turnover in drug treatment services were associated with staff feeling underprepared for their role and requesting additional professional development to enhance their competence and ensure their own safety and well-being.¹⁸

Capacity-building for expansion and improvement of CBTC services

Capacity-building is frequently misunderstood and often considered to be synonymous with training. However, a focus on training underestimates the contribution capacity-building can make when carefully planned and systematically applied to transforming services and service systems. It also confines the focus of capacity-building to increasing individual competence rather than increasing the capacity of the whole organization. This paper follows a practical working description of capacity-building:

*Capacity building in drug use treatment and rehabilitation services is the process of developing and enhancing the knowledge, skills, attitudes, values, strategies, structures, and resources that individuals and organizations require to meet the complex needs of people who use drugs and their communities and to support them in achieving positive bio-psycho-social outcomes.*¹⁹

The terms capacity, capability, and competence are used interchangeably in the literature, so it is worth describing and distinguishing these concepts to promote greater clarity. An individual's *competency* is demonstrated by their ability to apply acquired knowledge and skills, and these can be measured against well-accepted standards required in employment and assessed against evidence in the workplace.²⁰ *Capability* is having or developing the ability to do something—in other words, it is the skills, knowledge, and attitudes necessary to complete a particular task to a level of competence. *Capacity* is the amount of time, resources, appropriate personnel available, and supporting structures and processes that enable staff and volunteers to apply their capabilities to achieve their organization's objectives (e.g., quality of care and optimal client outcomes).

Capacity-building helps create the structures and systems that enable practice skills and knowledge (i.e., capabilities) to be applied. It can also address some of the most immediate barriers to expanding voluntary, evidence-based CBTC services in the community. There is an interplay between

the concepts of capacity and capability-building. Building individual competencies (e.g., knowledge, attitudes, and skills) enhances a worker's capability (e.g., the practice of assessment, counseling, or case management), which they can apply if their organization has the capacity (e.g., the policies, systems, and procedures) to enable them to do so. In many cases, building capability by increasing a team's knowledge and skills can help expand capacity. This is the idea of working smarter, not harder.

Empowerment through capacity-building

The literature raises the concern that the term capacity-building suggests no preexisting capacity.²¹ However, the reality is that many countries have been providing various forms of care and treatment for people who use drugs for generations, so *capacity-strengthening* or *enhancing capacity* would be a more accurate and fair description. This discussion will assume a base level of specialist or generic capabilities supported by organizational leadership, structures, systems, and resources upon which capacity can be further built or strengthened to achieve improved client outcomes.²²

The literature also distinguishes two major capacity-building orientations—the “deficit” model versus the “empowerment” model.²³ The deficit model emphasizes an external intervention to di-

agnose weaknesses or gaps in capacity and fill those gaps. This is contrasted with the empowerment model, where the emphasis is on enabling organizations and their personnel to identify and respond to the problems and opportunities they face. The empowerment model has been particularly emphasized in community development and international development, where significant inequalities of power and resources often exist that can undermine capacity-building processes.²⁴ These two orientations are perhaps best regarded as opposite ends of a spectrum, with many approaches to capacity-building lying somewhere in the middle.²⁵ It is generally held that participatory and collaborative approaches using a combination of external and internal expertise produce more significant sustainable change in capabilities and capacity. The technical input of an external expert can help initiate change. However, to institutionalize and sustain that change and associated reforms requires purposeful efforts to expand and upgrade individual capabilities and organizational capacity.²⁶

However, a more incisive and nuanced examination of the difference in capacity-building development approaches is emerging from research on Indigenous empowerment initiatives that distinguish between technical assistance done to, for, with, or by the intended beneficiaries (see Table 2).²⁷ These are highly relevant to capacity-build-

TABLE 2. Types of engagement: Capacity-strengthening done to, for, with, and by local community-based treatment and care services and national service systems

Type of engagement	Description
To	Local CBTC services have no say or control over the capacity-strengthening process, and donor worldviews and practices prevail.
For	Clear benefits for local CBTC services from capacity-building and their aspirations are acknowledged, but there is minimal consultation with these services or their communities. Capacity-building is designed and managed without reference to local values, principles, or priorities. Decision-making power resides with the external advisor, and donor worldviews and practices prevail.
With	Stakeholders from local CBTC services make up most of the capacity-building team. Capacity-building is responsive to and respectful of community contexts and utilizes local knowledge. Power and decision making is shared and negotiated. Local and international approaches and practices are utilized.
By	Local CBTC services lead capacity-building, and local CBTC services have the overall authority and power to make decisions about the capacity-strengthening design, approaches, and practices.

Source: Adapted from N. Wehipeihana, “Increasing cultural competence in support of Indigenous-led evaluation: A necessary step toward Indigenous-led evaluation,” *Canadian Journal of Program Evaluation* 34/2 (2019)

ing efforts in local CBTC services and salient for how people who use drugs are engaged in capacity-building processes.

Local services and communities stand to gain or lose far more from a capacity-strengthening approach than an external consultancy team, which usually leaves once the plan is in place and may never see the results of its work. Indeed, the local community must live with those results for better or worse. Therefore, these actors should not be considered passive recipients of technical assistance but active participants in addressing their health and social issues. Harnessing the expertise of local experts, including those with lived experience, is critical. Doing so transforms capacity-strengthening from something done *to* the national CBTC sector and local services and done *for* people who use drugs into processes undertaken *by* CBTC *with* key stakeholders, especially people who use drugs. Assessment and planning for capacity-strengthening are unlikely to be effective or sustainable if, for example, they are applied as part of a standard template prescribed by an external or foreign advisor. Local experts are best placed to understand capacity gaps, assets, and the opportunities for strengthening capacity. They understand the factors (political, economic, social, cultural, legislative, and environmental) at play in their national context. They also have the local knowledge, experience, and networks to plan the necessary and pragmatic changes appropriate to their service system and the needs of their CBTC workforce. Finally, when local CBTC services manage the capacity-building knowledge transfer, they make adaptations and generate innovations that contribute to and expand the global knowledge base and can be adopted by either Global North or other Global South actors.

A systematic approach to capacity-building considers development on at least three levels—individual, organization, and service system or sector.

- The individual: The focus here is to equip individuals with the right cognitive tools, knowledge frameworks, and skill sets to perform effectively.
- The organization: The focus here is on the institutionalization of capacity-building and

integrating skills and training into the organization's policies, programs, and processes.

- The service sector: The focus here is on collaboration with and integration of the service system.

These can be described and analyzed as the micro, meso, and macro capacity and capability-building levels. Although the three streams are conceptualized separately here, they are integrated, work synergistically, and may overlap—for example, communities of practice may occur at a sector-wide level with organizational support to improve the skills and knowledge of individual practitioners.²⁸

A systematic approach to capacity-building enables the appropriate sequencing of mutually supportive actions, prioritizing high-need areas for development, and helps maximize outcomes in those areas. It also encourages a longer-term view of building an enduring organizational culture of continuous reflection and improvement in supporting clients in achieving their treatment outcomes. In other words, it promotes the sustainability of those strengthened capacities. WHO notes that capacity-building requires individuals and institutions to have a clear capacity-building mission or strategy and adequate supporting organizational structures and systems.²⁹ It also requires that staff have sufficient autonomy, incentives, and supervision to apply their drug treatment knowledge and skills. A systematic approach to capacity-building begins with a comprehensive assessment that informs the development of a capacity-strengthening plan. If well supported and thoughtfully managed at all levels, this promotes the development of a self-sustainable organizational culture of reflective practice and continuous improvement.

Steps in developing a capacity-building strategy

It is widely recognized that there is no single treatment or program that works for all people who use drugs under all circumstances. Perhaps best expressed by Steve Allsop and Sue Helfgott, “Most interventions are effective under some circumstances, while no single strategy is effective

under all circumstances.³⁰ It is typical rather than exceptional for people to try multiple treatment options (where available) before finding the form of treatment and the treatment provider that works best for them, at that time, and in those specific circumstances.³¹

Similarly, there is no one-size-fits-all approach to capacity-building. Each organization and its service context are unique, as are its capacity assets and needs at any point in time. Instead, each service or organization can benefit from creating its own unique and fit-for-purpose capacity-building strategy. When planning a capacity-building strategy, we must first define its purpose: What do we want the organization and the staff practice to look like when we have achieved this capacity increase? Part of the answer to this question emerges from the foundations upon which we build—the guiding principles for CBTC service provision, as outlined by WHO and UNODC and listed in Table 1.³²

The following framework is presented to assist organizations in planning for capacity- and capability-strengthening to enhance the quality and outcomes of their services, improve the proficiency of their personnel, and reduce burnout and turnover of staff and volunteers.

Step 1: Systemic community-based assessment

While there are various capacity-building approaches, any strategic approach to capacity-building planning should be preceded and informed by an assessment of organizational capacity assets and needs. For example, developing capacity in one area alone may not be effective if there are problems in other areas. The capacity-building assessment must be systemic to diagnose accurately the capacity strengths, gaps, and support needed. Barbara Blumenthal argues that assessment using a skilled consultant is more likely to uncover underlining problems than self-assessment.³² Another critical part of a comprehensive assessment is examining “the internal and external organizational context, power hierarchies, administrative culture, and decision-making processes.”³⁴

Step 2: Planning

To be effective, a capacity-building strategy must be tailored to the organization’s needs, the environment in which it works, and its life cycle.³⁵ A planned and coordinated approach to capacity-building that considers tailored and mutually supportive interventions targeting capacity gaps or needs at each level is more likely to produce better outcomes than single interventions.³⁶ Building capacity is an investment in the long-term success of an organization. A step-by-step process to institutional strengthening and building capabilities is essential due to its dynamic nature. Maintaining flexibility in designing capacity-building projects and associated frameworks enables better adaptation to that dynamism and better enables alignment with changing priorities and emerging trends or needs.

Thomas Backer suggests that while narrowly defined interventions can work, those capacity builders with the most impact offer a range of services such as assessment, technical assistance, financial assistance, and other support.³⁷ First, they need to choose a primary focus for their work.³⁸ It may be general or aimed at strengthening a specific area (e.g., a particular priority topic or client target population) and is likely to prioritize the most significant unmet demand areas. Many of them are easily identifiable and already well known to service providers and their communities. Typical examples may include services for young people, homeless people, women with children, people identifying as LGBTQIA+, and Indigenous people.³⁹ Alternatively, an organization might not want to initially choose the areas of greatest need but those areas with the most potential to improve. Getting a few early wins may help encourage support and alignment with the strategy and attract or justify resources allocated to capacity-building.⁴⁰ Another consideration is that “capacity can often be increased more effectively by reinforcing existing structures than by building new ones.”⁴¹

Capacity-building is likely to be an iterative process, such as a series of phases or stages targeting prioritized areas or levels of capacity.⁴² The flexibility of a staged or iterative approach can be

necessary because, for example, the allocation of time and scarce resources must be prioritized. The acquisition of new practice skills may require sequential scaffolded learning approaches. Work in one area often exposes limitations in another. Additionally, some capacity-building outcomes are

TABLE 3. Examples of areas for strengthening capability and capacity in community-based treatment and care services

THE INDIVIDUAL
Leadership
Mentorships, preceptorships, clinical supervision, etc.
Reflective practice individually or in teams
Appropriate qualifications and certifications
Structures and systems
Clinical supervision procedures
Networking and learning events
Professional development plans are created and updated regularly
Resources
Externally provided education, professional development courses, and learning materials
In-service or on-site education, training, courses, and learning materials
Supervisors and peers
THE ORGANIZATION
Leadership
Strategic direction and drive, communicating a vision for client-centered continuous improvement
Professional development programs and standards
Strengthening governance mechanisms
Structures and systems
Human resource practices for recruitment, development, and retention
Monitoring systems and evaluations
Practice supervision and support
Information management or knowledge management systems
Resources
Funding, budgets, and financial management systems that support capacity-building
Guidance, information materials, operating procedures, and updates
Infrastructure such as facilities, libraries, equipment, and tools
Quality framework integrating the organization's policies and procedures
THE SERVICE SECTOR
Leadership
Professional structures for standards, registration, representation, and accountability
National qualification frameworks and credentialing
Communities of practice share emerging evidence and innovative practice
Continuing professional development standards and opportunities
Structures and systems
Sector coordination and networking mechanisms promoting collaboration in the sector and with other sectors
Referral protocols and pathways
University and vocational training institute courses and educators
Nationally endorsed practice guidelines and standardized CBTC service workers' curricula
Resources
National standards and accreditation of service organizations
Research and evaluation evidence, including drug use trends, context, clients, and quality of service outcomes
Professional networks
Secondary consultations and joint case management between sectors

preconditions for others. For example, establishing a national professional credentialing system and registration may precede the requirements for continuing professional education and the delivery of professional development programs.

Step 3: Research, evaluation, and monitoring

Increasing the overall volume of CBTC services provided is essential, but equally important is increasing the quality of those services. Monitoring and evaluation can help assess and improve the effective and efficient achievement of clients' outcomes. However, capacity-building is often vaguely defined in the literature, and descriptions lack precision. Without precision, it is difficult to measure or evaluate progress in achieving capacity-strengthening objectives.⁴³ Monitoring and evaluating any capacity-strengthening efforts requires a detailed plan that explicitly defines the intended outcomes. This will, in turn, support better decision-making, improve the allocation of resources, improve the understanding of capacity strengths and challenges, and promote organizational learning.

Research and evaluation are essential for generating, testing, and continually improving the evidence base of policies, programs, procedures, and practices. These activities require the specialist skills of researchers and evaluators. However, to be well informed and to be of actual practical benefit, evaluation and research must engage CBTC practitioners, the communities in which services are based and into which clients will return, and, most importantly, those with lived experience (i.e., people who use drugs). Working collaboratively with people who use drugs, their families, and communities helps interpret evidence and synthesize lessons learned through the lens of lived experience, which promotes practical responses to immediate capacity issues. Leonora Angeles and Penny Gurstein call this "the inclusion of innate wisdom and knowledge of those affected in decision making."⁴⁴ They advise this can result in more manageable processes that are less reliant on external tools and technologies, cheaper, and more likely to be sustained.

Table 3 summarizes common areas for

strengthening capability- and capacity-building. This list is intended to be illustrative, not exhaustive. There is overlap between levels; for example, the sector might fund an organization to promote education and training in which individuals strengthen their practice skills. For ease of reference, items have been classified under leadership; structures and systems; and resources. However, many could be listed under more than one; for example, professional bodies that establish standards, registration, and accountability may be considered structures that provide leadership.

These are not prescribed steps but examples to consider, and while each capacity-building strategy is unique, any strategy should place the client at its center and work outward. For example, one planning technique could be to answer a series of questions such as the following:

1. What outcomes does the client want to achieve?
2. What do our staff and volunteers need to be able to do to help clients achieve those outcomes?
3. How can our organization support its staff and volunteers in that work?
4. How can our organization better engage with our sector and other sectors to support our staff and volunteers' work and assist our clients in achieving their outcomes?

Individual capacity-building

Any individual capability plan is more likely to be effective and lasting if based on an assessment to identify areas in which staff require additional professional development. This assessment is incorporated into a formal plan, such as professional development plans, created and updated regularly for all staff and volunteers. These plans can include internal and external education opportunities, qualification and certification planning, development milestones, career trajectories, and structured opportunities for reflective practice.

While education and training are not the only (or necessarily most critical) tactics in a ca-

capacity-building strategy, they can be indispensable, for example, in establishing foundational knowledge, attitudes, and values. In addition, education and training initiatives need to be sophisticated enough to target the desired outcome level—that is, the content, structure, and delivery determined by whether they are designed to raise awareness, increase practice knowledge, increase skills development, influence attitudes and beliefs, or change behaviors.⁴⁵

Internal learning opportunities may include various forms of formal in-service training. These can be more effective and enduring if supported with experiential learning opportunities, including supervised, structured programs such as probationary placements, internships, preceptorships, and mentoring programs. Specialist CBTC sector knowledge and skills must be learned and practiced in a combination of experiential learning and formal training.⁴⁶ Combined approaches like these allow for scaffolded learning in which each learning approach supports the understanding, application, and extension of the knowledge frameworks and skills learned earlier.⁴⁷ Those opportunities must match the person's current skills and occur in an environment that encourages taking risks and is challenging without being overwhelming.⁴⁸

Learning knowledge frameworks and skills is facilitated through reflective practice and by “reflective practitioners who are able and willing to challenge continuously their own assumptions and the assumptions of their colleagues in a constructive way which generates new insights and leads to the development of explicit wisdom.”⁴⁹ Self-reflection and reflective practice can be further facilitated in clinical supervision, mentoring relationships, team reviews, or communities of practice.⁵⁰ Building capacity not only entails learning technical concepts and processes but also, if it is to be self-sustaining, requires learning soft skills. For example, while harnessing scientific evidence to guide good practice is crucial, it is equally important to use critical thinking and practical experience to ensure that evidence is applied appropriately and adapted to the service context and individuals' needs. Stan-

dard practice guidelines can be a helpful point of reference for ensuring consistent quality outcomes. Even so, if used mechanically without interpretation and adaptation to contexts and needs, they may be ineffective or even harmful.⁵¹

Access to external education, seminars, conferences, and webinars is also valuable because it creates open information exchange systems and exposes personnel to emerging trends, innovative practices, and new knowledge from the evolving scientific evidence base. External events can also promote a sense of professional identity: formally, when they involve consultation and development of professional standards and guidance, as well as qualification and certification frameworks, or more informally, with opportunities for expanding professional networks, advocacy, and peer support.

Organizational capacity-building

Leadership is essential to strengthening organizational capacity. The support of CEOs, managers, and other key decision-makers helps in developing and sustaining organizational capacity because it provides strategic direction and drive and communicates a vision for client-centered continuous improvement.⁵² Leaders who are well informed about the context and needs of people who use drugs make better advocates for policy change, service design, and resource allocation. They also offer guidance and encouragement, support the development of staff and volunteers, and steward institutional change for a sustainable organizational culture. Therefore, CBTC service strengthening must invest in developing organizational leaders, ensuring that they are well informed about what constitutes current good practices in service delivery and achieving client outcomes.

An organization's systems and staffing structures mediate its members' ability to interact, collaborate, and communicate.⁵³ Joanne Sobeck and Elizabeth Agius suggest that building peer support networks for sharing information and mentoring can also greatly enhance the effectiveness of capacity-building interventions.⁵⁴ To strengthen their

capacity, organizations need to establish, maintain, and improve their supporting structures and systems. Effective governance structures, for example, provide direction, guidance, and accountability for immediate and long-term capacity-strengthening activities. They are independent, hold the leadership team accountable for meeting strategic and operational objectives, and have clearly defined succession plans.⁵⁵

Organizational policies are vital because they guide why, when, and how procedures and practices are carried out within the specific organizational, cultural, and political context. In this way, evidence-based policies serve as mechanisms to institutionalize good practice in CBTC services and help build genuine learning organizations.⁵⁶ Each CBTC organization's systems will vary in type and form, but key elements include the following:⁵⁷

- quality frameworks integrated across the organization's policies and procedures
- information or knowledge management systems
- human resource practices for recruiting and retaining capable committed staff and volunteers
- monitoring and evaluation systems to track progress toward client outcomes and organizational objectives

A systematic and comprehensive capacity-building strategy requires resources. Specifically, it requires dedicated funding, an endorsed budget, and sound financial management systems. Therefore, the ability to raise funds in a structured and targeted manner and maintain relationships with potential funders is important for supporting capacity-building programs and achieving sustainable impact at scale. It can be challenging to make a case for capacity-building funding in services that a government considers low priority or for politically unpopular people. However, the case can be strengthened by using robust evidence. This is another critical reason to strengthen systems to monitor, evaluate, and report service outcomes and to promote research demonstrating the benefits of good treatment practices.

Service sector

Improving care systems within and between the treatment sectors relies on sector workforce development, sector-wide data collection systems, and strengthening service connections and networks within the CBTC sector. This includes broader initiatives such as national accreditation of service organizations, national qualification frameworks and credentialing, CBTC curricula by universities and vocational training institutes, and research to generate evidence about client needs and effective interventions.

Cooperation and collaboration among CBTC services can maximize opportunities for practice learning, promote consistent and reliable high-quality service delivery, and shape that service delivery with an understanding of what constitutes good practice.⁵⁸ In addition, coordination across sectors is crucial for the CBTC sector because it interacts with many other service systems (e.g., primary health care, mental health, vocational, and justice service sectors). Effective and efficient sector coordination and networking can improve treatment and care provision, help ensure the consistent and reliable delivery of high-quality services, and facilitate seamless referrals within and between service sectors.

Developing an organizational capacity-building culture

Organizational change influences organizational culture, and organizational culture can facilitate or hinder organizational change. A comprehensive long-term capacity-building strategy should consider the intended impact of its activities on the organization's culture. Organizational culture comprises an enduring system of traditions, values, attitudes, rules, norms, and symbols upon which members agree is the basis for their actions—in other words, consensual notions of how things are done around here.⁵⁹ The culture of a learning organization “must encourage questioning of organizational processes and experimenting with new approaches” and include simple, practical steps such as the institutionalization of routine profes-

sional learning and reflective practice.⁶⁰

Evelyn Pitre and Henry Sims state, “The essence of cultural change is the replacement of one consensual pattern with another.”⁶¹ They highlight that leadership is of prime importance in strengthening or changing an organization’s culture. The leader’s vision (i.e., their ability to formulate, articulate, and share new ways of thinking or presenting innovative knowledge frameworks) drives the organization toward its objectives. Susan Labin and colleagues advise that the factors that influence the extent to which an organizational learning culture will become sustainable (adapted here to capacity-building of CBTC) are (1) the strength of CBTC services leadership support, governance, and oversight of capacity-building; (2) the resources available for strengthening capacity-building in CBTC services (staff, time, and financial); (3) the amount and type of internal capacity-building expertise applied to workplace learning and practice improvement; and (4) the degree of capacity-building mainstreaming in CBTC services—that is, how widely capacity-building is considered a routine part of organizational policies, procedures, and practices.⁶²

Strengthening and shaping the organizational culture can also contribute to sector-wide capacity more broadly. Particularly when an organization is well networked, diffusion of knowledge and practices occurs through interactions with other services, civil society organizations, and sector peak bodies.

Conclusion

Globally, the capacity of available CBTC services is not even close to meeting the enormous demand for such services. The effectiveness of all currently available drug treatment services varies as much as the plethora of treatment approaches offered. Governments, regulatory bodies, and service managers urgently need to apply the available scientific evidence on what works, for whom, and under which circumstances to all drug treatment services and in ways that treat clients with care, dignity, and respect. The CBTC model developed and promoted

by WHO and UNODC is underpinned by such principles. Capacity-building can help increase the scale of those interventions and improve their quality. At the level of the organization and the individual worker, capacity-building can help increase the quantity and quality of treatment episodes delivered and client outcomes achieved through CBTC services. A comprehensive and systematic approach should be taken to maximize the return on investment of capacity-building. Taking a longer-term strategic approach to developing organizational and individual capacity enables the growth of a sustainable organizational learning culture. This paper has described one way to plan and implement such an endeavor. Governments and donors should seriously consider investing in the capacity-building of CBTC. One component of this investment should come from diverting funding from compulsory detention centers and promoting CBTC as an alternative.

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VIRTUAL ROUNDTABLE

Compulsory Drug Treatment and Rehabilitation, Health, and Human Rights in Asia

QUINTEN LATAIRE, KAREN PETERS, AND CLAUDIA STOICESCU

Claudia, Karen, and Quinten: *Thank you all for participating in this virtual roundtable. Let's get things started with a key question: Why do so many countries, including in the Asia region, continue to rely on punitive approaches to drug use and dependence when such approaches are unsupported by evidence?*

Ajeng: This is an excellent, and complex, question. The six decades-long “drug war” propaganda is a key contributor. From generation to generation, we have been falsely told that drugs are evil. I still remember seeing huge banners in Jakarta’s streets portraying two men, one in a coffin—supposedly the person who uses drugs—and the second one—who does not use drugs—in a graduation cap. We have been taught to blindly hate drugs, and to (wrongly) believe that drugs are harmful for society. The punitive approach is seen as a “course correction” for drug use, although there is no evidence of a correlation between punitive approaches and decreases in drug use and dependence.

Karyn: The lack of informed political leadership promoting failed approaches such as the criminalization of people who use drugs is a recipe for disaster in terms of promoting effective and rights-based approaches to drug-related issues in society. Until there was an organized movement of people who use drugs—who’d been through the system (forced rehabilitation, prison, detention, etc.)—to protest their “treatment” and conditions, and the inhumanity and disproportionality of punitive drug-related policies and the law, most of these approaches went unchallenged.

Governments themselves housed drug control under criminal justice rather than public health systems and remained ignorant—willfully or otherwise—of innovative approaches such as opioid substitution therapy in the 1960s and harm reduction after the 1980s. They got away with this due largely to an uninformed public, which was generally fed terrifying images of “drug addicts” blamed for criminal behavior in communities. The media was often complicit. Even people who use drugs, who had suffered so many injustices in the grip of the system, had internalized the messages that they were “garbage,” “enemies of the state,” and not worthy of equal treatment as human beings.

Claudia: *What about the broader context of these political choices?*

Judy: I think it’s important to take a longer historical view: people have been using drugs for centuries,

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and it has been a common practice across diverse cultures, societies, settings, and contexts. Drug use has been a part of religious rituals and everyday life. Yet there has always been a tendency to categorize, shame, and stigmatize that which is different, that which is not understood by the majority. Despite the fact that drugs are used widely in society, this has been used as a political tool to target and marginalize. We have seen the same strategies being deployed against certain identities and communities—whether they are women, people of color, gay and bisexual men, sex workers, transgender people, migrants, or others. These groups are demonized, dehumanized, and pathologized, sometimes in equal measure, in the name of “protecting society” from deviant and morally polluting forces.

Gloria: Understanding the historical and cultural context is important, but there is also a very simple political context: criminal justice and law enforcement institutions have become accustomed to operating with bloated budgets and do not want to see them reduced or shifted to other agencies. For governments to undo the institutionalization of drug-free ideologies and to invest in health-, harm reduction- and human rights-based response

measures to drug use and dependence, there would need to be greater incentives for them to do so.

Francis: From the perspective Gloria raises—the political and economic incentives of punitive approaches—it’s an inconvenient fact that the majority of drug use is manageable without any intervention. It’s in the interest, then, of governments to promote the idea that any drug use is immoral and deserving of punishment in the name of achieving abstinence. We have seen numerous examples of the atrocities that transpire inside compulsory centers in the name of treatment.

Apinun: I think another aspect is that decision-makers want social problems to vanish quickly, and addressing the root causes humanely requires patience and experience. Punishment provides a “quick” solution to the perceived social problem of drug use.

Quinten: *The reliance on detention in the name of drug dependence treatment in Asia is well documented.¹ In many countries in the region, people who use or are suspected of using drugs are detained involuntarily without adequate due process and le-*

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gal safeguards, allegedly for the purpose of receiving drug “treatment” or “rehabilitation.” Despite the evidence of inefficacy and harms to individuals, there has been little progress toward discontinuing compulsory and other punitive approaches to drug treatment across the Asia region. Why does this approach seem so rooted in this region?

Gloria: There are several issues at play here. Looking back at history, in times of political upheaval, such as in China before and after the Opium Wars with Britain, government leaders have often attributed blame for economic and social problems to drug use.² People who use or are dependent on drugs are cast as social deviants who will inevitably commit crimes and cause trouble to hurt others. Given such a portrayal, governments and many members of the public then consider it an imperative to force people who use drugs to undergo measures to stop them from using drugs. Such thinking is not unique to Asia and continues to be proposed and implemented in other regions of the world. However, the degree of brutality and widespread nature in which compulsory rehabilitation has been implemented in Asia is due at least partly to the lack of transparency and accountability of governments and severe limitations to civil society advocacy.

Apinun: A culture of paternalism as well as wide socioeconomic and income gaps are two additional factors that have sustained compulsory treatment approaches in Asia.

Krisanaphong: Agreed. In most countries in Asia, the rich are normally well treated even though they might engage in harmful behaviors or even break laws. On the other hand, the poor are treated badly, including in terms of drug treatment. Therefore, people who use drugs, many of whom have a low socioeconomic status, become an easy target group for law enforcement officers, particularly when there are arrest quotas.

Sangeeth: I would like to add that historically a key policy development behind compulsory treatment approaches were the United Nations international

drug control treaties, which are fundamentally based on prohibitionist approaches to controlling drugs. In practice, prohibition has been highly unsuccessful and in fact has increased disease transmission, violence, and displacement and has denied people’s right to health. In Malaysia, there are ingrained cultural beliefs that abstinence should be the ultimate goal of treatment and rehabilitation and that this can be achieved only in high-security compulsory centers. Socially, people who use drugs are seen as not being able to contribute to the community.

Sam: I also suspect that the early approach to dealing with psychoactive drug use was based on approaches to mental illness, which historically has often involved compulsory treatment.

Karyn: Religion has also played a role. Many religions paint drug use as a sin and people who use drugs as bad people. Often, people in the general public see it as better than prison (since the “patients, not criminals” message gained traction) and better than having people who use drugs in the community. Again, this links back to the lack of political leadership and options available, as well as the lack of safe space for people who use drugs to provide alternative narratives.

Historically, it is clear that a combination of ignorance (of a harm reduction approach, and of the devastating impact of laws and policies on the lives and health of people who use drugs), apathy, and awful stereotypes perpetuated by media and others led to the constant scapegoating of people involved with drugs and produced deep-seated fear in communities that was hard to counter, especially by people who use drugs themselves, who were the only ones advocating and with few allies.

However, if you scratched beneath the surface, especially in places where drugs were so prevalent—areas near the Burma border where opium is grown, or in urban slums—so many families were affected by the drug epidemic and desperately wanting help, but shame and religious and other influences prevented them from standing up to demand or participate in more humane solutions,

none of which were being provided by the state anyway. There were exceptions, always led by people who use drugs themselves—for example, a Muslim living with HIV drug user activist in Satun Province, southern Thailand, who got the blessing of his elders to run a harm reduction-style treatment center in his community, that also provided methadone—but these types of programs were a hard sell.

At the outset of our work with the Thai AIDS Treatment Action Group, we heard many stories of people who use drugs who were arrested by the police as a result of calls made by their own parents, out of desperation to get them off drugs. This was reported to us in both Thailand and Myanmar and continues to happen. People who use drugs would also agree to be chained and fed herbal concoctions to induce vomiting for a week at a Buddhist temple so they could quit heroin, in places where there were no other options. In early 2003, many expressed “support” for Prime Minister Thaksin’s war on drugs in the hopes that a zero-tolerance approach to drugs and dealers would “work” and they could finally get off drugs, even though the campaign was ineffective in achieving this.

There were (and still are) few to no options for living as a person who used drugs without needing to assert oneself on a spectrum of detox and “rehabilitation” (i.e., boot camps run by the military consisting mainly of exercise and Buddhist prayer). There were no public conversations, and it was hard to find a sympathetic ear or support—even among fellow nongovernmental organizations, most of whom bought into the narrative that drugs are bad, people who use drugs are bad, and one should just buck up and stop using them. There was extraordinary intolerance, ignorance, and lack of compassion, as well as significant self-stigma by people who use drugs themselves, that hampered social and political progress.

But once users—who are brothers, mothers, fathers, sons, and daughters—started organizing and bringing alternative solutions, and mounting stories of horrors inflicted on them in the system, slowly there became more sympathy—for example, a progressive parliamentarian over here, an

interested nongovernmental donor over there, a human rights lawyer. Thus, a movement against the criminal justice punitive approach and for harm reduction, rights-based approaches, and a public health approach began to grow. Once space for discussions and conversations could be had, change became more imminent and victories were achieved, but never without a struggle. And non-coercive, punitive measures to address drug use remains a contentious and unresolved issue in the region as users’ movements struggle for space and legitimacy.

Karen: *A few of you touched on this earlier in the conversation, but can you speak more directly to the role of the media in relation to compulsory treatment practices in the region?*

Apinun: Unfortunately, people tend to consume media stories that serve existing beliefs; it is rare for them to seek stories that expose painful, inconvenient truths. The only exception I’ve seen is when relatives or loved ones suffer from the negative impact of compulsory measures. If there are a few sustainable positive or best practices available in their areas, either from faith-based or private organizations, these could be used for changing their attitudes. A sustainable government-supported program could be a great best-practice example for advocating through the media. However, such measures often are not a high priority for the government and may not enjoy the same popularity as tough-on-drugs policies.

Francis: The media has always been very critical toward drug use and people who use drugs and has played a major role in demonizing drug use that has led to stigma, discrimination, and hatred against us within the general population. Even the smallest incidents related to drugs and drug use have been displayed as a house of horror within the mass media. Instead of generating awareness on drug use and its negative impact on the health of people who use drugs, the media has horrified drug use to such a level that has led to the general population considering drug use as akin to terrorism.

Inez: Francis is right—the media plays a significant role in the perpetuation of beliefs about people whose lives include drugs. News reports on drug-related cases tend to lack nuance, often focusing on numbers and figures devoid of context. An example in the Philippines is the barrage of news reports on the number of “graduates” from so-called community-based programs as proof of “drug-cleared barangays.” Numbers and percentages provided by government agencies are often reported by the media without details on what “achieving” this “drug-cleared barangay” status may have entailed (e.g., forcing people into treatment, arbitrary arrests, or forced drug testing). Through the constant labeling of people as “surrenderees,” “reformists,” “drug personalities,” and even “PWUDs,” the media boxes individuals into stereotypes and reinforces caricatures about drug use in people’s minds.

The rush to be the first to report, or “scoop,” an incident also makes it a challenge time-wise to do deeper investigation into an incident. During a seminar where we had the opportunity to share about harm reduction and have a nuanced discussion on drugs, I will never forget how some of the young journalists leaned back on their seats, the dilemma showing on their faces, saying how they understand the need for taking the time to investigate further in order to provide nuance and context, but how they are also pressured to be the first to publish the news report.

Karyn: It’s important to keep in mind the legal environment that inhibits freedom of the press and puts restrictions on legal registration, freedom of movement, assembly, expression, and so forth. This makes it more difficult for people who use drugs to safely open up to the press and have their stories told and to organize around their drug use in a way that allows the public to see another side to the story. Independent media outlets also don’t have access to compulsory drug detention centers to be able to report on how these centers violate rights and are failing to provide treatment.

Claudia: *What about the role of faith-based organizations and private (non-state-run) treatment*

centers in relation to compulsory treatment practices in the region?

Inez: Yes, in the Philippine context, the role of faith-based groups is critical, as well as distressing. The Catholic Church has a very strong presence and is a perceived authority by followers. It was disheartening that the church and other faith-based groups did not speak up as soon as the extrajudicial drug-related killings in the Philippines became evident in the first days and weeks of this current administration. At the time, one regular bible-study attendee even remarked: “They [the government] are only doing cleansing. Like Sodom and Gomorrah.” A review of the pronouncements of the Catholic Bishops’ Conference of the Philippines also captures how the church perceives people whose lives include drugs. For example, in a pastoral letter dated January 28, 2019, the president of the Catholic Bishops’ Conference of the Philippines stated, “We are not against the government’s efforts to fight illegal drugs. We do respect the fact that it is the government’s duty to maintain law and order and to protect its citizens from lawless elements. We have long acknowledged that illegal drugs are a menace to society and that their easier victims are the poor.”³

With regard to treatment facilities established and run by private operators, the treatment landscape is dominated by abstinence-based 12-step and therapeutic community ideologies. Many of the people working in these facilities also serve as consultants to the government and promote this approach. During one meeting with government representatives, one of these consultants insisted there was no need to develop redress mechanisms for people confined or forced into treatment. Having consultants with this ideology in the government not only demonstrates the conflict of interest reflected in the strong objection to having redress mechanisms in place but can also perpetuate a compulsory, punitive mindset in the government’s health response. This also spills over to influence societal attitudes.

And because of the common narrative that has been perpetuated about drugs, punitive acts become a logical response. So much so that there are

government officials who seem to genuinely believe that such acts are appropriate, especially when the heads and staff of treatment programs display the same punitive, authoritative mindset in providing their services. We thus need to also look into how the health and treatment response itself may be perpetuating this public narrative so that this may be understood, addressed, and rectified.

Priya: At the Working Group on Arbitrary Detention, we found that private drug treatment centers exist on a significant scale in Asian countries, including Bangladesh, India, Indonesia, and Nepal. In these facilities, there are serious human rights violations, resulting in the beating, shackling, and sometimes death of people who use drugs. People are involuntarily brought to private facilities by law enforcement officials, family members, or staff of the centers. Staff at private facilities try to intimidate people into signing consent forms by threatening them or their families if they refuse to do so. In our research, we also found that private drug treatment facilities may have a financial conflict of interest since they benefit from payment from the state for cases referred by drug courts or regular courts, providing a financial reason for the continued detention of people in their facilities beyond what may be strictly necessary. Noting this, it is perhaps unsurprising that the working group has described private drug treatment centers as a “disturbing development,” has called on states to investigate and take appropriate action, and in fact has called for their closure as well.⁴

Ajeng: I agree completely with Priya and the findings of the working group. Let’s also note that many of these facilities implement non-evidence-based and ineffective treatment modalities.

Karen: *Recent reports on the state of the transition from compulsory treatment in Asia paint a bleak picture of cautious, slow progress toward expanding evidence- and human rights-based approaches to drug use and dependence, including harm reduction. Over the past decade, there have been several rhetorical commitments made by states in the region*

aimed at effectively moving forward on this issue, but little has changed in practice. What needs to be done to meaningfully engage states and keep them accountable when it comes to transitioning from compulsory treatment toward voluntary community-based approaches?

Priya: It is important to hold countries accountable to their international human rights obligations. To this end, the United Nations Working Group on Arbitrary Detention conducts country visits. During these visits, we have observed the negative effects of punitive approaches adopted by countries vis-à-vis drug use and dependence. For example, during the working group’s 2017 visit to Sri Lanka, we noted that “almost 50 per cent of the persons deprived of their liberty in the criminal justice system have allegedly committed non-violent crimes related to drugs, which is a very high percentage.”⁵ During the group’s 2019 visit to Bhutan, we also noted that “drug and alcohol addiction is a serious and growing concern across Bhutan” and recommended that Bhutan “avoid criminalization of consumption and detention of substance consumers.”⁶

We also completed a study on arbitrary detention relating to drug policies in 2021 and presented it to the Human Rights Council in July 2021. In this study, we found that people who use drugs are particularly at risk of arbitrary detention, and noted with concern a continuation of what was already reported in 2015: “increasing instances of arbitrary detention as a consequence of drug control laws and policies.”⁷ As a result of this study, we emphasized that the absolute prohibition of arbitrary deprivation of liberty and the safeguards to prevent such instances apply to everyone, including those who are arrested, detained, or charged with drug-related offenses and those undergoing rehabilitation for drug dependence, in accordance with international human rights obligations. There is a need for all drug policies to serve a necessary, proportionate, and legitimate aim. Imprisonment for drug-related offenses should be a last resort and in principle should be used only for serious offenses, with diversion or a decision not to prosecute used most often for lesser offenses.

The threat of imprisonment should not be used as a coercive tool to incentivize people into drug treatment. While some defendants, when given a choice, have refused drug treatment and accepted a prison sentence as an outcome, the measure of coercion involved in such a choice is too great and is an unacceptable infringement on the right to choose one's treatment freely, to refuse treatment, or to discontinue it at any time.⁸ Courts should also not order compulsory or forced drug treatment. Drug treatment should always be voluntary, based on informed consent, and left exclusively to health professionals. There should be no court supervision or monitoring of the process, which should rest exclusively with trained medical professionals.

Ajeng: To add to what Priya said, one sector that we need to engage better in this advocacy is national human rights institutions and other bodies whose task it is to monitor the government (such as ombuds offices). Compulsory treatment is a clear human rights violation. National human rights institutions must play a bigger role in calling out the state to stop compulsory treatment practices, including by carrying out research on compulsory treatment practices and requesting government accountability. They can also document and monitor the situation of compulsory treatment practices in their country as part of the Universal Periodic Review process. Ombuds offices can also encourage people to submit complaints against state-run compulsory treatment programs. These bodies can keep calling for the necessary transition to voluntary community-based treatment as part of their reports and recommendations.

I also believe that we need to continue providing evidence of the benefits of redirecting funding from compulsory detention (in fact, from the punitive approach as a whole) to voluntary community-based treatment and harm reduction. Harm Reduction International's *Divest. Redirect. Invest* study reports that "decriminalising drug use and closing compulsory drug detention centres could dramatically reduce the number of people detained in prisons and detention centres, save

governments money and help prevent public health emergencies."⁹

Judy: I agree and I'd like to expand on Ajeng's point. Successful advocacy depends on legitimacy, and that legitimacy rests with communities that are most directly impacted by an issue. This time around, we need to be directly resourcing drug user-led networks, if not nationally then regionally to push for the shift from compulsory drug detention and treatment to voluntary community-based harm reduction services that put people at the center, with no compromise. Drug user-led networks should be supported by United Nations agencies, and they should work together to set measurable targets and accountability frameworks that can be used on the ground.

Sam: We also need practical examples of alternatives that can be easily adopted and scaled up, many of which are offered by peer-led organizations. For example, in 2010, I established Rumah Singgah PEKA in Bogor, Indonesia, because I wanted to provide a new drug treatment option for people who use drugs that integrated a harm reduction approach and did not require individuals to be abstinent to improve their quality of life. The Rumah Singgah PEKA model has been adopted in four cities (Bandung, Bogor, Cirebon, and Medan) in Indonesia by other community-based organizations.

Judy: When the 2012 joint United Nations paper on compulsory drug detention centers was published, civil society celebrated and saw this as a potential turning point that would lead to their eventual closure. Sadly, 10 years on, less progress than we had hoped has been made. As we reflect on this lost opportunity, renewed efforts need to be made. Successful efforts to close compulsory drug detention centers depends on clear, realistic, and time-bound targets and stronger accountability mechanisms from United Nations agencies; but most importantly, it requires engaged community and civil society who are motivated and have the necessary financial, technical, and political resources to both hold

governments to account for global commitments and targets and create a political cost of inaction.

Krisanaphong: Policy makers have a major role to play here. The Royal Thai Police, for instance, is under the Prime Minister's Office. The prime minister has absolute authority to reform policies away from arresting people who use drugs toward voluntary and evidence-based drug treatment and health services. However, stigma and public attitudes toward people who use drugs are likely to be a key concern for policy adjustment.

Sangeeth: There must be political will and commitment in order for anything to change. As was outlined in the transitional framework recommended by the regional expert advisory group, a national task force should be formed with all relevant stakeholders, including the Ministry of Health, Ministry of Home Affairs, and the community of people who use drugs. There should be separate committees to review and amend current drug laws. The Ministry of Health needs to be committed to improving health care services and scaling up harm reduction and voluntary community-based treatment services. This means that there should be continued dialogue and involvement of the community in developing a comprehensive national drug policy.

Francis: Right, Sangeeth, ultimately the decision to stop or reduce drug use is an individual choice that must happen organically and never by force. Pitying and humiliating us for using drugs will never work. Compulsory drug treatment approaches prevent an individual from being able to access health care or other therapeutic modalities according to their needs, their choice of drugs, the results of medical assessment of their drug use, and with informed consent. We need to educate and empower individuals to reduce drug-use-related harms and to make informed decisions while respecting their human rights and dignity. Voluntary drug treatment approaches ensure better outcomes and a whole-person recovery with little chance of a relapse.

Quinten: *What are the main barriers to scaling up voluntary evidence- and rights-based approaches to drug use and dependence?*

Apinun: I agree with what was mentioned by Karyn earlier. The main barriers I see are a lack of strong leadership on this issue in the region.

Sangeeth: The main barrier is the archaic punitive laws that need to be reviewed and amended. But corruption is another major barrier.

Sam: In my experience, the main barrier is lack of commitment from donors and governments to support promising approaches.

Inez: Another is the blind obsession with a drug-free goal—drug-free Philippines, drug-free society, drug-cleared barangays—giving tacit permission for the different actors to do whatever it takes to be able to demonstrate this status. A striking conversation with a high-level government official representing a primary agency in the drug response captures this. He had been in a seminar on HIV where harm reduction was discussed. During one meeting, he said he feels for the people at risk for or who may be living with HIV, and understands how harm reduction may be helpful—but, he added, the fact remains that we are supposed to be going for drug free, and that was not what harm reduction was going for. Where health and abstinence collide, the latter still wins where programs and policies are concerned.

Gloria: The lack of expertise and willingness among government agencies is a barrier, as is the shortage of experts who may advise them on how to develop and implement effective approaches to drug use and dependence that are genuinely voluntary and evidence- and rights-based. It is the result of decades of investment in punitive approaches enforcing abstinence. Overcoming this barrier requires adequate investment, and of course time, to attain the capacity to scale up improved measures responding to drug use and dependence.

Claudia: *What has been the impact of COVID-19 on efforts to transition away from compulsory centers toward voluntary community-based approaches in Asia?*

Apinun: In Thailand, the COVID-19 pandemic appears to have reduced compulsory treatment admissions. However, it has not automatically led to an increase in voluntary community-based treatment.

Sam: The situation is different in Indonesia. COVID-19 contributed to even more punitive than voluntary based approaches (e.g., more people who used drugs arrested and sentenced to prison).

Sangeeth: COVID-19 has had a big impact on community-based programs because it has prevented many people who use drugs from accessing harm reduction services in the community and has increased law enforcement's access to health care services.

Francis: Related to this, COVID-19 lockdowns led to severe casualties among people who use drugs who were, out of desperation, trying newer combinations of substances that resulted in many overdose-related deaths. Like the absence of drugs, there was an absence of life-saving drugs, such as naloxone.

Krisanaphong: The pandemic has also been linked to a worsening of mental health and an increase in substance use.

Inez: The assumption of this question is that there were efforts to transition away from compulsory centers. At least where we are at in the Philippines, there were no such efforts or initiatives. In fact, after 2016, more funds were poured into constructing additional compulsory rehab detention facilities. Sure, there were limits and restrictions imposed, especially during the peak of COVID-19, limiting the number of people entering facilities, but that was in no way because of an intent to transition. Because once restrictions were lifted, people continued to be brought to the facilities. Many in jails

who had availed of plea bargains and were court mandated to attend "treatment and rehabilitation programs" still ended up attending these programs within the confines of overcrowded jails or rehab detention facilities.

Ajeng: Let me, for once, focus on the positives rather than the negatives. A key finding from Harm Reduction International's study on the impact of COVID-19 on harm reduction services in seven Asian countries is that harm reduction services adapted quickly and made innovations to improve their processes to respond to COVID-19 conditions.¹⁰ Moreover, people who use drugs have played an important role in providing critical harm reduction interventions during the pandemic. This shows that voluntary treatment, especially that delivered by peers, can adapt to diverse situations.

Gloria: The COVID-19 pandemic shifted health resources away from other health issues, so I think any transition efforts would have slowed down in the past two years. There is advocacy in countries such as Malaysia that appear to call for non-punitive responses to drug use, but the alternative to imprisonment proposed is placing people into drug rehabilitation centers—quite possibly compulsory rehabilitation centers.¹¹ This brings up another concern around proposals made by various well-meaning advocates for reforming punitive responses to drug use: the alternatives proposed are also punitive (e.g., compulsory drug rehabilitation programs).

Claudia: *Are there promising responses in the Asia region that we can look to for renewed hope?*

Karyn: Yes. Though underfunded and generally small scale, there are many projects across the region trying to promote access to justice and generally establish community-based harm reduction services, including outreach and education, needle and syringe programs, naloxone distribution, HIV and hepatitis C testing and treatment support, and other services (such as takeaway methadone and methadone in prison, and work with youth, eth-

nic minorities, trans people, and women-specific groups addressing sexual and reproductive health and rights). But sadly, they are often one-off or not nationally scaled, as well as underdocumented, so support for these models is currently inadequate to meet the need.

Sangeeth: As Karyn mentioned, some of the promising responses are harm reduction interventions, including needle and syringe programs and opioid agonist therapy, which have been adopted successfully in many countries in the region and have contributed to successfully reducing HIV transmission among people who use drugs. The pandemic highlighted the issue of overcrowding in prisons, where almost 60% of inmates are people who use drugs with minor drug-related offenses. There has been a positive initiative to reduce overcrowding by studying alternatives to drug-related offenses. We have seen some progress in establishing dialogue regarding the death penalty and legalizing medical marijuana in Malaysia.

Apinun: In Thailand, there are a few non-punitive community-based responses to drugs. The new drug law puts more emphasis on engaging people who use drugs in voluntary community-based treatment and long-term health and social care. But we need to have a proper framework for scaling up these best practices. These small-scale practices should be implemented across the region in order to be ready to expand once a more enabling political environment is possible.

Sam: Rumah Singgah PEKA, the harm reduction-focused treatment center I founded in Bogor, which is free for everyone, is an example of such an initiative. Every client makes their own decision to participate voluntarily. But what makes us different from government treatment centers is that clients are not required to pursue abstinence in order to join our program and improve their lives. We see our relationship with clients as a partnership. We offer a broad range of harm reduction interventions, including outreach, needle and syringe programs,

links to methadone services, addiction counseling, and case management. We take a client-centered approach to drug treatment, so each person's treatment plan and goals look quite different. What they have in common is a desire to improve the quality of their lives.¹² Unlike most drug treatment programs in Indonesia, clients are free to leave anytime they want, but the overwhelming majority stay and complete their goals. It's the first rehab program that takes this approach in Indonesia.

Inez: In the Philippines, there are pockets of hope and existing programs that were in place long before 2016 but which were not perceived as "community-based programs" for drug-related concerns. One example of a remarkable community-based, community-led program is IDUCare, which is led by peers who understand the challenges of seeking and accessing the appropriate treatment and support. This includes the provision of physical and psychological spaces that are accessible and safe; outreach services (unlike most "community-based programs," which wait for individuals to come in); and an array of health and support services (including for HIV, hepatitis C, and other health related concerns). IDUCare also employs a "two expert" model whereby the individuals accessing the services play an active role in the design of the services they receive.

There are also existing services provided by nongovernmental organizations whose work is in communities where drugs are present but whose primary mission is not about being a "community-based treatment program." For instance, this might mean a religious-run program working with women (including those engaged in sex work) that provides a place for rest, shower, food, other basic needs, and social support services and which does not let a woman's continued use of drugs constitute an obstacle to receiving services and support. It might also mean a child rights organization that works with families, helping them, for example, with housing concerns, legal assistance, and rights protection, again recognizing that abstinence from drugs is not a precondition to receiving support nor

the be-all and end-all of any response.

A major need is to navigate and address the still deeply embedded belief that a person has to be abstinent or “drug free.” Another need is to address the fact that drug use and related acts continue to be criminalized and that our current drug law in the Philippines penalizes those perceived to be knowledgeable of continued drug-related acts and not reporting them.

Judy: Reflecting on what Inez shared and in my observations, I am concerned about the lack of a shared understanding—and by extension, standards on voluntary community-based harm reduction services. Very often, these services are also experienced as punitive by people who use drugs, in the name of control and “care.” Too many harm reduction programs put strict time limits on how long people can stay on methadone or buprenorphine, require supervised urine testing, and ban take-home doses. In no other health service or program is there so much social control, denial of agency, ability to voluntarily enroll and dismiss, and marginalization of people’s voices, choices, and perspectives on what they need to enhance their quality of life. The principles of agency, rights, and dignity need to be centered in all discussions on the health and rights of people who use drugs—not just in the Asia-Pacific but worldwide.

Gloria: At the end of 2021, legislative reforms in Thailand indicated a further move away from compulsory rehabilitation; however, it remains to be seen whether drug treatment and rehabilitation programs will become genuinely voluntary and human rights-based. The reforms to legalize cannabis use for medical purposes in Thailand can also foster greater acceptance of the idea that drug use is not inherently “bad” or “evil” and that a policy response grounded in the principles of harm reduction and human rights is far better than punishment. Last but not least, communities of people who use drugs, who have borne the brunt of punitive drug policies, continue to work for the betterment of the lives of their peers and surround-

ing communities, such as by supporting their basic livelihoods, health, and social needs.

Karen and Quinten: *The International Guidelines on Human Rights and Drug Policy outline potentially eight human rights violations linked to compulsory treatment.*¹³ *How do you see the situation of compulsory facilities for people who use drugs in Asia a decade from now?*

Ajeng: I am not convinced that we will have zero compulsory treatment in Asia a decade from now. But I am hopeful we will be able to make progress for the following reasons: The community of people who use drugs is more and more aware of their rights and has taken part in claiming their rights. Civil society and community-based organizations continue to provide evidence to show the effectiveness of voluntary community-based treatment and call for rights-based drug policies—including an end to compulsory treatment. Various United Nations bodies and Special Procedures have also been condemning compulsory treatment and recommending that countries provide voluntary community-based treatment, as shared by Priya regarding the study of the Working Group on Arbitrary Detention.

But this is not enough. Governments continue to fiercely advocate and defend punitive approaches to drug policy, and with funding for harm reduction services at only 5% of what is needed, civil society, media, United Nations bodies, and donors all need to work hand in hand to make a case for a shift away from punitive approaches and toward voluntary community-based treatment.¹⁴

Sangeeth: In a decade, compulsory facilities for people who use drugs will continue to exist; however, I do not see an increase in the number of compulsory detention centers. We will continue to see an increase in community-based centers and an increase in the awareness and acceptance that drug dependence is a bio-psycho-social problem and is a chronic relapsing disease that needs medical attention and can be treated in the community.

Apinun: In the past, politicians enjoyed popularity by appealing to tough approaches to drugs. After several years of such policies, the public is slowly and painfully learning of the negative impacts of such policies. There has been increasing resistance to zero-tolerance policies on drugs. With strong leadership and proper technical support and coordination, in the next decade I see many best practices sustained and scaled up. I believe that when there are better choices available for their communities, people will be less supportive of compulsory and punitive approaches.

Karyn: It's largely fallen off the radar as a high-level political issue. Not only do we need new allies, but the current expert advocates already working on the issue need urgent and adequate support.

Gloria: More people are seeing the devastating harms of compulsory rehabilitation facilities and are understanding better the need to pursue harm reduction responses to drug use, including drug policy reforms to end the criminalization of and punishment against people who use drugs.¹⁵ There have been decades of advocacy from nongovernment organizations, civil society, and affected communities for voluntary and harm reduction-focused responses to drug use and dependence. As this advocacy continues, I think support will grow incrementally for humane and progressive measures.

Judy: To see change, we need United Nations agencies to act, and donors to get behind funding civil society and community action.

Additionally, we need to be funding sociological research on the topic of compulsory drug detention and compulsory treatment in order to better understand and identify levers of change, from culturally informed perspectives. The need for this is greater than ever before, as countries that support compulsory drug detention, such as China, seek to export this model to other regions.

Without focused attention and resources that aim to equip civil society and communities with the necessary tools and political, technical, and social

capital, we don't know whether we will be back here 10 years from now making the same arguments, on an endless feedback loop.

Inez: There's a lot of work that still needs to be done to disrupt dominant discourse around drugs. In the Philippines, there has been an increase in statements referring to drugs as a "health issue" (as opposed to a criminal issue) and an increase in "community-based programs," which, on the surface, sounds like positive change. Unfortunately, this supposed shift still comes with the same punitive mindset and pejorative perception of people who use drugs.

Because of the very strong drug-free mindset of those currently involved in the design and implementation of "community-based drug treatment programs" and policies, one potential pathway that seems worth exploring is engaging with groups and organizations who already work in the community (e.g., women's groups, child rights groups, etc.) but that were not set up specifically for the purpose of providing "drug treatment." It is then a matter of integrating the principles of harm reduction and ethical provision of or referral to treatment and support services. In that work, we need to create more empowering and liberating spaces for people whose lives include drugs.

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