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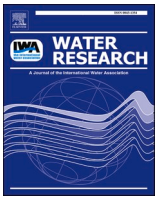

Making Waves: A justice-centred framework for wastewater-based public health surveillance

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ABSTRACT

Since 2020 wastewater-based surveillance has quickly been established as an effective and cost-efficient tool for monitoring public health. In this *Making Waves* article, we argue that these programs must be grounded in principles of justice to achieve global water and health equity. Ethics initiatives to date have focused primarily on privacy, legality, and institutionalised research reviews, often, if not exclusively, in North America and Western Europe. We draw from our interdisciplinary, multisectoral, and international expertise and experience to develop a justice-centred framework for wastewater-based surveillance. First, we identify common concerns across diverse surveillance programs including: defining community, transparency and accountability, and uneven geographies. Second, we draw on political theorist Nancy Fraser's framework of justice to evaluate site-specific practices identifying maldistribution, misrecognition, and exclusion. We suggest that Fraser's framework offers a common approach for evaluating just outcomes rather than specific regulations for governing wastewater surveillance across different and unequal contexts.

1. Introduction

In the past four years health authorities in partnership with utilities across the world quickly rolled out wastewater-based public health surveillance programs. In doing so, health officials have partnered with scientists, private firms, and foundations to demonstrate the efficacy of monitoring sewage as a reservoir of public health data for managing the COVID-19 pandemic. While wastewater surveillance has been used for disease outbreaks since the 1930s (Diamond et al., 2022) and for monitoring health trends since the early 2000s (Singer et al., 2023), the

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speed and scale of wastewater surveillance during the COVID-19 pandemic has been unprecedented. Wastewater surveillance has now become one of the lasting sources of data about SARS-CoV-2 prevalence and the field is expanding its applications. But what are the ramifications of developing a robust field in a short period of time, with the stakes of managing global health so high? We argue that interdisciplinary and international collaboration is needed to anchor wastewater-based surveillance in principles of justice to ensure its place as a lasting tool in global public health and sanitation.

Reflecting on the field's expansion, researchers have pointed to ongoing uncertainties in wastewater surveillance, including how wastewater data is used to inform public health action, the paucity of social scientific and policy research into the governance and impacts of this technology, the lack of access to data and methods for affected communities, and concerns with the ethics of surveillance. (Keshaviah et al., 2023; Shaw et al., 2023) The World Health Organization published ethics guidelines for public health surveillance in 2017, (World Health Organization 2017) but did not explicitly mention wastewater or environmental surveillance. More recently, the WHO has released interim guidelines for wastewater surveillance of SARS-CoV-2 that briefly reference ethical issues. (World Health Organization 2022; National Academies of Sciences, Engineering, and Medicine 2023) In addition to this guidance, there are existing codes of duty-bound professions (such as engineering and planning) that engage with wastewater surveillance and a burgeoning set of academic, government, philanthropic, and industry groups working towards more explicit ethical and legal standards for the field. (Canadian Coalition on Wastewater-related COVID-19 Research 2020; Biobot Analytics 2023; Gable et al., 2020; Mansfeldt et al., 2023; Jacobs et al., 2021; Ram et al., 2022; Nainani et al., 2024; Bowes et al., 2023) However, initiatives to date have focused primarily on privacy, legality, and institutionalised research ethics reviews, often, if not exclusively, in North America and Western Europe.

While such work is important, we argue it overlooks how wastewater-based surveillance is embedded in global and geographically specific inequalities that could marginalise and discriminate against certain populations. Surveillance is a key component of monitoring global health across the global North and South, but robust clinical testing for infectious disease remains out of reach for many resource-starved public healthcare systems. (Castillo-Salgado, 2010; Worsley-Tonks et al., 2022) In this context, wastewater surveillance has been an important intervention to monitor large catchment areas at a relatively low cost and to measure positivity of presymptomatic or asymptomatic cases. (Thompson et al., 2020) Surveillance studies and health justice scholars argue, however, that surveillance initiatives can also increase vulnerability of particular populations in many ways including, but not limited to: socially sorting populations into categories so that "groups can be treated differently" (Lyon, 2022) through stigmatising, discriminating against, and/or overpolicing; (Anderson, 2022; Benjamin, 2019) unevenly distributing public health goods as a result of undercounting and undersurveilling; (Dencik et al., 2022; Milan and Treré, 2020) presenting data to key actors in an incomprehensible manner; (Ananny and Crawford, 2018; Kitchin et al., 2015) using data for profit rather than investing in public systems; (Dalton et al., 2016; Zuboff, 2019) undermining principles of data sovereignty whereby monitored populations do not have control over the processes through which their data is collected and used; (Thatcher et al., 2016) and presenting poor health outcomes as a function of essential demographics or geographic location rather than targeting the social processes (like racism or poverty) contributing to health and disease. (Lyon, 2022; Marmot, 2015; Taylor, 2017)

The above inequalities are not solely caused by individual initiatives, but are the cumulative results of what public health scholars like Farmer call structural drivers of health inequality. (Farmer, 2004) Structural drivers are historically rooted systems, institutions, and practices that create lasting disparities. Thompson et al.'s *Making Waves* piece published early in the COVID-19 pandemic articulates the necessity of considering structural inequality in wastewater surveillance, especially when certain populations may be over-surveilled and overpoliced, and others may not be captured by centralized sewerage monitoring. (Thompson et al., 2020) Although these structural drivers shape health and surveillance initiatives, they often lie outside of the methodological scope of researchers and public officials. (De Wolfe et al., 2021) As such, these drivers are not often directly addressed in legal regulations or ethical research guidance, including those that govern wastewater surveillance. We argue, however, that with coordinated effort, wastewater surveillance initiatives could contribute to changing the structural drivers of health through an agenda that places justice at its foundation. As Borras argues, discussions of justice are not absent from public health or water governance, but its many definitions "are often assumed rather than explicitly explained". (Borras, 2021) Defining this agenda is an interdisciplinary and geographically expansive undertaking, requiring the participation of academic researchers, wastewater professionals, and public health officials who have the expertise in the technical and policy tools, as well as social scientists, communities, and grassroots movements who are familiar with the social and political dimensions of surveillance, control, access, and community benefits. (Arefin and Prouse, 2023)

To articulate a justice-oriented approach to wastewater surveillance, the authors of this paper gathered in June of 2023 as part of an international and interdisciplinary workshop. Attendees, who are authors on this manuscript, spanned from North and South America and South and East Asia. They included practitioners from municipal bodies, state programs, foundations, and community groups; researchers with expertise in engineering, public health, and social sciences; and those with direct experience conducting research with marginalised communities surveilled using wastewater-based technologies. Nine of the authors are from and/or work at institutions outside North America and Europe. The many differences that arose in our conversations demonstrated the need not for a single definition of justice, but instead, a framework for evaluating place and program specific practices. We also saw a need for a situated framework that could identify points of translation between highly context specific issues and between disciplines. In other words, we identified the need for a *common framework of justice rather than specific regulations* for governing wastewater surveillance across different and unequal contexts. This situated approach draws on scholars of water policy and justice, who, in this journal, argue that, "water governance can be furthered through democratic, overarching principles, but is, at the same time, often highly context specific, requiring approaches embracing participation. "(Duckett et al., 2024) In what follows we articulate some common concerns across programs that arose during our workshop conversations. We then turn to Fraser's justice framework to show how these concerns can be ameliorated through accounting for maldistribution, misrecognition, and exclusion. (Borras, 2021; Fraser, 1995; Fraser, 2005)

2. Concerns of inequity within wastewater-based surveillance programs

Our interdisciplinary group of workshop participants identified equity, justice, and structural concerns in their various engagements with wastewater surveillance programs. It is important to note that the wastewater surveillance programs represented by our authorship team and more broadly differ tremendously in their aims, scope, and funding. We do not suggest that these concerns or our proposed framework equally applies across all programs; rather, as outlined in the next section, we are proposing an evaluative framework as opposed to generalised guidelines or regulations. Across design, implementation, operation, and evaluation of surveillance projects, participants spoke to three common concerns: defining community, transparency and accountability, and uneven geographies.

2.1. Defining community

Wastewater surveillance practitioners identified the term 'community' as generally ill-defined and ambiguous. Our discussion of 'community' demonstrated a need to better delineate who can and should be represented, recognized, and receive the benefits of wastewater surveillance. Communities may be defined by geographic or legislative boundaries when serviced by public health entities. In wastewater surveillance, specifically, communities are most often delineated by sewersheds. However, this delineation may inaccurately capture groups like commuting workers, tourists, students, or other transient populations. This transience creates a challenge for health equity when marginalized groups are surveilled but not understood as part of the community. For example, one workshop participant explained how, in their context, communities defined by sewershed is an inadequate proxy because their municipality is a space many unhoused people move in and out of; these temporary residents are surveilled, but not reached through the municipalities' traditional community engagement strategies associated with wastewater surveillance like public townhalls. Outside urban settings, those whose shelter is unsewered or who use pit latrines are part of the broader community but either are not monitored or are monitored on a near-source scale that could compromise privacy. There also remain important questions about how the communities of people who contribute data may differ from those impacted by the outcomes of surveillance; and how the concerns of wastewater professionals and workers (i.e. possible hazardous exposure and increased work due to surveillance sampling) are considered alongside those of formal and informal users of wastewater systems. These issues highlight the need for a framework approach that can inform conversations about community in upstream data collection and analysis and downstream public health decision-making and policy implementation without prescribing a one-size-fits-all approach.

2.2. Transparency and accountability

Transparency is often cited as a key indicator of equity in surveillance. Yet our discussions revealed the limitations of current efforts in wastewater surveillance: is there transparency in the collection process as well as in sharing the findings through publicly accessible dashboards? For whom is the data transparent and who can understand this data in a way that informs their actions? In Bangalore's surveillance programs, for instance, only those who have access to education (a function of social power and income) are able to interpret the wastewater signal data presented on live dashboards. (Ishtaiq, 2023) Further, with biotechnology companies (which have different interests and incentives from public health bodies) increasingly mediating the flows of surveillance data, and even getting involved in deciding what communities to surveil (such as prisons, dormitories, or refugee camps), issues of transparency and accountability are becoming increasingly murky. This murkiness can be compounded by unresolved questions over materials transfer agreements and who owns the samples and data; these stipulations are often set by funding agencies, and different arrangements of paid participants, volunteers, and uninformed data providers, all of which complicate transparency and accountability processes and expectations. (Robinson and Ward Mather, 2022)

2.3. Uneven geographies

Geographic location and inequities in national and international economic development create obstacles to achieving equitable surveillance initiatives. For instance, Naughton et al. show how wastewater surveillance is unevenly distributed between rural and urban areas (Medina et al., 2022 Jun 1) and between high and low-middle income countries. (Naughton et al., 2023; Naughton et al., 2022) In our convening, scholars working in Brazil and Bangladesh raised concerns over surveillance itself as a potential injustice, framing it as a possible violation of a community's control over its data in the context of legacies of colonial experimentation, (Towghi and Bodies, 2014) racial capitalism, (Wispelwey et al., 2023) and mistrust. These concerns were raised both at the local and state level with reference to violent policing practices in Latin America that could use and deploy data in harmful ways and at the national and international level with the uneven benefits of donor-reliant health and water systems in South Asia. Structural issues are exposed with the differential funding of wastewater surveillance and sanitation: investments in expanding a novel mode of surveillance may replace investments in basic sanitation services, the latter a problem still widespread in the global South and rural global North; (Benezra, 2023; Deitz and Meehan, 2019) and countries in the global South often must rely on international funders for investment and capacity building in their wastewater surveillance programs, rendering these projects financially uncertain. Furthermore, while a local community might be represented in decision-making at a smaller scale, there remain questions as to how communities made vulnerable to infectious disease are involved or consulted in global health governance, including any wastewater surveillance regulations decided at the scale of global health institutions. Such problems are compounded by a global health agenda often driven by interests in the global North and companies touting profit-driven solutions that can run counter to investment in public health and infrastructure. (Paremoer, 2020; Ramani et al., 2023; Sparke, 2020)

3. A justice-centred framework for wastewater surveillance

The above concerns, articulated by our authorship team and based on extensive experience with specific programs across the world, point to issues of structural inequity and injustice shaping wastewater surveillance programs. Each area of concern highlights, to different degrees, issues of access to infrastructure and resources; various forms of stigma, discrimination, or assumptions about who specific groups of people are and what they can understand; and differences in the ability to assert power and control over the means and results of surveillance. To analyse these concerns, we build on a justice framework developed by political theorist Nancy Fraser that delineates three different dimensions of justice-oriented work. Fraser's framework is distinct in that it emphasises a multi-pronged approach that must address three axes simultaneously. (Fraser, 1995; Fraser, 2005)

1. Economic: distribution (where public goods are fairly and equitably distributed);
2. Cultural: recognition (where all social groups are valued); and
3. Political: representation (where all of those who are entitled to just distribution and reciprocal recognition are included in both making claims and constructing the processes through which claims are adjudicated).

Fraser's approach to justice is an important intervention into the field of water governance and public health surveillance because it speaks to the interrelatedness of economic distribution, cultural recognition, and political representation. While distribution has indeed been a focus of discussions around wastewater surveillance policy thus far, especially with respect to sewerage connectivity, Fraser's framework speaks to how a surveillance program cannot effectively and justly distribute public health resources if it does not also account for who has a say in this distribution and how different kinds of groups may be valued differently when recognizing who should or does have access.

Fraser's integrated framework offers an approach through which programs and practices can be evaluated for their efficacy in identifying maldistribution, misrecognition, and exclusion and strengthen capacity to change these dynamics. This framework can be used to evaluate all stages of wastewater-based surveillance - both upstream and downstream - including defining needs and research design, data analysis, and the mobilisation of findings into action. We proceed by applying Fraser's

framework to the three common concerns highlighted above that were identified in the workshop to show how attention to justice can ameliorate issues of equity in wastewater surveillance (Fig. 1). In Fig. 2, we illustrate how this framework can generate broad guiding questions, within and beyond the concerns articulated by the authorship team, that one could ask of already-existing programs to move them towards reducing maldistribution, misrecognition, and exclusion.

3.1. A justice-centred approach to defining community

A justice-centred approach requires an explicit but open definition of community to begin working towards the goals of recognition and representation which underpin distribution (Fig. 1). In defining a community, a justice-centred approach recognizes the inherent inclusions and exclusions embedded within the process of delineating a given community. Attention must be paid to how the benefits and harms of surveillance may be maldistributed because of inequalities in community representation: some communities might be undercounted for uneven economic distribution reasons (e.g., inequalities in sewage infrastructure). Moreover, some communities may be overcounted and overpoliced because of the different values attached to particular groups and neighbourhoods (e.g., oversampling poorer areas for opioids) - a problem of injustice in recognition. Further, a justice-centred approach recognizes that there may be discrepancies between the community surveilled by a wastewater company contracted to collect the data and the community defined by the health authorities interpreting and acting on the data. A justice-centred approach therefore requires deep and ongoing engagement about who is defining the community, who is in that community and who is left out, and whether the community in question wants additional surveillance or would rather see resources allocated through other means. Furthermore, clear and explicit definitions of community should be re-articulated at every stage of the surveillance process, from data collection to interpretation to policy development and implementation, to share the material and immaterial benefits of those surveilled.

3.2. A justice-centred approach to transparency and accountability

A justice-centred approach would acknowledge that making part of a data set visible through a dashboard is "not the same as holding the [the system and its actors] accountable." [21] Producing data in this way can lead to what Shapiro et al. call "the data treadmill," whereby data and funding enter into cycles "eternally requiring further verification and precluding more expansive lines of inquiry." (Shapiro et al., 2017) Furthermore, people cannot fully participate and be represented in decision-making around public health actions if they do not have the requisite knowledge and tools to understand the data that is being presented in platforms and databases. When and where these surveillance programs are being driven by or in partnership with private companies that are testing their technologies on precarious populations such as in prisons or refugee camps (which represents in Fraser's framework an injustice in recognition), efforts must be made to make private sector interests (such as, but not limited to, profit or regulatory avoidance) visible, with requisite attempts to ensure an equitable distribution of public health goods that arise from any private research. In other words, benefits from wastewater surveillance should be governed by and distributed to surveilled communities and public entities rather than private firms. Ultimately, a justice-centred approach to transparency and accountability: (1) establishes a clear articulation of why something should be monitored and made visible; (2) reflects on the systems of power that mediate the multi-stage processes of 'making visible'; and (3) is aware of the phenomena that these systems are not able to see or represent in dashboard data, guiding policymakers to make decisions based on these reflections. While health authorities are currently the primary users of data, justice-based approaches call for greater public participation in the design of systems and collection of data. Such participation often translates to a more diverse user-base for the data ensured by baking participation and mechanisms of accountability into all steps of a program. Successful models for participation exist in water-shed management (Gilmour and Stacey, 2024) and environmental impact assessment. (Korfmacher, 2001) Justice involves full political participation of affected communities in defining the specific problem that is being addressed, a set timeline for surveillance, and a mechanism for the community to respond to determine if it is desirable for the program to continue and/or expand.

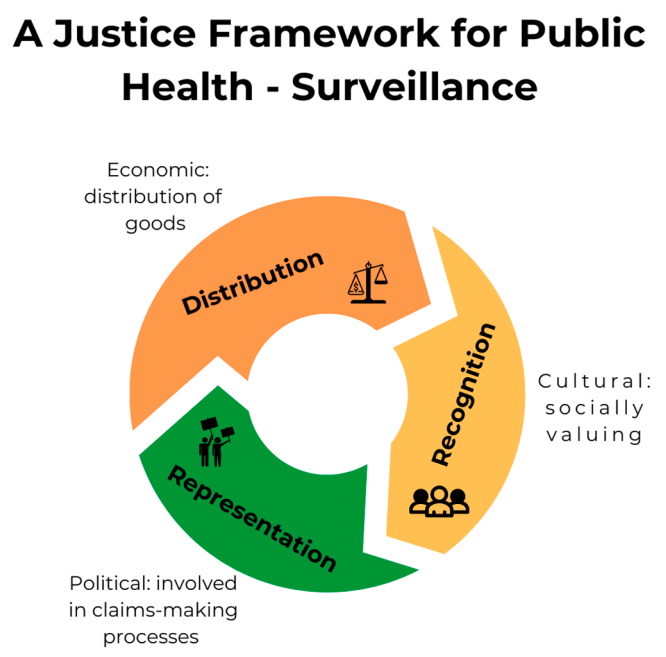

Fig. 1. Author-created illustration of Nancy Fraser's three-pronged justice framework.

3.3. A justice-centred approach to uneven geographies

A justice-centred approach to tackling issues of wider geographical and structural inequalities that shape wastewater surveillance would make legible the institutions, infrastructures, and investments produced by historical and ongoing colonialism and uneven economic development. Instead of isolating a spot on a map that has a higher rate of viral load shedding and prioritizing temporary solutions there, a justice orientation might use the data as a starting point to begin interrogating why a particular neighbourhood is more susceptible to disease as a function of uneven resource distribution, social devaluation, and lack of political representation at multiple scales of governance. A just wastewater surveillance program would address why some populations might resist wastewater surveillance in their communities, and work closely with them to share decision-making around what data is collected, how it is used, who owns it, and when to stop collection - ultimately, to build trust. Justice in wastewater surveillance would also look to longer term capacity building and investments in health and sanitation. Crucially, those most affected by disease and marginalised by the maldistribution of global wealth should have a say at all levels of decision-making around the rollout of specific wastewater surveillance projects and the more general regulations that guide health surveillance at a broader scale.

4. Conclusions

- Domestic and international water and health institutions often operate through emergency response management and prevention using global best practice models and therefore are not fully

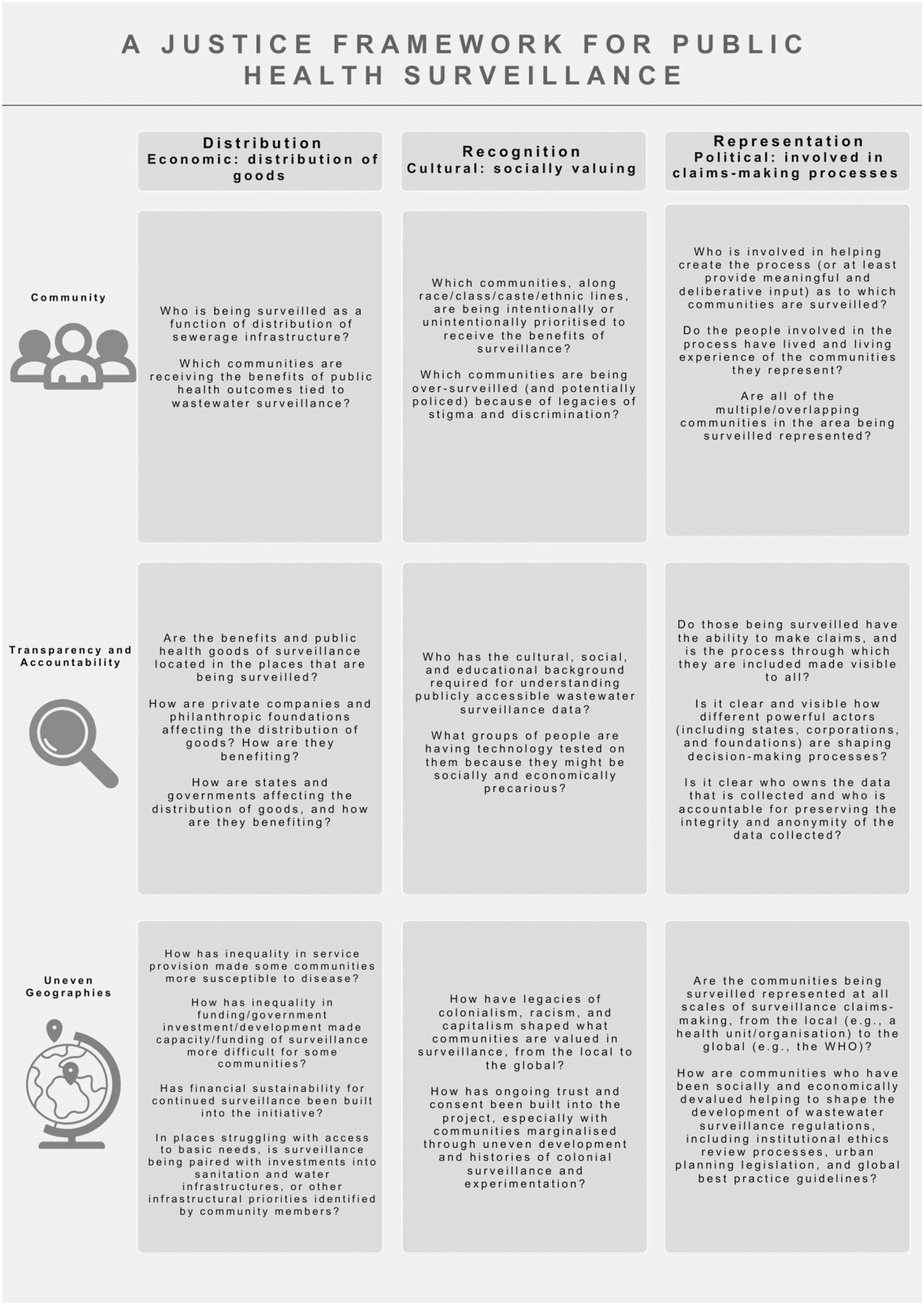

Fig. 2. Guiding questions of already-existing programs to move them towards reducing maldistribution, misrecognition, and exclusion.

equipped to identify and intervene in the structural forces that produce health and water injustices.

- Wastewater surveillance programs should take seriously the three prongs of Fraser's approach to justice by foregrounding structural concerns of maldistribution (economic); misrecognition (cultural); and exclusion (political).
- Building a justice-centred approach will help articulate and ameliorate concerns associated with defining community, transparency and accountability, and uneven geographies in conducting wastewater surveillance. We recommend using the momentum and models of the National Academies' wastewater surveillance research group and professional communities of practice such as the Water Environment Federation's networks to build a geographically diverse community of praxis (theory and practice) that is interdisciplinary, multisectoral, and responsive to structural inequities with the capacity to find points of common translation across differentiated local and national contexts.
- Implementing this framework can ensure that wastewater surveillance diminishes inequalities rather than reinforces them, serving as a model of public health surveillance and sanitation governance more broadly.
- Funding structures may present a barrier to implementation. This framework can offer a tool for researchers and practitioners (as well as grant makers) to advocate for resources to be more equitably distributed and for greater resource allocation to community engagement and responsiveness initiatives in both wastewater surveillance and public health more broadly.

CRediT authorship contribution statement

Mohammed Rafi Arefin: Writing – review & editing, Writing – original draft, Supervision, Project administration, Methodology, Funding acquisition, Data curation, Conceptualization. **Carolyn Prouse:** Writing – review & editing, Writing – original draft, Supervision, Project administration, Methodology, Funding acquisition, Data curation, Conceptualization. **Josie Wittmer:** Writing – review & editing, Writing – original draft, Supervision, Project administration, Methodology, Funding acquisition, Conceptualization. **Nuhu Amin:** Writing – review & editing, Investigation, Formal analysis, Conceptualization. **Monique Assunção:** Writing – review & editing, Project administration, Formal analysis, Data curation. **Amber Benezra:** Writing – review & editing, Investigation, Formal analysis. **Angela Chaudhuri:** Writing – review & editing, Investigation, Formal analysis. **Megan Diamond:** Writing – review & editing, Investigation, Formal analysis. **Shirish Harshe:** Writing – review & editing, Investigation, Formal analysis. **Kimberly Hill-Tout:** Writing – review & editing, Investigation, Formal analysis. **Vanessa Koetz:** Writing – review & editing, Project administration, Formal analysis, Data curation. **David Larsen:** Writing – review & editing, Investigation, Formal analysis. **Cresten Mansfeldt:** Writing – review & editing, Investigation, Formal analysis. **Lucas Melgaço:** Writing – review & editing, Investigation, Formal analysis. **Dhiraj Nainani:** Writing – review & editing, Investigation, Formal analysis. **Amrita V. Nair:** Writing – review & editing, Project administration, Formal analysis, Data curation. **Colleen C. Naughton:** Writing – review & editing, Investigation, Formal analysis. **Margaret O'Donnell:** Writing – review & editing, Project administration. **Christopher Reimer:** Writing – review & editing, Project administration, Formal analysis, Data curation. **Pamela Robinson:** Writing – review & editing, Investigation, Formal analysis. **Jacob Shelley:** Writing – review & editing, Investigation, Formal analysis. **Vishwanath Srikantaiah:** Writing – review & editing, Investigation, Formal analysis.

Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:

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Data availability

No data was used for the research described in the article.

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