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PERSPECTIVE

Indigenous data protection in wastewater surveillance: balancing public health monitoring with privacy rights

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Wastewater-based epidemiology (WBE) has revolutionized public health surveillance by enabling real-time monitoring of disease patterns across populations through analysis of community wastewater. This innovative approach provides precise geographical tracking of pathogen levels and disease spread by detecting viral RNA and bacterial DNA signatures. Beyond pathogen detection, wastewater analysis reveals comprehensive community health data, including human genomic information and biomarkers of prescription medication and substance use patterns. For Indigenous populations, whose communities often occupy distinct geographical areas, this detailed biological data collection raises significant privacy and ethical concerns, particularly given historical patterns of research exploitation. By examining international case studies, we analyze instances where Indigenous genomic data and traditional knowledge have been misused in psychiatric and neuroscience research contexts, highlighting violations of informed consent principles, data sovereignty rights, and reinforcement of harmful stereotypes. The current regulatory gap in wastewater surveillance ethics necessitates the development of specialized WBE protocols for Indigenous communities. These guidelines must balance public health benefits with stringent privacy protections through authentic community engagement and Indigenous data governance rights recognition. This framework supports both epidemiological research advancement and the protection of Indigenous communities' autonomy in the age of genomic surveillance.

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Introduction

It is widely accepted that genetic factors contribute to the risk of developing a neuropsychiatric or neurodevelopmental disorder such as depression, schizophrenia, autism spectrum disorders, and addiction, among others (1–4). In 2023, for instance, a large multivariate genome-wide association meta-analysis showed 19 independent single-nucleotide polymorphisms (SNPs) significantly associated with general addiction risk and 47 SNPs for select substance disorders in individuals of European ancestry (5). In those of African descent, however, only a single SNP was associated with general addiction risk and another for risk of alcohol use disorder.

This study has a couple of noteworthy points. First, the authors were careful to point out that, despite interesting associations between polygenic risk scores and substance use disorders, their findings are not prognostic of future disease risk. This is an essential statement as past genomic studies have been used to promote the idea of genetic determinism, leading to racism and stereotyping (6, 7). For example, there has been a (not so) historical belief that alcoholism in Indigenous peoples was biological and that substance use and dependence in these communities was heritable (8), without any consideration of the transgenerational impacts of colonization and the colonial power structures that exist to this day. The second point of note is that the sample size for those of European descent (>1 million) was over 10 times higher than that of African descent, and those of Indigenous descent were not included in the study. This highlights the lack of participation of those from marginalized communities, and especially Indigenous communities, in genomic studies (5). There are reasons for this, a predominant one being a lack of transparency in many genomics research investigations that has led to a long-lasting mistrust of both research and researchers.

Wastewater-based surveillance and epidemiology (WBE) is an innovative public health approach that analyzes biological and chemical markers in wastewater to monitor the health of communities. Initially developed to assess trends in illicit drug use, WBE has expanded to include infectious disease surveillance, antimicrobial resistance tracking, and environmental monitoring. The COVID-19 pandemic highlighted the utility of WBE, as it served as an early warning system for outbreaks and a valuable tool for tracking viral variants in communities (9, 10). WBE provides critical insights into public health by enabling early detection of disease outbreaks through analyzing nucleic acid and other biomarkers in wastewater. This capability allows health authorities to implement timely interventions, potentially mitigating the spread of infections (11, 12). Beyond infectious disease monitoring, WBE assesses the presence of environmental pollutants, such as pesticides and pharmaceuticals, offering a holistic view of anthropogenic impacts on ecosystems (13).

DNA degradation in wastewater is influenced by a combination of chemical, biological, and environmental factors, including temperature, pH, microbial activity, and exposure to ultraviolet light. While wastewater treatment processes are designed to degrade organic materials, studies have shown that extracellular DNA can persist through various stages of treatment, raising concerns about the potential for recovering sensitive genetic information. Additionally, if nucleic acids are extracted from wastewater and stored in purified form at −80°C, they can remain intact indefinitely. For instance, Farkas *et al.* (14) demonstrated that while extensive decay of viral nucleic acids was observed during the storage of raw unprocessed wastewater, purified nucleic acid extracts stored at −80°C for 8–24 months showed little signs of degradation. Additionally, Acharya *et al.* (15) observed that specific bacterial DNA sequences exhibit resistance to degradation, especially in disinfected systems. This persistence has significant privacy implications, particularly in the context of WBE, where the unintended capture of human genomic material could threaten individual privacy if data are not adequately anonymized (16).

WBE holds significant potential for public health, but it also carries the risk of misuse, particularly in closed or marginalized communities such as Indigenous communities. Due to the substantial amount of human DNA in wastewater, detailed genomic analysis can reveal sensitive information about the genetic makeup, ancestry, health predispositions, and disease prevalence within a population. Those data could be used in

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closed communities to reinforce stereotypes, stigmatize groups, or exert control through targeted policies that disproportionately affect these populations. For example, genetic data could be linked to the prevalence of certain conditions to justify discriminatory health care practices or policies that ignore social determinants of health. Further, the small population sizes in these communities increase the risk of re-identification, breaching individual privacy despite aggregate-level analyses. Without stringent ethical guidelines, such practices could erode trust, infringe on autonomy, and exacerbate historical inequities faced by Indigenous peoples (17, 18). Ethical governance is critical to ensure that WBE serves public health purposes without exploiting or marginalizing vulnerable populations.

Building on these concerns, the potential misuse of wastewater surveillance to identify psychiatric disorders or drug use in marginalized populations raises additional ethical challenges. Psychiatric conditions are often stigmatized; therefore, associating these disorders with specific communities through wastewater analysis risks reinforcing harmful stereotypes and exacerbating social marginalization. This is particularly concerning in Indigenous communities, where historical trauma and systemic discrimination have already contributed to disproportionate mental health burdens (19). The ability to infer prevalence rates of psychiatric medication use, illicit drug use, or genetic markers associated with mental health conditions from wastewater data could inadvertently or intentionally be used to justify punitive or discriminatory interventions rather than addressing root causes such as poverty or inadequate access to healthcare. Furthermore, such data might be weaponized in policy debates, framing psychiatric conditions as cultural deficits rather than addressing structural inequalities (6, 20, 21). This underscores the urgent need for stringent data governance frameworks and community involvement in decision-making processes to prevent the misuse of surveillance technologies and respect these populations' autonomy and rights.

Mistakes of the Past: Genomics and Genetics Research in Indigenous Communities

Indigenous peoples are of great value in genomics research in large part due to their isolated genetic history. Whereas some researchers are interested in population genetics or genetic ancestry, that is, what the patterns of genetic variation can reveal about a community's history, societal structure, migration patterns, etc., others are interested in genetic information that may be medically (and commercially) valuable. Despite this, Indigenous communities are substantially underrepresented in genomics and genetics research, with many refusing to take part in these types of studies due to past exploitation. Examples include the unauthorized use, sharing, and patenting of genetic data, the lack of informed consent, cultural insensitivity, and the perpetuation of racial stereotypes (22–27).

One of the first recorded negative interactions between geneticists and an Indigenous community involved the Nuu-chah-nulth First Nations of Canada's Vancouver Island in British Columbia and a geneticist at the University of British Columbia (UBC) (27). In the early 1980s, the Nuu-chah-nulth provided blood samples for research into genetic causes of their high rates of rheumatoid arthritis. The researcher was unable to discover a genetic linkage to the disease; however, when they left UBC, they took the Nuu-chah-nulth samples with them to use in genomic ancestry research without the knowledge or consent of the tribe. Genomic ancestry research is a serious concern for many Indigenous peoples due to a disconnect between Indigenous origin stories and research findings. Notably, the DNA was not returned to the Nuu-chah-nulth until 20 years after sampling.

Perhaps one of the most egregious examples involving psychiatric research involves the Havasupai, a Native American tribe who live at the bottom of the Grand Canyon in Arizona in the United States (26, 28–30). In the early 1990s, community members approached researchers at Arizona State University (ASU) to initiate genetic research into diabetes as they were concerned about the increasing prevalence of the disease in their community. The Havasupai were told that the focus of the study would be on diabetes, but the project was designed to also focus on identifying genetic markers for schizophrenia. Researchers then generated a broad consent form to study "behavioral/medical disorders" signed by participating community members when the blood samples were taken. The ASU researchers were unable to find a genetic link to diabetes. Still, samples continued to be used for other research without specific consent, including studies on alcoholism, population migration, and inbreeding. They also continued the study into schizophrenia, which included unauthorized access to medical records. The Havasupai discovered the unauthorized use of their samples when a community member attended a seminar at ASU in 2003. In response, the tribe initiated legal action against ASU, which was resolved in a settlement in 2010. After the case, the Havasupai banned ASU researchers from entering their lands and conducting any form of research, following in the steps of the Navajo Nation, which passed a moratorium on genomic research within its boundaries in 2002.

At about the same time as the Havasupai study was being conducted, the Human Genome Diversity Project (HGDP) (31), the first large-scale genomics study, was initiated to explore global human genetic diversity by taking samples from isolated Indigenous populations (32). Some Indigenous communities had concerns over biopiracy, exploitation for profit, or that there would be access to the samples by an unknown number of researchers with various scientific goals (33). These concerns were not without merit (22, 33). Some participants were told their blood was being taken for pathology tests and then given to the HGDP. Cultural values in handling the samples were also not considered, and commercialization potential was not disclosed. In addition, informed consent was not always obtained. The enmity of Indigenous communities for the HGDP was only heightened when an anthropologist involved with the project was found to be also linked to the controversial collection of another set of samples collected from the Hagahai, an Indigenous people of central Papua New Guinea. The controversy surrounded a patent filed in 1990 by the National Institutes of Health (NIH) for a cell line derived from a Hagahai donor to commercialize his DNA for commercial profit (23). Shortly after the HGDP's failure, in 2005, another large-scale project, the Genographic Project, was launched to trace the migratory history of the human species through DNA. Like its HGDP predecessor, Indigenous communities also denounced it due to a lack of engagement and transparency (34). Sampling from Indigenous communities was prioritized as there was concern surrounding the mixing of the populations (34), thus building upon the old myth of the "Vanishing Indian." It was postulated that any subsequent findings of the HGDP and Genographic Project could lead to the genetic appropriation of culture, challenging cultural narratives about a people's origins and altering a group's understanding of themselves as a people (35).

In another example, geneticists from the Institute for Environmental Science and Research in New Zealand obtained samples from the Māori people with the intent of analyzing the monoamine oxidase-A (*MAOA*) gene as a marker for alcohol and tobacco dependence (25, 36, 37), as the enzyme MAO-A is involved in the breakdown of neurotransmitters such as dopamine and serotonin. In 2006, during the 11th International Congress of Human Genetics in Brisbane, Australia, the researchers announced that they had identified a genetic polymorphism in *MAOA* that was associated with low enzyme activity and higher dopamine levels in over half of the samples obtained from Māori men ($n = 17$) (25, 36, 37). A controversy ensued when one of the researchers mentioned the "warrior gene," a nickname given to the *MAOA* gene due to its reported link to aggression and criminal behavior (38, 39) in a media interview, also inferring that these attributes exist in the Māori people (25, 36, 37). In this example, the scientists drastically misstepped, not only by providing a harmful narrative unsupported by their findings to perpetuate racial stereotypes but also by generalizing to the entire Māori population.

The final example highlights the failure of research ethics boards (REBs) to ensure that adequate protocols were in place to protect Indigenous peoples. The Indigenous San peoples of South Africa are among the most sought-after Indigenous groups for population genomics research. In this case, the genomics research aimed to examine the genetic structure of four Indigenous Namibian "hunter-gatherers" and to compare their findings with that of a "Bantu from southern Africa." The findings were published in 2010 (40) and, along with its supplementary material, included conclusions and details (e.g., the terminology used) that the San regarded as private, pejorative, discriminatory, and inappropriate

(41). The San leadership was not consulted prior to publication, and their requests to the authors for information on the informed consent process were denied on the grounds that several REBs had approved the research. This interaction resulted in the development and publication of the San Code of Ethics (42) by the leaders of three San groups: the !Xun, Khwe, and !Khomani, a code that emphasizes respect, honesty, justice, fairness, care, and process.

The historical exploitation of Indigenous communities in genomics research offers critical lessons for contemporary challenges in WBE, particularly regarding ethical considerations such as informed consent, data ownership, community engagement, and the potential for stigmatization. The examples of the Havasupai Tribe (26, 28–30) and Nuu-chah-nulth First Nations (27) underscore the importance of transparency and highlight the consequences of neglecting autonomy and informed consent, such as long-term mistrust in scientific practices. Although data are collected at the community level rather than from individuals in WBE, concerns about privacy and consent persist, particularly when surveillance may expose sensitive health information without explicit community approval (43). The backlash against the Genographic Project by Indigenous groups (34) due to inadequate community engagement reflects the importance of involving affected populations in decision-making processes to foster trust—a principle equally applicable to public health surveillance initiatives. Moreover, data ownership and governance issues, as highlighted by the San Peoples' experience with genomics research (41), stress the necessity of clear data control frameworks in WBE to prevent misuse and ensure that communities benefit from the data collected. The harmful stereotyping seen in the Māori "warrior gene" controversy warns against using scientific findings to perpetuate negative narratives—a risk in WBE if data is poorly contextualized, potentially stigmatizing communities linked to specific health outcomes (25, 36, 37). Finally, the failure of REBs to adequately protect Indigenous interests in past genomics studies emphasizes the need for robust ethical oversight in public health surveillance to proactively address legal and privacy concerns (44). By applying these historical lessons, wastewater surveillance programs can balance public health benefits with respect for individual rights, data sovereignty, and cultural sensitivities, ultimately fostering greater public trust and ethical integrity.

A Call for the Development of an Ethical Indigenous Research Policy for WBE

The provided historical examples highlight past injustices that we, as neuroscientists and genome scientists, must be diligent not to repeat. Efforts to thoughtfully and respectfully engage with Indigenous communities have resulted in the development of several guidelines and strategies. In 2007, Indigenous Peoples' right to self-determination was internationally recognized in the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) (45), which includes the right of Indigenous peoples to maintain, control, and protect their genetic resources (Article 31, p.11). In 2019, the Collective Benefit, Authority to Control, Responsibility, Ethics (CARE) Principles for Indigenous Data Governance were developed to advance Indigenous Peoples' governance of their own data in response to the growing desire for open science and data sharing (https://www.gida-global.org/care). Some Indigenous communities, such as the aforementioned San people of South Africa, developed their own policies to promote responsible research conduct and ensure Indigenous data are protected. In Canada, the OCAP Principles of ownership, control, access, and possession were developed to support data sovereignty for First Nations, providing guidelines on how First Nations data should be collected, protected, used, and shared (https://fnigc.ca). Similarly, in the United States, guidelines generated specifically for genomics research within Indigenous communities highlight important principles for ethical and respectful engagement (46, 47).

These existing guidelines provide high-level directives for Indigenous community research that should occur in tandem with institutional or community REBs. Yet wastewater sampling from Indigenous communities is a relatively new epidemiological approach that poses a unique set of ethical issues, underscoring the need for a comprehensive, robust, and ethical policy for WBE research that protects privacy, confidentiality, and data integrity while respecting Indigenous sovereignty. As WBE is also not currently evaluated by REBs, the potential risks for misuse of wastewater samples and any community data derived from those samples remain high, and we argue that all WBE studies involving Indigenous communities should continue only under REB oversight.

As Indigenous communities are diverse, the policy or framework should outline overarching principles and guidelines rather than prescriptive actions, but with full consideration of the specific issues surrounding WBE. Before their development, researchers should fully understand existing national and international governance frameworks for genomic data stewardship, particularly focusing on the unique challenges related to wastewater sources and Indigenous communities. Throughout, the policy should emphasize core principles of self-determination (Figure 1), that is, choice, partnership, and governance, and should include the following elements:

Respect Transparency and Cultural Humility

Listening and respect when working with Indigenous communities is paramount, and researchers should be mindful of when to step back so Indigenous ways of knowing and doing take precedence. There is a collective responsibility to ensure that the outcomes of genomics studies derived from Indigenous peoples prioritize the benefits to those communities, and there should be transparency in all things, including sample use, research findings and dissemination, and commercialization potential.

Notably, there should be both cultural competency and humility. Researchers should first demonstrate competence by doing their research on the communities they wish to engage with. They should appreciate that there will likely be differing ideas and points of view. The cultural significance of personal and biological (genetic) information and each community's traditional knowledge and world views should always be respected. Throughout the collection and research process, researchers should also be sensitive and respectful of Indigenous ways of doing things to ensure sample collection, data analysis, and dissemination are conducted according to the specifications detailed by the community. To effectively decolonize community-engaged research, it is necessary that researchers also express cultural humility (48), which is an openness to learning that involves acknowledging others' values, beliefs, and experiences, listening without judgment, and is a process that seeks to redress power imbalances. It is considered a lifelong commitment that begins with honest self-reflection to understand one's own values and biases. Strategies for the incorporation of cultural humility into community-based research have been developed. Itchuaqiyaq *et al.* (49), for example, base their guidelines on the experience of a collaboration between Aqqaluk Trust, a tribal organization serving the Iñupiat of northwest Alaska, and interdisciplinary researchers at Virginia Tech in the United States. These high-level strategies include respecting community leadership, knowing yourself and adjusting to community needs, accepting your role, avoiding manipulation of the project, and maintaining connections and trust. The Iñupiat Elders Council also provided specific instruction surrounding humility (49). Researchers who show cultural humility do not infer that their own knowledge is superior to the communities they are working with, and they value Indigenous ways of knowing and doing equally alongside Euro-Western ways.

Community Engagement

Although WBE is not presently under REB oversight, researchers should still have an understanding of the community governing and ethics structures, including leadership and relevant boards or committees, before engagement. Once engaged, researchers should design the study, acquire the data, and disseminate the findings in full partnership with Indigenous communities, giving the time required to build trust through relationship building. This can be facilitated through established community engagement strategies, examples that include Community-Based Participatory Research (CBPR) (46), Two-Eyed Seeing (50, 51), or Kaupapa Māori Methodology (52). Though CBPR is not Indigenous-specific, all three approaches value the importance of community engagement, transparency, and involving members of a study population as active and equal participants in all phases of the research project. However, in more recent years, there has also been a push for Indigenous leadership to be included within

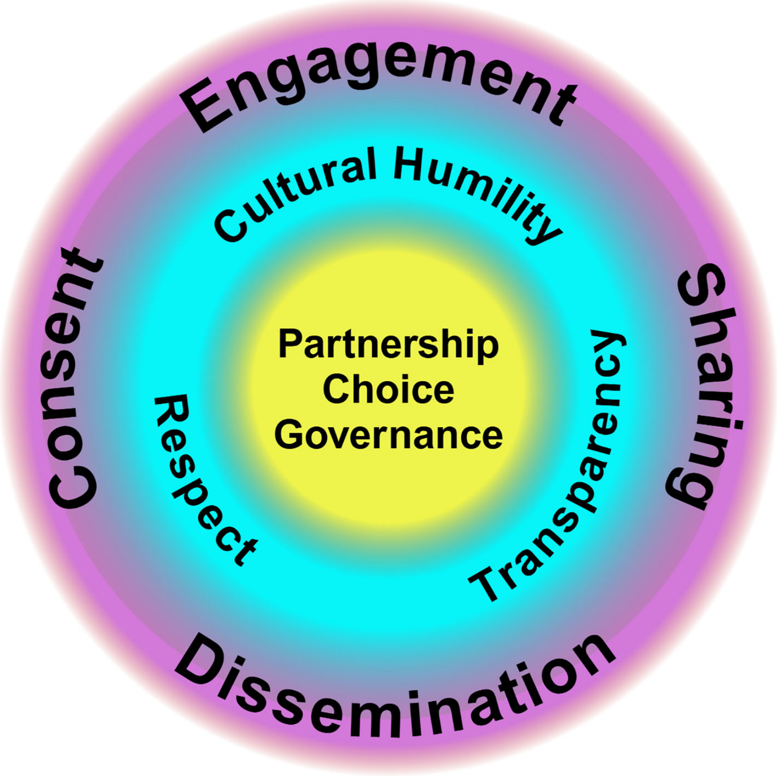

Figure 1. Guidelines for developing policy for ethical WBE research with Indigenous communities. The guidelines are built upon Indigenous self-determination, with partnership, choice, and governance as the foundational components. Researchers should exhibit respect, transparency, and cultural humility at all stages of the process. Guidelines should include recommendations for appropriate community engagement, sample and data sharing, consent, and knowledge dissemination. The image was generated with Biorender.

the research teams (e.g., academic, Elder, or Knowledge Keeper), which we strongly endorse.

Consent

Within the guidelines, a strategy for developing a robust consent process for wastewater sampling should be present, and the principle of Free, Prior, and Informed Consent (FPIC) should be followed. References to FPIC are found throughout UNDRIP (45), which emphasizes the importance of ensuring that Indigenous peoples' have effective and meaningful participation in decisions affects them, their communities, and their territories. More specifically, FPIC describes that consent must be given freely, without pressure or coercion, that sufficient time is given for communities to review all relevant information, and that communities have access to all the necessary information to determine the risks and benefits. The consent process should therefore be thorough with assurance that Indigenous communities fully understand the implications of wastewater sampling on their lands and the benefits and potential risks associated with human genomic DNA and/or drug residues in the samples.

In community research, consent must be obtained first from community leaders (e.g., Elders, Knowledge Keepers) before individuals are approached. This is particularly relevant to wastewater collection as samples are taken from community repositories and may contain the DNA of hundreds of individuals that would be subsequently analyzed as aggregated data. This poses additional challenges to consider, such as sampling locations and the possibility of individual and/or family privacy breaches. Indeed, the chances of identifying one individual from wastewater samples are extremely low but certainly not zero, leading to the question of who gives consent. Can one person have the authority to refuse sampling on community land due to the possibility of their DNA being in the samples? This question requires discussion far beyond what we can offer here. While some may argue that individual consent may not be the most practical approach, ultimately, that would be a community decision. On the other hand, if Indigenous leaders are chosen to consent on behalf of the community, it is essential to consider the possibility of community leaders changing with time. Therefore, specific timelines where consent would remain valid should be established, as wastewater surveillance generally takes place over long periods.

Sample Storage and Sharing

Implementing best practices for wastewater sample storage and sharing is essential to maximize the benefits of WBE while safeguarding ethical considerations, especially for Indigenous communities. One practical approach is to establish data sovereignty frameworks that empower communities to maintain control over their samples. For instance, community-led agreements could specify how samples are collected, stored, and used, ensuring alignment with local cultural and ethical standards. Co-designing sampling protocols, using a Two-Eyed Seeing approach to integrate Indigenous and Euro-Western ways of doing (50), for example, can ensure that collection practices align with Indigenous stewardship principles, emphasizing sustainability, reciprocity, and minimizing environmental disruption. Clear protocols, such as secure, anonymized storage systems, can protect individual and community privacy by deidentifying data before analysis. However, this would involve critical discussion as the community may want the samples returned. Additionally, a tiered consent process could be adopted, where communities provide informed consent for specific uses of their wastewater samples, preventing misuse or unauthorized sharing.

The sharing of wastewater samples should be governed by agreements prioritizing transparency and accountability. For example, researchers can adopt collaborative sample-sharing platforms where Indigenous representatives actively participate in decision-making. These platforms can ensure that the wastewater samples are used only for agreed-upon purposes and that results are reported back to the community in accessible formats. Regular audits of sample usage and storage practices can further build trust and demonstrate adherence to ethical guidelines. Moreover, integrating traditional ecological knowledge into WBE practices can foster mutual respect and enrich public health strategies. By codifying these best practices into formalized policies, WBE can continue to advance public health goals while ensuring that communities, especially Indigenous populations, are respected and protected.

Data Governance and Knowledge Dissemination

Recommendations for Indigenous data governance should also be prioritized, ensuring that Indigenous communities are central in decisions affecting their information. Protocols surrounding data sharing should also be present. This is particularly important as open science remains a significant deterrent for Indigenous peoples for several reasons, including unrestricted access to personal samples and data, an overall inability for Indigenous people to govern their own personal information (53), and the substantial commercialization potential arising from their data alongside a lack of benefit to the communities themselves. Given that the data are aggregated, ownership of the data to the community should be clear. Finally, relationships with the communities should be maintained once the research is completed. There should be ongoing consultation with the communities regarding dissemination of the findings, and consideration of best practices for knowledge sharing should be prioritized for each community. Communities should be informed of and have the opportunity to review all findings before disseminating them to the public, government, researchers, and any other external stakeholders.

Conclusions

Emerging technologies in wastewater analysis, such as advanced metagenomics, real-time biosensors, and WBE, have revolutionized the monitoring of public health, environmental pollutants, and microbial communities. However, these advancements raise critical concerns regarding Indigenous data sovereignty and privacy. The granular data obtained from WBE can inadvertently capture sensitive information about specific communities, including genetic material and health indicators, which may conflict with Indigenous data governance principles. The ethical and legal challenges posed by the datafication of wastewater emphasize the need for robust frameworks to protect community-level data (54). Similarly, ethical engagement with Indigenous communities when deploying WBE technologies advocating for culturally sensitive practices that respect Indigenous data sovereignty, is imperative (55). There needs to be a balance between open scientific data and the privacy concerns of marginalized groups, highlighting the acute need for transparent data management policies that align with Indigenous rights (56). REBs and oversight committees at all levels—local, academic, and governmental—must incorporate WBE ethical guidelines into their standard protocols. This integration is essential to safeguard Indigenous communities from exploitative research practices and ensure their fundamental right to control their personal data.

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Author Contributions

M.L.P. and L.D.G conceived the manuscript topic and wrote the paper. M.L.P. generated the figures. All authors have read and approved the manuscript. Both authors take full responsibility for all figures and text and approve the content and submission of the study. No related work is under consideration elsewhere.

Corresponding authors: M.L.P. for the Indigenous aspects of the work and L.D.G. for queries associated with WBE. These corresponding authors take full responsibility for the submission process.

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Author Disclosures

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