

## PERSPECTIVE

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## Wastewater research and surveillance: an ethical exploration

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The current COVID-19 pandemic has given wastewater research a huge impetus. While wastewater research has some promising applications, there are as yet no well-developed ethical guidelines on how and under what conditions to use wastewater research. The current perspective paper aims to explore the different ethical questions pertaining to wastewater research and surveillance and to provide some tentative guidelines on the desirability of different types of applications. This paper shows that wastewater research offers interesting possibilities, but that legal regulation and ethical guidelines are still lacking, while there are ethical risks involved. The perspective indicates that it is important to look beyond the regulation of data collection and to shift the focus to the question how the analysis and use of wastewater data can be supervised.

### Water impact

This perspective discusses the ethical aspects of wastewater research and surveillance. The COVID-19 pandemic has shown the potential of wastewater research for public health purposes. However, wastewater research uses personal data and people have not given consent to these data being used for research purposes. This prompts the question under what conditions and for what purposes these data can be used.

## 1. Introduction

Over the past 15 years, wastewater research has developed into a mature field, with a growing variety of uses.<sup>1–4</sup> With wastewater research, the use of, or exposure to, chemicals or pathogens in a population can be determined through wastewater biomarkers, substances excreted by humans into the wastewater system that can be used to mark a certain biological state. These substances can be remnants of illegal drugs, but also prescription drugs, or substances that indicate the functioning of certain organs or disease processes. This directly indicates the breadth of possible applications, which can vary from criminal law applications to preventive public health care.

Because the measurements are usually taken at the wastewater treatment plant (WWTP), wastewater research delivers results at the population level. Studies in the early 2000s focused primarily on tracing drug residues in wastewater to map narcotic use and identify trends in this use. In recent years, the field of applications has expanded

to public health and anti-doping. Building on successful applications in, among others, Finland, the Netherlands, and Israel, the World Health Organization (WHO) has included wastewater surveillance in their Strategic Plan of the Global Polio Eradication Initiative for years 2010–2012.<sup>5</sup> Also water-borne viruses, such as noroviruses, adenoviruses, and the hepatitis A virus, are increasingly screened through wastewater surveillance.<sup>6</sup> The current COVID-19 pandemic has given wastewater research further impetus. In a growing number of countries, wastewater research is used as a surveillance tool to monitor the spread of SARS-CoV-2.<sup>7–13</sup>

Among the advantages of wastewater surveillance are the speed and high sensitivity of detection.<sup>14</sup> In wastewater, the spread of the virus can be detected with high precision earlier than through testing by the regular municipal health services, because the latter is highly dependent on testing policy and testing behavior.<sup>15,16</sup> The viral signal is also detectable in feces before infected individuals develop symptoms, let alone before any personal test result is known.<sup>17</sup>

The growing use of wastewater surveillance also raises ethical questions associated with generating and handling of human health data. However, there are as yet no well-developed ethical guidelines on wastewater surveillance. Early

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discussions on the need for ethical guidelines focused on the question whether certain applications require ethical oversight in the first place – the World Bank, for instance, radically distinguished between research-related and non-research-related applications and held the view that surveillance should be assessed in economic terms, not in ethical terms.<sup>18</sup> In 2017, the World Health Organization developed the first international framework on public health surveillance, discussing not only the tension that public health surveillance may pose to civil liberties, but also the responsibilities of countries *vis-à-vis* other countries.<sup>19</sup> These guidelines, however, did not focus on wastewater surveillance specifically. Since then, several studies have been published on the ethical aspects of wastewater research generally and wastewater surveillance with a public health purpose particularly.<sup>20–24</sup> Prompted by the COVID-19 pandemic, the need for ethical guidelines was discussed also from within the water engineering sector<sup>24</sup> and tentative guidelines for wastewater surveillance were derived from the WHO guidelines on public health surveillance.<sup>25</sup>

While it is not surprising that the ethical issues of wastewater surveillance are often discussed from a public health perspective, it may provide a too limited view. In a sense, wastewater surveillance, like wastewater research more generally, uses personal data – mostly without consent from the persons whose data are being used – and the ethical aspects are therefore also about data collection and data use. This suggests that we may also look at wastewater research from a data ethics perspective.

The current perspective paper aims to explore the different ethical questions pertaining to wastewater research and surveillance and to provide some tentative guidelines on the desirability of different types of applications. While the COVID-19 pandemic has given wastewater research a huge impetus in the direction of surveillance, it may be good to start from a broader perspective and first see what different subfields within ethics have to contribute to this exploration, focusing particularly on data ethics, public health ethics, and research ethics. Once we have done so, we will turn to the different types of applications.

## 2. Wastewater research as a confluence of different ethics fields

Several applied ethics subfields can provide a relevant perspective to look at the ethical questions of wastewater research.

### 2.1 Data ethics

Data ethics is a relatively young subfield within applied ethics and it is still developing rapidly. Where data ethics started with a strong emphasis on protecting privacy, partly due to the current rise of artificial intelligence and algorithmic decision-making, more attention is now also being paid to other harmful consequences, such as decision-

making based on coupled data sets and biases in the data used, often particularly detrimental to minority groups.<sup>26</sup>

**Privacy and the protection of personal data.** Concerning privacy and the protection of data that can be traced back to an individual, the European General Data Protection Regulation (Regulation (EU) 2016/679 or GDPR) has established an extensive legal framework. ‘Ordinary’ personal data, which are data such as name, address, and date of birth, may only be processed based on a limited set of six principles: 1) the person whose data are processed has given permission, 2) processing of the personal data may be necessary to protect vital interests (*e.g.* in a life-threatening situation or other crisis), 3) the data processor may be required by law to process personal data (*e.g.* tax payments), 4) processing of the personal data is necessary to protect vital interests (*e.g.* in case of an emergency situation), 5) processing of personal data is necessary to perform a task carried out in the public interest or to exercise public authority, and 6) there may be a legitimate interest of the data processor that prevails over the right to privacy of the person from whom the data are collected. The word ‘necessary’ is key: if there is a less intrusive way to achieve the purpose for which the data are collected, these personal data may not be processed.

The above framework concerns ordinary personal data; stricter requirements apply to special and criminal personal data. Special personal data include data revealing race or ethnicity, political opinions, and religious or philosophical beliefs, as well as genetic data and biometric data to uniquely identify a person. These data may not be collected, unless an exhaustive set of exceptions applies or a legal basis has been given for this in national law. Personal data processing is also not permitted for criminal personal data unless this data processing is supervised by the government or permitted by national law.

Although the GDPR does not fully overlap with data ethics, it makes some important points explicit. First, the purpose for which data are used determines what may and may not be collected. Not all data are equally sensitive and to determine whether data collection for a certain purpose is lawful, it is important to see whether the intended purpose cannot be achieved in a way that requires less personal data collection. This provides a clear framework for thinking about how questions regarding privacy and data processing can be approached. Is the purpose for which data are collected a legitimate purpose? If so, is there a less intrusive way to achieve the stated goal? Only if this is not the case, the relevant data may indeed be collected.

As mentioned, the GDPR concerns data that can be traced back to individuals. This is not yet the case for wastewater research, although the technology itself does in principle allow for such individual data collection. Whether data can be traced back to individuals or specific groups depends primarily on where the sampling takes place. Precisely in the context of virus detection, sewer measurements at the district or institutional level, for example at nursing homes, are also discussed as a possibility to detect and isolate a possible



source of infection more accurately and quickly than through traditional monitoring and testing.<sup>27</sup> Hence, the more specific the source of the wastewater can be demarcated and isolated, the more effective the method is but also the more it affects people's personal sphere.

**Data analytics, big data & decision making.** An important and relatively new topic within data ethics is decision-making based on large amounts of data ('big data'). Nowadays more and more personal data of citizens are available. Many consumer electronics are equipped with sensors and internet technology, with which personal data can be collected, stored, and exchanged. Citizens partly share these data consciously, for example *via* social media, but governments and companies are also collecting a lot of data from citizens. There is an ever-increasing link between different data sources, sometimes blurring the line between public and private sources.

By cleverly combining all these data, a profile of citizens can be drawn up that can be used to approach citizens in a targeted manner with information tailored to them, so-called micro-targeting, which is used extensively for marketing purposes by commercial parties but increasingly also by political parties to reach out to potential voters in times of elections.<sup>28,29</sup> However, it can also be used by the government for investigation and surveillance. By combining various data, governmental agencies can draw up profiles of people who are subject to extra checks for, for example, benefit fraud, or map out criminal networks to facilitate the identification of perpetrators.

Data analytics in general and big data in particular are based on the smart combination of various unstructured data: new data are collected and combined with existing data sources. The strength lies in the multitude and diversity of the data, which, when combined, can provide new information that cannot be extracted from individual data sets. But it is precisely in using data that has been collected for very different purposes that there is also the danger of function creep, where data are used with a different purpose than what they were originally collected for.<sup>30</sup> Admittedly, it is partly characteristic of big data that the purpose for which data are collected is not known in advance. It becomes problematic when these data are sensitive or when they concern personal data that may only be used for clearly described purposes. In addition, big data applications can lead to anomalies and the reproduction of anomalies, which can cumulatively lead to discrimination and unfair treatment of certain minority groups in society. For example, based on statistical profiles, police officers may choose to check people with certain characteristics more intensively. This in turn may lead to higher crime rates among people who meet the relevant profile, not because they display more criminal behavior but simply because the chance of being caught is higher.<sup>31</sup> In the case of automated decision-making, this can lead to a violation of the fundamental rights and freedoms of individual citizens. For that reason, most data ethics scholars warn against fully automated decision making where there is

no possibility of discretionary deviation from what emerges from the multitude of data.

Although big data primarily refer to digital data, wastewater data can also be seen as an additional data set that further feeds big data. Wastewater research has already been proposed to complement census data for assessing population socioeconomics, and be used to infer characteristics such as the education level, proficiency of English language, and presence of a physical or mental disorder.<sup>32,33</sup> Dependent on the level aggregation, these data may allow third parties to target their activities to specific individuals or groups of individuals. For example, health insurance companies may apply higher insurance premiums in neighborhoods where wastewater data suggest an unhealthy lifestyle, or liquor shops may open in neighborhoods with already high alcohol consumption. Unlike the spread of infectious diseases, such applications do not serve the interests of the local communities nor are they necessary for the common interest. These examples show that the wastewater data should not be seen in isolation from other data and that the type of characteristics derived from the wastewater data and the level at which these data are aggregated require due care to avoid wastewater research contributing to the further datafication of society, with corresponding risks.

## 2.2 Public health ethics

Public health ethics is concerned with health at the population level and the ethical questions raised by interventions aimed at improving this health.<sup>34</sup> While the protection of the dignity and autonomy of the individual is central to medical ethics and research ethics, public health ethics often revolves around the question of whether and, if so, to what extent, choices in the interest of public health that infringe on individual freedom rights are acceptable.

In the literature, the following conditions are mentioned to justify forced, freedom-restricting measures. First, the damage to be expected if the measure is not taken must be significant.<sup>35</sup> For example, forced vaccination in the event of a non-fatal disease is not justifiable. The enforced measure must be effective.<sup>36</sup> Since this often cannot be proven, it must at least be made plausible. Second, the measure must be proportional to the possible damage and it must also be the least intrusive alternative.<sup>37</sup> The possible threat of a bioterrorist with a deadly smallpox virus justifies stricter measures than a possible measles outbreak. Third, and finally, enforced measures must be applied in a fair and non-discriminatory manner.<sup>38</sup>

In this context, wastewater research could well offer a promising alternative to regular forms of testing, precisely because wastewater research involves pooling and the results cannot yet be traced back to an individual. Reference is often made here to the objectivity of wastewater measurements.<sup>39</sup> Because the regular health services are highly dependent on the willingness to test, the test data from these organizations



do not always provide an accurate picture of the spread of the virus. Usually not all neighborhoods in a city are represented in the same way in the clinical test facilities. If in a future scenario, more mandatory testing is considered to obtain a more accurate picture of the distribution, wastewater research may well be the less drastic, and therefore preferable, alternative. Additionally, in situations where access to clinical testing and vaccination is unevenly distributed, wastewater research may also offer a more equitable and representative disease surveillance strategy.<sup>40,41</sup>

### 2.3 Research ethics

In a broad sense, research ethics is aimed at safeguarding the integrity of research conduct. This also includes aspects such as reliability of the research results, reproducibility, and the prevention of plagiarism. In a narrow sense, research ethics focuses mainly on the protection of human participants in human-related research.

**Belmont principles.** Most ethical frameworks developed in the context of research ethics refer to the Belmont report.<sup>42</sup> This report was prepared in 1978 by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research in the United States in response to several cases of abuse in the conduct of human research, and it has since become the standard for reflection on human-related research. The Belmont report lists three guiding principles for human research: 1) respect for individuals, which in this context means that the autonomy of study participants must be respected by the researchers and that participants must give informed consent; 2) benevolence, which means that risks for research participants must be minimized; and 3) justice, which indicates a reasonable and fair distribution of benefits and burdens among potential participants of the study. Many countries have legislation that regulates medical research with people and in which the Belmont principles are also reflected. While wastewater research will often not fall under this legislation as the results cannot be traced back to individuals, it can still be useful to see to what extent the underlying principles can be respected. Informed consent in the strict sense is virtually impossible to achieve in a collective setting, as this means that every individual has the opportunity to veto.<sup>43</sup> Such a veto opportunity may be undesirable. In those situations, it may be better to focus on the underlying principle, respect for autonomy, which can for example be interpreted as the requirement that the research is approved by a democratically legitimized body, such as a water board or municipality, or by having the research reviewed by an independent ethics committee, similar to what is legally required in medical research involving human subjects.

The principles of benevolence and justice require the protection of vulnerable groups and a fair distribution of the risks and benefits of research. For wastewater research this means, for example, avoiding measurements in very narrowly

demarcated areas if this could lead to disadvantages for certain groups. A report by the Sewage analysis CORE group Europe (SCORE) mentions possible stigmatization of vulnerable communities and disproportionate police presence in neighborhoods with relatively high drug use.<sup>44</sup> The authors of the report mention the risk that mismanagement of wastewater research data may lead to media reports on prison drug consumption that contribute to negative community sentiments about the rehabilitation and reintegration of ex-prisoners back into society. While measurements at specific locations, such as schools, prisons, or factories, have the potential to directly transfer the benefits of such research to study participants, these benefits are unlikely to outweigh the risk of stigmatization according to the authors of the SCORE report. Compared to the example of illicit drug use, wastewater surveillance for monitoring the spread of infectious viruses seems more in line with the principles of benevolence and justice, as it may lead to direct benefits, for example when access to clinical testing is poor. However, also here, using wastewater surveillance to identify “high risk COVID-19 premises”<sup>27</sup> may have negative implications for the residents of those premises if disproportionately strict measures are imposed. The authors of this study on wastewater surveillance for monitoring COVID-19 cases in a residential building justify the use case by stressing that it causes “minimal inconvenience to the community” and that it is able to detect viral shedding by even a single case in the wastewater. While this may in many situations indeed be the case, it is ultimately also a matter of proportionality: how many residents are affected by this measure based on a single case only, how is the vaccination rate at that moment? If the authorities decide on strict measures for all residents based on this one single case, the application may not be as innocent as the authors present it to be.

### 2.4 Environmental and water ethics

As the last applied ethics subfields with relevance for wastewater research, environmental and water ethics should be mentioned.<sup>45–47</sup> In these fields, the appreciation of nature, and the water system in particular, plays an important role. While both the treatment of wastewater and wastewater research are relevant topics for these fields, they are not discussed in the environmental and water ethics literature. In that sense, this literature has little to add to the current ethical exploration of wastewater research. This lack of attention for wastewater is an unfortunate omission though. First, the operation of WWTPs not only has an impact on human health but also on the ecological health of water systems and wildlife.<sup>48</sup> If the presence of pesticides, pathogens, hormones, or medicinal residues in the water system is assessed only from the point of view of human health and the quality of our drinking water, we may decide on different treatment procedures than when the impact of these substances on fish and other aquatic animals is also





considered.<sup>47</sup> Second, wastewater research could also provide an indication of the ecological health of the water system. In that way, wastewater research can also be used to choose certain treatment methods over others to improve the ecological health of water systems.<sup>49</sup>

### 3. Outline of an ethical framework for wastewater research

The description above shows that existing ethical frameworks cannot straightforwardly be translated to wastewater research. Because the data that are collected cannot yet be traced back to individuals, existing ethical and legal frameworks aimed at personal protection do not formally apply to the context of wastewater research. On the one hand, labeling ethics as irrelevant to wastewater research because the data cannot yet be traced back to individuals seems to sidestep important ethical concerns that may still be relevant, even if the data cannot be traced back to individuals. On the other hand, taking an overly precautionary approach by considering all data collected through wastewater research as personal data may lead to an overly restrictive framework.

In many countries, the focus of the legal frameworks is on regulating the collection of data. The regulation and supervision of the *analysis* and *use* of big data are still relatively underexplored. This is as surprising as it is undesirable. After all, existing legal and ethical guidelines for data protection all indicate that it matters for which purpose data are analyzed and used. The GDPR, for example, is largely organized around purpose and necessity, and these are inseparable from the analysis and use of the data. By regulating the collection of the data itself too strictly, also important benefits of data analytics would be missed. It is therefore important to anchor the responsibility of the data processing party in law as well and not focus on the party collecting the data only. This data processing party should monitor the correctness of the results of data processes, but it should also make clear how their data analyses lead to certain outcomes. It is exactly for this reason of explainability that some people argue for a ban on fully automated decision-making processes in which there is no possibility for human interference and in which it is often unclear how a decision is arrived at.<sup>50,51</sup>

For the purpose of developing ethical guidelines for wastewater research, it may be helpful to see these data as one of the many data sets that are collected and that can be used in various decision making processes. Following the distinction between data collection on the one hand and data processing and use on the other, the focus should probably move away from the collection of the epidemiological wastewater data themselves and shift to the question under which conditions the analysis and use of these data is ethically acceptable.

The analysis concerns the question of what information comes from the data. In the literature, a broad distinction is made between descriptive, explanatory (diagnostic),

predictive, and prescriptive analyses.<sup>52</sup> These different analyses also allow for different uses. While descriptive and explanatory analytics mainly attempt to understand the past or present, predictive and prescriptive analytics focus more on the future or attempt to intervene in the present based on real-time data or analyses of the future.

One of the strengths of wastewater research lies in those future-oriented applications. However, these are also the applications with the greatest risk of function creep. A well-known example is the use of cameras above the highway: originally placed to monitor traffic flow with the aim to increase road safety, the cameras are now used for investigative purposes, thus assuming the function of surveillance and detection. Function creep usually involves small incremental steps: two information systems that are being combined, a new organization that gains access to certain data, and so on. While each of the individual steps may seem justified, the cumulative impact is often much higher than the sum of its parts and for that reason sometimes undesirable.

This prompts the need to examine which applications of wastewater research are ethically acceptable. Following the GDPR, but also in line with public health ethics, it is important to ask the following questions: is the application legitimate? Is a possible infringement proportional to the intended purpose of the application? Is it possible to achieve the same purpose with less intrusive interventions?

In answer to the first question, it seems useful to distinguish between 1) public health applications, 2) criminal and/or public law investigation, and 3) research purposes.

In principle, wastewater research seems promising for application in the field of public health, precisely because it offers the possibility of less intrusive forms of monitoring of, for example, infectious diseases or antibiotic-resistant bacteria. If it is used for this purpose, data must be collected at a sufficiently high aggregation level so that they cannot be traced back to individuals or groups that are too small and that the use does not lead to stigmatization. Since it will not be possible to obtain consent at an individual level, some alternative procedure must be followed. I will get back on this issue of consent in the section on data collection and publicity.

The use of wastewater research for criminal or public law surveillance is controversial precisely because the necessary legal frameworks and safeguards are currently lacking. Using wastewater research for investigating criminal offenses that are not directly related to the primary task of water authorities, such as investigating illegal drug use or anti-doping applications, does not seem legitimate. For the investigation of environmental crimes, the answer is more nuanced. Most water authorities are responsible for the protection of the quality of the water system and for treating wastewater. Some environmental offenses directly affect the quality of the water system or the operation of the WWTP. Wastewater surveillance – if provided with good safeguards – could play a role in detecting environmental offenses that directly affect the water system or the functioning of the WWTP. In addition to the usual requirement of necessity and



proportionality, such research must only be carried out if it serves the primary task of these water authorities.

While the number of potential viruses that is mapped through wastewater surveillance is growing, a significant part of the wastewater research still has the character of application-free research without direct use in practice. If we were to judge application-free wastewater research in terms of necessity, this would inevitably lead to the conclusion that the research is not necessary as there is no clearly described purpose. However, given the potential of wastewater research, it does not seem desirable to put a hold on all application-free wastewater research. The ethical assessment of application-free wastewater research will mainly come down to the question of how the data are collected, recorded, and possibly made public.

### Data collection and publicity

The SCORE report quoted earlier gives some suggestions on how to handle data collection responsibly. The first suggestion concerns guaranteeing anonymity. This means that only sufficiently highly aggregated data are made public. This is all the more true when the measurements are taken in specific locations, such as at a school or a prison. For scientific publications, it may be desirable to omit geographical names altogether, whereby a distinction can be made between the data that are shared with the reviewers of the article and the data that become public through the final publication. Although anonymity must also be guaranteed in the review process, more information can be shared about, for example, the geographical characteristics and location of a river basin when this is necessary to check the accuracy of the scientific analysis.

The SCORE report also pays attention to public-oriented communication about the research. Even more so than with scientific publications, researchers have to be careful about how research results are published. The subject lends itself easily to sensational reporting on, for example, drug use and health.

Thirdly, the SCORE report mentions permission from a recognized medical ethics review body, similar to medical scientific research. Although this is not mandatory, it can still be useful to have wastewater research tested by an independent committee with relevant expertise and possibly also representation from society.

A final point that requires attention is the ownership of the data. One of the responsibilities associated with data ownership is to prevent the data from being improperly shared or otherwise used for improper purposes. Because ownership also comes with responsibilities, it is important that ownership is properly recorded and this may also be something that can be part of the ethical review. Ownership includes the question of who is authorized to decide with whom the data are shared, who is responsible for the correct storage, but also who is liable in case something goes wrong. This is not only a discussion about the division of ownership

between the WWTP and external public health researchers, but also between these WWTP and public health actors and the citizens whose wastewater is used. Collecting data based on wastewater that people freely discharge into the sewer is so new that the question of who is the 'owner' of these data has not matured yet. It is important to make concrete agreements about ownership, precisely because it is not possible to fall back on existing legal and ethical frameworks. This ownership must also be communicated to citizens, so that citizens know whom to address when they have questions.

## 4. Concluding remarks

This paper shows that wastewater research offers interesting possibilities, but that legal regulation is still lacking, while there are ethical risks involved. This is a well-known phenomenon in the development of new technologies and it inevitably requires a balancing act to establish guidelines that are not either too permissive or too restrictive. We often only really learn what the risks are when we start using the technology. But if we already use it on a large scale, it is difficult to regulate the technology properly.<sup>53</sup> Some scholars therefore argue that we should experimentally use such technologies in a controlled manner, while also applying the ethical and legal criteria of experimental research as much as possible.<sup>54,55</sup> In addition to the review body already suggested above, this means that there must be procedures in place to stop the experiment if it leads to undesirable consequences and that potential risks should be contained, for example by starting with small pilots only. However, the most important feature of regular experiments is that we learn from them. Responsible experimentation with wastewater research requires that, with the technical research itself, also more insight is obtained into its ethical acceptability.

## Conflicts of interest

There are no conflicts to declare.

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