Human Rights Council

The balance between the right to privacy and public health

Research Report

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The power of the Internet

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Introduction

The recent pandemic has highlighted the difficulties in finding or maintaining a balance between privacy on the one hand, and the importance of public health on the other. Governments around the globe scramble to find solutions to curb the spread of the virus. One of the more widespread ways of doing so is through contact tracing apps which, while effective against the virus, have proven to breach the privacy of their users in many cases, through governmental or non-governmental means, which raises the question: Is there a way for governments to achieve a balance between individual privacy and public health?
This question also exists outside the current fight against the COVID-19 pandemic. In recent years, there has been a continuous debate over the use of individual data in public health studies and practices. The increase of laws and regulations whose well-meaning goal is to protect individual privacy has led to a decrease in the efficacy of public health studies, as their access to information has been greatly limited. These privacy protection laws have been largely applied globally, especially in countries with rich welfare systems such as most European countries.

Definition of Key Terms

Privacy:
A state in which one is not observed or disturbed by other people.

Individual Data:
Any information that relates to an identified or identifiable individual. Examples of such data include names, email addresses, IP addresses and in general, any piece of information that can be traced back to an individual.

Public Health:
The science of preventing disease, prolonging life and promoting health through the organized efforts of society.

Public health surveys:
Surveys are an important means of collecting health and social information from a sample of people in a standardized way to better understand a larger population.

Welfare System:
Welfare refers to a range of government programs that provide financial or other aid to individuals or groups who cannot support themselves. In this case, the network of medical units throughout a country is part of its welfare system.

Contact tracing apps (CTA):
Contact tracing is the process of identifying all people that a patient of a specific disease has come in contact with within a certain time window.

General overview:

Defining Public Health Studies and its role.

The public health community is responsible for studying diseases and conditions from afar and then subsequently leading the welfare system to find solutions for the problems at hand. The field of public health is very diverse, tackling both minor and major issues within the medical field. Public health research has saved countless lives before they even entered hospitals. Part of the reason why public health is so effective is the fact that the largest part of its community is focused on research.

Under both the HIPAA Privacy Rule and a US federal regulation known as the Common Rule, research is defined as "a systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge." This is a broad definition that may include biomedical research, epidemiological studies, and health services research, as well as studies of behavioral, social, and economic factors that affect health.

One of the most familiar forms of health research is the clinical trial in which patients volunteer to participate in studies to test the efficacy of new medical interventions. Today, though, an increasingly large portion of health research is information-based.

However, a now increasing amount of research entails the analysis of data and biological samples that were initially collected for one purpose and are now being used for research. In the fields of epidemiology, health services research, and public health research, the use of existing data to conduct research is common. Existing data is analyzed to identify patterns of occurrences, determinants, and the natural history of disease; to evaluate health care interventions and services; to perform drug safety surveillance; and to perform some genetic and social studies. A prime example of the benefits of research using already existing data derived from patients is the development of trastuzumab (Herceptin), a treatment used for some kinds of breast and stomach cancer.

Furthermore, findings from research using patients' medical records have changed and evolved the way we practice medicine. For example, research has shown that tens of thousands of patients lose their lives annually due to medical errors and has provided valuable information to hospitals in order to reduce these errors by implementing methods such as e-prescribing. In other cases, studies have found links to staff shortages and patients suffering complications, such as infections and internal bleeding. In any case, as the usage of electronic medical records

increases, so does the pace at which public health research can be facilitated, thus allowing the medical field to rapidly expand based on the newfound information.

Moreover, due to the large variety of methods of carrying out public health research, we are able to gather complementary insights. For example, while it is useful to carry out clinical trials where certain variables can be controlled, feedback from real-world patients is also crucial for expanding and improving the efficacy of the subject that the feedback concerns.

Public health is just as, if not more, important as privacy is. It can be the deciding factor when it comes to saving people's lives. Collectively, the public health community can provide information about diseases, treatments and the risk factors that come with them, or even public health interventions. The article "Beyond the HIPAA Privacy Rule: Enhancing Privacy, Improving Health Through Research" states that "If the health research enterprise is impeded, or if it is less robust, important societal interests are adversely affected".

Defining privacy and its importance.

Privacy is a term that was first defined by Louis Brandeis in 1890 in the popular study "The Right to Privacy". He defined it as "the right to be left alone". In the context of the medical field, privacy is the question of who, under what conditions and to what extent has access to patients' personal information.

Issues about personal data collection include whether specific types of data can be collected at all as well as the potential for pieces of data to be used in ways that may cause harm to the patient in the future. For example, disclosure of personal medical information to an insurer or an employer could result in stigma and discrimination against the individual. Another particular issue is whether an individual has given consent to the data being collected for particular uses. What makes the concept of privacy even harder to qualify is the fact that it is subjective and context-specific, meaning that data can be considered private in specific cases but not in others. This means that the autonomy of an individual must be placed in high regard, as ultimately, personal data used in the wrong ways is very harmful to a person's well-being. Treating individuals with respect is essential as to ensure that they can make choices about when and whether personal information can be shared with others.

A rise in concern about privacy and the effect it has in public health research:

In recent years, the number of concerns about identity theft, misuse of data and patient privacy has led to increases in the severity of privacy laws, which negatively affect public health by preventing researchers from accessing the data they need.

These well-intentioned national and local laws and standards, such as the HIPAA in the USA, are designed primarily to protect patients' rights and confidentiality, but they also negatively affect the efficiency of public health systems. Many have argued that these laws are too radical, and in the cases that they are not, they do not work as well as they should while also impeding with the conduct of important public health research. This is due to the tense climate of modern society; constant fears of data leaks and identity theft make it easy for the public to lose

perspective on how restrictions of how much information is available can undermine efforts to better understand and improve public health and welfare systems in general.

The field in public health which is most greatly affected by privacy protection laws is public health surveillance, which entails accessing routinely collected, population-based data. This method of public health research has been extremely successful in tackling public health concerns.

For example, in the 1950s, John Snow was able to identify the source of deadly cholera outbreaks in London as contaminated drinking water by mapping the relative geographical position to the water source of those who died versus those who did not. In 1975, The National Cancer Institute published the first Atlas of Cancer Mortality, which used geographic information for discovering new or confirming suspected etiologies and identifying high-risk populations. In the early 1990s, multiple studies established clear links between short-term changes in air quality and the frequency of acute and chronic cardiorespiratory disease and mortality in individuals; results which, to this day, are being confirmed.

These studies were all conducted to some degree through the method of public health surveillance, which would mean that it would be very difficult and impractical to repeat those studies but by obtaining consent from individuals. In addition, consent in these cases is not ethically required since the use of data is already limited to aggregating results. However, increasingly restrictive regulations continue to restrict access to crucial data necessary to conduct research on a greater scale.

Researchers within the public health community have repeatedly stated that some restrictions are too harsh and limit the potential of the medical system. This is not to say that privacy is undermined in any way. On the contrary, most find privacy and confidentiality to be a very important part of healthcare. For the issue at hand to be solved, a middle-ground in which data that public health researchers need is readily available while also keeping the identity of the patients confidential.

Case studies:

COVID-19 Pandemic

Since the start of the pandemic in 2020, the debate of privacy versus public health has been amplified, as privacy concerns have returned to the spotlight for both individuals and companies. Governments worldwide have been utilizing contact tracing apps (CTAs) to curb the spread of the virus and the data being collected is used for prevention and public health research. Even so, some fear that CTAs and other tracking methods can be classified as breaches of privacy by either governments or external factors, such as data breaches, leaks and hacks.

Moreover, many countries are now mandating vaccinations for people returning to work after the lockdown, leaving them with no option but to submit personal information into a governmental database, which could be subject to external and internal breaches as well as potential loss of data through means such as natural disasters and workplace accidents.

India

On the 2nd of April 2020, the Indian Government released Aarogya Setu (Bridge to Health), a CTA meant to combat COVID-19 which reached 50 million downloads in a mere 13 days, making it the world's first application to reach the milestone in such a short period. The app requires personal details such as the user's name, gender, profession, smoker status, travel history as well as biometric information, which is all stored in a centralized database held by the government. Even more controversially, the application uses GPS to track infected individuals' locations, which is shared both with other users and the government. According to many parties, the app invades people's privacy at an unacceptable level.

Dr. Michael Ryan, the executive director of the WHO's health emergencies program, has warned that "the right to privacy after the collection of personal data while tackling this pandemic cannot be overlooked". The right to privacy is outlined in Article 21 of the Indian Constitution, but even so, many fear that Dr. Ryan's concerns are justified. There is no dedicated legal framework to manage and protect the public's personal information, and what little legislation does exist is subject to inconsistencies in application and enforcement.

People's Republic of China:

China was the first country to implement CTAs globally as a means of curbing the spread of COVID-19 worldwide. The government has partnered with tech giants Alibaba and Tencent for the development of the app. Like many other CTAs, it uses a green-yellow-red system in which individuals labeled green are cleared to enter public spaces. Those labeled yellow may have come in contact with a COVID patient and those with red apps are registered patients.

The app's system works by tracking the locations of all its users and then comparing them to hotspots or the locations of verified patients that were previously cleared. The Chinese CTA has the same issues that the Indian variant has, with the main difference being that the former is said to outlast the pandemic. Coupled with the fact that this CTA is mandatory in contrast to its European counterparts, the Chinese government is criticized by many members of the global community.

Indonesia:

Launched in 2021, the electronic Health Alert Card, or eHAC, was Indonesia's solution to the problem of travelers transmitting COVID within the country. The app keeps track of the users' health status including COVID test results, personal information and other data.

Later on, in the summer of the same year, researchers with vpnMentor uncovered a data breach in the app, which essentially exposed all the aforementioned information of more than 1.3 million users. This was attributed to the app's protocols or rather, lack thereof.

Major parties involved:

USA:
The USA is the country with the most COVID-19 cases globally currently. In addition, most US citizens are opposed to the use of CTAs and other data-gathering methods that could aid in stopping the spread of disease. Furthermore, the USA has historically been at the forefront of the fight to establish rights to privacy for its citizens.

People's Republic of China:
The Chinese government has been taking decisive steps to strengthen individual rights to privacy over the past decade. With the newly announced Personal Information Protection Law (PIPL) the country is taking privacy as seriously as ever. On the contrary, many view the liberal use of CTAs as a violation of privacy by the government, and with rumors that these apps might outlast the pandemic the suspicions are further solidified.

New Zealand:
New Zealand was the first country globally to declare itself COVID-free after the first wave of the pandemic hit. The government's approach to public health has proven effective, with rapid action and trust in its citizens at the forefront, without violating their privacy.

Timeline of Events:

1890	Privacy Defined by Louis Brandeis in "The Right to Privacy"
1948	UN Declaration of Human Rights
1960	Privacy torts outlined by William L. Prosser in "Privacy"
1967	Katz vs United States Supreme Court Case
1974	Privacy Act of 1974
1975	Atlas of Cancer Mortality
1995	EU Data Protection Directive
1996	Health Insurance Portability and Accountability Act (HIPAA)
2020-2021 (ongoing)	COVID-19 Pandemic

Possible solutions:

Striking a perfect balance between privacy and public health without at least partly compromising one or the other is an arduous task, especially because this issue concerns every member state. This is not to say that it is impossible, but it would be very difficult to achieve.

In most cases, external data leaks are mostly facilitated through the exploitation of weaknesses in cyber security measures. Therefore, governments should allocate resources to the development of more secure platforms and systems that have to do with any kind of personal information to ensure the safety of the information they withhold. This is especially important when one considers past occurrences of data breaches concerning the personal data of millions of people, which could result in spikes of identity theft and fraud which some law enforcement and judicial systems are not equipped to handle. In other cases, data loss could occur through natural disasters or other causes, which would render an entire system meant to combat a disease completely useless. Redundancy for databases and systems containing personal data should also be at the forefront of governments' attention.

Many argue that limited access to medical records is almost required to more efficiently deal with diseases and conditions, especially when it comes to specialized cases and diseases that are more widespread, like malaria, AIDS, and even mental disorders. Access to information is one of the factors that constitute a welfare system. A stable and reliable source of information could save thousands of lives and by extension, aid in the global economy. In addition, in the age of the internet, this information can become accessible to medical practitioners worldwide, which would mean that LEDCs have a better chance at tackling widespread illness, for example.

In the case of public health studies, a universal standard that would determine the extent to which medical information about a patient could be publicized should also be decided upon. This is to avoid giving out an individual's personal information to the public while also providing scientists with the information they need to conduct effective research. In other cases, however, where the disease or condition is rarer, scientists do not have as large of a sample size to examine. Therefore, governments would either need to permit the scientists to collect personal data, or they would compel the researchers to obtain consent from the patient.

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