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Placing the “radar” under the radar: Ethics of public health surveillance

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Abstract

Public health surveillance (PHS) is an essential public health activity, which entails collecting data on diseases and disease-related states in a timely manner to aid in international health regulations and in local health planning. Opinions differ sharply on whether it is a research or non-research activity. In recent years, most low- and middle-income countries (LMICs) have been establishing their own PHS systems, with or without support from external donors, to comply with the stipulations of international health regulations. With the expansion of the scope and role of PHS in ensuring the health security of countries, it is important to understand the ethical principles of PHS and the specific ethical issues involved in it, as well as the need for ethical oversight of PHS. This paper deals with these aspects of PHS, and highlights the need for specific ethical guidance and oversight mechanisms in LMICs that are setting up their own PHS systems.

Introduction

Public health surveillance (PHS), also referred to as the “radar” of public health, can be defined as the ongoing, systematic collection, collation, analysis, interpretation and dissemination of health-related data in a timely manner to those who need to know, so as to effectively plan, implement and evaluate public health activities (1). The National Institute of Communicable Diseases, South Africa defines it as “continuous analysis, interpretation and feedback of systematically collected data, generally using methods distinguished by their practicability,

uniformity and rapidity” (2). According to an older definition, PHS is “a system of close observation of all aspects of the occurrence and distribution of a given disease through the systematic collection, tabulation, analysis and dissemination of all relevant data pertaining to that disease” (3). This activity is essential for the proper planning and delivery of public health interventions. Originally, the term PHS was used to refer to infectious disease surveillance, but now it encompasses a wide array of targets that are under scrutiny. These are chronic diseases, chronic disease risk factors, and environmental exposures. Several modalities of surveillance of health-related states and events have been in use. The most common and time-tested modality is the reporting of diseases by health providers, health facilities and laboratories. Of late, non-surveillance data are being used for PHS. Vital registrations, health information systems, disease registries, demographic and health survey data, law enforcement records, etc are all used as sources of data for PHS (4–6). The social media and Internet-based data are also used for PHS (7). Given this expansion of the role and scope of PHS in recent years, the ethical considerations in the practice of PHS are now a matter of global concern. Several important ethical issues are involved in the practice of PHS. These are as follows.

Ethical imperative to perform PHS

Conducting PHS is necessary to ensure local and global health security. Health security has been defined in several ways. Health security includes protection against threats such as poverty, hunger, disease, pandemics and bio-terrorism; the provision of medical aid and humanitarian assistance during conflict; and the involvement of military and political interests to prevent the cross-border spread of diseases (8). The International Health Regulations, which were modified in 2005 and came into force in 2007, have been ratified by 196 countries. They aim to “prevent, protect against, control and provide a public health response to the international spread of disease” (9). The recent Ebola epidemic in West Africa created awareness of the collective threat to health security

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and more importantly, of the threat to the health security of each individual in these countries. The epidemic revealed the fragile nature of international boundaries when it comes to global health threats. It also exposed weaknesses in the PHS mechanisms in vulnerable countries. The most vulnerable countries in terms of the capacity to perform PHS face the greatest threat to global health security and hence, it is a moral imperative to support the establishment of good surveillance systems in these countries through international cooperation (10). Non-communicable diseases (NCDs) place a huge burden on the low- and middle-income countries (LMICs). A strong PHS system would protect the vulnerable countries from NCDs too (11). A strong PHS is not only important in the global context, but is also very helpful in checking the local spread of diseases. It provides data that are useful for the effective planning of the delivery of health services. PHS provides data on the magnitude of specific health problems in the local area, portrays the natural history of the disease, shows the distribution and spread of the illness, provides information on the most effective control measures that can be taken and indicates the resources required to implement these. It thus facilitates the effective planning of public health interventions in the local area (12). There are several important ethical principles which govern and direct PHS.

Ethical principles involved in PHS

As with any public health activity, the key ethical principle underlying PHS is the *common good*. The concept of common good extends beyond the provision of good to the individuals in the community. It includes the good that accrues to the community as a whole, including even those who do not participate in PHS and those who are not yet born into the community (13–15). Those who are part of the community may not be able to shun the benefits even if they fail to participate in PHS.

The principle of *equity* is integral to PHS, as it is the most underdeveloped areas with poor PHS capacity that face the greatest threats to health security, besides posing the greatest challenge to the global spread of disease. This was evident from the recent Ebola epidemic in West Africa, where countries with a poor PHS capacity not only suffered the brunt of the disease, but also posed a serious global threat (10). Considerations of equity demand that PHS include marginalised and vulnerable populations as much as mainstream populations. The benefits and burdens of PHS should be distributed equitably between the well off and the vulnerable. Often, high-income countries support the establishment of PHS in LMICs, targeting specific diseases that are a threat to the high-income countries. This places an ethical burden of compromising on privacy and confidentiality on the low- and middle-income regions that is disproportionate to the benefits which accrue mainly to the high-income regions. An example of this kind of inequitable surveillance plan is the establishment of surveillance of disease pathogens in the LMICs by the USA under the

Global Pathogen Surveillance Act. The USA offers training, capacity-building and the establishment of high-technology laboratories in these countries in exchange for surveillance of pathogens that are of research and academic interest in the USA (16). This type of inequity should be addressed and the benefits and burdens balanced (14, 17).

Individual autonomy, privacy and confidentiality have a secondary role among the ethical principles of PHS because the effectiveness of a surveillance activity will be compromised if all members of the community are not included. However, no explanation based on the common good can justify disproportionate violations of the respect due to an individual as a member of the community. The principles of *proportionality and public justification* of the PHS are important (15,18). Are the burdens of intrusion into the individual's privacy by accessing his/her disease-related information proportional to the common good accrued to the community? Sometimes, PHS involves the collection of people's personal identifying information, such as their names and contact details, to ensure that they are treated, trace their contacts to prevent the spread of infection and institute control measures in the neighbourhood. In the case of certain stigmatising diseases, such as leprosy, tuberculosis and HIV/AIDS, it is important to assess whether such name-based disease surveillance and consequent stigmatisation of the patient, is proportional to the benefits of having such data and reporting it. In such stigmatising conditions, anonymous reporting or reporting stripped of identifying information may be more proportional to the benefits. In some settings, unlinked anonymous testing (UAT) has been suggested for HIV as a method to avoid selection bias. The testing is not based on "informed consent"; there is no breach of confidentiality and at the same time, effective PHS data may be collected. However, UAT is associated with an ethical burden, which is that the results of the test can never be traced back to the patient and declared (19). Such burdens of PHS should be publicly justifiable and acceptable to the community.

In relation to the community's acceptance of such infringements of individual privacy emerges the principle of *community engagement*. Community engagement is the process of working collaboratively with and for groups of people who are connected by geographical proximity, special interests or similar health-related factors that affect the health of the community (20). Community engagement is essential for the ethical delivery of PHS since it entails better protection of the community's interest, creating and sharing benefits for the community, establishing the legitimacy of the surveillance effort, and encouraging the sharing of responsibility for benefits and risks (21).

Accountability is another important ethical principle of PHS. It is defined as answerability for interventions, along with sanctions for poor performance (22). Proper accountability is ensured by setting up monitoring and evaluation systems and good governance systems for PHS. Accountability to the community in the matter of health security can be achieved by

having proper standard operating procedures, effective quality assurance mechanisms, incentives and sanctions to regulate the performance of the surveillance (22). In many LMICs, PHS is implemented in a programme mode, with the support of an external donor. In such situations, the *sustainability* of the PHS is of prime importance. Sustained PHS leads to long-term benefits, covers the latency period between the introduction of PHS and the time by which it begins to have favourable effects on populations, and promotes and maintains the trust of the community in the activity (23). Several important ethical issues that are specific to PHS emerge from these central principles.

Specific ethical issues in PHS

Certain ethical issues arise when setting up a PHS system for an area. These are how far it is responsive to the local health priorities; whether the human resources used are adequate and appropriate; and whether the system focuses on strengthening of the overall health system (unlike vertical surveillance programmes). The PHS system should be *responsive to local health needs*. LMICs such as India are facing a dual epidemiological burden of communicable as well as non-communicable diseases (24). Therefore, PHS systems should focus on both these aspects. The capacity of LMICs to actively monitor and perform surveillance of the risk factors for and outcomes of NCDs is poor, and with the changing epidemiology of NCDs in these countries, there is a need for PHS to be responsive to the situation (25). Malaria, tuberculosis and HIV/AIDS receive a lot of global attention, and there is a good amount of funding for research and capacity-building in these areas. This is because these are focal diseases in the Sustainable Development Goals agenda (26). However, there are neglected tropical diseases, such as dengue, leprosy, leptospirosis, cholera, hookworm, leishmaniasis, rabies, chikungunya, cysticercosis and hydatid cyst, in the LMICs that do not receive the same kind of attention. The local PHS systems should keep these in mind (27,28). Apart from setting priorities for PHS, there is also a need to set up efficient systems in LMICs at a cost that is affordable.

The *appropriate use of human resources for health* is essential in this context. The PHS system may rely on hospital/health facility-based reporting, laboratory-based reporting, syndromic surveillance by field-level community health workers, media news surveillance or rumour surveillance. Human resources are essential for all these approaches. In India, syndromic surveillance driven by community health workers has been used in several vertical surveillance programmes. The existing Integrated Disease Surveillance Programme (IDSP), sponsored by the World Bank and established in 2006 (29), is also based on this approach. In this context, the issue of overburdening health workers should be borne in mind. Attempts to appropriately motivate the health workers involved in surveillance, such as with incentives, may be helpful in improving efficiency (17). *Conflicts of interest* may also arise as the health worker plays the dual role of delivering preventive health service and performing the syndromic surveillance. As a person delivering preventive care, he/she is supposed to

ensure low rates of disease in the population. This conflicts with the role of being a surveillance reporter, who has to accurately report every person who has the disease.

A *systems approach to PHS*, rather than an approach based on a vertical programme, is likely to improve the performance of the public health system. It is well known that health systems are complex, adaptive systems, the components of which work in a non-linear and dynamic manner. There is mutual feedback and learning between the components, patterns emerge through interaction between them, and the behaviours of the system are often unpredictable (30). Therefore, the establishment of a PHS system may have synergistic and multiplicative beneficial effects on the overall health system. For example, training health workers to effectively capture illness by syndromic reporting may sensitise them to the need to intensify preventive measures and strengthen the public health interventions. It may also make them stronger health advocates. This is a typical effect of one component of the system feeding into and enhancing the other.

In the context of PHS, we come across another unique set of ethical issues, ie infringements into the privacy and confidentiality of community members, potential use of healthcare service data for PHS purposes, dissemination and sharing of PHS data, and establishment of appropriate standards of care for those diagnosed through surveillance. In epidemiological and public health activities like PHS, especially those that involve infringement of the private space of the community members and the collection of health-related information, the ethical burden of *breach of privacy and confidentiality of participants* emerges as an important issue (31). In the case of passive surveillance based on health facilities, the patients provide implied consent to share their confidential and private health information with the providers for the sake of treatment. This usually does not mean that their data can be accessed for the purpose of maintaining a surveillance database. On the other hand, in the case of active surveillance based in the community, patients may hesitate to provide confidential information to a surveillance officer who is not the care provider. In most surveillance activities, access to identifying information, such as name, address and telephone number, is protected. However, despite this protection, several concerns remain regarding the confidentiality of the data collected. These include (i) to what extent the data is protected; (ii) who gets access to the data; (iii) whether the community knows who gets access; (iv) how long the data will be maintained; and (v) for what purposes the protected data will be used. For example, an implementation research study was carried out in Tanzania on the control of lymphatic filariasis. The study involved the mass administration of drugs and utilised routine surveillance data for research purposes (32). If the use of surveillance data is allowed without adequate ethical oversight, it might constitute an unethical breach of the participant's privacy, with the participant having no knowledge of how the data will be used. If the community members refuse to voluntarily share data, it will compromise the efficacy of PHS. On the other hand, in order to ensure the efficacy

of surveillance, the community members cannot be forced to share their private information. In this context, adequate community buy-in into the PHS activity becomes important. This can be achieved through active community engagement. Though it may not be feasible to obtain the *informed consent* of each community member to share his/ her data for the purpose of PHS, the lack of consent cannot undermine the need for the community to know about PHS and its potential implications. The principle of *solidarity*, which reflects what community members are willing to do for the sake of other members of the community, either for the sake of future self-interest or for the sake of genuine altruism, plays an important role in the community's willingness to share data to promote a strong PHS system (33).

At times, healthcare service data may be used in PHS. With the development of electronic health records, the accessibility of healthcare service data for purposes of PHS has increased. However, this gives rise to several ethical issues. Individual patients might face stigmatisation and other consequences of breach of confidentiality. Patients have the right to know how their health data are being used; this right is violated if the data are accessible to PHS without their explicit consent. Moreover, the PHS having such access to patients' information may break public trust in the health system. In addition, when there are no regulations to supervise the open sharing of patients' information, there is a chance of the data being commercially exploited (34). For example, in India, as in many LMICs, there is an active electronic health record of all maternal and child health services delivered through the public health system, known as the Mother and Child Tracking System (35). This system is password-protected and accessible to those who need the information. The data, including identifying information, are accessible to researchers and programme evaluators. There is no system in place for the ethical evaluation of access to this electronic data. Though the Guidelines for Electronic Health Records in India, proposed by the Ministry of Health and Family Welfare, lay down strict regulations for the protection of personal information, a good part of the regulations have yet to be operationalised at the field level (36).

Often, PHS data are analysed and utilised for the specific evaluation of programmes, situation analysis and inferences. In a programme based on the mass administration of drugs for lymphatic filariasis, the routine filarial smear surveillance was analysed to make inferences on the effectiveness of the programme. It is important to remember that surveillance data are neither collected rigorously to ensure the scientific validity required for research, nor are they sampled in a representative manner. Using surveillance data out of context can be an ethical problem since the results are likely to be misleading. The *dissemination and sharing of PHS data* also pose important ethical dilemmas. In the spirit of solidarity, it may become necessary to share PHS data locally and globally. The International Health Regulations mandate the sharing of PHS data on certain important diseases (37). For public health emergencies of international concern, the IHR

recommend global surveillance systems which share data from different countries (38). However, while disseminating and sharing the data, adequate precautions must be taken to prevent breach of confidentiality, with the data being stripped of identifying information. Rather than discussing and debating the ownership of data, ethical discourse should focus on transparency in data sharing, accountability and the justifications for data sharing.

Lastly, *setting up appropriate standards of care* for patients diagnosed with any of the diseases included in the PHS is an ethical obligation. While setting up PHS, consideration should be given to the strengthening of healthcare delivery for the diseases reported by the people and detected by surveillance. In certain situations, specific disease surveillance is set up with the support of a donor. In these situations, treatment facilities should be established for patients who have been found to have the disease. Further, the PHS system should consider the provision of ancillary care (39). Should care be provided even to those patients diagnosed with diseases that are not covered by the PHS? It may not be possible for the PHS to address all ancillary care responsibilities. However, the strengthening of the overall health system should be able to take care of this.

Ethical oversight for PHS

Whether PHS is research or a public health activity is a contentious issue. Specific guidelines suggest that those activities which collect more data than that required for the delivery of essential services, the findings of which can be generalised to populations other than those that directly participate in the data collection, and which can be used to generate new knowledge are referred to as research. Those activities which collect less data than that required, are applicable to only those from whom the data has been collected, and do not lead to generalisable results are classified as non-research activities (40). If PHS is considered pure research, it would have to be subject to the rigours of research ethics, such as obtaining informed consent and the approval of an independent, impartial ethics committee (18). This may not be feasible in the case of PHS, given that some PHS activities must be undertaken on an urgent basis. On the other hand, if PHS is deemed a non-research activity, it escapes ethical review and is not bound by the other considerations unique to research activities. This may not exactly be a comfortable situation, given the potential ethical burdens involved in PHS. Therefore, some form of ethical oversight is essential for PHS, albeit not a full-fledged review by a research ethics committee. Depending on the individual state's capacity, this oversight may be provided by regular research ethics committees, or specific public health ethical committees for each public health activity. In LMICs, where the capacity to perform PHS is developing and limited, PHS may take different forms. Sometimes, *ad hoc* surveillance is established following the outbreak of an illness, such as influenza, for a specific period of time. There may be surveillance of the quality of the air and water immediately after a disaster situation. Such *ad hoc* PHS activities require a very different form of ethical oversight

than does a standard well-established, systematic PHS system. Therefore, the state may not be able to develop a uniform mechanism of ethical oversight for all forms of PHS. Moreover, such ethical oversight may be problematic in LMICs, which have a limited capacity even insofar as regular research ethics committees are concerned. To ensure ethical oversight, there is a need for strong ethical guidance, based both on the main ethical principles and specific ethical issues involved in PHS. It is necessary to build the capacity of public health practitioners, members of ethical committees, policy-makers and other stakeholders to understand the ethical burdens associated with all forms of PHS. A State-level discussion could be initiated to agree upon the most appropriate mechanism of ethical oversight of PHS, and thus institutionalise the ethics of PHS.

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Revisiting New Zealand's "Unfortunate Experiment": Is medical ethics ever a thing done?

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Abstract

An experiment dating from the 1960s in New Zealand has eerie similarities to research begun in 1976 in India. In both cases, women with evidence of early cervical cancer or pre-cancer went untreated, despite known treatments that could have prevented their condition from worsening. This Comment on carcinoma cervix research grew out of my reading of a new book by Ronald W Jones about the New Zealand experiment. Jones, a recently retired obstetrician/gynaecologist, worked at the hospital where the controversial research took place and was a whistleblower in the case. His book provides a meticulous account of internal struggles within the hospital over what has been called "the unfortunate experiment." Readers might fairly ask whether a detailed examination of a decades-old research scandal in New Zealand can usefully inform ethics debate in India today, where conditions are so different. I argue that Jones's account does indeed provide valuable insights for understanding research wrongdoing in other contexts, including low-income countries. Jones challenges some widespread assumptions about why such cases occur and how to combat them, as do several other recent analyses of research scandals.

Introduction

Medicine has a sad legacy of research scandals, and discussions of how to eliminate them are central to medical ethics. Among the most infamous is the Tuskegee study, in which researchers at the US Public Health Service followed 400 African American

men with syphilis for 40 years and withheld treatment, in order to understand the progression of the disease (1). Similar in many respects is a study of women with cervical cancer in situ (CIS), carried out in New Zealand from 1966 to 1988, and the subject of a new book, *Doctors in denial: The forgotten women in the 'Unfortunate Experiment.'* (2). Herbert Green, a professor and senior physician at the National Women's Hospital (NWH) in Auckland did not believe CIS was a precursor to invasive cancer of the cervix and, to prove his point, continued to record the untreated lesions of dozens of women, even as their cancers progressed and some patients died. In *Doctors in denial*, Ronald Jones describes the New Zealand case as an insider with a strong point of view.

Two questions come to mind. First, does Jones's book on the New Zealand case add to the existing mountain of documentation, analysis and debate that this particular experiment has already generated? And if Jones does offer new insights, do they have any relevance to medical ethics in India, which has its own cervical cancer scandals? The answer to both questions, I argue, is an emphatic "yes."

Pitfalls and potential of cross-cultural comparisons

First, some valid concerns. In an editorial in this journal in 2012, Mala Ramanathan and Amar Jesani noted that ethics teaching and scholarship in India tend to foreground international research cases from high-income countries, to the exclusion of home-grown scandals (3). They pointed out that, to spur the development of a homegrown bioethics movement, India's own local cases need to be written about, debated and discussed as part of bioethics teaching. Excessive focus on international cases, they cautioned, might breed complacency, sending the implicit message that such breaches only happen elsewhere. Furthermore, these cases from high-income countries might obscure local realities central to ethics in India,

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