

Health and Demographic Surveillance System Sites: Reflections on Global Health Research Ethics

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Abstract

Although there should be no ambivalence regarding the importance of the Health and demographic surveillance System (HDSS), surveillance and research on human populations is beset with a variety of ethical issues. This is particularly true in the area of global health research, which merits attention in health policies related to research ethics. The objective of this paper is to analyze the use of HDSS sites to obtain data and to resolve ethical conflicts over HDSS approaches, such as those related to data collection, surveillance, and research. This analysis is done in light of guidance on central ethical issues relating to health research such as the International Ethical Guidelines for Health Research. This paper is a critical review of literature of ethics in health and demographic research and surveillance, which has identified and analyzed the major areas of contemporary ethical concerns with respect to surveillance and research conducted by HDSS in accordance with existing ethical guidelines for health research. Concerns addressed in this paper are an overt admonishment about the importance of a range of issues from informed consent, beneficence, and justice, to advice on the best means to utilize surveillance data. Although use of HDSS allows for invaluable contributions by providing longitudinal data for in-depth understanding of surveillance areas, which indirectly guides policies, programs, and interventions at national and international levels, studies using this means of gathering data are beset with multidimensional ethical concerns with respect to the research and surveillance they carry out. Many of the ethical concerns cannot be resolved under the broader ethical standards set by the major sources of international ethical guidelines or frameworks. Thus, the paper stresses that different and innovative lines of thinking and approaches are required for studies employing HDSS to ensure the best ethical conduct in health research for the improvement of global health.

Key words

Health and demographic surveillance system; global health; research ethics

Background

Developing countries in general lack effective civil registration and vital statistics systems, and hence there is always a deficiency of necessary and systematic demographic data and health information (Adazu et al., 2005; Byass, Worku, Emmelin & Berhane, 2007; Ye, Wamukoya, Ezeh, Emina & Sankoh, 2012). Health and demographic surveillance system (HDSS) sites have been established in the developing countries of Africa, Asia, and the Pacific region as an alternative to a well-organized and comprehensive civil registration and vital statistics system, and to serve as a continuing and systematic process for longitudinal health and demographic data collection and analysis from defined populations at particular

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geographic locations. HDSS sites originated in the 1960s (Delaunay et al., 2013). Although in 1990 there were only a few HDSS sites, there are myriad now in this increasing trend in establishing these means for gathering needed data. The International Network of Demographic Evaluation of Populations and Their Health (INDEPTH) is a membership organization for HDSS sites. INDEPTH extends its technical support to undertake site-specific studies as well as cross-site scientific research. As of 2017, INDEPTH now has 49 HDSS sites monitoring more than three million people (INDEPTH, 2019). INDEPTH gathers data across HDSS and establishes standards for data acquisition (Herbst et al., 2015).

HDSS sites, or data gauges, are largely considered to be very effective and comprehensive data collection systems, as they focus respectively on small and clearly defined populations of particular geographic areas, and thus allow more accurate sampling frames at multiple levels and by different strata. Although there is no real ambivalence regarding the importance of HDSS, surveillance and research on human populations is beset with a variety of ethical issues in the area of global health research, which merit attention in health research ethics policies (Carrel & Rennie, 2008). Central to the ethical concerns are the principles of autonomy, respect for individuals, beneficence, and justice (Page, 2012). The major sources of international ethical guidelines include the *Nuremberg Code*, the *Declaration of Helsinki* designed by the World Medical Association (WMA), the *International Ethical Guidelines on Biomedical Research involving Human Subjects* formed by the Council on International Organizations of Medical Sciences (CIOMS), and various research ethics guidelines issued by the World Health Organization (CIOMS, 2016; WMA, 2013). All of this guidance places restrictions on research to protect the interests of research subjects and prevent ethical wrongdoing (Alcabes & Williams, 2001; WHO, 2015), but it can be argued that in the presence of faulty, inadequate, or ill-conceived ethics regulations, confidentiality and protection of sensitive information such as participants' records will still be vulnerable to misuse. As research involves myriad individuals, everything possible should be done to ensure that misuse of data does not occur.

The aim of this paper is to elucidate the ethical concerns that need to be addressed in all HDSS operations in relation to global health research in general and surveillance in particular. Here it can be noted that health surveillance is also the basis for public health research. The areas of inquiry that have guided this research are: (i) whether HDSS sites reflect adequately upon ethical issues (informed consent, beneficence, and justice) of global health research, with particular reference to surveillance; (ii) whether the defined populations at long-term HDSS sites, which have been in existence for a couple of decades, are truly reflective of the national population for extrapolation to the national level, and create reliable evidence for policies and interventions; (iii) whether the enormous amounts of routine data collected at HDSS sites were fully used, and justified the massive resource allocation for that purpose; (iv) whether research in HDSS suffers from selection bias due to migration; (v) whether repeated studies on the same populations lead to disinterest by requiring these individuals to participate in too many studies as subjects; (vi) and whether HDSS sites' universal claim of contributing to health policies and interventions can be substantiated. These areas of inquiry have been framed through surveys of literature which, generally, are related to global health research ethics, and more particularly, in direct and indirect surveillance.

Methods

The study is based on a critical review of relevant literature. The literature pursued for this study was accessed through the PubMed, PubMed Central, and Google Scholar electronic databases to find relevant studies published since the year 2000. Key search words included:

“ethical issues in HDSS”, “informed consent in HDSS”, “beneficence and justice in HDSS”, “use and representativeness of HDSS”, “HDSS and their contributions to health policies and programs”, “privacy and confidentiality of research subjects in HDSS”, and “selection bias in HDSS”.

Only literature having relevance with the objectives of this study were selected. In addition to these electronic data base searches, the WHO and INDEPTH websites were consulted for the literature review. Some of the literature was also identified through reference lists of literature that had already been selected and then they were located using names of the authors in the electronic data bases. Since studies on HDSS sites are mostly available from the year 2000, this particular paper has limited the literature search to the year 2000 and subsequent years.

Using the key words of ‘ethical issues in HDSS’ through PubMed, nine items were found and only one was selected, but in PubMed Central, 1,020 items were found and four were selected, and in Google Scholar, 2,220 articles were found and sixteen items were selected. Using the key words of ‘informed consent in HDSS’ through PubMed four items were found with none of these items selected, but in PubMed Central, 905 items were found and two were selected, and in Google Scholar, 2,140 items were found and three were selected. Using key words of ‘beneficence and justice in HDSS’ in PubMed and Pubmed Central, no literature was found, but in Google Scholar, 21 items were found and three were selected. Using the key words of ‘HDSS and their contribution to health policies and programs’ in PubMed no literature was found, however in PubMed Central, 175 items were found and two were selected, and in Google Scholar, 2,650 items were found and three were selected. Using key words of ‘privacy and confidentiality of research subjects in HDSS’ in PubMed, no item was found, but in PubMed Central, 13 were found even though none was selected, and in Google Scholar, 536 items were found and one was selected. Using key words of ‘selection bias in HDSS’ in PubMed, no items were found, but in PubMed Central, 324 items were found and one was selected, and in Google Scholar, 1,800 were found and only one was selected. In the following, Table 1 shows a summary of the literature search by key words and by respective electronic data bases.

Table 1: Literature search summary by key words by respective electronic database

Search terms	PubMed		PubMed Central		Google Scholar	
	Found	Selected	Found	Selected	Found	Selected
Ethical issues in HDSS	09	01	1,020	04	2,220	16
Informed consent in HDSS	04	0	905	02	2,140	03
Beneficence and justice in HDSS	0	0	0	0	21	01
Representative use of HDSS	0	0	48	0	185	02
HDSS and their contribution to health policies and programs	0	0	175	11	2,650	03
Privacy and confidentiality in of research subjects in HDSS	0	0	13	0	536	01
Selection bias in HDSS	0	0	324	01	1,800	01

Findings and Discussions

1) Ethical dilemmas related to health research, health surveillance, and public health

The protection of human research subjects is the primary ethical consideration of health research. This concern originated from the Nuremberg Trials of 1947 following the medical

experiments conducted in concentration camps in World War II. The principles that emerged from these trials are known as the Nuremberg Code. Two important guidelines on ethical regulations for health research that were developed thereafter at the international level were the Declaration of Helsinki, issued by the WMA in 1964 and revised most recently in 2013, and the 1988 guidelines issued by CIOMS in association with WHO that was revised in 2016. These guidelines, like laws and constitutions, do not cover every possible circumstance, and thus require thoughtful interpretation for their application in varied situations (Benatar, 2002).

Ethical issues in health research and public health mainly concern informed consent of the research subjects, avoidance of harm to individuals, beneficence, public good, and justice. Thus, it has been incumbent on researchers working with HDSS populations to formulate approaches that ensure an appropriate balance between promoting public health goals and ensuring research subjects' autonomy, privacy, beneficence, and justice (Carrel & Rennie, 2008). The following two sections present these areas of ethical concerns related to HDSSs and pave the way for further research and dialogue towards resolving these issues and concerns.

Issues of informed consent in health research and the HDSS perspective

The autonomy of human research subjects is a core ethical principle in health research, and all international guidelines for health research consider informed consent to be imperative for safeguarding that autonomy. The issue of informed consent has deeper implications for fulfilling ethical obligations in health research and requires going beyond the formal process of documenting consent. Researchers need to provide full and transparent information to research subjects about the intent and procedures of the study, the nature of their participation or involvement with the research, and the potential benefits and risks to the subject associated with such involvement (Bhutta, 2004). Furthermore, informed consent also implies giving information on future uses and consequences of data (Mittelstadt & Floridi, 2016). It should be made clear to research subjects that it is their right to withdraw from a study at any time, and not just before giving formal consent to participate in it. This concern is particularly important for all programs in HDSS, in which there are often many adults who were brought up during the surveillance period and often feel it is obligatory on their part to respond to requests made by HDSS personnel (Carrel & Rennie, 2008). Long and complex informed consent documents may even do disservice to achieving the real goal of seeking informed consent (Hallinan, Forrest, Uhlenbrauck, Young & McKinney Jr, 2016). Good communication and culturally sensitive consent procedures are critical for actually informing research participants before seeking their consent. Consent procedures adhered to in developing countries are often lengthy and generally drawn from developed countries, and hence are not connected to local norms and contexts. Such consent is more focused on providing legal protection to researchers than on informing research subjects (Bhutta, 2004).

The issue of informed consent is different and far more complex in the case of surveillance of a geographically defined population than it is for an individual research subject in clinical research. In surveillance sites, the concept of autonomy, the position and role of individuals within the household, and the multi-generational nature of longitudinal surveillance complicate the issue of informed consent (Carrel & Rennie, 2008). The very first requirement of selecting an HDSS site is getting community approval. Thus, in selecting a site for HDSS, individual-level consent is irrelevant. However, it is widely contended that community consent cannot be a substitute for individual consent because of the intense scrutiny that takes place at the household and individual levels by HDSS sites.

This issue of consent gets more complicated if data collection takes place on residential, household, and individual levels. Household level consent is often criticized for not being

adequately respectful of individual autonomy. The ethics of seeking consent from a given male head of a household for his family's participation in surveillance has also been questioned (Carrel & Rennie, 2008). Furthermore, the intergenerational nature of surveillance sites raises questions about validity in terms of duration of consent. For surveillance sites that have existed for decades, the question of whether consent given by the previous generation also applies to the next is relevant. Although research ethics calls for obtaining new agreements of consent at household levels, the HDSS sites generally consider this too time-consuming and a waste of resources.

It has also been argued that obtaining individual consent for surveillance is not practical and therefore is not a relevant ethical concern. Some argue that, in certain cultures, community consent is more valued than individual consent (Cassell & Young, 2002; Diallo et al., 2005). The importance of community leaders and families in decision-making processes is gaining wider acceptance. However, issues of individual and community consent should not be glossed over to the extent that community consent supersedes individual consent. There should first be an in-depth study in which the community is able to identify its legitimate representatives to attend introductory and formal meetings with researchers. The process should be a means of widely dispersing knowledge about research within the community. Evidence shows that a thorough process of obtaining community consent by involving multiple community stakeholders can offset the effects of not obtaining individual consent. Getting involved with the community at different levels, with different stakeholders and on a wider scale, is a means of taking into account the opinions of all types of stakeholders (Diallo et al., 2005). However, such processes take up considerable resources, and sharing content is often considered labor-intensive (Bhutta, 2004).

Beneficence, justice, and the distribution of risks and harm to research subjects and HDSS

□ Confidentiality and distribution of risk and harm

Health research has ethical obligations to maximize benefits and minimize risks to research subjects -- and even more so when those subjects are members of vulnerable, marginalized, and socio-economically disadvantaged populations, or are children, elderly persons, prisoners, and other disenfranchised minority populations (Coughlin, 2006). Research subjects in public health research are particularly burdened with loss of privacy and time, labelling or stigmatization of individuals, or psychological effects such as enhanced grief, stress, and anxiety (Coughlin, 2006). There needs to be a fine balance between generating and using epidemiological data to promote population health, on one hand, and protecting the privacy of individual research subjects by ensuring the confidentiality of health information, on the other (Stoto, 2008; Carney et al. 2000; Chevrier et al. 2019; Williams & Pigeot, 2016). Even though protecting the confidentiality of health information is challenging in the wake of massive technological advances in data handling and sharing, individual privacy can be protected by releasing only aggregate data or removing personal identities from databases. Other effective means of maintaining confidentiality in data are "limiting access to confidential records, discarding personal identifiers from data collection forms and computer files... encrypting computer databases, limiting geographic detail, and suppressing cells in tabulated data where the number of cases in the cell is small" (Coughlin, 2006).

□ *HDSS sites and issues of beneficence and justice*

Issues of justice arise whenever a change is made to geographic boundaries of an HDSS site. Here, the main egalitarian concern is whether to continue providing care or other accrued benefits to residents of the study area if that area has shrunk in size, or if there is a closing of the local HDSS. In HDSS sites that provide healthcare irrespective of participation status, a reduction in geographic coverage has no effect in terms of beneficence or justice on research subjects. Impacts will be felt, however, on HDSS sites that do not provide services to non-study populations, i.e., that provide services only to study subjects. In such cases, the question arises as to whether former participants of the HDSS should continue to receive study benefits when no longer providing personal information for a study. For HDSS sites, possible solutions to such issues would be to work with the ministry of health and gradually transfer these services to local or national health services or to integrate surveillance activities into local or national healthcare systems (Carrel & Rennie, 2008).

The fatigue of respondents is another issue that arises with frequent and rigorous data collection by HDSS sites that update the data of local populations multiple times each year (Oduro et al., 2012; Ye et al., 2012). Another consideration is the high expectations of research participants in being financially compensated for the time that they expended -- expectations that HDSS sites, due to lack of resources, cannot satisfy (Wanyua et al., 2013). Thus, prior to conducting research, adequate funding or allocation of budget to support such participants must be ensured.

There is growing recognition amongst both the population and HDSS researchers that it is the right of residents to have clear knowledge of what is being done with the vast amounts of data and information collected from them through demographic follow-up and additional surveys over a long period of time. Reporting research results back to communities can help them understand how various projects can affect their health patterns and can provide incentives for improving their participation in surveillance and research activities (Mondain, Delaunay & Ouédraogo, 2016). However, reporting results to the residents of HDSS sites is neither simple nor easy to do, and it raises many questions. Among those questions are how widely and to whom the results should be reported (i.e., to the entire population, or to selected representatives); how best to identify that which should be reported; and determining the appropriate mode of communication (Mondain et al., 2016). Resolving these issues is vital for meaningful dissemination and communication of research results to the residents of HDSS sites.

2) Use of HDSS data, its representativeness, and the issue of extrapolation of HDSS data to the national level

Use of HDSS data to maximize benefits

Use of data generated by HDSS sites encompasses both their use in the surveillance system and their use by other public health professionals and health staff to maximize benefits. There is a risk that if data are overly constrained by the means imposed to ensure maximum autonomy and confidentiality, that the little data that will be generated from it might be of limited use for the ultimate goal of public health research. Therefore, the utilitarian purposes of huge amounts of data generated by HDSS sites by multiple stakeholders and at multiple levels is a primary concern, and it is from this that there is a *raison d'être* for the work and existence of those systems.

For HDSS data, a core issue around data sharing is that there is never a point in time when data collection is complete. This makes data sharing complex for HDSS sites. But as these conceptual issues must be frequently addressed, specific periods of data sharing from HDSS sites need to be announced in advance. INDEPTH has initiated the iSHARE portal for public availability of data from HDSS member sites (Sankoh & Byass, 2012). Even so, there are still calls for making HDSS data sharing simplified and more widespread (Clark, 2015; Sankoh & Byass, 2012).

Features of HDSSs and the issue of extrapolating HDSS data on the national level

- *Representativeness of HDSS sites and the issue of extrapolating HDSS data to the national level*

To enable the generalization of findings at a national level, the surveillance system should accurately reflect the characteristics of health-related events with respect to time, place, and persons under surveillance (German, Horan, Lee, Milstein & Pertowski, 2001). There are persistent claims that HDSS sites, being located in particular geographic areas, and each covering small populations, cannot collect sufficient data from which to draw inferences at the national level (Ye et al., 2012). HDSS sites are typically located in rural areas, and site selection criteria are not always clear (White, 2017). Thus, inferences made in rural areas and attributed to urban populations, or even to broader rural populations, may be inaccurate due to inherent biases (Sankoh & Byass, 2012; White, 2017).

There are claims that populations in HDSS areas may receive benefits that those in other areas do not receive. Furthermore, intense surveillance and repeated measurements at HDSS sites are also considered to be passive interventions. Too many concurrent projects at any HDSS site can overburden the people under surveillance, which can lead to distortion of the outcome measures of the projects and result in imprecise interpretations and conclusions (Baiden, Hodgson & Binka, 2006). Therefore, there is concern that as populations in HDSS areas are often dissimilar, data obtained from discrete HDSS sites should only be generalized as applicable to other or all HDSS sites with extreme caution (Ye et al., 2012).

However, such claims are not always adequately substantiated with evidence. A comparison of HDSS and DHS mortality surveillance in Ethiopia found comparable overall mortality data (Byass et al., 2007). In fact, HDSS data are thought to be less susceptible to recall bias than DHS data and other sample surveys (Ye et al., 2012).

To overcome any of such limitations of HDSS data, or putative limitations, for wider applicability and inference, it has been suggested that HDSS should track certain key indicators from other geographic regions of the country for comparative study and to correct potential biases in HDSS data, should any exist. Comparing HDSS data with other data sources, such as censuses and cluster sample surveys, has also been suggested as a means of overcoming such limitations. Another tactic would be to establish additional HDSS sites in other parts of the country for geographic balance (Sankoh & Byass, 2012; Ye et al., 2012).

- *The issue of migration in and out of HDSS sites and selection bias in research*

Demographic events in HDSS sites are recorded at regular intervals based on the principle of universal coverage, which enables the collection of more precise and valid information and results in less underreporting of events. However, as in all multi-wave longitudinal studies, drop-out or attrition occurs in HDSS sites due to migration and other reasons, and if systematic – i.e., if the losses of residents are related to their social or behavioural

characteristics -- may lead to selection biases, and incorrect results that might be drawn from the study (Asendorpf, Van De Schoot, Denissen & Hutteman, 2014; Wolke et al., 2009). Population migration within the surveillance setting produces change in the characteristics of the sample population, and this affects the representativeness of the population and thereby affects any inferences made from it. These biases may stem from changes in the population at risk, or in the characteristics of the population on which the study is based. For instance, in the case of an education-related intervention, if a portion of students with the greatest potential leave the site with their parents to seek better educational opportunities elsewhere, any results based on the remaining students may be biased. In this regard, considering migration as a loss-to-follow-up, i.e., a random censoring may be customary in the case of a short-term intervention, but may cause bias in the longer term (White, 2017). The attrition of populations at various HDSS sites is connected to issues of representativeness and extrapolation of HDSS data to the national level. However, researchers have been formulating computer applications to minimize such biases, and are also engaged in making such knowledge widespread (Asendorpf et al., 2014).

3) Issues concerning HDSSs' contributions to health policy and intervention

INDEPTH members have recognized that HDSS sites need to work directly in close contact with local and national authorities to be able to directly influence national policies, rather than working indirectly through their partners. Furthermore, these sites also need to generate information that is more relevant to national policy than to the policies of international external agencies (Ye et al., 2012). HDSS sites can make immense contributions by partnering their staff with national staff members to allow their local data to become integrated with national statistics and information systems. District health systems can benefit enormously from having information on population distribution, demographic characteristics, health characteristics, causes of death, etc. (Tollman & Zwi, 2000). However, HDSS sites are staffed more with those possessing expertise in science and technology and thus lack expertise in policy and program management. Effective communication and dissemination of descriptive statistics on vital features of health and demography are crucial for effective resource allocation, priority setting, and targeting at the implementation level. Thus, HDSS sites tend to emphasize the funding of academic theses for Masters and Ph.D. programs and publishing academic articles in peer-reviewed journals more than recommending implementation of specific policies (Ye et al., 2012). This emphasis is fulsome as agency briefs are of greater importance and relevance to national policies and programs than are publications in peer-reviewed journals.

Conclusions

Health and Demographic Surveillance System Sites (HDSSs) make invaluable contributions by providing longitudinal morbidity, mortality, and fertility data for in-depth understanding of surveillance areas, which guide policies, programs, and interventions on national and international levels. These HDSS sites are beset with multidimensional ethical concerns with respect to the research and surveillance that they carry out. However, these HDSSs are confronted with multidimensional ethical concerns with respect to the research and surveillance they carry out. This paper has identified and analyzed the major areas of contemporary ethical concerns with respect to surveillance and research conducted by HDSS

sites in light of existing ethical guidelines for health research. Here, most of the ethical concerns that have been raised cannot be resolved within the existing broad ethical guidelines or frameworks. Therefore, it is time to work on how to resolve such conflicts and respond to such circumstances in the best ways that are possible. One important strategy in working towards that goal would be to organize academic brainstorming initiatives on such issues at the national and international levels involving cross-sections of stakeholders.

Abbreviation

HDSS: Health and Demographic Surveillance System Sites; WHO: World Health Organization; WMA: World Medical Association; CIOMS: The Council on International Organizations of Medical Sciences; INDEPTH: International Network for Demographic Evaluation of Populations and Their Health.

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