Is There a Duty to Share? Ethics of Sharing Research Data in the Context of Public Health Emergencies

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Making research data readily accessible during a public health emergency can have profound effects on our response capabilities. The moral milieu of this data sharing has not yet been adequately explored. This article explores the foundation and nature of a duty, if any, that researchers have to share data, specifically in the context of public health emergencies. There are three notable reasons that stand in opposition to a duty to share one’s data, relating to: (i) data property and ownership, (ii) just distribution of benefits and burdens and (iii) the contemporary ethos of science. We argue each reason can be successfully met with corresponding rationale in favour of data sharing. Further support for data sharing has been echoed in policies of health agencies, funding bodies and academic institutions; in documents on the ethical conduct of biomedical research; and in discussions on the nature of public health. From this, we ascertain that sharing data is the morally sound default position. This article then highlights the key roles reciprocity and solidarity play in supporting the practice of data sharing. We conclude with recommendations to regard public health research data as a common-pool resource in order to build a framework for stable data sharing management.

Introduction

Scientific data leading to health research is a foundational and necessary component of medicine and healthcare policy and practice. Making research data available and readily accessible during a public health emergency can have profound effects on our response capabilities (Toronto International Data Release Workshop Authors, 2009). Public health emergencies of international scope require the coordinated efforts of many groups and individuals; scientists are integral in conducting research that may lead to improved responses, in addition to the prevention and management of future emergencies.

The consequences of the failure to share data in public health emergencies was well documented during the SARS outbreak in 2003. Poor information sharing and lack of agreement on data sharing protocols were identified as important barriers to an effective response to a novel pathogen. These failures occurred in communication between levels of government and in the effective translation of new science into practice. (Public Health Agency of Canada, 2003) While many recommendations were made in the wake of SARS, these recommendations focused on technical specifications of information systems and legal agreements. In the recent H1N1 pandemic, similar issues arose with respect to sharing data related to full disclosure of possible increased risks of H1N1 infection associated with previous H3N2 influenza vaccination. Failure to fully disclose the research data led to confusion in the mind of the public, reduced acceptance of vaccination and conflicting vaccine schedules in adjoining jurisdictions in Canada.

Clearly, the issue of data sharing is important in public health response to a variety of threats. However, little guidance has been offered regarding the appropriate framework by which data ought to be shared and the moral milieu of data sharing has not yet been adequately explored, particularly in the context of public health and public health emergencies. This article will explore the foundation and nature of a duty, if any, that researchers have to share data, specifically in the context of public health emergencies. First, we provide
some definitions of key terms. Second, we will provide some context for the debate on data sharing. Third, we will briefly present what we consider to be the principal arguments against sharing data. Finally, we will investigate arguments in favor of sharing data and the role that the ethical principles of reciprocity and solidarity play within this debate.

Definitions

Samples, data and results are three distinct concepts: samples often refer to the physical materials that are used to investigate some phenomenon, data are generated based on experimental and statistical tests upon the samples, while results generally refer to the fruits of analyzing data. Although arguments in favor or against sharing samples, data and results likely overlap, for the purpose of this article, we will concentrate on sharing data. By sharing, we understand the collaboration between researchers themselves and between researchers, public health agencies, funding bodies and those charged with reviewing and publishing scholarly research.

The World Health Organization’s (WHO) International Health Regulations (IHR) defines a public health emergency of international concern as a case of a particular disease whose emergence is unusual or unexpected and may have serious public health impact (e.g. an influenza virus caused by a new subtype or severe acute respiratory syndrome—SARS), or any event of potential international public health concern including those of unknown causes or sources. Further, the IHR consider an event involving particular diseases that have demonstrated the ability to cause serious public health impact and to spread rapidly internationally, such as cholera or yellow fever, as a public health emergency of international concern (World Health Organization, 2005: 43). Therefore, when referring to public health emergencies, we imply emergencies that may be of local or international scope.

Finally, we define ‘duty to share data’ as an obligation that a person or institution has made their data publicly available.1 It is both a positive duty to share, that is actively making ones data available, as well as a negative duty to refrain from preventing others from doing so. Both of these features will be explicated further below. We hold also that a duty to share data is an-all-things-considered duty, which is a duty one has if the appropriate grounds that support it outweigh any considerations that count against it.2 In what follows, we will show that it is indeed the case that the grounds for a duty to share data in public health emergencies outweigh competing claims.

Context

Traditionally, peer-reviewed publications and professional status has incentivized research in formal academic settings, such as universities. The sharing of data both before and following publication has not been similarly prioritized (‘Sharing Public Health Data’, 2010). It is generally agreed that in non-emergency contexts, scientists have a proprietary moral and legal right to the data obtained from their research projects (Bernard et al., 2009). However, given the public nature of public health emergencies (further explained below), a balance must be struck between the intellectual rights of researchers and their concerns with promoting professional interests with the broader social interest to protect the public.

There is little literature regarding the ethical issues of sharing samples, data and results during public health emergencies. Improved data sharing and the creation of protocols to achieve this end were recommended in the aftermath of SARS (Public Health Agency of Canada, 2003). Policy guidance regarding data sharing between scientists in non-emergency situations is also quite sparse, but the issue has become one of importance recently. The International Society for Biological and Environmental Repositories – Best Practices Document does outline some basic principles on the sharing of samples between countries (2008: 1–58). Some organizations, such as the World Health Organization, acknowledge the importance of respecting individual research efforts while equitably sharing benefits (WHO, 2007). Further, the movement to publish research results in open source journals implicitly applies the principle of sharing scientific information with little-to-no barriers to others (Biological innovation for Open Society, 2009) However, it remains the case that no document or policy provides guidance on how to share data, and the respective benefits and burdens of doing so, especially in the context of public health research (Bernard et al., 2009). Recently, eight of the largest health agencies argued for the need for greater access to health data and for those creating health data to make data more readily available (Chan et al., 2010). Included in this proposal is a call for greater data sharing. As well, in genomics research, the ethical basis of data sharing has been explored (Kaye et al., 2009).

While no explicitly argued position exists against a duty to share data (in emergencies or otherwise) there
is a sense of an implied opposition to sharing data from the behavior and conduct of individual researchers with regard to data sharing in the wake of the SARS outbreak and the recent H1N1 Influenza Pandemic. At the very least, there seem to be a great number of individual researchers and institutions that behave on the assumption that there is no operating duty to share their data. In fields such as genetics, data withholding in academia has been significantly observed (Campbell et al., 2002). There is currently little understanding of the extent of data withholding in public health research, though significant examples through SARS and H1N1 have indeed shed light on the potential consequences of this behavior. This, combined with a lack of clear official guidance, indicates that a duty to share data is by no means self-evident and a sound position must be advanced. The following sections explore at some depth the possible reasons both in opposition to and in support of a duty to share research data with the aim of weighing the respective positions on the merits of the arguments advanced.

Arguments Against Data Sharing

There are three reasons that have been invoked as speaking against a duty to share data: scientists have ownership of the data, data sharing gives unfair advantages to other researchers, and data sharing is against the culture of science. These may be classified as belonging to (i) arguments from private property and ownership, (ii) arguments from fairness and just distribution of benefits and burdens and (iii) arguments from the ethos of science.

In the first instance, one is faced with the inescapable fact that, put frankly, data does not grow on trees. Researchers make substantial investments of time, resources and effort in the collection, conceptualization and creation of usable data. Having mixed their labor with the data, it follows that researchers have a claim to it as their private property and the research ethos would favor the liberty of researchers to dispose of property as they see fit, and to not permit access to that property without permission or payment. Sharing of data would be on mutually agreed and contractually based terms, with the data owner possibly reserving the rights over its future use.

A closely related consideration that speaks against sharing of data derives from the notion that open sharing of data may constitute an unfair advantage to other researchers who did not exert effort in its creation. Data are not generated for their own sake, but rather to facilitate further research and insofar as it has the potential of doing so if it constitutes a benefit to those who possess it. Other researchers may benefit from the data and may in fact be able to make discoveries in a more rapid fashion. If data is freely shared it creates an opportunity for free-riding, which is considered unethical because it supports parasitic relationships, fails to provide incentive or reward for intellectual creativity, and may create conditions where scientists no longer want to engage in primary data collection. This would thwart the long-term aims of scientific discovery and would facilitate an unfair distribution of the benefits and burdens within the process of research.

Finally, one has to face the competitive reality of science and the demands that this places on the researcher. Many, if not most, institutions have adopted publication volume and citation rates as standards of excellence, thus exerting a lot of pressure on researchers to publish as much and as frequently as possible. The success of a research program in terms of high impact publications and securing grants and awards is dependant on being the first to publish results. This highly competitive environment makes data that much more of a valuable commodity to each researcher and sharing one’s data can be seen as directly helping competing groups and hindering one’s own professional development and career.

While the above discussion of reasons in opposition to increased openness and sharing of data raise legitimate and weighty concerns, it should nonetheless be made clear that they do not provide a conclusive rebuttal to a duty to share data. In the following section, we undertake a close examination of the reasons that may and have been advanced in support of a duty to share data. As will be made clear, each of the concerns raised above can be addressed with a satisfactory response in kind.

Why Data Sharing is the Morally Sound Default Position

Each of the previously stated challenges to a duty to share data, we argue, can be successfully met with corresponding reasons that speak in favor of such a duty. There are three moral reasons: (i) data ownership can be broadened to include the public that funds it; (ii) as such, maximizing the social benefits of research is of great import; and (iii) the collaborative nature of contemporary science calls for the sharing of data.

A comprehensive look at the contemporary state of science reveals that research can no longer be regarded
as an activity divorced from its broader social context. Most research has a social dimension; not only is the individual researcher part of society, and thus subject to social norms, but his research is also inescapably embedded in the social milieu. Economic, political, social and cultural values play a fundamental role in virtually every aspect of a research project from the goals and objectives of research, to the allocation of resources for the project, to the practice with which these are actualized. (Jasanoff, 1990, 1995; Longino, 1990; Guston, 2000) Furthermore, public funding and support has become an integral part of virtually all research. From assisting in the training of the investigators to the provision of funds and resources for the experiments themselves, the public has made significant investments and holds a substantial stake in science. Within the field of genomics, the debate on data sharing has developed so as all of the major funding bodies now make data sharing a requirement of support for all projects. The rationale behind these policies has reflected the arguments that science is not only furthered by access to openly available data, but also that the data created by publicly funded bodies should be freely available in the research community (Kaye et al., 2009).

This should lead us to a critical re-examination of the claim that research data ought to be considered as the private property of the researchers, the research team or even the corporate sponsor. The public, most easily conceived as taxpayers, have also made substantial investments alongside the researchers into the generation of useful data. As such, research data is more accurately described as common property shared among, at best, equal partners in its creation: the researchers and the public. It is therefore wrong to claim that researchers, institutions or sponsors should have exclusive rights over the data they collect. To be sure, they ought to be considered significant partners, perhaps even equal partners, in the decisions degrading the distribution and dissemination of data but they cannot claim to be exclusive possessors.

Recognizing the stake that the public and society at large has in science generally and research data in particular (of both values and resources) should also help in addressing the challenge. In considering the just distribution of the benefits and burdens of data sharing the benefits and burdens of individual researchers or research teams should be considered alongside the benefits and burdens to the greater public and society at large. To put things simply, it is not enough to establish a claim of injustice or unfairness to point out that someone other than the researchers that generated the data will stand to benefit from it. Given the social investment that is inevitably made into the generation of research data an additional and powerful consideration is whether society as a whole will benefit from greater openness in access to data. Given that there is a researcher–society partnership in the generation of data, the resulting distribution of benefits and burdens may still be fair if the public, as a legitimate partner, stands to benefit from the sharing of data.3

Lastly, there is the challenge of a fundamental tension between an attitude and practice of openness and sharing of data and the competitive ethos of contemporary science. It should be recognized that research is not, or at least it is no longer, a solitary activity. Collaboration and cooperation are increasingly recognized as vital to continued progress in virtually every area of science today. Dissemination of work and data is essential to the advancement of science as a whole. No single researcher has an absolute claim on truth and in so far as he considers himself a ‘scientist’ (itself a social construct residing in a social context, as mentioned above), there exists for him an obligation to share his work with colleagues and the public for scrutiny and review.

Support for Data Sharing in Policy and Ethics

Many public and private funding agencies recognize the value of shared data and this is clearly reflected in the requirement that grant proposals specify plans for the dissemination of proposed research and a requirement to report to the funding agency about publications that result from the grant (Grinnell, 1992). A clear example of this is the requirement on data sharing that are part of the National Institutes of Health policy on data sharing: 

In NIH’s view, all data should be considered for data sharing. Data should be made as widely and freely available as possible while safeguarding the privacy of participants, and protecting confidential and proprietary data. (NIH, 2005)

In addition, there is a general recognition of the obligation of sharing data that is reflected in NIH policies that require researchers to state their plans to share data, reagents, or organisms in their grant applications or to explain any proposed restrictions on sharing (NIH, 1998b, 2003).

Second, related to arguments from the raison d’être of science, there are ethical considerations that support an obligation to share research data. For over 50 years, the ethical conduct of biomedical research has been guided by such fundamental documents as the Belmont Report,
as evidenced by such integral and commonly accepted
science is grounded in a social context, so is health itself, health is public by its very nature. Just as modern-day
i.e. that a large portion of what we commonly mean by
mental is the idea that health is a public good or burden,
public health is challenging, but at least partially funda-
mentally, this
restriction of access is, all things equal, directly antithet-
ic to realizing those benefits. This is particularly rele-
vant to the very least, it should be clear that arguments to the
contrary face a significant burden of proof if they are to be
decisive. Nevertheless, it must be noted that there
seems to be (at least) a compelling interest for society
generally and the scientific community in particular to
actively facilitate sharing of data and make it more feas-
ible for individual researchers. As mentioned above, the
efforts and contributions of researchers in the gener-
ation of data is an important and weighty consideration
and it deserves the fullest recognition. We engage with
this issue of recognition and due credit in the following
section.

Ethical Principles for Consideration

Reciprocity

While data sharing aims to benefit society as a whole, it
may place large costs on the researchers attempting to
share their data. Combining this fact with the inade-
quate incentive or recognition that is given to those
who do share data, researchers are less inclined to
make their data sets publicly available. Thus, reciprocity
and incentives from other researchers and society to the
initial data contributors is needed to promote data shar-
ing (Piwowar et al., 2008). Without reciprocity from
those who benefit from the shared data, initial data con-
tributors will not be persuaded to share research infor-
mation. This can lead to problems during crisis
situations, such as an influenza pandemic, where re-
search data are needed to facilitate the production of
vaccines or antivirals. Societies can facilitate reciprocity
by providing infrastructure, which make data sharing
easily understood and accessible. For example,
Theologis and Davis discuss the need to develop a federally funded research institute that ‘. . . will facilitate the distribution of materials produced by a small laboratory with limited funds’. In doing so, costs and efforts can be prevented from being an excuse for partaking in data sharing (2004: 4–9).

Once data has been contributed to the public stream, researchers and end users of shared data must not fail to provide appropriate acknowledgement to the colleagues who collected and shared data (Bernard et al., 2009). Proper recognition in publications must be given for both authors and data contributors. As data collection and analysis may at times require expert skills, it is important that these efforts are highlighted in publications (Kaye et al., 2009).

Academic institutions can also promote data sharing practices to demonstrate the value of the activity. By implementing policies that recognize data sharing as an aspect used to help determine professional advancements in academia, the act of data sharing can be encouraged. Rewarding researchers, who are sharing data, via professional bonuses, funding or promotions can help break current academia norms on sharing (Piwowar et al., 2008).

Solidarity

A deadly global pandemic, or comparable public health emergency, leaves almost no lives untouched. Such dramatic events bring to the surface the deep interconnectedness and interdependence that we share as human beings. It is in such times that solidarity, that bond that integrates individuals into a people, a society and a community as a greater entity than a mere collection of persons, is put to the test. The magnitude of the threat that something like global pandemic represents demands a common and unified response. It is a common enemy against which, to borrow from Benjamin Franklin, ‘We must, indeed, all hang together or, most assuredly, we shall all hang separately’.

The nature of the threat of large-scale public health emergencies highlights the importance of solidarity as a value that generates a moral impetus to pandemic preparedness and response (Thompson et al., 2006). The health research community, as a community, is and ought to be regarded as united under a goal of combating disease. Individual researchers should see their work not simply as parallel to or concurrent with the work of others, but rather as an integral part in a greater project of preventing disease and securing human flourishing. Similarly, researchers, insofar as they are just as vulnerable to the harms of public health emergencies, share a bond of solidarity with the greater public.

What is important in discussions about sharing of public health and relevant biomedical data is that this information and the resulting knowledge are among our most potent defenses against the suffering of others from infection and disease. Embracing the value of solidarity highlights our common interests and shared vulnerabilities, providing additional impetus for collaboration in protecting human health and promoting human well-being.

Conclusions

Our positive case in favor of an all-things-considered duty to share research data should be viewed as equally relevant in cases of both (in reference to primary funding) private as well as public research. To be sure, our case is significantly stronger in the context of data generated with the use of public resources, but the considerations presented above should nevertheless be taken into account when dealing with research data of public health significance even if it is generated through private means. Although there are legitimate and weighty considerations that may oppose sharing of such data or impose limits what and how much is to be shared, it is undeniable that these do not invariably or necessarily trump the reasons in favor as they have been presented above.

The possible distinction between national and international levels of sharing of research data may be addressed in a similar vein. While considerations of the stake that the general public holds in generating public health research data are most applicable on a national scale, there is no obvious reason why arguments from solidarity, reciprocity and potential public good should be considered as any less relevant at the international level in cases of globe-spanning public health concerns such as pandemics. As with the case of privately funded research, there may be unique and legitimate countervailing considerations regarding the particular economic or political realities of certain states, but it begs the question to insist that these are the only things that ought to be considered or that they are necessarily dominant in balancing the pros and cons of an all-things-considered duty to share research data internationally.

Our experience from the H1N1 influenza pandemic has shown how in times of urgent health concerns such as pandemics and other significant disease outbreaks, ready access to research data is critical in providing effective public health response. Data sharing is not only constitutive of good scientific practice, but is the
morally sound default position in public health emergencies. Reasons supporting a duty to share research data stem from concepts relating to: a broadened understanding of data ownership, the social context of public health, and the normative underpinnings of scientific research. Though these reasons successfully challenge corresponding arguments that oppose a duty to share, measures should still be in place to alleviate the costs borne onto researchers. Ethical principles of reciprocity and solidarity help support the practice of data sharing by providing recognition for contributors. However, in order to establish sustainable data sharing practices, more work must be done to develop an appropriate framework by which data can be shared.

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Notes

1. In principle, we do not see a hard distinction between making data accessible to the wider research community as opposed to the wider general public. For the purposes of our article, however, making data ‘publically available’ should be primarily understood as referring to other researchers.


3. To be sure, this is premised on the assumption that the sharing of data merely fails to benefit the researchers involved and does not positively harm them.

References


