

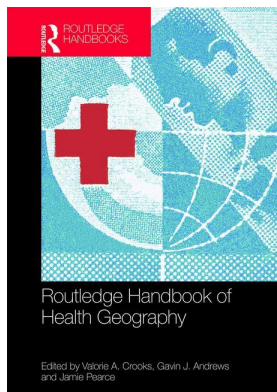
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NAVIGATING RESEARCH ETHICS IN HEALTH GEOGRAPHY

The case of big data

Nina J. Morris

Increasingly stringent governance of professional academic conduct in recent years has seen the review of proposed studies by institutional or national Research Ethics Committees (REC) become a standard feature of health-geography research (Boden, Epstein and Latimer, 2009; Burr and Reynolds, 2010; McCormack et al., 2012). This shift, stemming from a series of 20th century biomedical research scandals (e.g., medical experimentation in 1940s Nazi Germany, the 1932–1972 Tuskegee Institute Syphilis Study in the United States) and the ethical codes published in their wake (e.g., Nuremberg Code, Declaration of Helsinki, Belmont Report) (Dyer and Demeritt, 2009; Hoeyer, Dahlager and Lynöe, 2005; Schrag, 2011), has meant that academics' compliance with ethical standards is now a personal duty rather than simply a matter of "personal and professional integrity" (Dyer and Demeritt, 2009, p. 47). Recent interest in research ethics, however, has also been fueled by growing concerns over economic inequalities, international human rights, increasing public interest in scientific endeavors (Molyneux and Geissler, 2008) and broader social trends toward *accountability* (Boden, Epstein and Latimer, 2009). So, what began as an attempt to regulate medical research practice (Hammersley, 2009) has expanded to encompass "everything that might be considered 'human subjects' research, and [. . .] politically extended to almost all academic research" (Emmerich, 2013, p. 177). Health geography is no exception, and in this chapter I discuss the ethical implications of research with large datasets with particular reference to issues of consent and re-identification. These issues are important not only for researchers who undertake secondary data analysis, but also for those involved in primary data collection who intend to make their data available for reuse.

The rationale for ethical oversight is largely accepted (Klitzman, 2011; Librett and Perrone, 2010; Nind et al., 2012). RECs are credited with raising researchers' ethical awareness, promoting good-quality research with favorable risk-benefit ratios and reducing exploitative research (Molyneux and Geissler, 2008). Ethical codes of conduct are acknowledged to (a) promote the aims of research (knowledge, truth, avoidance of error) and the values that are essential to collaborative work (trust, accountability, mutual respect, fairness), (b) provide researchers with guidance and a consistent set of expectations, (c) ensure that researchers are accountable, build public support for research (trust in quality and integrity) and (d) promote other important values (social responsibility, human rights) (Madge, 2007; Metcalf and Crawford, 2016; Resnik, 2011).

Over the last decade, however, some have expressed concerns regarding the perceived bureaucratization of ethics through REC regulation (Hammersley, 2009; Pickersgill, 2012) and the applicability of biomedical-research governance procedures to social-science research including health geography (Bond, 2012; Emmerich, 2013; see Chattopadhyay and De Vries, 2008, for a discussion on non-Western contexts). For example,

RECs often require researchers to take precautions to ensure the safety of their research participants (Dingwall, 2008; Klitzman, 2011) without taking into consideration the varying power differentials that may be in operation depending on the status of the researcher/participant, the research topic and the methods being used (Burr and Reynolds, 2010). Research participants are not always vulnerable (Dyer and Demeritt, 2009), and those in powerful or elite positions may use ethical regulations (e.g., informed consent) to avoid close scrutiny (Boden, Epstein and Latimer, 2009). Conversely, those labeled “vulnerable” may feel that ethical standards such as anonymity disassociate them from the research (Metcalf and Crawford, 2016) or silence them entirely (Boden, Epstein and Latimer, 2009).

There is also frustration at the inability of standardized ethics-review procedures (often deemed to be rule-bound, formulaic and inflexible) to accommodate the often unpredictable (Hoeyer, Dahlager and Lynöe, 2005; Dyer and Demeritt, 2009; Hammersley, 2009; Burr and Reynolds, 2010), subjective and messy (Butz, 2008) nature of social-science research. A particular fear is that as REC protocols become ever more prescriptive, researchers will become more conservative in their choice of subject matter and methods (Bond, 2012; Librett and Perrone, 2010; Nind et al., 2012) or, worse, will be untruthful about the true nature of their research (Boden Epstein and Latimer, 2009; Hammersley, 2009) in order to get ethics approval. Likewise, there is a worry that if doing ethics becomes nothing more than a box-ticking exercise, researchers will lose their capacity for ethical reasoning (Dyer and Demeritt, 2009), thus limiting their ability to adapt their methods as circumstances change (McCormack et al., 2012), and that ethical debates will become entirely depoliticized (Blee and Currier, 2011; Molyneux and Geissler, 2008; Schrag, 2011).

A rapid rise in the application of big-data methods and secondary analysis (Zook et al., 2017), particularly in health geography, has brought with it a new series of ethical dilemmas (Metcalf and Crawford, 2016; Zook et al., 2017). Indeed, the “speed with which these new sources of data have emerged, as well as the increasingly imaginative ways that researchers are using them, risks running ahead of the development of an appropriate ethical framework for their use” (McKee, 2013, p. 299). For example, in the not-so-distant past, researchers were required to destroy their data on completion of a project as an absolute way of dealing with issues of confidentiality and data protection (Morrow, Boddy and Lamb, 2014). In recent years, however, opinion has shifted in favor of reusing quantitative and qualitative data – also known as secondary data collection or analysis – whenever possible. Using secondary data is said to be ethical in and of itself because it promotes research integrity by making data available to others for validation, thus acting as a safeguard against fraudulent research (Grinyer, 2009). Economically, reuse maximizes the value of any investment made in data collection (Morrow, Boddy and Lamb, 2014). Morally, it ensures that individuals from potentially vulnerable populations are not over-burdened by research. It ensures replicability of study findings and, as a result, greater transparency of research procedures and integrity of research work (Morrow, Boddy and Lamb, 2014). However, the reuse of data collected in either the course of one’s own research or that of another (Grinyer, 2009) raises significant issues relating to consent, anonymity and representation (Blatt, 2012).

Of course, some argue that big-data research does not require ethical review because it does not involve direct intervention into the human body or because the data are public (Metcalf and Crawford, 2016) even if they originated from a breach or other illegal activity (Leetaru, 2016; Metcalf, Keller and boyd, 2016). Incorporating information derived from multiple sources (for health geographers, these might include hospital episode statistics, mortality and demographic data, land cover databases or social media), big data is characterized by its high volume, velocity, variety, exhaustive scope, resolution and indexicality, relationality, and flexibility (Kitchin, 2013), all of which can lead to an illusion of anonymity. Projects in the United States, for example, that make use of already existing, publicly available datasets are exempt from REC regulation because they are considered to “pose only minimal risks to the human subjects they document” (Metcalf and Crawford, 2016, p. 1). Others would argue that we should jettison consent altogether for research that uses anonymized personal data, because contributing our data is a social good and because requiring consent would limit researchers’ potential to have an impact on long-term community health outcomes (Millett and

O’Leary, 2015). It has become rapidly clear, however, that the “scope, scale and complexity of many forms of big data creates a rich ecosystem in which human participants and their communities are deeply embedded and susceptible to harm” (Zook et al., 2017, p. 1).

Consent

Consent is a central pillar of ethical research. Previously, emphasis has been placed on the need for primary researchers to gain participants’ voluntary informed consent prior to the data-collection phase; however, big-data research, involving the archiving and reuse of data, complicates this type of up-front contractual agreement (Morrow, Boddy and Lamb, 2014). Much attention has been paid to consent in relation to the ethics of *archiving* qualitative data, while relatively little attention has been paid to the ethical practicalities of *using* secondary data, be it qualitative or quantitative (Grinyer, 2009; Morrow, Boddy and Lamb, 2014), although it is generally agreed that context is crucial. If secondary data users understand the source of the datasets they are using, the rules and regulations with which they were gathered (Metcalf and Crawford, 2016; Morrow, Boddy and Lamb, 2014; Zook et al., 2017), they are much more likely to avoid misrepresenting or misinterpreting the data or acting contrary to the original consent agreements (Morrow, Boddy and Lamb, 2014). Exploring the use of Twitter as a method of surveillance for seasonal influenza, for example, Aslam et al. (2014) noted that, despite the many benefits of this technique, their inability to access demographic information such as age, gender and race made it difficult to determine precisely who was tweeting about the flu and to whom public-health efforts should be directed.

Of course, problems are more likely to arise when the data have been collected outside of research frameworks (Metcalf and Crawford, 2016). As our lives become increasingly digitized, we leave traces of personal data (e.g., records of commercial transactions, administrative data, medical test results, closed-circuit television images, internet usage records, photographs) everywhere we go, much of it “collected under mandatory terms of service rather than responsible research design overseen by university compliance officers” (Zook et al., 2017, p. 4). Social-media sites, for example, require new users to tick that they have read the terms and conditions, but many people will simply tick the box without reading the information, which is frequently written in legalese (Leetaru, 2016; Metcalf and Crawford, 2016). As a consequence, secondary data users cannot assume that informed consent for the data to be reused in research has been granted (Leetaru, 2016; Bishop, 2017). Opt-out consent is a possibility (Millett and O’Leary, 2015), but one with several drawbacks: it can be costly and time-consuming for large datasets, tracing participants can be impossible even when the owner grants permission to access them, it places a burden on participants and it can introduce bias (Bishop, 2017; Grinyer, 2009).

Likewise, it has become common for people to share highly detailed information about their daily lives online (McKee, 2013; Sui, 2011). Yet, this does not mean that they (as data creators) are making this information available on a public platform for anything other than their own private purposes (Zook et al., 2017). It is not easy to distinguish between public and private data on the internet (Bishop, 2017; Markham and Buchanan, 2012; Madge, 2007; McKee, 2013). For example, individuals:

may operate in public spaces [e.g., Twitter, Instagram, discussion groups, forums] but maintain strong perceptions or expectations of privacy [or] they may acknowledge that the substance of their communication is public, but that the specific context in which it appears implies restrictions on how that information is – or ought to be – used by other parties.

(Markham and Buchanan, 2012, p. 6)

The people who communicate in these public settings often do so believing that settings to be more private or, at least, fail to remember the longevity and accessibility of the information they post (Bishop, 2017;

Madge, 2007). Breaching privacy is the primary way in which big-data research can do the most harm (Zook et al., 2017). When using data derived from this type of source, an understanding of the research subjects' expectations is critical (Madge, 2007; cf. Doyle's (2013) work on the *Children's Health* section of Mumsnet Talk forum). One approach, suggested by McKee (2013, p. 299), in such instances is to apply a notion of reciprocity whereby the researcher asks himself or herself, *How would I feel if the roles were reversed?* “[W]hile the researcher might post information on his or her public profiles to be shared by friends or peers, this does not mean that they have consented for this information to be collated, analysed and published, in effect turning them into research subjects.”

Re-identification

Datasets are said to have been de-identified if “elements that might immediately identify a person or organization have been removed or masked” (Bishop, 2017, p. 5). In recent years, as the volume of readily available personal data has increased (Gellman, 2007; Metcalf and Crawford, 2016) and our ability to connect disparate datasets through algorithmic analysis has improved (Metcalf, Keller and Boyd, 2016), it has become increasingly easy for re-identification to occur. As Zook et al. (2017, p. 2) note, “even seemingly benign data can contain sensitive and private information” and, when used in conjunction with other datasets, has the potential to produce “unanticipated ethical questions and detrimental impacts.” Indeed, there have been a number of cases in recent years where the profiling of individuals and groups (e.g., according to race, gender, class, propensity to certain diseases) in this way has led to severe discrimination (e.g., restricted access to treatments or services) (Zook et al., 2017). One method of combating re-identification is to release data only within safe settings; either secured physical sites, which researchers travel to in order to access confidential data (Richardson et al., 2015), or user- and/or function-restricted computer environments (Bell et al., 2006; Hartter et al., 2013) also known as geospatial virtual data enclaves (see Richardson et al., 2015). Researchers can analyze the data in, but not remove it from, these safe settings, and all outputs must be risk-assessed by a member of staff before release (Richardson et al., 2015).

For health geographers combining big health data – such as medical data or ambulance-dispatch records – with geospatial technologies, the ethical issues are even more complex (Blatt, 2012; Sui, 2011). GIS practitioners are now able to perform complex spatial analyses by conjoining databases that include not just people's individual attributes, but also their activities and details of their surrounding environment (Styblńska, n.d.). Datasets can range from large government or corporate databases (Richardson et al., 2015) down to an individual's geotagged tweets (Sui, 2011; Zook et al., 2017). Of course, there are a number of societal benefits that might accrue from “an improved understanding of how place influences an individual's space-time path, the activities they undertake, and ultimately their well-being” (Rainham et al., 2009, p. 671). However, Richardson et al. (2015, p. 102) note that “the potential of GIS to be far more invasive of personal privacy than many other information technologies has caused serious concern among privacy advocates, GIS researchers, and the public.” Conjoining spatial information with another dataset can contradict confidentiality agreements made at the time the data were collected, in perhaps unforeseeable ways (Gellman, 2007; Kounadi and Leitner, 2014). Zook et al. (2017, p. 3) note that there are “numerous examples of researchers with good intentions and seemingly good methods failing to anonymize data sufficiently to prevent the later identification of specific individuals.”

A number of masking methods – applied either before or after analysis – have been developed to protect locational privacy while allowing valid spatial analysis to be performed (Kounadi and Leitner, 2014). These include spatial, temporal or point aggregation, affine transformation, random perturbation, and flipping (Bell et al., 2006; Kounadi and Leitner, 2014; Richardson et al., 2015). Spatial and temporal aggregation have long been the most popular methods used to maintain the confidentiality of spatial health data used by health geographers (Bell et al., 2006); however, both have limitations (Kounadi and Leitner, 2014). They can limit the resolution of the data and thus their interpretability (e.g., the detection clusters, other spatial

relationships), they increase the possibility of bias (under- or over-reporting the number of cases over time or in a subgroup) and they can greatly affect or prevent adjustments for bias, confounding and effect modification (Bell et al., 2006; Kounadi and Leitner, 2014).

Future ethics

Given that the ethics of big-data research are emergent, complex and often beyond the experience of many RECs, it is essential that health geographers seek advice from as many sources as possible (Zook et al., 2017). These sources might include fellow researchers/practitioners, relevant ethics guidelines, academic literature (within, and outside, one's discipline) and legal frameworks (Markham and Buchanan, 2012). As Zook et al. note (2017, p. 6), "understanding the different ways people discuss these challenges and processes provides an important check for researchers, especially if they come from disciplines not focused on human subject concerns." There can never be a universal checklist for ethical social-science research, especially where big data is concerned, given the range of data sources, research topics, and methodological approaches taken (Markham and Buchanan, 2012). Although formal ethics guidelines are a useful starting point, ethical decision-making will always be necessarily contextual, processual and negotiated. This requires health geographers to be sensitive to the specificities of the dataset(s) they are working with (Markham and Buchanan, 2012), as well as the governing regime of their local REC – or, as Heimer (2013, p. 371) puts it, the "gap between official ethics (ethics on the books) and ethics on the ground (ethics in action)." This is the case both for those who wish to archive their data and users of secondary data.

The most critical point for health geographers to remember when undertaking ethical big-data research, however, is that all big data relating to health are linked in some way to individual persons (Markham and Buchanan, 2012; Zook et al., 2017). As such, it is necessary to consider the ethical principles relating to research on human subjects, even if one disagrees with standardized pronouncements relating to the minimization of harm and/or consent. One should not assume that data cannot be re-identified (Zook et al., 2017), because identifiability is not a constant (Gellman, 2007). De-identification will always be an essential tool in minimizing risk, but only "as part of a broader approach to ensuring safe use of data" (Bishop, 2017, p. 5). This includes acknowledging that identifiability cannot be viewed in binary terms (and as such can never be eliminated) and that privacy is both contextual and situational (Zook et al., 2017).

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