

**Consent and Confidentiality:
Exploring Ethical Issues in Public Health Social Network Research**

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Abstract

Current ethical regulations were necessarily developed in response to unethical treatment of human subjects by clinical and social researchers in settings ranging from Nazi concentration camps in the 1940s to U.S. government offices in the 1960s. Due to a focus on relationships, social network studies pose complex ethical dilemmas regarding consent and confidentiality that often challenge these ethical regulations. These issues have kept social network projects from receiving Institutional Review Board (IRB) approval, and, in the case of Virginia Commonwealth University, halted human subjects research university-wide. In public health, social network analysis is an effective method for understanding how diseases are transmitted, how health messages are spread, how social support impacts morbidity and mortality, and how public health organizations collaborate. A review of 50 public health articles using social network approaches showed that few authors discussed issues of consent and confidentiality. Without accessible examples of how others have addressed consent and confidentiality, these issues will continue to challenge public health social network researchers and their IRBs.

Keywords: social network analysis, public health, ethics, consent, confidentiality

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Introduction

Social network analysis (SNA) is a set of theories and methods widely used to examine relationships in fields like sociology, business, and public health. For public health researchers, using social network analysis is a uniquely effective method for understanding how diseases are transmitted, how health messages are spread, how social support can impact morbidity and mortality, and how public health organizations collaborate (Luke & Harris, 2007). However, researchers using this tool often face complex ethical dilemmas when designing and conducting social network research with human subjects. Specifically, obtaining consent and maintaining confidentiality pose challenges in public health social network research.

Although the ethical challenges posed by social network research are well-known among social network researchers, there is little discussion in the published network literature of how these issues impact public health network research projects and how they are addressed. Two things result from this limited visibility: 1) public health social network researchers have not had the opportunity to learn from each other in developing strategies for addressing consent and confidentiality; and 2) Institutional Review Boards (IRB) have not had the opportunity to learn about ways these issues have been addressed. As a result, network researchers may not be using the most effective or efficient strategies for conducting ethically sound network research, and, even more seriously, some network research projects may never get off the ground due to lack of IRB approval.

This paper will cover three topics: 1) the origins and content of current ethical regulations for human subjects research, 2) a

brief introduction to social network research methods and its applications in public health, and 3) an analysis of how ethical issues have been covered in published public health social network research.

Ethical Regulations for Human Subjects Research

The development of current human subjects regulations began just over 60 years ago in response to the unethical treatment of research participants by physicians in Nazi Germany. Following their involvement in medical experiments ranging from injecting children's eyes with chemicals to freezing people to death (Spitz, 2005), many Nazi physicians were charged with war crimes and crimes against humanity and put on trial in Nuremberg, Germany. The 1947 verdict of one of the Nuremberg Trials, the Doctors' Trial, contained ten points describing ethically sound medical research. These points are known as the Nuremberg Code and became part of international law and the basis of ethical human subjects research (Nuremberg Military Tribunal, 1996). In 1953 in response to the trials and the Nuremberg Code, the World Medical Association (WMA) began drafting the Declaration of Helsinki, another document designed as guidance for conducting ethically sound medical research. The Declaration was adopted in 1964 and remains the international standard for ethically sound medical research (Blackmer & Haddad, 2005; World Medical Association, 2007).

Even after the Code and Declaration were developed and distributed, United States physicians continued to conduct medical experiments showing little regard for their study participants. In his 1966 article, "Ethics and Clinical Research,"

Harvard professor Henry Beecher identified 22 studies (Beecher, 1966) with ethical deviations ranging from withholding penicillin from service men with rheumatic fever to inducing hepatitis in children at an institute for “mentally defective children.” In the opening comments of his paper Beecher suggested the problem of unethical medical research was widespread. It appears he was right, as one of the most notorious examples of unethical conduct in medical research, the Tuskegee Syphilis Study, did not appear on his list. The Tuskegee Study was conducted from 1942 to 1972 by the United States Public Health Service (USPHS). In this study, 399 African-American men were denied available syphilis treatment in order to study the natural history of syphilis in African-Americans (Gamble, 2001). The study rationale was withheld from participants, who were uneducated and low-income. The men were kept from obtaining treatment even when drafted into the military and offered penicillin (Jones, 1993). The study ended in the early 1970s after embarrassing publicity for the USPHS. Sadly, this was only after 28 of the men died of syphilis, 100 died of related causes, 40 of their wives had contracted syphilis, and 19 of their children had been born with congenital syphilis (Jones, 1993).

While the syphilis study and the 22 studies identified by Beecher were primarily clinical research, social scientists were also involved in questionable ethical treatment of human subjects during this time. Two commonly discussed social science studies that challenged ethical boundaries were the Milgram obedience experiments in 1963 (Milgram, 1977), and the Tearoom Trade sex study in the early 1960s (Warwick, 1973; Humphreys, 1970). The Milgram experiments tested how far people would go in obeying an authoritative figure when

asked to administer electric shocks to another person (Milgram, 1974). In the Tearoom Trade study, sociologist Laud Humphreys posed as a lookout for men meeting other men for anonymous sex in public restrooms (dubbed ‘tearooms’) (Warwick, 1973; Humphreys, 1970) and made note of their license plate numbers, later using the information to locate and survey the men he had observed. While not inflicting the same sorts of physical harm as the clinical studies, Milgram and Humphreys, along with other social scientists, employed deceptive techniques which had the potential to inflict mental and/or social harm on unwilling participants.

These studies challenged several of the principles outlined in the Nuremberg Code and the Declaration of Helsinki. For example, the Nuremberg code begins with the statement, “The voluntary consent of the human subject is absolutely essential,” and also specifies that, “the experiment should be so conducted as to avoid all unnecessary physical and mental injury” (Nuremberg Military Tribunal, 1996). Neither Milgram nor Humphreys obtained consent, and, arguably, Milgram’s study may have inflicted unnecessary mental injury on participants. However, the Code and Declaration served as ethical norms, not legal documents in the United States. As such, there were no specific risks or legal consequences for the researchers if found not following the ethical norms in the Code and Declaration. Following the publicity surrounding the Tuskegee study, Congress appointed the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. Five years later, in 1979, the Commission presented the Belmont Report, a document designed to guide researchers in ethical conduct.

The Belmont Report describes three fundamental principles to guide all research

involving human participants (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979): 1) Respect for Persons – Individuals should be treated as autonomous agents, and persons with diminished autonomy are entitled to protection; 2) Beneficence – Make effort to secure the well-being of participants by doing no harm, maximizing benefits, and minimizing possible harms; and 3) Justice – Equals ought to be treated equally. To ensure researchers employed these principles, the Belmont Report was codified into The Code of Federal Regulations (45CFR46). This section of the Code is often referred to as the Common Rule. In the Common Rule, the three principles of respect for persons, beneficence, and justice were applied through informed consent, assessment of risk/benefit, and selection of research subjects.

As part of federal regulations, the Common Rule is subject to enforcement. The federal government polices its own research and other entities are policed by Institutional Review Boards. Both the FDA and the Office of Human Research Protection (OHRP) conduct inquiries and investigations into reports of noncompliance. If an investigator or an IRB is found noncompliant, the OHRP may take measures including: suspending or revoking approval of an institution's Assurance of Compliance,¹ suspending institutions or investigators from participating in specific projects, and/or requiring that peer groups be notified of an institution's or investigator's past noncompliance.

Many types of research pose challenges for researchers in adequately adhering to the

Common Rule. For example, clinical researchers conducting studies that could potentially inflict physical harm, such as testing a new vaccine, must put many safeguards in place and provide evidence that they are making the maximum effort to secure the well-being of participants before they are granted approval to proceed. In social science research, adhering to the Common Rule often means minimizing potential harm that could occur if sensitive information were made public. For example, failing to keep an individual's HIV status confidential may cause them harm. Because of its' unique characteristics, social network research poses unique challenges for researchers in adhering to the Common Rule. The following section discusses applications of social network analysis in public health and the specific issues that arise in addressing the Common Rule in social network research.

Social Network Analysis

Network analysis is a set of theoretical, graphical, and statistical methods for examining relationships. It has roots that are centuries old and draw on mathematics, sociology, anthropology, and a number of other fields. Recently, social network analysis has solidified its place in popular culture through New York Times articles such as the web of who-thanks-whom at the Oscars award show (Cox & Duenes, 2007), pervasive new social networking websites like Facebook, and best-selling books like Malcolm Gladwell's *The Tipping Point* (Gladwell, 2000). Charles Kadushin probably said it best in his 2005 article, "the success of social network research has led to expectations that in addition to academic research, social network research can introduce people to one another, solve organizational problems, map the

¹ The Assurance of Compliance is necessary in order to receive federal funding, so suspension or revocation is a serious matter for investigators and institutions.

epidemiology of AIDS, and catch criminal terrorists” (p. 139). To accomplish these sorts of feats, social network analysis takes the focus off individual attributes and puts it instead on relationships such as who-talks-to-whom and who-sleeps-with-whom. Data collection, analysis, and reporting all take this unique relational perspective into consideration (Luke & Harris, 2007). It is this perspective that not only makes social network uniquely useful, but also ethically problematic.

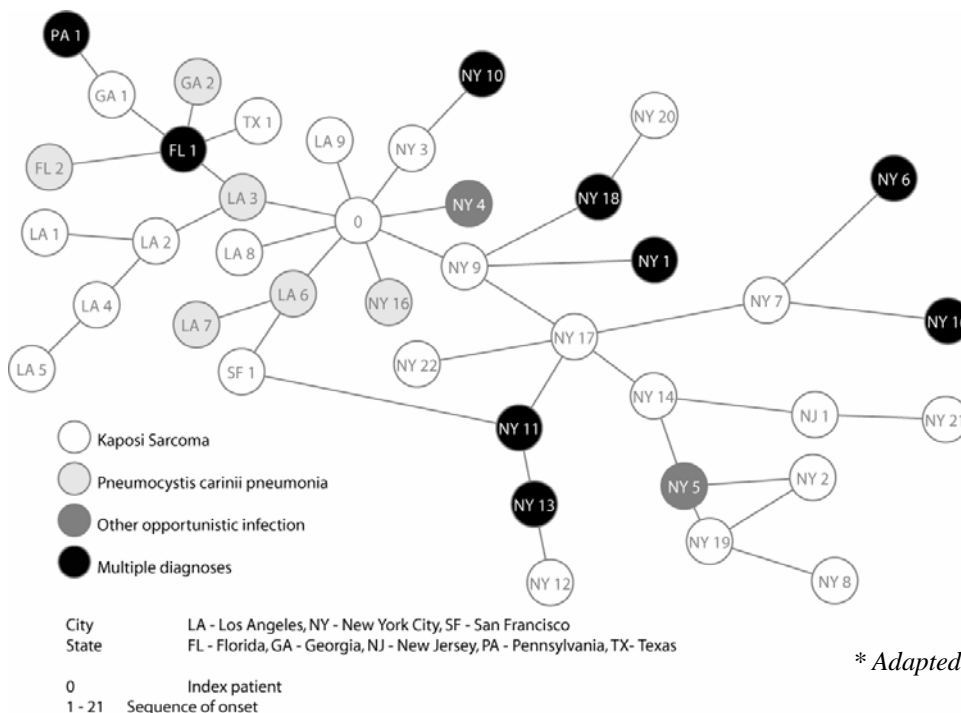
Social Network Analysis in Public Health

In public health, SNA is used to examine three types of networks: 1) transmission networks; 2) social networks; and 3) organizational networks (Luke & Harris, 2007). Transmission networks carry a tangible entity such as infection or information. Social networks show the structure of social ties and can help determine how the ties impact health and health behaviors. Organizational networks allow researchers and practitioners to better

understand agencies and organizations working on public health issues.

While disease transmission has been depicted in network formats since the 1940s (Burnet & White, 1972), they really became part of the modern arsenal of tools for understanding the spread of disease in the early days of the AIDS epidemic. Before researchers even understood exactly what AIDS was and how it was transmitted, one team of researchers collected the names of sexual partners from a number of individuals infected with this new disease (Auerbach, Darrow, Jaffe, & Curran, 1984). Through this method, they were able to connect 40 infected men in 10 cities to a single individual, patient 0 (Figure 1). The resulting network was among the first evidence that AIDS was sexually transmitted. Since then, network analysis has been used to learn more about HIV/AIDS transmission as well as Chlamydia, Gonorrhea, Syphilis, tuberculosis, and other infectious diseases.

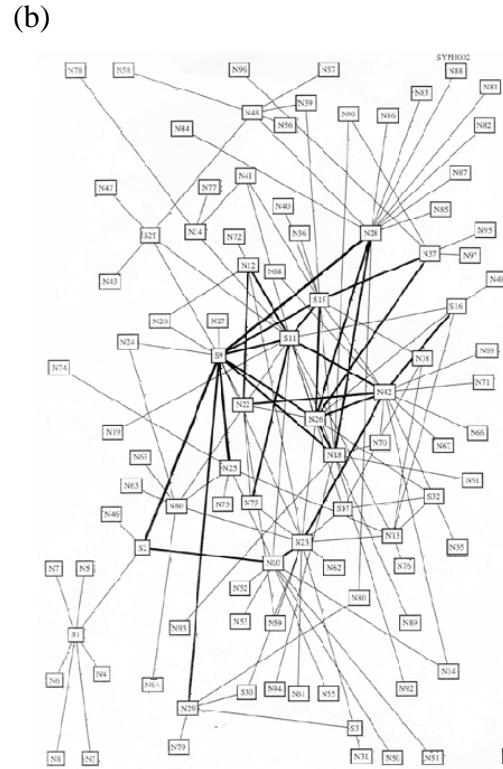
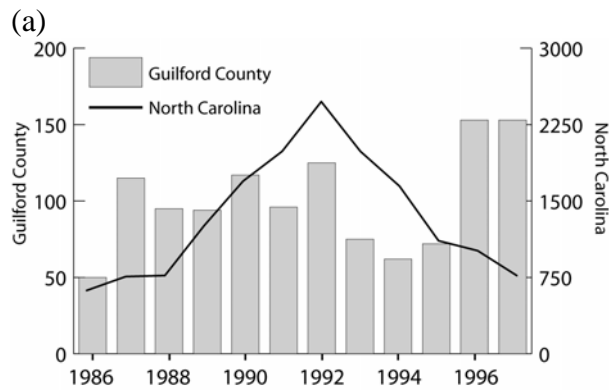
Figure 1. Network Showing Sexual Connections Among 40 of the First AIDS Patients*



* Adapted from Auerbach et al., 1984

Epidemiologic studies of disease outbreaks typically follow the number of cases over time, while network models of disease transmission show how the relationships among individuals facilitate the spread of disease; Figure 2 shows this distinction (Luke & Harris, 2007). The figure shows an epidemiologic model of syphilis transmission (Figure 2a), and a network model of syphilis transmission (Figure 2b). While both contain useful information, the network model allows public health practitioners to understand exactly how syphilis is being transmitted from person-to-person in this population. This information may be useful in developing appropriate interventions.

Figure 2. A Comparison of (a) an Epidemiologic Model of a Syphilis Transmission (CDC, 1998) and (b) a Network Model of Syphilis Transmission (Frontline, 1999)*



* This figure was printed in Luke & Harris, 2007

In addition to understanding the spread of disease, public health network researchers have used network methods to understand the spread of health information and interventions. For example, network studies of how family planning and reproductive health information spread through communities revealed that both the composition of an individuals' network and having a direct link to a source of the information led to increased knowledge about family planning or increased use of contraceptives (Boulay, Storey, & Sood, 2002; Stoebenau & Valente, 2003; Valente & Saba, 2001). This type of information is useful to public health researchers and practitioners in their efforts to educate people about health issues.

Another type of public health network research utilizes information about

participants' social networks to understand how the size and composition of these networks impact health and health behavior. One of the major findings in this research area is that having a large social network improves health and reduces mortality (Barber & Crisp, 1995; Bland, Krogh, Winkelstein, & Trevisan, 1991; House, Robbins, & Metzner, 1982). In addition, social network size and composition have been linked to health behaviors such as adolescent smoking (Ennett & Bauman, 1993; Valente, Unger, & Johnson, 2005), condom use (Bettinger, Adler, Curriero, & Ellen, 2004), and health screening (Allen, Sorensen, Stoddard, Peterson, & Colditz, 1999).

Finally, a relatively new area of public health network research involves public health organizations. This type of network research typically examines collaboration among public health agencies with the goal of understanding how these systems work. Public health organizational network researchers have examined systems of organizations working to address areas such as HIV/AIDS (Kwait, Valente, & Celentano, 2001), mental health services (Nakao, Milazzo-Sayre, Rosenstein, & Manderscheid, 1986), and tobacco use prevention (Krauss, Mueller, & Luke, 2004).

In all, using a social network approach to public health problems has given unique insights into disease, health behavior, and the structure of public health systems. However, along with the advances for the field of public health and benefits for the public come unique ethical considerations.

Ethical Considerations in Public Health Social Network Research

Kadushin (2005) states in the introduction to his paper on who benefits from social network analysis, “[t]he ethical issues [in social network research] are both

straightforward and complex” (p. 140). In addition to all of the ethical issues that come with social science in general, social network research adds two wrinkles: 1) the collection of names is critical, and 2) the collection of names of people outside the study is common and often necessary to answer specific research questions (Kadushin, 2005; Borgatti & Molina, 2003). The first article to address these and other ethical issues specifically pertaining to social network research was published in the *Journal of Applied Behavioral Science* (Borgatti & Molina, 2003). In this article, Borgatti and Molina focused on *organizational* network analysis and on the ethical problems that arise in academic settings and management settings. In doing so they highlighted several differences between traditional research and network research: 1) anonymity is impossible in network data collection; 2) missing data is problematic; 3) non-participation by a subject does not mean they will be excluded from analyses; and 4) in conventional studies research participants report only on themselves, while in network studies participants report on themselves and on others.

Two years later the journal *Social Networks* published a special issue on ethical considerations in social network analysis. In his contribution to the special issue, Klov Dahl (2005) described a number of assumptions implicit in most public health social network research:

- 1) No surgical, pharmaceutical, or other medical treatment would be provided (or withheld);
- 2) The research usually would be based on personal interviews with primary participants;
- 3) Effective means for protecting the confidentiality of the research

- data – including the necessary hardware, software, and data handling protocols – would be in place and would be used;
- 4) Data would be ‘de-identified’ at the earliest date possible;
 - 5) No identifying information would be shared outside the project without IRB approval for any proposed sharing; and
 - 6) No data retained beyond the end of a project would contain information permitting the identification of any participant or network associate.

However, even if these characteristics described all public health network research, which is a tenuous assumption, the burden would still rest with investigators to develop ethically sound research methods that IRBs could confidently approve (Klovdahl, 2005). As such, Klovdahl (2005) identifies several issues that social network researchers should take into account when developing research projects, including: protecting confidentiality, identifying and applying appropriate waivers of consent, and balancing benefits against risks.

Consent in Social Network Research

The seriousness of issues of consent for network researchers was highlighted by a recent controversy at Virginia Commonwealth University (VCU) (Klovdahl, 2005). The case involved a woman in a twin study who was mailed a survey that included questions about the health of her family members (Botkin, 2001). The woman’s father read the questionnaire and was disturbed by two questions asking about abnormal genitalia and depression in male family members. He proceeded to contact National Institutes of Health OHRP, who ruled that the IRB

reviewing the study did not adequately consider whether family members were also research subjects. After further review, the OHRP and the FDA suspended human subjects research entirely at VCU. Because network analytic research is based entirely on questions (sometimes on less sensitive topics) like those in the VCU study, rulings like this are problematic for network researchers.

Applying appropriate consent procedures may be more difficult in network research since determining who qualifies as a human subject may be more complicated than in most research designs (Klovdahl, 2005; Borgatti & Molina, 2003). According to the Common Rule, a human subject either has interaction with the investigator, or has private identifiable information included in the study. Since many individuals named in network studies will not interact with the investigator, and since some studies do not collect private identifiable information (meaning information that can reasonably be expected to not be observed, recorded, or made public), secondary subjects would not be considered human subjects in these studies (Klovdahl, 2005). However, many studies do collect or use information about secondary participants that might be considered private. The National Human Research Protections Advisory Committee (NHRPAC) has made recommendations to the OHRP regarding secondary participants; however, the OHRP has not currently adopted a specific policy. The NHRPAC recommends the investigator and IRB consider the following:

1. The quantity of the information collected about the secondary participant;
2. The nature of the information collected, including the sensitivity of the information and the possibility

that it might cause harm to the secondary participant;

3. The ability of investigators to record information on secondary participants in a manner that protects their identity; and
4. The possibility that classification of a secondary participant as a human subject may impact the rights or welfare of the originally designated human subject requires the IRB to protect the interests of both the original human subject and the secondary subject (NHRPAC, 2002).

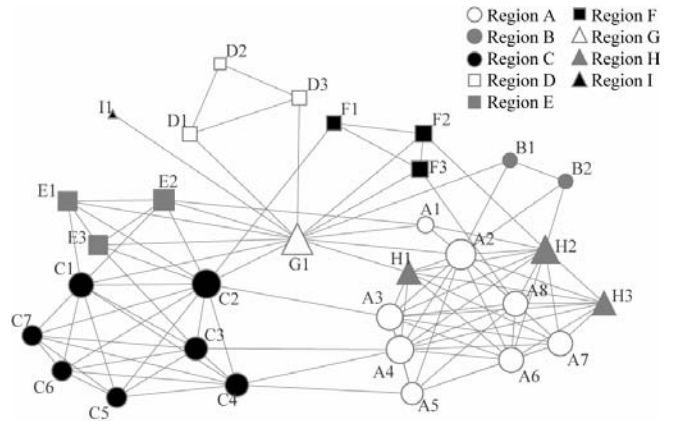
Should examination of these characteristics reveal that the secondary participant is identifiable (and therefore a human subject), the secondary participant would then have the rights and protections of the Common Rule, including confidentiality and consent. This could bring much of social network research to a halt since requiring consent from all named subjects would make many network studies simply infeasible (Klov Dahl, 2005).

In addition to the collection of information about people who have not given consent, there is also the ethical issue of misrepresenting the “true” network should those who have not consented be removed from the data set (Borgatti & Molina, 2003). For example, consider the networks in Figure 3. The nodes in this network represent the public health emergency planners in Missouri, and the links between them represent regular communication. Network 3a (top) is complete, showing all Missouri planners; network 3b (bottom) is missing planners G1 and A2 (Harris & Clements, 2007). By removing these two nodes we could draw completely different conclusions about the communication structure of Missouri planners. In the complete network (3a), the

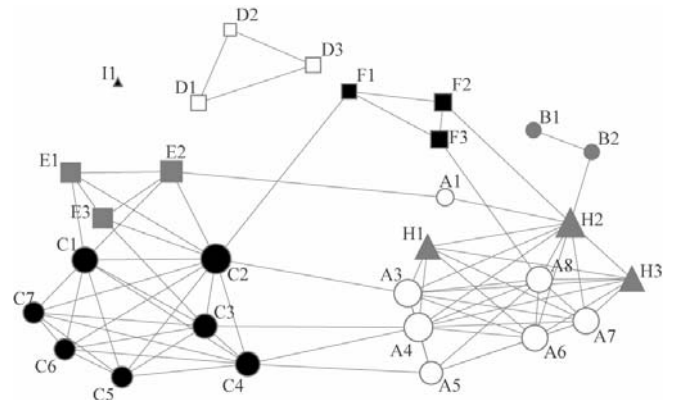
planners in regions D and I (D1, D2, D3, I1) are part of the communication network, while in network 3b, the planners in regions D and I are not “in the loop” at all.

Figure 3. The Problem with Missing Data in Social Network Analysis*

(a) All planners represented in the network



(b) Network missing planners G1 and A2.



*Adapted from Harris & Clements, 2007

Confidentiality in Social Network Research

In protecting confidentiality, a number of things should be considered: how sensitive is the data, how practical is maintaining confidentiality, and how valuable is the data to outside individuals (Klov Dahl, 2005). In addition, there are situations and topics that may be considered

more sensitive than others and which may require more attention to confidentiality. First, studies about illicit activities, such as intravenous drug use, may require more attention to confidentiality than studies about everyday conversational contacts. Second, data gathered for social networks studies in organizations is often highly sensitive as the people involved may be risking their careers by giving management certain information (Borgatti & Molina, 2003). Third, information regarding secondary participants may be especially sensitive if the secondary participant is not involved in the study other than being named by a primary participant.

Weighing Risks and Benefits in Social Network Research

Borgatti and Molina (2005) describe the risk that comes with most survey research, including most social network research, as being limited to embarrassment resulting from breeches of confidentiality and discomfort from being asked sensitive questions. Borgatti and Molina (2005) and Kadushin (2005) agree that the researcher and organization typically benefit from social network research, but that the participants often do not, "...academic researchers always benefit, organizations, society and science may benefit, but individual respondents rarely do" (p. 139).

Recommendations for Social Network Research

The authors of the five articles on ethics in social network research provided a number of practical recommendations for future network research:

1) Recommendations regarding confidentiality:

- Use someone outside the research team to hold the only codebook linking names to ID numbers. This person could even be located outside the country if litigation is a potential issue (Borgatti & Molina, 2005).
- If the data being collected includes sensitive topics that could be the basis of prosecution, the researcher may obtain a Federal Certificate of Confidentiality, which states that the benefit of the research outweighs the prosecution of illegal activities by the research participants (Klovdahl, 2005).
- Segment the instruments for data collection to keep identifying information separate from other information (Klovdahl, 2005).
- Restrict the number of project personnel who have access to identifying/linking information (Klovdahl, 2005).
- Use the most secure computers available to assign network members unique non-linkable identifiers (Klovdahl, 2005).
- Do not connect the computers used for processing the raw data (with identifying information) to any network (Klovdahl, 2005).
- Never transfer files including raw data over the internet and never transport encrypted data and passwords together (Klovdahl, 2005).
- Lock-up storage media containing raw data and store back-ups securely (Klovdahl, 2005).
- Destroy any identifying information at the earliest possible date (Klovdahl, 2005).

- Train all project personnel in confidentiality protection (Klovdahl, 2005).
- Anonymize or aggregate data to the group level prior to giving the data to management in organizational studies (Borgatti & Molina, 2005).
- Write up an agreement between the researcher and management that indicates (a) what data (and in what form) management will see, and (b) how the network data and analysis will be used by the organization (Borgatti & Molina, 2005).

2) Recommendations regarding consent:

- Develop and implement a thorough and explicit consent form. This may include writing in exactly who will see what data and potentially asking management to sign a disclosure contract prior to data collection (Borgatti & Molina, 2005).
- Provide organization members with the option to exclude themselves from the study as a whole (Borgatti & Molina, 2005).
- When possible, researchers should solicit participation themselves rather than receive help from management, which can be seen as an indirect order (Borgatti & Molina, 2005).
- Offer participants *Truly Informed Consent*, meaning that participants see the management disclosure contract and are given an example of the kinds of outputs management will see. In addition, we suggest that the researcher also sign the consent form to reinforce the view that it constitutes a contract between the researcher and the respondent (Borgatti & Molina, 2005).

3) Recommendation regarding benefits:

- After the data are collected, provide the participants with specific personalized feedback, including information they might use to improve their personal networks or that might be useful in their employment (Borgatti & Molina, 2005).

An additional overall recommendation was provided by Goolsby (2005), who said that, since codes of ethics are often outdated because they were created in response to historical events and have not been reconsidered, social scientists should work together to develop an “ethical imagination” that will move social science forward to meet the needs of the funding agencies, researchers, participants, and society.

Given the unique ethical considerations facing public health social network researchers, it appears that specific examples of effective ethically sound network studies that have gained IRB approval are needed. One way to make such examples available and accessible to both researchers and IRBs is to include information about how consent and confidentiality were addressed in published network research. The final section of this paper examines the coverage of ethical issues in published public health social network research.

Coverage of Consent and Confidentiality in Public Health Social Network Research

The ethical issues of consent and confidentiality pose dilemmas in social network research different from those faced in research not utilizing relational data. Although public health social network researchers and their IRBs are in need of examples of how these issues have been successfully addressed, published social network research, like most published social science research, does not typically include much discussion of the ethical decisions made in designing and carrying out studies. This section examines whether and how investigators conducting public health social network research included discussions of consent and confidentiality in their published research. To be clear, coverage (or lack of coverage) of these topics in an article does not imply that researchers have or have not used ethical practices in their research.

Methods

To examine how public health social network researchers have addressed consent and confidentiality, the author reviewed fifty public health social network research studies. The studies were published between 1984 and 2005 in 34 different journals and covered the three areas of network research found in public health: 1) transmission networks; 2) social networks; and 3) organizational networks.² The articles were selected from the bibliography of a recent review of social network analysis in public health (Luke & Harris, 2007). Articles were selected that were 1) empirical, 2) took a network approach, and 3) represented the variety of network approaches and topics that exist in public health social network

research. A full list of the articles reviewed is available from the author.

To determine how and how often consent and confidentiality were discussed in public health social network research, basic information was collected on each article including: publication year, publication journal, author, and title. In addition, each article was coded for: article topic, data source, data type, vulnerable populations, discussion of consent, and discussion of confidentiality. The rationale for including variables such as data source, data type, article topic, and vulnerable populations was to assess whether articles including sensitive topics and populations were more likely to include discussion of consent or confidentiality.

Results and Discussion

Of the 50 studies reviewed, 36 (72%) used name-generation data. Name generation prompts ranged from, "Name up to six best friends" (Pearson & West, 2003) to having participants name their social network and, "[Specify] their age, HIV status, whether they were living or had died of AIDS, and whether they had ever been a sex partner" (Morris, Zavisca, & Dean, 1995). Seven studies included questions about needle-sharing or other aspects of intravenous drug use, and 18 articles were about HIV/AIDS or other sexually transmitted diseases. Over a third of the articles included members of vulnerable populations; the main subjects were children or youth in 13 articles. Sixty percent of the studies included primary data; the 40% of studies based on secondary data used regional and national data sets such as the National Longitudinal Study of Adolescent Health (National Institute of Child Health and Human Development, 2006).

² See above for definitions and examples of each.

Consent was discussed in 18% of the articles and confidentiality was discussed in 24% of the articles. Compared to the rates in the entire sample, studies with vulnerable populations were more likely to include discussions of consent and confidentiality, as were studies with primary data collection, studies using name data, and studies on disease transmission. Compared to the entire sample, articles on social networks (i.e., networks comprised of social relationships

like social support among individuals; see above for description) were more likely to include discussions of confidentiality, but less likely to include discussions of consent.

Organizational network research articles were the least likely to discuss issues of consent and confidentiality. None of the 10 organizational network articles discussed consent and one discussed confidentiality. Table 1 shows additional characteristics of the articles.

Table 1. Characteristics of 50 Public Health Social Network Research Articles

Article Topic	n	%	Discussed Consent		Discussed Confidentiality	
<i>Transmission Networks</i>	21	42%	7	33%	4	19%
Disease	20	40%	6	30%	3	15%
HIV/AIDS	9	18%	2	22%	1	11%
STD (non-HIV/AIDS)	9	18%	2	22%	1	11%
Other infectious disease	2	4%	1	50%	0	0%
Information	1	2%	1	100%	1	100%
<i>Social Networks</i>	19	38%	3	16%	8	42%
Health behavior	7	14%	2	29%	6	86%
Social support/Social capital	12	24%	1	8%	2	16%
<i>Organizational Networks</i>	10	20%	0	0%	1	10%
Public health systems	10	20%	0	0%	1	10%
Other characteristics						
<i>Vulnerable populations</i>	18	36%	4	22%	9	50%
Children/Youth	13	26%	4	31%	9	69%
Low SES	3	6%	0	0%	0	0%
Mentally ill	2	4%	0	0%	0	0%
<i>Data Source</i>						
Primary data collection	30	60%	7	23%	9	30%
Secondary data analysis*	20	40%	2	10%	3	15%
<i>Data Type</i>						
Name data	36	72%	9	25%	11	31%
Other	14	28%	0	0%	1	7%

* For the purpose of this paper secondary data analysis is defined as: *The analysis of data collected by someone else, perhaps for some purpose other than that of subsequent analyses* (Babbie, 1983).

Consent and/or confidentiality issues appeared in 17 out of the 50 articles; however, the discussions were generally brief. Statements regarding consent consisted of either the parent or the participant giving informed consent for participation, for example:

“There were 2,002 eligible students (those with parental consent and student assent) who completed a baseline survey” (Valente et al., 2005).

“Because of ethical concerns about participants' disclosing their drug use prior to informed consent, the screening did not include questions about individuals' own risk behaviors. ...Potentially eligible individuals were asked to come to the clinic to provide informed consent, approved by the Johns Hopkins School of Public Health's Institutional Review Board, and complete a face-to-face baseline interview” (Latkin, Sherman, & Knowlton, 2003).

One study out of the 50 also discussed obtaining consent from the secondary participants named by the primary subjects: “Written, informed consent was obtained from each patient or his sexual contact before interviews were conducted” (Auerbach et al., 1984).

The 12 studies that provided information on confidentiality included either a description of the level of privacy granted to the participant during the survey/interview process, or the process of assigning identification numbers for confidentiality of participant data. For example:

“An additional advantage of this data involves the use of laptop computers to maintain confidentiality about sensitive subjects such as delinquency. This method of data collection allowed

respondents to maintain their anonymity by listening to pre-recorded questions about participation in different delinquent activities and then entering their responses directly into a computer” (Haynie, 2001).

“The surveys were identified only by a code number, not with the students' names or any other identifying information” (Moultapa, Valente, Gallaher, Rohrbach, & Unger, 2004).

One study provided a comprehensive description of their process for maintaining confidentiality:

A high priority was given to ensuring the confidentiality and security of the data. An encoding scheme was developed to protect the identity of all respondents. Personal computers were used for data entry and most processing. Removable hard disks were purchased for data storage and then locked away when not in use. The personal computers were not part of any network. The database design involved segmentation of information and required encrypted files to be brought together (physically) to access sensitive data. Only "sanitized" data (no identifying information) were processed on mainframe (or networked) computers (Klov Dahl et al., 1994).

Overall there was limited discussion of consent and confidentiality in this set of articles. Again, that is not to say that the researchers did or did not make ethical choices and follow ethical practices, just that they did not include descriptions of these in their publications.

Conclusions

Despite expectations that social networking could be used to catch terrorists, cure HIV, and introduce you to your partner

(Kadushin, 2005), social network research typically does not claim to solve all the problems of the world or single-handedly prevent all future disease (Klov Dahl, 2005). However, social network research does contribute valuable information to many fields, including public health. Along with those contributions come complex ethical decisions regarding, among other things, consent and confidentiality. Without

accessible examples of how others have addressed consent and confidentiality, these decisions will continue to challenge public health social network researchers and their IRBs. Including discussions of specifically how consent and confidentiality were addressed in public health social network research publications could ease the burden on future social network researchers in designing studies and gaining IRB approval.

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