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Social network research and human subjects protection: Towards more effective infectious disease control

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Abstract

The issue of human subject protection in relation to social network research on the spread and control of human pathogens is considered. As this area derives most of its concepts and methods from social network analysis more generally, the present discussion has wider relevance. One problem is that some Institutional Review Boards (IRBs) have assumed that if a participant (who gave informed consent) is to be asked to name network associates these too — automatically — would be human subjects from whom informed consent also must be obtained. Invariably, if this occurs proposed research — whatever its funding and potential contributions might be — is blocked. A conservative approach is taken here. The Common Rule is assumed to provide relevant guidance, the responsibility of IRBs is to make decisions based on the Common Rule, and in consequence the burden is on those proposing social network research to design — and defend — their planned work with this in mind. At the same time, it is argued that it is important not to stifle beneficial research by adding to one inherently conservative review process (of grant proposals) another (of IRBs) so that work is prevented simply because it is research at the frontiers rather than 'safe' research.

Keywords: Research ethics; Network structure; Human pathogens; Third parties; Pick gun principle

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1. Introduction

A study associated with Virginia Commonwealth University (VCU) in which family pedigree data was sought for research on genetic causes of health problems is one of the

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better known cases leading to increased concern about human subjects protection. That is, in a mail questionnaire a woman (an adult twin) was to be asked inter alia if her father had abnormal genitalia. The father happened to read the question, brought it to the attention of the National Institutes of Health (NIH), and NIH and the Food and Drug Administration shut down human subjects research at VCU. Their view was that the relevant Institutional Review Board (IRB) should have considered whether family members about whom information was to be sought were also human subjects (i.e., not only those asked to answer questions themselves) (Botkin, 2001).

Cases such as this one have resulted in more discussion about human subject issues (across a range of disciplines and countries) and in IRBs (and ethics committees generally) looking more closely at proposed research that seeks information from study participants about identifiable others. As social network research requires information — identifying information — not only about primary human subjects but also about the others (network associates) to whom they are linked, inability to obtain such nominative data would bring social network research to a grinding halt. In fact, informal discussions have indicated that some proposed social network research projects — focussing on quite innocuous subject matter (by seemingly any standard) — already have been prevented from proceeding by American IRBs.

The emphasis here is on social network research in relation to the spread of human pathogens and the design of better strategies for the control (ideally, prevention) of disease outbreaks. Although many once believed medical science had conquered infectious disease — with vaccines and antibiotics — few believe this now. Many see pathogens as ever-evolving challenges requiring on-going research at the highest levels, across a broad range of disciplines, if adequate tools are to be available for the serious threats (including possible bioterrorism threats) likely to arise in the future.

In spite of the present focus it is important to keep in mind that basic research on social networks — independent of any interest in human pathogens — is the principal source of network concepts and methods. Hence, it is hard to conceive of work on networks and pathogens fruitful over the longer term without tools developed and tested in basic social network research. These tools range from those allowing large masses of network data (including data from outbreaks) to be processed quickly and accurately, to statistical methods for estimating the number of people with particular attributes in a population (e.g., injecting drug users who share needles), to quantitative measures that capture structural properties of complex networks (e.g., average distance between nodes), to mathematical models of flow through networks (e.g., information, influence, infection), and beyond. Thus, irrespective of the present focus it is essential not to lose sight of the human subjects issue in relation to social network research in its broadest sense.

2. The research challenge

The study of social networks and the spread of human pathogens began with the human immunodeficiency virus (HIV)/acquired immune deficiency syndrome (AIDS) pandemic. Indeed, most research on networks and pathogens to date has focussed on HIV/AIDS and other sexually transmitted diseases (STDs) (Altmann, 1993; Aral, 1999; Curtis et al., 1995;