Brian Schrag's Commentary on "Political Points"

Commentary On Political Points

Scenario 1

Scenario 2

Scenario 3

This case raises a host of ethical issues, including a researcher's responsibility to ensure good design in human subjects research, particularly for topics that are politically sensitive. The case presents issues of truth telling and deception in the reporting of findings and of the relative strength of obligations to report findings honestly as weighed against harms those findings might cause to others. Finally, it raises issues of the degree to which researchers have a responsibility to ensure their findings are not misreported or misused.

In this case, there are a number of stakeholders, and Lang may have moral obligations to most of them. Stakeholders include the general public, which relies on solid scientific information for making sound health policy and promoting public health; the scientific community; the needle exchange activists; the needle exchange participants, the opponents of needle exchange; the funders for Lang's research. Lang might also consider her own self-interest.

One can start with the observation that all stakeholders are ultimately best served if Lang is doing good science. One of the scientist's primary obligations is to design studies that have potential to provide useful results. One issue raised by this case is whether Lang has done that and consequently, whether she has results worth reporting.

Whether Lang has fulfilled this obligation depends in part on the study's objective. The point of needle exchange programs (NEP) is to reduce the spread of HIV by reducing needle sharing by injection drug users. Lang "designed a study that would

provide data about the seroprevalence of HIV injection users in Capitol City. . . and track seroprevalence over time in a population that used needle exchanges and a group that did not." The significance of that data depends on the precise objective of her study. 1) One could do a study to determine NEPs' effectiveness in reducing HIV transmission. Answering that question would presumably require a randomized, controlled clinical study. As described, Lang's is not such a study but rather an observational study. So presumably her objective is not to determine NEPs' effectiveness in reducing HIV transmission. 2) Lang may be trying to simply a) measure the level of seroprevalence among NEP participants and b) monitor that level of seroprevalence over time compared to some other group; this objective could be achieved by an observational study. Lang appears to be doing the latter, but her objective is still not clear.

Surely she is not simply interested in measuring the initial level and continuing levels of seroprevalence among NEP participants, *simpliciter*, but rather those levels compared to some other group. One must have some context in which to make sense of the significance of measured levels of seroprevalence. For example, one could compare levels of seroprevalence among NEP participants to nondrug users, to the general population, to drug users who are not participants in NEP programs, or to drug users who are not participants in NEPs but who are otherwise *relevantly similar* to NEP participants.

Even if this is an observational study and not a clinical trial, the nonparticipant group can be used to provide some context for interpreting the significance of the findings. In the design of a study, one always makes judgments about the criteria of relevant similarity of the observational and control groups. The very choice of the control group is always a decision about the criterion of relevant similarity of the control group to the study group.

Thus, one could compare the seroprevalence levels of NEP participants to a group of NEP nonparticipants whose only relevant similarity is that they are intravenous drug participants. They may vary completely with regard to other risk factors for HIV. Or, one could compare the seroprevalence levels of NEP participants to a matched group of NEP nonparticipants who are also relevantly similar with regard to other risk factors such as likeliness to engage in prostitution, "inject frequently, borrow injection equipment, frequent shooting galleries, share equipment with HIV positive injection drug users."(3)

If the researcher ignores such well-established risk factors in the criteria for selection of nonparticipants, what has one learned by such a study? If the seroprevalence levels of the NEP participants are compared to nonparticipants, the significance of the comparison is not clear. This measurement may be an instance of garbage in, garbage out. Since the comparison is between NEP participants and nonparticipants, and since needle exchange is such a controversial issue, one can predict in advance that activists on one side or the other are likely to use the results, whatever they may be, to bolster their positions. Thus, one should at least be sure that there is a possibility of useful results. The worst outcome is to generate scientifically useless data that is still used for political agendas.

Given the case description, it appears that Lang may have failed to pay sufficient attention to selection of the nonparticipant group. The candidates for the nonparticipant group were surveyed for risk behavior at the beginning of the study. At that point, Lang could have screened the nonparticipant group to include only those who matched the study group in terms of risk behavior. For whatever reason, she did not. There are several possibilities here, regarding her moral responsibility for what follows.

Scenario 1

First, suppose there is, in fact, a clear and significant difference between the nonparticipant group and the participant group regarding these risk factors and that that difference could have been anticipated and eliminated by careful study design. In that case, Dr. Lang has just done bad science, and there is no reason to suppose any results she may obtain from her study could tell us anything about the significance of the seroprevalence data for injection drug users in Capitol City and the tracking of seroprevalence over time in a population that used needle exchanges compared to one that did not.

If that is the case, Lang has certainly acted irresponsibly as a scientist and with respect to her funding agency by using the funds for a poorly designed study. In addition, if her study produces unreliable evidence, which somehow gets publicity and is then used to undermine the work of the activists and the welfare of drug users who cooperated with her, she has harmed them as well. Finally, her unreliable results may be used to shape public policy in a way that harms the public good. All

of these moral harms could have been avoided if she had taken care in the original design. Sometime scientists need to practice "preventive ethics," avoiding moral difficulties in the first place rather than having to resolve ethical issues afterward.

Scenario 2

It may be the case that there is in fact a clear and significant difference between the nonparticipant group and the participant group but for some reason, Lang was not able to identify that difference during the study's design. Perhaps the nonparticipant group misled her about their habits; perhaps some changed their behavior over the course of the three years. She may not be culpable for negligence in designing the study, but the study's results are no less suspect. We still have no reason to believe that the results tell us anything. It is still the case that if her unreliable evidence somehow gets publicity and is then used to undermine the work of the activists and welfare of drug users who cooperated with her, they may be harmed, and her results may be used to shape public policy in a way that harms the public good. Thus, harms may result from the study although not necessarily because she did poor science. The harms may result from her efforts to publicize her results, however.

Scenario 3

A third possibility is that some, but not all, of the NEP nonparticipant group did not share needles and some, but not all, engaged in less risky behavior than the NEP participant group and that these variations between the groups became clear only at the end of the experiment. At this point, Lang must try to determine whether the variations between the NEP participant and nonparticipant groups are sufficiently small to allow reliable conclusions to be drawn from the results.

In this last scenario, perhaps the results are indeed significant and that, for some reason, seroprevalence is higher among the study group than a relevantly similar nonparticipant group. If so, she has discharged her responsibilities as a scientist to design a good study that permits some confidence in the results. If those results run counter to the preponderance of studies, then perhaps she has identified some important factor overlooked by other studies. Consequently, our understanding of the epidemiology of the disease may be advanced.

As a scientist, Lang has an obligation to share those results with scientific community. The results, if published, may indeed be used in ways that work to the detriment of the activists and NEP participants. Unlike Scenarios 1 and 2, here Lang is not morally culpable for that harm either because of bad design or publicizing unreliable results. Neither is she culpable for the use of her results by others to mislead public policy deliberations simply because she publicized credible results that run counter to other results.

Some might say she is culpable for causing harm to the activists and NEP participants if she seeks to publish the results rather than to suppress them. She could refuse to publish the results. That criticism presumes that the results of the preponderance of studies are correct and that her results do not identify a factor that could improve the programs. However, if her results point to some significant factor overlooked by the other studies, suppression of the results would harm the addicts by depriving them of suitably modified programs.

There are additional moral issues regarding publicity about the results. Whether Scenario 1, 2 or 3 describes the situation, Lang is under pressure to publish for prudential reasons. Failure to publish may mean the current grant will not be renewed or future grants will not be forthcoming and her research career may be at an end.

In Scenarios 2 and 3, if she makes clear that the composition of the nonparticipant group is flawed, it is not clear that any journal would accept the paper. That may tempt her to omit the information or falsify information on the nonparticipant group in order to get published and to further or at least preserve her career in an important area of research. Lang has an obligation to the scientific community to include a full report of what she knows of the design flaws in her experiment or else not submit her paper for publication. Falsification or suppression of information regarding the nonparticipant group would not be justified by the need to publish. Deliberate suppression of information about the nonparticipant group would undermine the practice of science, undermine work in this field and undermine her own integrity. Even if she stands to gain as an individual by such an act, that is outweighed by the other considerations and is a morally unacceptable alternative. (4)

In Scenario 3, if she is satisfied that the match between the participant and nonparticipant groups is sufficient to produce reliable results, then she has an

obligation as a scientist to publish the results, even though she is concerned that others may misuse those results for political purposes. If researchers are to engage in research in areas that are politically sensitive, they must be prepared to let the chips fall where they may in terms of honestly reporting findings. Otherwise, why bother to do the science? The fact that some harm could come from honestly reporting her results does not necessarily justify falsifying results or suppressing results. She owes the truth about her findings to all stakeholders, including those who oppose needle exchange programs.

One consideration is the particular good and harm that publication of these results may do to various stakeholders (e.g., pro-NEP activists, anti-NEP activists, NEP participants and Lang's credibility and her future access to these populations). But an equally legitimate concern is whether one can justify a practice of deciding to report or publish scientific findings on the basis of the impact of the findings on some ongoing political debate. It is not clear that such a practice could be morally justified in scientific research.

One can also consider the researcher's responsibilities to ensure fair and responsible reporting, interpretation and use of the researcher's findings. The researcher has these responsibilities both *qua* researcher and *qua* citizen.

At one level, the researcher cannot be held morally responsible for others' irresponsible use of the researcher's findings. If a journalist is too lazy or ignorant to do responsible reporting, that behavior is beyond the researcher's control. If politicians or activists willfully misuse findings to support a political agenda, they must be held morally accountable for that. However, if the researcher is in the best position to anticipate that her findings will be misused or to recognize they are being misused, then she has some obligation as a scientist with a commitment to the truth and as a citizen with a commitment to honest civic deliberation to take whatever steps she can reasonably take to prevent that abuse or to set the record straight.(5)

In Scenario 3, for example, perhaps she can alert her colleagues before publication so they are aware of the problems her findings may create in the public sphere and so they can be prepared to respond. Perhaps she could meet with journalists prior to release of the results to ensure they can place the results in the context of other research in the field.

• (3)These risk factors are identified in a historically similar (but not identical) case.) See J. Bruneau et al., "High Rates of HIV Infection among Injection Drug

- Users Participating in Needle Exchange Programs in Montreal: Results of a Cohort Study" and P. Lurie, "Invited Commentary: Le Mystere Montreal," American Journal of Epidemiology 146 (1): 994-1005.
- (4)For a full general discussion of moral issues of lying and failing to reveal see Sissela Bok, Lying: Moral Choice in Public and Private Life (New York: Vintage Books, 1989) and Sissela Bok, Keeping Secrets: On the Ethics of Concealment and Revelation (New York: Vintage Books, 1989).
- (5)For other discussions in this series of researchers' obligations to counter misuse of their results, see the cases and commentaries in "Beyond Expertise: One Person's Science, Another Person's Policy" and "Crashing into Law" in Brian Schrag, ed., Graduate Research Ethics: Cases and Commentaries, Volume 2 (Bloomington: Association for Practical and Professional Ethics, 1998).