

Research with Groups: Group Rights, Group Consent, and Collaborative Research

Commentary on Protecting the Navajo People through tribal regulation of research (Brugge and Missaghian)

Brian Schrag, *Indiana University, USA*

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Introduction

In “Protecting the Navajo People through Tribal Regulation of Research,” Doug Brugge and Mariam Missaghian raise the important issue of obtaining consent from a group before conducting medical/health care research on the group.¹ Although the issue of the need, justification, and implementation for group consent has been increasingly raised in medical and health care research, particularly in genomic research, it is equally an issue for non-medical research in other disciplines, especially the social sciences.

The natural sciences and the social sciences come to the issue of group consent in research from somewhat different historical experiences in research ethics. Historically the notion of informed, voluntary consent of individuals was introduced first in medical and health research. Researchers in those areas may have been conditioned to think in terms of individual consent as sufficient for research; that in turn may have made it difficult for those researchers to recognize the need for considering the issue of group consent. On the other hand, researchers in some of the social sciences (anthropology, for example) were much slower to recognize the need for informed, voluntary consent even at the individual level. Some were unaccustomed to thinking about informed consent at all and so now confront increasing demands for group consent from a much different perspective than those in medical ethics.²

Research and harm to groups

One of the issues driving the debate about group consent is the awareness that research on groups can result in harm to individuals in the group as well as, in some sense, the

Address for correspondence: Brian Schrag, Ph.D., Executive Secretary, Association of Practical and Professional Ethics, 618 East Third Street, Bloomington, IN 47405, USA; email: bschrag@indiana.edu.

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group collectively. A brief list of actual instances of harm or possible harm can help focus the issue. It also draws attention to relevantly different types of subject groups. Gordon Mitchell and Kelly Happe cite a number of such instances:³

- 1) The testing of African Americans for sickle cell anemia reportedly led major airlines to grounding or firing employees who tested positive for sickle cell anemia and led Dupont Corporation to restrict workloads of employees who tested positive.
- 2) Researchers looking for mutations of BRCA I (Breast Cancer Gene) that might cause increased risk of breast cancer, identified a mutation in women of Ashkenazi descent. The published finding that as many as 1% of all women of Ashkenazi descent carried this mutation, “may have exposed women of Ashkenazi descent to discrimination in the employment and insurance markets.”^{3 (p.44)}
- 3) Corporate screening of groups of employees for susceptibility to toxins may result in individuals being denied certain jobs.
- 4) In 1991, research on human remains in a discovered 18th century African burial ground in New York City focused on answering the question, “Were they slaves?” which led to charges of racial stereotyping. African Americans organized to get some control and input into the research.

Others have identified harm to Native Americans as a result of research on the group.

- 1) “Early references to Hantavirus pulmonary syndrome as Navajo flu, stigmatized the Navajo community.”^{4 (p.59s)}
- 2) “Premature release of limited results of an alcohol use survey conducted among a largely Inupiaq community in Barrow Alaska led to sensational headlines that characterized Barrow as a city of alcoholics.”^{4(p.60s)} That in turn led to the municipality’s Standard and Poor’s rating dropping sharply and subsequent loss of financing for a number of important community projects.⁴
- 3) In a recently highly publicized case, members of the Havasupai tribe in Arizona have brought suit against a researcher who, they allege, “collected 400 blood samples from them for researching diabetes, but that additional unauthorized research was undertaken on those samples regarding schizophrenia, inbreeding and population migration. They assert that the research on schizophrenia and inbreeding was stigmatizing to them and that they would not have authorized the migration research because it conflicts with their religious origin story.”^{5 (p.10)}

One of the harms in this last case falls under the category of what Thomas Murray has called “inflicted insight.” A people, subject to research without their knowledge or consent are then forced to face research results which run contrary to their current beliefs about themselves.⁶ As one tribal member put it, “They challenged our identity and our origins with our own blood and without telling us what they were doing,”^{7 (p.1)} Other harms may arguably be to the collective body as much as to individuals. Some of the papers published from the blood studies focus on schizophrenia, and inbreeding, not diabetes. Bill Freeman, former director of research for Indian Health Service observed, “Schizophrenia is a stigmatizing condition, and we’re not talking about tomorrow’s stigmatization, especially with a

small tribe like [the Havasupai]... No one wants to be known as the, quote, ‘crazy tribe.’ Doing that kind of research without specific permission from the subjects is a real harm.”⁷ (p.4)

- 4) Population genetics research on groups may be a special challenge to the use of group consent to protect groups from the harm of research. Group consent may reify group characteristics and research results that can affect the entire group can be obtained from a single individual who gives consent, even if the group as a whole has refused consent. Eric Juengst has long been a critic of group consent in research in population genetics, arguing that group consent in population genetic research puts “the group in harm’s way and respecting their refusal would do nothing to protect them.”⁸ (p.191)

Group rights and group consent

Brugge and Missaghian¹ implicitly invoke an appeal to group moral rights to support the approach of Participatory Action Research (PAR) in doing research in or on communities and to justify the demand of group consent. They note in their essay that U.S. society is focused on the value of individual autonomy and individual rights and that federal regulations of research reflect that focus and were designed to protect the individual welfare of research participants. Brugge and Missaghian ask if communities are “living entities with (moral) rights”¹(p.3) and “if individual (moral) rights are protected in research, then should cultures or communities also be protected in research?”¹(p.3) They describe how Participatory Action Research could protect such group rights by means of, among other things, a process of group consent. Group rights could include a right to give consent for research and more broadly, a right to protect fundamental group interests such as the group reputation or image, protection from economic or social harm, or even survival of the group or its members.

It is important to note that the claim that groups, social groups, or communities can have moral rights is a contested issue in the philosophical literature. The argument, in part, is over whether groups can be agents at all, let alone moral agents.⁹ One argument against group rights is that groups, as such, have no capacity to reason, no capacity for moral choice, and no capacity to act. Hence they cannot be moral agents, cannot assert moral claims, or authorize others to act for them. All these so called features of groups are simply reducible to the individuals within the group. Furthermore, groups cannot have moral rights grounded in group interests since all group interests are reducible to the interests of specific individuals.¹⁰ On the other hand, some have argued that one can distinguish between individual rights and group rights. “Rights...are special protection for especially important interests. When viewed in this light, one can clearly see there can be group rights as well as individual rights... . Group rights are ascribed to collections of individuals and can only be exercised, invoked or waived collectively on behalf of the collective.”¹¹(p.44)

Ultimately the issue of individual or group moral agency may come down to competing ontological claims: Are the ultimate, irreducible constituents of the world “things” (in this case, individual persons) or do those constituents include “facts”

(individuals and their relations to one another, i.e., groups)? It is beyond the scope of this commentary to resolve such fundamental issues. Although I am inclined to argue that groups have some properties that are irreducible to the individuals within them and that gives moral weight to group consent, nothing that I will argue here will depend on that position.

Whether one acknowledges the existence of group rights or not, it is still of course possible to have group consent in research. As illustrated by the preceding examples of harm done by researchers to groups, the possibility of such harm to groups and individuals in the group underlines the fact that groups as well as their members have interests and that does place moral constraints on researchers. It is a mistake to assume that unless a case can be made for moral rights of groups then the researcher has no obligation to respect the moral interests or values of the group or that a group has no moral claims to have their interests respected. Hence the issue of researchers' obligation to obtain group consent is still relevant, whatever the status of group rights.

Group consent of sovereign nations: a special case

It is especially useful to think about the issue of group consent from the perspective of group research with certain Native American groups. Those Native American groups which have the status of sovereign nations may have group characteristics shared by other research subject groups. However, they also have something that most groups do not have: the legal power to control researchers and their research on the group. Most groups subject to research do not have such power and it is significant and instructive to see what a group, subject to research, would choose to do in controlling research on their group if they had the power to control the research process.

These sovereign nations can and do establish their own local and national research review boards (IRBs) and completely control the research process, including controlling access to the group members. This oversight applies to all research, not just human subjects research. Researchers must submit their proposed research to these boards for approval (sometimes multiple levels of boards), and the boards may judge the adequacy of the research proposal "with respect to its fit with the community priorities, the cultural relevance of the study design."⁴ (p.74s) They may also review the research process and data collection. Based on their assessment, the board may reject the proposal altogether and suggest an alternate project or suggest modifications to the study. The board may also require that manuscripts based on the research be submitted to the board for review and approval prior to publication. Some groups go even further; the Navaho Nation requires that equipment used in the research become property of the Nation at the end of the study and that data specific to the group become property of the group.⁴

One study of three different research projects involving Native American groups shows how this works out in practice. The authors report on three different health research studies they conducted with three different Native American groups in three different parts of the United States (Eastern Band Cherokee, North Carolina; Cherokee Nation, Oklahoma; and Lakota, South Dakota).⁴

In each case, researchers ultimately had to receive approval from at least one, and sometime multiple, Native American IRBs or review boards or governing councils, all representing and acting on behalf of the tribal group.⁴ That approval can reasonably be viewed as one form of group consent.

In order to get such approval and in order to carry out research so approved, the researchers collaborated with many members of the groups, not just members of the formal approval bodies. Thus, in one case, early consultation with group members led to modifying a proposal to be more culturally appropriate. In another case, focus groups with group members led by a local Native American discussion leader helped develop a culturally appropriate survey to ensure its relevance and comprehensibility for this group.⁴ Such collaboration with group members strengthened the quality of the proposed research study, according to the researchers, and was instrumental in getting the research approved by the IRBs. After such approval, group members, including those on the IRBs, facilitated the study in various ways including providing liaisons with group members, providing additional staff for carrying out the research, facilitating interaction with group clinical personnel, and assisting with recruitment of study participants. From the perspective of the researchers, the positive outcome of such collaboration was “a better, more efficient and well-supported study.”⁴ (p.70s) Most groups that are the subject of research are of course not sovereign nations. But we can learn from that situation for other sorts of research on groups.

Moral work of group consent

It is worth reflecting on the moral work that group consent might do. Obtaining informed, voluntary consent from a group for research on that group may serve several functions including, 1) showing respect for the group identity (Part of what it is to show respect for an individual is to show respect for their membership in a cultural group since that is part of what it is to be that individual.); 2) showing respect for the group by soliciting informed, voluntary consent from the group and not just from individuals; 3) showing recognition and respect for a group’s decision-making process by submitting the consent process to the group decision-making process and not just to individual decision-making; 4) to the degree that a process of obtaining informed, voluntary consent gives the group the fullest possible understanding of the research and does not coerce them into the research, it protects both the group and individual members from harm by the research. However, obtaining group consent does not necessarily achieve all or any of these things and some objectives, such as the protection of the individual, may be sacrificed in the achievement of some of the other research objectives.

Concept of groups

The term “group” is used in many ways in discussions of group consent for research. There is a minimalist sense in which a group is not much more than a set of individuals who have in common a characteristic that the researcher wishes to study, for example,

being a member of a chat room group on the Internet, or being an undergraduate at a particular university, or being an alcoholic, or having a particular gene mutation. At this level, there may be no shared identity, shared structure for reaching group consent, or even a representative deliberative body.

At a more robust level one could mean by a group: a) a collection of individuals who at least share some common cultural heritage, but have no structure for reaching group decisions (African Americans involved in the testing for sickle cell anemia or the African burial case, or women around the world of Ashkenazi descent, for example.); b) a collection of individuals who not only share a common cultural heritage but also some kind of collective decision-making procedure which would enable them to discuss and decide whether or not to give consent as a group;^{a, 12} c) a collection of individuals with shared cultural background, common decision-making procedure, and a shared way of life (e.g., many Native American groups who may live in various places around the country but fall under some representative governing council.); d) a collection of individuals with shared cultural background, common decision-making procedure, a shared way of life and a shared geographical location, for example, a community of Amish,¹³ a remote tribe in the Amazon, or a specific geographical community of Native Americans such as the Havasupai.

Groups and group consent

Corresponding to these levels of groups, one can distinguish two broad senses of group consent. There is a limiting sense of group consent, suggested by the minimalist sense of group above, in which each individual in a group gives consent based on an individual decision-making process. There is, if you will, a “cumulative consent of the group;” each individual independently agrees to the research without any group discussion or collective decision. Thus, if one means by a group, simply a collection of individuals who have in common only that quality that the researcher wishes to investigate, then group consent amounts to no more than the aggregate consent of the individuals involved. Presumably the consent of each individual would be made solely from that individual’s perception of his or her best interest (e.g., consent by a group of employees to screening for susceptibility to toxins).

There is also a more conventional notion of group consent in which the consent is the product of some sort of collective group decision-making process. In this case, the decision-making process may result in the unanimous consent of all members of the group, or of consent of the majority, or of some kind of consent by a representative

a. An interesting example of this sort of group may be the Thomas Woodson Family Association, a group of descendants of the purported Sally Hemmings-Thomas Jefferson liaison. Researchers were interested in determining if DNA testing of group members could establish that link. The Association was originally organized to maintain intrafamily contact and plan family reunions. It was not at all clear that such an organization could function as a collective or representative decision-making body to give consent for research on the group, although it seems to have gradually evolved into such a body.¹²

body. The content of the consent may even evolve over the course of the decision-making process.

In this category, one can distinguish various levels and qualities of consent. 1) One could mean by group consent, the unanimous consent of individuals who all share a common culture. Presumably individuals could conceivably make their individual decisions based not only on the basis of their self interest but also on what impact they perceive it might have on their cultural group (for example the case of African Americans and sickle cell testing). 2) Alternatively, group consent could mean the consent of a collection of individuals who share not only a common culture but also a common decision-making process (a National Native American Council, for example). One might argue that the feature of a common decision-making mechanism is a necessary condition of group consent. That decision-making process may not necessarily involve unanimous consent; it could involve a majority rule or decision by a representative body. 3) Group consent could also involve a collection of individuals with a shared cultural background, and a shared way of life, as well as a common decision-making procedure. The sense of community is tighter in that members of the group not only have a shared cultural heritage but also a shared way of life (unlike the previous level of consent) so that deliberations about a research project may well take into account its impact on their way of life. 4) Finally, group consent could involve collections of individuals with a shared cultural background, a shared way of life, a common decision-making procedure and shared geographical location. (The shared geographical location increases the likelihood that members of the group will have direct face-to-face discussions with each other before the decision to consent is given. If the research has some impact on the geographical location of the community, then that is more likely to be taken into account by group members in this last situation.)

Levels of justification of group decision-making

Although it may be customary to think in terms of group consent as having a single moral weight, I would argue that the strength of the moral justification for doing research on a group that is gained by obtaining group consent for the research varies with the quality or level of the group consent. That quality of group consent in turn varies with such factors as levels of group cohesion, degrees of shared cultural background, degrees of shared way of life, degrees of shared geographical location and group decision-making processes.

Hence, the strongest level of justification would come from the informed, voluntary consent of a group in which the members live together in the same geographical location, share the same cultural beliefs, the same lifestyle and have a decision-making process that leads to a unanimous decision to cooperate in research which directly affects only members of the group. A consensus model of decision-making is least likely to result in a group decision that will coerce individual members of the group. If all members are in the same geographical area, they are most likely to engage in full decision-making discussion with others in the group, and are most likely to consider the impact of the research on their physical community, their cultural life

and beliefs. Group consent in general and this level of group consent in particular, is most likely to give appropriate weight to the values of the community. (On this last point it is clear, for example, that the Havasupai weighed the impact of research on prevalence of schizophrenia in their tribe or research on migration patterns that contradicted their tribal beliefs, more heavily than did the researcher.)

This level of group interaction, compared to the other levels identified, maximizes the likelihood of informed and voluntary consent of the individuals and group. The relative moral weight of various levels of group consent derives from that. That assessment of moral weight parallels what Hans Jonas noted many years ago regarding the validity of informed, voluntary consent of an individual subject of research, “The higher the degree of understanding regarding the purpose and technique, the more valid becomes the endorsement of the will.”¹⁴ (p.49)

If all the above factors remain the same but the decision is made by majority rule of the group or by a representative governing council, the strength of the justification decreases, since the possibility arises that some individuals in the group will be coerced to go along with research and it will not be voluntary or perhaps not even fully informed (for example, medical research on the group decided by Amish elders or archaeological research agreed to by tribal elders without consultation with all members of the group). The issue is further complicated if there is no clear decision-making body within the group, or if there are competing decision-making groups. For example a tribal government may agree, and tribal elders may disagree. In some cases, the deliberative process is yet more difficult and the justification for group research is weaker if the group shares a common way of life and cultural beliefs, but individuals are not in a single location and hence make decisions on the basis of representative governance.

The moral strength of the group consent is weakest if there is a group with no common decision-making structure, no shared way of life, or common geographical location, but mainly a shared ancestry (for example, the cases mentioned earlier involving Ashkenazi women, African burial sites and a study of sickle cell anemia).

Protection and group consent

It is not the case that a group decision to refuse consent necessarily protects those affected by the research, whether in the group or as individuals, since the researcher may “shop” for subjects in the group but not under the control of the group, which apparently happens, for example, in population genetics research. A group may consent to research and the outcome of the research affects not only those who consent but also many others are not even in the group and who have not consented to the research as, for example, the Barrow, Alaska case illustrates. The majority of a group may give their consent, but the findings affects all members of the group including those who have not given informed voluntary consent. Moreover, when representatives of the group give their consent, other members of the group who have not made the decision to participate may feel coerced or pressured.

Collaborative research

The issue of collaboration in research is not strictly tied to that of informed, voluntary consent of groups. The point and value of collaborative research is not limited to obtaining group consent. Not all group consent requires collaborative research and not all collaborative research leads to group consent.

Research with Native American sovereign nations is one situation which has forced the issue of collaborative participation between a researcher and a group. The experience with Native American sovereign nations raises a broader question: If collaboration can be useful in cases where the researcher is forced by the power of the group to collaborate, why should researchers not do it when they are not forced to do so? Such “collaborative research,” can have other values than achieving group consent.

Brugge and Missaghian¹ refer to PAR which is an orientation to research that has developed from perspectives other than research ethics. PAR arises from two traditions. The first is Action Research with roots in social psychology and aims to deal with critical social problems such as poverty and minority issues. Participatory Research is rooted in work with oppressed peoples by adult educators, community organizers, and researchers in sociology, economics and political science. It combines research education and action with the idea that people in a community are in control of the entire research process.¹⁵

One can, however, think about collaborative research with groups without embracing or presupposing the ideological underpinnings of these approaches. As indicated in the discussion of informed, voluntary group consent with sovereign nations, collaboration with a group can occur at many levels. From the researcher’s perspective, collaboration of the researcher with key local stakeholders can help with refining the object of the research (including the cultural appropriateness of the study design); facilitate development of research instruments such as surveys to make them more appropriate for the group; help identify and gain cooperation of participants; increase credibility of researchers with participants; and improve the efficiency in data collection.⁴ It can involve the researcher calling on group members for consultation on the collection and interpretation of data.¹⁶ It may involve having the group review the report of findings, make determinations regarding dissemination of findings, and assume maintenance or ownership of data by the group.⁴ Any or all of these collaborations may imply the need to form explicit agreements between the researcher and the group on research design, individual roles and responsibilities, interpretation of data and ownership of data, as well as financial accountability.¹⁵ One result of collaboration at any of these levels is to promote in the subjects of research a greater understanding of the nature of the research and its implications for their lives and also for the group, and perhaps to create greater identification with the project.

Richard R. Sharp and Morris W. Foster, addressing the issue of research risk to subject groups in genetics research, have suggested a model of collaboration aimed more narrowly at the objective of risk management.¹⁷ They propose four levels of community review of research. Since the aim is primarily to identify and minimize research related risk, it can be thought of as a kind of community collaboration.

Nevertheless, it is a kind of collaboration that could have broader application to all sorts of research with groups, not just genetic research. They suggest four goals of collaboration: 1) identify and minimize research related risks for individuals, for the community and for those who share the social identity of the community; 2) help participants to assess risks and benefits of the research and understand how others may be affected. (This can lead to more informed decisions about consent.); 3) inform researchers and participating communities about shared areas of interest, thus promoting genuine collaboration; and 4) involve study populations in the review process to show respect for the social and cultural structures in the communities, and to establish trust between the researcher and the group.

They propose corresponding levels of community review of research to accomplish these goals. 1) Community dialogue can include both formal and informal discussion with members of a group regarding a researcher's proposed study involving the group. This involves focus groups of the sort referred to by Manson.⁴ 2) Community consultation is a more structured review of the research that involves consulting with a representative subset of members and organizations. The aim is to provide information for independent community review boards or IRB forums and review boards outside the group, such as those at the researcher's university. 3) Formal Community approval requires a formal contractual agreement between researchers and a study population. Members of the study population or recognized political representatives are asked to give collective permission for study. In order to protect individual members in the group, however, that agreement is not binding on members. 4) Community partnership involves the group early on in the design of a research project and review of the study by helping to define its goals and methodology and to implement its experimental design.¹⁷

Collaboration at any of these levels can be of some benefit to the researcher in improving the quality of the research for the reasons mentioned earlier. However, depending on the level of collaboration, it can be very time consuming; it may result in a blurring of the distinction between the researcher and the group; there may well be a conflict between the value of applied research directly beneficial to the group and the value of basic research; the researcher's findings may be subject to review by the group and the publication of results controlled by the group; and the researcher may be required to cede data ownership to the group. On this latter point, it is worth noting that negotiation over ownership of data is not new.

From the perspective of the group, collaboration may result in research that is directly beneficial to the group, result in more input and control over research done on the group and more control over the publication of results. On the other hand, depending upon the nature of the research, the group could be made more vulnerable. Individual members may also be made more vulnerable and see their interests subordinated to the welfare of the group.

It is clear that there are moral constraints on a researcher who is doing research on a group that may warrant obtaining some form of group consent. However, the exact nature and content of that consent, which may include some form of collaboration, may necessarily vary with the kind of group and be the subject of negotiation. Various

forms of collaboration may be morally appropriate independent of the issue of group consent. That collaboration may involve negotiation but may well be beneficial to both the researcher and the group under study.

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REFERENCES

1. Brugge, Doug and Missaghian, Miriam. (2006) Protecting the Navajo People through tribal Regulation of research. *Science and Engineering Ethics* **12**/3: 491-507.
2. Fluehr-Lobban, Carolyn. (2003) Ethics and Anthropology 1890-2000: A Review of Issues and Principles in Fluehr-Lobban, Carolyn ed. (2003) *Ethics and the Profession of Anthropology: Dialogue for Ethically Conscious Practice*, 2nd edition, Altamira Press, Walnut Creek, p.19.
3. Mitchell, G and Happe, K. (2001) Defining the Subject of Consent in DNA Research. *Journal of Medical Humanities*, **22**: 41-53.
4. Manson, S., Garrouette, Goins, E. and Nez Henderson, P. (2004) Access, Relevance and Control in the Research Process: Lessons from Indian Country. *Journal of Aging and Health* Supplement to Vol. **16**, No. 5: 58s-77s
5. Andrews, L. (2004) Havasupai Tribe Sues Genetic Researchers. *Lab Report: Law and Bioethics Report* Volume **4**, Issue 2: 10-11.
6. Murray, T. (1980) Learning to Deceive. *The Hastings Center Report* **10**: 11-14.
7. Rubin, Paul. (2004) Indian Givers. <http://www.phoenixnewtimes.com/issues/2004-05-27/news/feature.p.1-9>.
8. Juengst, E. (1998) Groups as Gatekeepers to Genomic Research: Conceptually Confusing, Morally Hazardous and Practically Useless. *Kennedy Institute of Ethics Journal* **8**.2: 183-200.
9. Wellman, C. (2001) Alternatives for a Theory of Groups Rights in Sistare, C., May L., and Francis, L. eds. *Groups and Group Rights*, University Press of Kansas, Lawrence. 17-43.
10. Wall, E. (2003) Problems with the Groups Rights Thesis: American Philosophical Quarterly, **40**: 269-285.
11. Buchanan, A. (1991) The Right to Self Determination: Analytic and Moral Foundations. *Arizona Journal of International and Comparative Law* **8**: 44.
12. Williams, S. (2005) A Case Study of Ethical Issues in Genetic Research: The Sally Hemmings-Thomas Jefferson Story” in Turner, T. ed., *Biological Anthropology and Ethics: From Repatriation to Genetic Identity*. State University Press of New York; 185-208.
13. Anonymous. “Forbidden Knowledge,” (2000) in Brian Schrag, ed. *Research Ethics: Cases and Commentaries*, Vol 4, Association for Practical and Professional Ethics, Bloomington. 25-28.
14. Jonas, Hans. (1969) Philosophical Reflections on Experimenting with Human Subjects, *Daedalus*, *Journal of the American Academy of Arts and Sciences*, Spring. Boston Massachusetts. Reprinted in Munson, R. (2004) ed. *Intervention and Reflection: Basic Issues in Medical Ethics*, 7th edition, Thompson/Wadsworth, Belmont, p.49.
15. Khanlou, N. and Peters, E. (2005) Participatory Action Research: Considerations for Ethical Review,” *Social Science and Medicine* **60**: 2333-2340.
16. Colwell-Chanthaphonh, C. and Ferguson, J.T. (2004) Virtue Ethics and the Practice of History: Native Americans and Archaeologists along the San Pedro Valley of Arizona. *Journal of Social Archaeology* **4**: 5-27.
17. Sharp, R. and Foster, M. (2000) Involving Study Populations in the Review of Genetic Research. *Journal of Law, Medicine & Ethics*, **28**: 41-52.