

Conflicting notions of research ethics The mutually challenging traditions of social scientists and medical researchers

Klaus Hoeyer*, Lisa Dahlager, Niels Lynøe

*Department of Health Services Research, University of Copenhagen, Øster Farimagsgade 5, P.O. Box 2099,
DK-1014 Copenhagen K, Denmark*

Available online 25 April 2005

Abstract

Tensions over ethics in research occasionally arise when anthropologists and other social scientists study health services in medical institutions. In order to resolve this type of conflict, and to facilitate mutual learning rather than mutual recrimination, we describe two general categories of research ethics framing: those of anthropology and those of medicine. The latter, we propose, has tended to focus on protection of the individual through preservation of autonomy—principally expressed through the requirement of informed consent—whereas the former has attended more to political implications. After providing few examples of concrete conflicts, we outline four issues that characterise the occasional clashes between social scientists and medical staff, and which deserve further consideration: (1) a discrepancy in the way anthropologists perceive patients and medical staff; (2) ambiguity concerning the role of medical staff in anthropological research; (3) impediments to informed consent in qualitative research projects; and (4) property rights in data. Our contention is that enhanced dialogue could serve to invigorate the ethical debate in both traditions.

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Keywords: Research ethics; Anthropology; Clinical medicine; Informed consent; Politics of research

Social scientists entering medical settings

An increasing number of social scientists, notably anthropologists and sociologists, are conducting research on health services in medical institutions, using medical staff and researchers at these institutions as informants in their projects. These encounters occasionally create tensions or even conflicts around ethical issues: tensions which we have come across in our own work, as well. To gain a better understanding of the

problems in these encounters, and to make the collaboration between social science and medicine more fruitful, we wish to explore the different notions of research ethics in what we identify as two clusters of research cultures: clinical medicine and socio-cultural anthropology. Research ethics in the social sciences is less codified than in medicine and we focus on anthropological debates to avoid lengthy discussions of minor disciplinary differences. We do believe, however, that debates in other qualitative social sciences relying on interpersonal relationships share a number of research ethical challenges with anthropology.

Durkheim (1957) argued that a profession is constituted partly through development of an ethical

*Corresponding author. Tel.: +45 35 3279 96;
fax: +45 35 32 76 29.

E-mail address: k.hoeyer@pubhealth.ku.dk (K. Hoeyer).

tradition; hence, the research ethics debate lies at the core of a professional identity. It is therefore important to avoid evaluating one tradition by the standards of another. Rather than encouraging the confrontation between traditions, we hope to enlarge the scope of ethical reflection in both traditions through increased awareness of areas of concern particular to each tradition.

There seem to be commonalities in the historiographies of the medical and anthropological traditions of research ethics: a golden age of assumed beneficence at the beginning of the 20th century; some ethical awakening through the respective research contributions of the two traditions during the second World War; an intensified preoccupation with ethical issues from the late 1960s onwards, and a current sense of predicament. The two traditions have differed remarkably, however, in their perception of ethical problems. Specifically, we suggest that anthropology has come to view the political implications of the research endeavour as a key concern, whereas medicine has focused on respect for the individual and the use of informed consent.

Firstly, we provide brief sketches of the development of ethics and ethical reflection within the medical and anthropological research traditions. Secondly, after examining instances of conflict between the different research ethics traditions, we tentatively outline four issues that we believe characterise these clashes between social scientists and medical staff. Finally, we use this discussion as a stepping stone for suggesting ways in which the two traditions might learn from one another.

The emergence of medical research ethics

The medical profession has often referred to the Hippocratic Oath as its ethical foundation and has taken the principle of benevolence as its starting point, conditioned by the key restriction “Do no harm”. As medicine broadened its parameters to include research, and as wider processes of democratisation changed the perception of the relationship between doctor and patient, the adequacy of the Hippocratic Oath was questioned. For many, however, the oath still exemplifies the key virtues of a doctor in its emphasis on the obligations towards the wellbeing of the individual patient or research participant.

There were several early attempts to articulate codes of ethics in medical research. In 1803, Thomas Percival presented *Medical Ethics; or, a Code of Institutes and Precepts, adapted to the Professional Conduct of Physicians and Surgeons* (Lynöe, 1999, p. 30) and the Weimar Republic in Germany passed a directive, in 1931, which included a demand for the informed consent of research participants. On the whole, however, the question of ethical regulation of medical science was

only of peripheral concern until World War II. Following the experiments in Nazi concentration camps, several German doctors were convicted in Nuremberg for violations of human dignity, and informed consent was codified on the principle that individuals must never be sacrificed for the benefit of society. The Nuremberg trial, however, did not have any major, practical influence on research ethics in the rest of the world (Rothman, 1991). Indeed, a push for greater patient autonomy seemed only to emerge in the US in the 1960s. Various national policy changes in 1953, the 1954 *Resolution on Human Experimentation*, and the Jewish Chronic Disease Hospital case in 1963, lead to the World Medical Association’s Declaration of Helsinki in 1964 (Brody, 2001). The Declaration stressed the importance of RECs (institutional review boards in the US) and stipulated that researchers should not take ethical responsibility entirely on themselves: a view later sustained by Henry Beecher’s oft-cited whistle-blowing article in the *New England Journal of Medicine* (1966).

The US has been described as a highly litigious society (Nader, 2002): an inclination that probably motivates interest in clear guidelines and rules. Several court rulings have held that the individual holds the right not only to know of, but also to accept or decline, risks imposed on his/her body (Rothman, 1991). Informed consent has thus gradually become a matter of key importance in medical research, sustained and codified by the Food and Drug Administration (FDA) and major funding bodies (Rothman, 1991). Subsequent cases where consent procedures were overruled only underscore its dominance in medical research ethics.

Partly through the international spending of the National Institute of Health (NIH), the demands of the FDA, and the standardisation of publication requirements, American ethical standards have influenced Europe and the rest of the world, granting the rights of the individual pivotal attention in medical research ethical debates. This reflects what has been described as the Western notion of individuality, which also influenced the Human Rights Declaration. Thus, medical research ethics has tended to take the *protection of the individual* as its main objective irrespective of the political or cultural context.

Interestingly, the emphasis on *protection* signifies an important development in what we might term the medical ethos. From the basic intention of beneficence, the introduction of research necessitated balancing of interests among various actors: present and future patients, researchers, and the subjects of research. With the Tuskegee syphilis study in 1972, and the resulting Belmont report, the idea of non-maleficence gained increasing importance, changing the understanding among many clinical researchers of what medical ethics is: it is now often reduced to doing no harm. In this form, it is sometimes regarded as an obstacle to research

and often devolves into tedious and sometimes questionable rules about informed consent and approval procedures. Most medical researchers, however, are conscientious in securing the rights of their research participants. Informed consent is integral to these aspirations, and it is now applied even in cases in which the initial right to assess risks imposed on the body of the individual is not necessarily at stake (e.g., biobank-based research).

Debates on research ethics in anthropology: A recent invention?

The social sciences hold a shorter history than medicine and a less-established tradition of research ethics. Modelled as it was on the natural sciences, knowledge was for many social scientists an aim in itself; and, in the case of British anthropology, early research was stimulated by a sense of urgency to collect and preserve information on what were believed to be rapidly vanishing cultures (Kuper, 1999). More profound concerns about beneficence, however, have come to characterise anthropological research ethics during the past few decades. Some instances of ethical dilemma have been widely debated; for example, the political uses of anthropology in Project Camelot during World War II, the probable exploitation of the Yanomani, and the release of the diary of the founding father of modern fieldwork, Malinowski, which revealed an almost racist view of the local population (see Mills, 2003). However, unlike Nuremberg or the Belmont report, these debates did not as systematically result in a codification of ethics in anthropology. In fact, there has been a reluctance to accept ethical oversight procedures in anthropology (Marshall, 2003). The American Anthropological Association has adopted a code of ethics (last revised June 1998), as has the equivalent British association (ASA). Also, the Economic and Social Research Council in the UK has recently commissioned the development of an ethical framework for all the social sciences (see <http://www.york.ac.uk/res/ref/>), but the various associations have not managed to agree on a set of universal rules. A central argument against ethical rules has been that they might serve as an impediment to political awareness (Amit, 2000) and activism (Harrison, 1991). Recently, one anthropologist even argued that “ethics, with its impossible conceit of impartiality, only *masks* politics” (Pels, 1999, p. 103).

The mention of politics is a striking feature of the anthropological debate on ethics, which might reflect a trajectory of research ethics different from that of the biomedical tradition. In early British anthropology, research projects were allowed by colonial authorities, because knowledge of indigenous forms of social organisation was expected to be useful for British

colonial administrations operating under the principle of indirect rule. American anthropologists were engaged to a similar end by military authorities during World War II. Unlike the exposure of individuals to the risk of physical perils in medical research, the embarrassing collective memory of the past in anthropology relates to complicity in the execution of power over societies and groups. Political unawareness has been viewed as the major misdeed in this narrative, rather than infringement upon individual rights. The prominence of the focus on political implications in anthropological debate does not mean that no one has argued for impartiality (D’Andrade, 1995). It indicates only that political implications have become an integral part of the body of literature used in the training of young anthropologists. Thus, at the expense of respect for the autonomy of individuals, the methodological emphasis on participant observation seems to have amplified the ethical concern with political implications.

The role of the politics has also run through debates about relativism (Geertz, 2000), representation (Butt, 2002), participatory methods (Arnst, 1996), and even the relationship between anthropologists and their informants. In the last case, anthropological reflections on the level of trust between researcher and informant have taken on a very different form from that in medical research. Few researchers have promoted informed consent in anthropology, for example (Fluehr-Lobban, 1994), and the proposition has been countered by scholars preferring to give more weight to reciprocity and rapport (e.g. Wax, 1995). In striking contrast to the medical tradition, covert participant observation (e.g. Humphreys, 1975) has been seriously discussed as a reasonable method of ensuring access to research settings that otherwise avoid scrutiny (Bulmer, 1982). In place of informed consent, confidentiality and anonymisation have been the standard approach to protection of informants. The reluctance to embrace an informed consent requirement might also be related to anthropologists having so many different contacts throughout fieldwork, of varying intensity and importance, that consent from everyone is regarded as a practical impossibility.

The political ambition in social science, and its related attacks on the discipline’s past, matured in the 1970s. Group solidarity and alliances with weaker parts of the population became important markers of professional identity. Simultaneously, more anthropologists began to follow the appeal from Laura Nader to study people in power, and not only marginalised people around the world: as Nader put it, to “study up” (Nader, 1972). As anthropologists, concurrently with the growing awareness of patients’ rights in medical research (Caplan, 2003), began turning their attention to medical settings in their home countries, they brought along the inclination to view their task as partly political: to

reveal the work of power and side with patients against presumably more powerful doctors (Gabe, Calnan, & Bury, 1991).

Anthropologists and other social scientists using personal interaction in their research depend heavily on good rapport and have therefore traditionally been concerned not to infringe upon their individual informants. However, as anthropologists deal with groups of people with conflicting interests, it has been viewed as futile by most ethnographers to expect that everyone will support the social scientific endeavour. It has furthermore been argued that if particular, powerful informants are given the right to decide what types of research projects are to be performed, social science will have nothing to offer but a reproduction of the images that elite groups wish to present (Scheper-Hughes, 2000). In sum, a politically informed concern about the overall beneficence of the research endeavour has become central to most practitioners' understanding of their task as social science researchers.

Conflicting notions of research ethics?

As with the social sciences in general, ethical deliberation in anthropology has shown greater emphasis on group commitment and political effects of research, whereas ethical deliberation in medical research has tended to focus on the individual's rights, that is, on what should not be done to the research participants. In our opinion, this type of simplified outline of two particular forms of framing research ethics can be helpful in understanding what we see as a characteristic form of conflict: that between people educated through the divergent traditions described above. We wish to suggest that an increased awareness of the differences between the ways of construing ethical problems might prove helpful: firstly, when seeking to understand the controversies emerging through their confrontation, and secondly, when addressing new challenges facing medical ethics today.

The tension created by the presence of anthropologists and other social science researchers in medical settings is becoming generally acknowledged. In Scandinavia alone, at least three cases have made it to the media and have affected the way social scientists are being received in some medical research institutions. We posit that these cases demonstrate a confrontation between the divergent traditions of research ethics framing outlined above. A characteristic feature of these conflicts is that the projects involved have been perceived by medical professionals as a breach of confidence. We suggest that this is because the type of research in question involves interpersonal relationships, regardless of the methods employed.

The first of the cases receiving press coverage occurred in the 1980s, when social scientists Rosmari Eliasson-Lappalainen and Pär Nygren studied a group of psychiatrists in Sweden, using ethnographic methods. They observed and interacted, also privately, with the psychiatrists, who were later somewhat startled as Eliasson-Lappalainen and Nygren wrote critically about their psychotherapeutic approach (Eliasson & Nygren, 1981, 1983). The psychiatrists felt that their offer of friendship had been violated, and the sociologists were accused of scientific misconduct, although they were later vindicated by the Swedish Research Council (Lappalainen, 1996). The Danish sociologist Lone Scocozza also collided with the doctors she studied in the 1980s. As they discovered that she was making what they perceived to be misleading conclusions, they unsuccessfully attempted to stop her from publishing (Hansen, 2003; Scocozza, 1994). In a Dutch case, a book was actually destroyed as a result of a court case (Van der Geest, 1989). More recently, the case of anthropologist Lisbeth Sachs has caused intense debate in Swedish research institutions.

Sachs embarked on a study of five women seeking cancer genetic counselling in the early 1990s, and the counsellor, Annika Lindblom, co-signed the application to the Research Ethics Committee (REC). As the work progressed, Sachs presented drafts of her work to the five women whose story she told, but not to the medical counsellor. When a book aimed at the general public was published with anonymised quotes from the counselling sessions (Sachs, 1998), the counsellor filed a complaint to the ethics committee at Karolinska Institutet (KI) where the study had taken place. She found that the work presented the genetic counselling unfairly: that she had been unjustly degraded from a co-applicant and collaborator to an object of study; that the study ran contrary to her motivation for participation, and that she, as any other research participant, should have the right to withdraw from further research and request that all tapes of the counselling sessions be handed over. Sachs nevertheless proceeded to publish using the tapes, whereupon Lindblom filed another complaint (Örn, 1999). The ethics committee of KI found that Sachs should have presented the material also to the counsellor. They deemed, however, that Lindblom had neither the right to prevent further publications nor rights to the tapes (which contained statements from the counselees, as well). The ethics committee of the national research council supported the KI committee in its verdict, albeit in general terms only.

The debate over Sachs brought forward views typical of the traditions outlined above, not least in the Swedish Medical Journal, *Läkartidningen* (Hydlye, 1999, 2000; Lindblom, 1999; Terenius, 1999). On the one hand, doctors were seen as lacking in ethical competence

because they focused on minor controversies between individuals, thereby sidestepping the wider social implications of new technologies (Hydle, 2000). On the other hand, social scientists and scholars from the humanities in general were described as “more unaware of research ethical issues than medical doctors... [as] medical doctors are, among other things, more accustomed to provide information and acquire informed consent in their studies” (Forsman in Örn, 1999, p. 4505, our translation). The positions taken by the respective parties in most of these conflicts also reflect an emphasis on individual consent and information levels by people trained in the medical tradition, as well as an emphasis on societal implications and use of power among social scientists. It is our contention, however, that this type of conflict is inadequately addressed if seen simply as one or the other tradition lacking in ethics.

In the following, an alternative approach is taken, as we outline and comment upon four issues we believe to be characteristic of the encounters between social scientists and medical staff: (1) the notion that patients and staff should be treated differently; (2) the ambiguity of the status of the research type and the uncertainty of the corresponding rights of research participants; (3) the complexity of providing information about explorative, qualitative research and its implications for participants, and (4) the question of who holds what rights to the data produced. The discussion of the four issues introduces a turn in the style of the argument, as we, in addition to describing different research ethical framings, seek to suggest ways of balancing them in relation to the issues discussed. Finally, we proceed to more general reflections on medical ethics, embracing insights from both traditions.

Four issues concerning encounters between medical staff and anthropologists

In her comments on the Sachs controversy, Hydle articulated the widespread idea that patients and staff have fundamentally different roles in social science research (Hydle, 1999). In this view, patients are perceived as weak (cf. studying down and advocating the case of the poorer and weaker party), whereas doctors, with their high social ranking, are perceived to be strong (cf. studying up and revealing the work of power), resulting in a discrepancy of rights. It is also argued that, as employees in public institutions (in many European countries, at least), doctors have an obligation to let their practice be scrutinised: much as politicians must face the scrutiny of journalists (Hydle, 1999). Thus, the political awareness of the anthropological tradition of research ethics would advise that public matters, including public documents and professional performance, be left open to debate and scrutiny. According to

this logic, it is important to remember that social scientists (themselves publicly employed) would also be obliged to allow unconditional scrutiny of their own practice. The medical tradition, on the other hand, would focus on the autonomy of the research subject and attune our ethical sensitivity to the personal concerns of medical professionals (or social scientists) as individuals.

We contend that the crux of the matter is the establishment of social relationships. Once a more or less intimate social relationship is built up, social rank and professional authority can be of minimal importance to the relative ‘power’ of the involved parties. Doctors may feel infringed upon, just as patients would, if they experience a breach of trust. In personal relationships, people want to feel personally respected. It is essential, therefore, to avoid duplicitous ‘friend-like’ behaviour (including acting friendly to get an interview) performed solely to ‘gather’ data expected to serve the honourable purpose of ‘revealing’ power. Social science researchers most abandon “the Gothic Vision, [which] proposes that, since evil is ruthless in pursuit of its objectives, virtue must be ruthless in self-defence” (Cavan, 1977, p. 88). People in positions vested with authority have an obligation, however, to let their practice be examined, and should not be entitled to bar a project altogether simply because they fear that it will portray them unfavourably. What they should be entitled to is a continuous renegotiation of the terms of their participation, which takes us to the second point, namely, the ambiguity of the status of research.

It is often unclear which rules and ethical guidelines apply to the social study of medicine. Some anthropologists are told that they should have medical ethical clearance, some that they should not. Some, like Sachs, find that it helps to have medical staff as co-applicants, thus allowing the study to be presented as quasi-medical. This, however, can create confusion concerning the roles of the participating medical staff, as we have seen. To pretend to be working toward the same ends might cause distress and friction, also for the ethnographers, who sometimes feel that they cannot produce the kind of results desired by their medical collaborators (Bosk, 1992). It is perhaps only reasonable that staff co-signs applications for studies taking place in their departments; but if they sign in the role of granting permission and accepting the role of research subjects, this should be clearly stated. Further, a signature can hardly be seen as a guarantee of agreement on the research objectives. As the study evolves, the terms of agreement must be continuously renegotiated. In some cases, the social scientist might encounter different forms of misconduct (e.g., abuse of authority), the revealing of which runs contrary to the interests of the participating staff. The staff could, however, reasonably be given the chance of responding to the accusations. This might also increase

their willingness to consider using the study constructively to improve their practices, which must be the expected purpose of a critique. Total agreement on research objectives, however, cannot be expected in complex interactions among several parties with different interests. It will remain an ethical quandary for the social scientist to balance personal respect for medical staff with honesty in reporting of research findings and commitment to the interests of other, perhaps more marginalised, stakeholders. It may become necessary to stipulate clearly that the relationship with staff is purely professional and that the anthropologist sees him or herself as representing the interests of the patients/society.

Thirdly, we suggest that it can be particularly difficult to communicate an understanding of an ethnographic study prior to its execution, because of its qualitative, explorative character. In most medical studies, the investigator can confer an understanding of the hypothesis being tested, and of the possible physical implications for the participant. Anthropological studies, on the other hand, rarely seek to test a hypothesis. There is no protocol, and the idea of a full presentation of the research endeavour is therefore implausible. The good study is characterised by its ability to present new questions and unrecognised connections. Furthermore, in spite of widespread ideas about anthropology as aiming for ‘the native’s point of view’, the goal is never this view alone. There are always many different views at play in any research context, and the goal would typically be to describe such views from a third position in order to place them in context and in relation to one another (Hastrup, 1995). This automatically obscures the goals from the immediate experience of the informants, and no number of safeguards will be able to guarantee that no one feels misled. The psychological reaction to seeing oneself and one’s ideas described, objectified and relativised, is difficult to predict and, thus, difficult to prepare for. Charles Bosk has argued that informed consent, for these reasons, is effectively impossible in ethnographic studies. He sees this as a reason for abandoning ethnographic methods (Bosk, 2001). The differences between clinical medicine and anthropology, however, might not be as overpowering as this sketch suggests. The actual implications of a clinical trial are also unknown, and to convey to research participants in double-blinded trials that they might or might not receive a drug is not without complications either (see e.g. Joffe, Cook, Cleary, Clark, & Weeks, 2001; Tattersall, 2001). Hence, we are less inclined to abandon ethnography on these grounds. While anthropological political awareness brings an end to illusions about total consensus and harmony, ethical respect for the individual, in the medical tradition, would advise anthropologists to attempt a personal dialogue with people they engage with in order to

discuss the type of knowledge they aim to produce and the uncertain direction of the research. It is important, however, not to recourse to a crude version of the biomedical model of consent: the dialogue should not be seen as merely a question of making the informant understand and accept a predefined research package.

Once a conflict between medical and anthropological researchers is exposed, the fourth issue outlined above becomes central. Who holds what rights to the data produced? Here, the medical research ethics tradition might advise us to respect the right of the individual to withdraw from the research project at any time, implicitly giving participants (non-commercial) property rights to the data. The anthropological tradition, on the other hand, might advise us to beware of the depoliticising effect of letting the more powerful party in the doctor/patient relationship possess the right, for example, to decide on publication in cases of abuse of power, however rare such cases might be. Also, given that most anthropological data are constructed in complex social relations with many people (in the case of Sachs, both the counsellor and the counselees featured on the tapes), who should have the right—and responsibility—to dispose of the data if not the principal investigator? Rather than giving medical staff the right to veto publications they find unfavourable, we suggest limiting objectionable publications by advising anthropologists only to publish what they have already dared to present to the people with whom there have been continuous relationships. Preferably, the property issue should be addressed right from the beginning as part of explicating the type of study and the role of the staff in it.

In all these cases, we seem to encounter the recurring concern for balancing respect for participating individuals against careful consideration of the political implications of granting people in power the right to bar scrutiny of the way they handle their mandate. The two traditions merge, however, in notions of responsibility and obligation. The researcher holds a responsibility towards every single research participant, as well as to society as a whole, and both traditions operate, albeit tacitly, with notions of obligation to participate in research. In the following, we wish to suggest that this common ground might prove useful for medical researchers as well, when facing new challenges to the traditional focus on the rights of the individual, which has been dominant in medical ethics.

Making the case for an invigorated medical ethics

In retrospect, Nuremberg and the Declaration of Helsinki have been important in teaching the medical community the need to safeguard and respect the individual, notably by introducing informed consent (World Medical Association, 2002). Helsinki, however,

in contrast to the War Crime Tribunal, also introduced a notion of proxy consent. In some situations, even in the medical tradition, offering information was seen neither as a way of showing respect, nor as a way of protecting the individual.

Recently, Joan Cassall and Allan Young have argued that health services research is a relevant example (Cassell & Young, 2002): a focus on the rights of the individual is misplaced because the interests of the individual are not in conflict with those of society. Another area in which the conflict between society and the individual need not appear is in certain population-based genetic databases. Despite emerging policies focused on informed consent (Beskow et al., 2001), individuals might have no particular interest in staying informed about specific research projects, as they experience no physical risk in relation to specific uses of tissue. The possible harm incurred through participation concerns confidentiality, and would probably be better addressed through institutional safeguards than through consent (Ashburn, Wilson, & Eisenstein, 2000).

Another interesting new challenge to the notion of individuals' informed consent emerges in other forms of genetic research where genetic information has direct implications to patients' kin. Genetics has also given rise to new debates within medicine of the need to assess group consent (Greely, 2001). Related issues include benefit sharing and property control in population genetics, where indigenous people have tried to retain rights to DNA extracted from them (Marks, 2001). All these instances serve to reintegrate the political into medical research. This challenge is worth meeting, and an awareness of both research ethical traditions might prove helpful in coming to terms with it.

Conclusion

This article has suggested that conflicts between social scientists studying the health services and the medical professionals enrolled as informants in their projects involve confrontations between two research ethics traditions. Rather than measuring one tradition by the standards of the other, we suggest facing the challenge of combining the medical inclination towards respect for the individual with the social scientific awareness of political implications and informants' conflicting interests. This approach also gives rise to a reconsideration of the informed consent requirement so revered in medicine and yet so criticised in anthropology. If we accept that informed consent is merely a means of showing respect, rather than an *end* in itself, we might also agree (1) that the social sciences are not exempt from the demands of informed consent when engaging in interpersonal relationships, and (2) that sometimes this end could be better attained by other means. This might facilitate a

less-procedural, juridical and ritualised perception of informed consent than is often the case in medical research, and a more transparent and respectful mode of conduct than is often practiced in anthropological research.

In preference to reliance on an once-and-for-all informed consent form, we suggest that social scientists and medical professionals who are about to commence collaboration contemplate and negotiate the four issues discussed above. For our part, we conclude that:

1. Medical staff should be treated with the same sensitivity as patients, once the researcher has engaged in an interpersonal relationship with them. People in influential positions, however, have an obligation to let their practice be scrutinised as long as they are informed about how and when they are studied.
2. It is essential that medical professionals are made aware of their status as research subjects, rather than research partners, when enrolled in social science studies of the health services.
3. The complexities of informing subjects in explorative, qualitative research should be mentioned as a project is commenced. Preferably, researchers should establish an ongoing dialogue with the people they study regarding the type of knowledge they aim to produce.
4. While research subjects should be given a fair opportunity to comment on analyses of data they have contributed to the production of, it must be made clear that the researcher holds the rights to the data produced and makes the final decision on publications.

Proper consideration of these four issues does not imply that consensus can or must be reached or that no problems will arise. On the contrary, it could be seen as an overall obligation resting on the anthropologists to specify that informants *will not* be allowed to change conclusions and that they *might* feel infringed upon.

In sum, we have outlined two traditions and argued that they can help us in understanding a type of conflict in which social scientists infringe upon medical practitioners' sense of reasonable ethical standards, and vice versa. Rather than perceiving one or the other tradition as simply being misguided, we suggest using both traditions to clarify our aims, standards and limitations. Furthermore, we suggest that public health studies, genetic medicine, and other challenges facing medical ethics today may be better addressed once medical ethicists actively engage with the concerns articulated in the research ethical tradition of the social sciences. This constitutes a call for further collaboration in the teaching of ethics to public health students, coming medical professionals, and social scientists.

Acknowledgements

The authors would like to thank Allan Krasnik, Lene Koch, senior editor Peter Davis and two anonymous referees for comments on an earlier version of the article. This work has been supported by the Swedish Ethics in Healthcare Programme (Grant no. 2000/56).

References

- Amit, V. (2000). The University as Panopticon. Moral claims and attacks on academic freedom. In M. Strathern (Ed.), *Audit cultures. Anthropological studies in accountability, ethics and the academy* (pp. 215–235). London: Routledge.
- Arnst, R. (1996). Participation approaches to the research process. In J. Servaes, T. Jacobsen, & S. White (Eds.), *Participatory communication for social change* (pp. 109–126). London: Sage Publications.
- Ashburn, T., Wilson, S., & Eisenstein, B. (2000). Human tissue in the genomic era of medicine. *Archives of International Medicine*, 160, 3377–3384.
- Beskow, L. M., Burke, W., Merz, J. F., Barr, P. A., Terry, S., Penchazadeh, V. B., Gostin, L. O., Gwinn, M., & Khoury, M. (2001). Informed consent for population-based research involving genetics. *Journal of the American Medical Association*, 286(18), 2315–2321.
- Bosk, C. (1992). *All god's mistakes. Genetic counseling in a pediatric hospital*. London: University of Chicago Press.
- Bosk, C. (2001). Irony, ethnography, and informed consent. In B. Hoffmaster (Ed.), *Bioethics in social context* (pp. 199–220). Philadelphia: Temple University Press.
- Brody, B. (2001). A historical introduction to the requirement of obtaining informed consent from research participants. In L. Doyal, & J. Tobias (Eds.), *Informed consent in medical research* (pp. 7–14). London: BMJ Books.
- Bulmer, M. (1982). Ethical problems in social research: The case of Covert participant observation. In M. Bulmer (Ed.), *Social research ethics. An examination of the merits of covert participant observation* (pp. 3–12). London: Macmillan Press.
- Butt, L. (2002). The suffering stranger: Medical anthropology and international morality. *Medical Anthropology*, 21(1), 1–32.
- Caplan, P. (2003). Introduction: Anthropology and ethics. In P. Caplan (Ed.), *The ethics of anthropology: Debates and dilemmas* (pp. 1–33). London: Routledge.
- Cassell, J., & Young, A. (2002). Why we should not seek individual informed consent for participation in health services research. *Journal of Medical Ethics*, 28, 313–317.
- Cavan, S. (1977). Investigative social research: Individual and team field research. A review. *The American Journal of Sociology*, 83(3), 809–811.
- D'Andrade, R. (1995). Objectivity and militancy I: A debate. Moral models in anthropology. *Current Anthropology*, 36(3).
- Durkheim, E. (1957). Professional ethics. In E. Durkheim (Ed.), *Professional ethics and civic morals*. London: Routledge.
- Eliasson, R., & Nygren, P. (1981). *Psykiatrisk Verksamhet. Samhälle, Människosyn och Modern Självvård*. Stockholm: Prisma.
- Eliasson, R., & Nygren, P. (1983). *Närstudier i Psykoterapi. Psykiatrisk Verksamhet II*. Stockholm: Prisma.
- Fluehr-Lobban, C. (1994). Informed consent in anthropological research: We are not exempt. *Human Organization*, 53(1), 1–10.
- Gabe, J., Calnan, M., & Bury, M. (1991). Introduction. In J. Gabe, M. Calnan, & M. Bury (Eds.), *The sociology of the health service* (pp. 1–10). London: Routledge.
- Geertz, C. (2000). *Available light. Anthropological reflections on philosophical topics*. Princeton: Princeton University Press.
- Greely, H. (2001). Informed consent and other ethical issues in human population genetics. *Annual Review of Genetics*, 35, 785–800.
- Hansen, E. H. (2003). Censorship or bias: The conditions for critical medical sociology. *Social Science and Medicine*, 56(6), 743–744.
- Harrison, F. V. (Ed.). (1991). *Decolonizing anthropology. Moving toward and anthropology for liberation* (pp. 1–13). Arlington, Virginia: Association of Black Anthropologists American Anthropological Association.
- Hastrup, K. (1995). *A passage to anthropology. Between experience and theory*. London: Routledge.
- Humphreys, L. (1975). *Tearoom trade, impersonal sex in public places*. Chicago: Aldine.
- Hydle, I. (1999). Snedviden Debatt om Forskningsetik [Twisted debate about research ethics]. *Läkartidningen*, 96(48), 5338–5339.
- Hydle, I. (2000). Reflexion Över Vad Medicinsk Kunskap Gör Med Människor. *Läkartidningen*, 97(4), 351.
- Joffe, S., Cook, F., Cleary, P., Clark, J., & Weeks, J. (2001). Quality of informed consent in cancer clinical trials: A cross-sectional survey. *The Lancet*, 358, 1772–1777.
- Kuper, A. (1999). *Anthropology and anthropologists. The Modern British School* (3rd ed.). London: Routledge.
- Lappalainen, R. E. (1996). Står Yrkesetikerna över vanlig moral. En Fallbeskrivning. *VEST*, 9(4), 57–65.
- Lindblom, A. (1999). Jag Bör Ha Sama Rätt som Alla Försökspersoner [I should have the same rights as every research participant]. *Läkartidningen*, 96(48), 5339.
- Lynöe, N. (1999). *Mellan Cowboyetik och Scoutmoral. Medicinsk Forskningsetik i Praxin [Between cowboy ethics and scout morality. Medical research ethics in practice]*. Stockholm: Liber.
- Marks, J. (2001). “We’re going to tell these people who they really are”: Science and relatedness. In S. Franklin, & S. McKinnon (Eds.), *Relative values. Reconfiguring Kinship studies* (pp. 355–383). Durham and London: Duke University Press.
- Marshall, P. (2003). Human subjects protections, institutional review boards, and cultural anthropological research. *Anthropological Quarterly*, 76(2), 269–286.
- Mills, D. (2003). ‘Like a Horse in Blinkers’. A Political History of Anthropology’s Research Ethics. In P. Caplan (Ed.), *The Ethics of Anthropology: Debates and Dilemmas* (pp. 37–54). London: Routledge.
- Nader, L. (1972). Up the anthropologist—perspectives gained from studying up. In D. Hymes (Ed.), *Reinventing anthropology* (pp. 284–311). New York: Pantheon Books.

- Nader, L. (2002). *The life of the law. Anthropological projects*. Berkeley: University of California Press.
- Örn, P. (1999). Skilda Synsätt på Forskningsetik Upphov till Långdragen Konflikt [Conflicting views on research ethics reason for protracted conflict]. *Läkartidningen*, 96(42), 4503–4505.
- Pels, P. (1999). Professions of duplexity. A prehistory of ethical codes in anthropology. *Current Anthropology*, 40(2), 101–114.
- Rothman, D. J. (1991). *Strangers at the bedside. A history of how law and bioethics transformed medical decision making*. New York: BasicBooks.
- Sachs, L. (1998). *Att Leva med Risk. Fem Kvinnor, Gentester och Kunskapens Fruktar [Living with risk. Five women, genetic tests and the fruits of knowledge]*. Smedjebacken, Sweden: Gedins.
- Scheper-Hughes, N. (2000). Ire in Ireland. *Ethnography*, 1, 118–140.
- Scocoza, L. (1994). *Forkning for Livet. De Medicinske Forskningsetiks Forudsætninger og Praktikker—En Sociologisk Analyse [Research for life. The preconditions and practices of medical research ethics—a sociological analysis]*. Copenhagen: Akademick Forlag.
- Tattersall, M. (2001). Examining informed consent to cancer clinical trials. *The Lancet*, 358, 1742–1743.
- Terenius, L. (1999). Citaten Borda ha Kontrollerats [The quotes should have been verified]. *Läkartidningen*, 96(48), 5340.
- Van der Geest, S. (1989). Censorship and medical sociology in the Netherlands. *Social Science and Medicine*, 28(12), 1339–1341.
- Wax, M. (1995). Commentary. *Human Organization*, 54(3), 330–331.
- World Medical Association. (2002). Declaration of Helsinki.