



Birzeit University's Research Ethics Committee commissioned, in 2012, a review of the literature on research ethics with a focus on research ethics understandings and practice in the global South. The review was necessary for enlightening the committee's discussions about the kind and scope of ethical review that needs institutionalization in the university, and the development of a model of research ethics that is appropriate and relevant for the context of scholarly research at Birzeit University. The committee, in particular, had concerns regarding possible reproduction of hegemonic structures within the review process and its procedures. It sought to develop a review model that ensures and fosters autonomy, and the positive impact of research on the public good.

## Research Ethics: A Review of Relevant Research Literature

*Sunaina Maira\**

This paper provides an overview of recent scholarly literature on research ethics and key issues pertaining to the work of research ethics committees and relevant to the development of research ethics guidelines at Birzeit University. It will offer a glimpse into some crucial debates about the operationalization of research ethics guidelines across the disciplines, particularly as they bear on research in the global South, in order to provide a framework for discussion of research ethics in scholarly work in and about Palestine. The paper cannot be a comprehensive account of all literature on the topic, but it is a window into the major topics that may need to be considered in developing a model of research ethics appropriate to the Palestinian context and a resource for scholars and students.

The major topics addressed in the paper are:

1. Research ethics models in the global North and South
2. Procedural and processual approaches to research ethics
3. Research ethics in community-based, participatory research
4. Ethical research and indigenous communities
5. Ethical issues in research in the global South and with vulnerable populations
6. Protocols and methods in relation to research ethics
7. Challenges for researchers in doing ethical research
8. Research ethics committees

### I. Research Ethics Models in the Global North and South

The formalization of research ethics guidelines, reflecting growing academic concern about the “abuse of individuals” and “good scientific practices,” began after World War II, which marked

\* Sunaina Maira is Professor of Asian American Studies, and affiliated with the Middle East/South Asia Studies program and the Cultural Studies Graduate Group at the University of California, Davis. Her research and teaching focus on Asian, Arab, and Muslim American youth culture, migrant rights and refugee organizing, and transnational movements challenging militarization, imperialism, and settler colonialism.

a “watershed” moment in debates about research ethics in the global North (Juritzen, Grimen, and Heggen 2011). The Nuremberg Code (1947), introduced in response to European atrocities in research experimentation, was the first formal articulation of research ethics principles and emphasized “the voluntary consent of the human subject” as a cornerstone of ethical research (Aluwihare-Samaranayake 2012, 64; UNICEF 2012, 12). Other shocking revelations of abuse in research on human subjects, notably the Tuskegee experiments in the U.S in which 400 African Americans with syphilis were deliberately left untreated for research purposes, also brought attention to ethical problems in research (Aluwihare-Samaranayake 2012, 65; Juritzen, Grimen, and Heggen 2011, 641). The Helsinki Declaration was the first internationally recognized code of research ethics, adopted by the World Medical Association in 1964, and focused primarily on “biomedical clinical studies” (UNICEF 2012, 12).

It should be noted that ethical guidelines initially emerged in the context of medical research and were later applied to the social sciences and other fields. It also must be acknowledged that the literature (in English) generally situates the codification of research ethics in a Western genealogy of formalization of research ethics, and that this has implications for the traditional approaches to ethics that are the basis of national guidelines for research ethics developed in what is now called the global North. These implications will be discussed in some depth later, but the linkage of histories of racism, warfare, and colonialism with human rights abuses in research is worth noting, as are the apparent absences in this genealogy of research ethics that could be traced to a much longer history of exploitation of non-Western subjects for research purposes, for example.

One of the striking features of early European research ethics codes, such as the Nuremberg Code, was that they were “based on Anglo-American law” and on notions of personal integrity and “individual autonomy” (Osirin et al. 2009, 772; UNICEF 2012, 12). This emphasis on “morally acceptable ends . . . and means” in research and on the duty to protect the vulnerable was a response to historical tragedies, but they were also a product of ethics embedded in “European enlightenment thinking” (Osirin et al. 2009, 772). In other words, there was a particular ethical tradition that was codified and that prioritized individual rights and (beneficial rather than harmful) outcomes, rather than notions of distributive justice and collective rights; critics suggest the latter may be more important in the global South or for disadvantaged groups in the global North (UNICEF 2012, 18). For example, a study comparing professional ethics among Canadian and Cuban psychologists and social workers concluded that Canadian conceptions of ethics are generally “individualistic” and clinical ethical codes act “as a form of self-regulation” and individual discipline; in contrast, Cuban conceptions of ethics are rooted in a “collectivist vision for society,” even though this ethos may also be (self-) regulated (Rossiter 2002, 546, 550). These cross-cultural differences are one of the key debates in discussions of research ethics, and one that alternative or newer approaches to research ethics focused on indigenous or marginalized populations have attempted to address.

The paper will not delve in detail into philosophical theorizations of ethics, but it is helpful to consider the four major frameworks for ethics that generally shape existing research ethics guidelines: duties, best outcomes (benefit versus harm), rights, and virtues (UNICEF 2012, 2). There is a fifth principle that is not always part of these frameworks, that is, justice (Burden, Schuck, and Aubusson 2012, 18). The principle of justice is related to collective rights and both are highlighted in community-based, participatory research models that will be discussed later. The *duty* to treat research participants as they have a right to be treated (“deontological morality”), underpins the notion of voluntary consent and the individual’s freedom to participate or withdraw from research; it is the major focus of research ethics committees, particularly in Europe according to some (UNICEF 2012, 12). A *best outcomes* approach promotes benefits over harm and serving the interest of society or the “greatest number of

people,” emphasizing the “nature of consequences” (consequentialism) (Osrin et al. 2009, 772; UNICEF 2012, 14). This utilitarian approach, which some suggest is generally prioritized in the U.S. and in Canada, can operate as a “technology to avoid wrong-doing between individuals,” leading to the problem of justifying research benefits for the larger society that may sacrifice individuals to harm, particularly those who are vulnerable or marginalized (Osrin et al. 2009, 772; Rossiter 2002, 547; UNICEF 2012, 14). A *rights-based* approach focuses on the rights or interests of the individual, including the right to non-discrimination in research and the “right to be heard” (UNICEF 2012, 15). In addition, there is the “right to be properly researched” which draws attention to the need to properly recruit, train, and supervise researchers (UNICEF 2012, 16). *Virtues* or moral characteristics, while not necessarily used directly as principles undergirding research ethics, often infuse the language framing ethical guidelines; for example, “honesty/truthfulness, justice, courage, . . . and kindness” (UNICEF 2012, 16). Thinking about virtues in relation to ethical dilemmas may provide a moral compass that is not reducible to guidelines or procedures, but morality is also not a universally legible framework. There is the question of “who gets to decide what is good and what is bad,” which is political and also culturally contingent (Aluwihare-Samaranayake 2012, 65). Furthermore, it is apparent that notions of duty, beneficence/harm, and rights are also not universally understood concepts and are associated with various schools of philosophy (Arda 2000, 459).

In the global North, these approaches to ethics have shaped various national research ethics guidelines in countries such as the U.S., Canada, UK, and Australia; for example: the US Office for Human Research Protections, Canada’s Tri-Policy Statement, the UK’s National Research Ethics Service, and Australia’s National Statement on Ethical Conduct in Human Research (Guillemin et al. 2012, 38; Sleem et al. 2010, 86). National as well as local or institutionally-based research ethics committees (RECs) have by now been established all over the world. It is apparent that the scholarly literature in English about research ethics is largely from Canada, Australia, and the U.S. and that much of it speaks to issues and debates in public health, biomedicine, nursing, development, and, to some extent, in social sciences. This is because, according to Marilyns Guillemin et al. (2012, 38), health research has “the longest history of formal ethical review” and is “rich in ethical issues.” There is very little scholarly research literature on research ethics in the Middle East or in Arab countries (in English), and negligible published work (in English) on Palestine.

According to some scholars involved in developing research ethics programs in the Middle East, this is a “region where the concept of research ethics has just come to the forefront” (Silverman et al. 2010, 76). For example, there was no legal regulation of human subjects research in Turkey until 1993 and RECs developed in the wake of controversies over medical research trials (Arda 2000). “In response to the increased conduct of clinical trials in the developing world,” many RECs have sprung up across the region and the Strategic Initiative for Developing Capacity in Ethical Review (SIDCER) has also been established for evaluating RECs (Sleem et al. 2010, 88). Yet the accreditation and assessment of the work of these RECs often relies, as elsewhere, on “increasing requirements for meticulous documentation of compliance with regulations” that are not always directly relevant to human subjects protection (Sleem et al. 2010, 87). The Middle East Research Ethics Training Initiative (MERETI), partly sponsored by the National Institute of Health in the U.S., now offers a year-long certificate program in research ethics training and has developed a research ethics curriculum guide specifically for Middle East researchers (for sample workshop agendas and instructional strategies, see Silverman et al. 2010 and Appendix). In addition, given the absence of external bodies for evaluating research ethics committees, a self-assessment tool was developed by a MERETI working group comprised of scholars from Egypt, Jordan, Libya, and Saudi Arabia (see Sleem et al. 2010, 87). Studies note that in countries such as Egypt, as well across the

global South, the work of RECs is hampered by factors such as “inadequate training of members, . . . scarcity of resources, and lack of national regulations” (Sleem et al. 2010, 86). Birzeit University thus has an opportunity to create a rigorous discussion about research ethics, in a local context in which these issues are arguably very profound, and contribute to this growing effort across the region.

## **II. Procedural and Processual Approaches to Research Ethics**

One of the major critiques of research ethics review in the literature is directed toward procedural ethics, as a codified, regulatory, bureaucratic mechanism. Researchers increasingly call for a model of processual ethics that is dialogic, contextual, and relational. This shift has partly emerged from critical work on the negotiation of ethics in research in the global South. The tension between conceptions of ethics, and the role of the individual and the collectivity in ethical research, is captured in an observation by Joseph Mfutso-Bengo, a Malawian bioethicist: “A person is not a separated and isolated individual but a community of related individuals. Despite all this, an individual has the right to self determination and authorization” (cited in Osrin et al. 2009, 772). That is, many (non-Western) cultures as well as feminist paradigms locate ethics in concerns related to the collective, not just individual, but there is still a need to balance individual and collective rights. These critiques have shaped a “growing movement calling for ethics-in-context” in research, grounded in reflexive research relationships, as opposed to the “abstract principles” and “universal propositional ethics” of most RECs or institutionalized research ethics bodies (Riessman 2005, 473, 487).

This debate has coincided with the turn toward dialogic models of research in the social sciences, in contrast to positivist methodologies premised on fallacies of objectivity and neutrality (which have long haunted research done in the global South by researchers from the global South, as in colonial anthropology). Writing about research in and on Palestine, Anne de Jong (2012, 194) critiques the fallacies of neutrality that mask colonial histories and argues for “continuous and critical reflexivity” among researchers, especially in zones of warfare and occupation, where researchers cannot hide behind the guise of academic neutrality but must take an ethical stance. Increasing criticism of the power differentials between the subjects and objects of research has also led to critiques of the transplantation of research ethics models from the global North to the South (Riessman 2005, 474). The turn to ethics-in-context or “ethics in practice,” the “everyday ethical issues that arise in conducting research,” also emerges from feminist critiques of traditional research frameworks and an acknowledgment of the affective and relational nature of research relationships and ethical decisions (Chenhall, Senior, and Belton 2011, 13).

The critique of procedural ethics has developed in response to what some describe as “ethics creep,” the expansion of regulatory mechanisms for research ethics that have become increasingly formalized and rigid (Guillemin 2012, 46; Juritzen, Grimen, and Heggen 2011, 645). While codifying research ethics was certainly a necessary step, the contemporary bureaucratization and “juridification” of research ethics has unfortunately transformed it into a “legalistic rationality,” particularly in the global North (Juritzen, Grimen, and Heggen 2011, 644, 645). The focus of many researchers who are accountable to RECs is often simply on obtaining formal approval for research in this “highly regulated domain” rather than on what actually constitutes ethical practices in their research process (Daley 2012, 27). Dilmi Aluwihare-Samaranayake (2011, 74) argues that while having “standardization of expectations of researchers is important,” the goal of research ethics guidelines and reviews should be not (simply) to create “space for procedures” but a “critical ethical consciousness” that interrogates moral judgments throughout the research process and does not reduce complex research

encounters to a set of “neat boxes” or pre-determined answers. Particularly in qualitative research—but also in quantitative research which deserves critical scrutiny--“static, formalized guidelines may render invisible the inherent . . . tensions, fluidity, and uncertainty of ethical issues” (Aluwihare-Samaranayake 2011, 66).

One of the alternative frameworks for research ethics offered by critical scholars is that of “micro-ethics,” which suggests a rigorous engagement with ethical issues throughout the research process and in specific contexts (Daley 2012, 28). Rather than thinking of research ethics review as a “one-time event” or official hurdle to be passed, there are multiple moments throughout the research process during which researchers need to engage in critical reflection on their ethical practice, which is a “continuous dynamic process” (Chenhall, Senior, and Belton 2011, 17; de Jong 2012, 194). These insights have generally emerged from critical theory and critical social science, feminist, and qualitative research, and they are valuable in stressing that research ethics extend beyond the process of informed consent and fundamentally respect the “autonomy, dignity, and privacy of research participants” (Chenhall, Senior, and Belton 2011, 13). The notion of grappling with research ethics on a case-by-case basis that is central to situational ethics also suggests that there is no “single right way to be an ethical researcher” (Daley 2012, 28)—without succumbing to moral relativism. While advocates of this approach acknowledge that there is a need for “prescriptive principles in human research ethics *guidelines*,” research practice must be informed by a relational ethics that can be expressed in multiple, contingent ways (Daley 2012, 33). For example, drawing on research with vulnerable populations, such as youth, some argue for a relational ethics, based on “caring for the other,” that is not universalist. Yet proponents of a relational ethics, such as Catherine Riessman (2005, 487) who has done ethnographic research in India, also caution against ethical relativism in research turning into “ethical opportunism,” noting self-critically that scholars from the North can sometimes engage in research practices in the South that would be impermissible elsewhere.

These debates lead to the central question of what it means to do “socially responsible research” (Aluwihare-Samaranayake 2012, 70). On the one hand, there is the concern about being responsible for “the protection of vulnerable persons (persons that are unable to protect themselves).” Critical theorists of research ethics argue that this is more than just about the “protection of human subjects” but about larger questions of social justice (Aluwihare-Samaranayake 2012, 70). In this context, one of the criteria for RECs to consider is whether the research is beneficial to society and to the community being studied, and if it constitutes a “public good” (Guillemin 2012, 41). The crucial question is: *who* benefits from the research? This is not just a risk-benefit calculation, but a question of whether research can actually lead to the transformation of social inequality. Is the research meaningful for those being studied and is it truly worthwhile? De Jong (2012, 200) argues that in the context of Palestine, an ethical approach demands that researchers act on their responsibilities to those who are facing colonial violence, human rights violations, or racial subjugation but use their research, as well as their academic privilege, to communicate truths about political realities to broader publics. Osrin et al. (2009, 777), commenting on public health research and clinical trials in low-income communities in the global South that have not always been beneficial to those communities, offer a challenging perspective: “We should also consider the ethics of *not* doing research. . . . ethics may be served equally by protecting people from exposure to costly and ineffective interventions” (*italics added*). This is a challenging proposition, and its thrust is to force academic researchers to consider the ethical implications of why they are doing the research they are doing and how they are doing it. The following section discusses a research model developed to address these questions directly and the ethical questions it generates.

### III. Research Ethics in Community-based, Participatory Research

A central ethical concern of researchers attempting to address issues of social justice, the benefits of research to the community and to disadvantaged groups, and the power differentials between the researcher/researched is transforming the relationship between the researcher and the research subject. The model of community-based or action research, sometimes called community-based, participatory research (CBPR) or community-engaged research, is based on the fundamental “shift from regarding individual community members as *research subjects* to engaging community members and the organizations that represent them as *research partners*” (Shore 2008, 1). CBPR challenges traditional approaches to research by emphasizing “community involvement and shared decision-making” and so raises new questions for RECs (De Schweinetz et al. 2009, 60; Shore 2008, 1).

CBPR draws on Paulo Freire’s notion of “participatory action research” emphasizing social emancipation and community leadership, feminist methodologies focused on relationality and “voice,” and Kurt Lewin’s “action research” (Schweinitz et al. 2009, 60). Some observe that CBPR is in actuality based on diverse approaches on a “continuum ranging from the radical ‘southern tradition’ of Freire to the pragmatic ‘northern tradition’ of Lewin” that allows for outsider expertise (Schweinitz et al. 2009, 60-61). CBPR grows out of critical theory, Marxist theory, and subaltern studies, and it suggests that researchers must acknowledge and grapple with “conflicts, contradictions, and oppositions” in the research process and in the production of knowledge (Aluwihare-Samaranayake 2012, 66). While one cannot expect power differentials to be completely erased in research, a critical approach to CBPR demands that researchers are aware of inequity and privilege and that both “researchers and participants . . . reflect and participate in meaning-making and emancipation” (Aluwihare-Samaranayake 2012, 67). One of the key principles of CBPR is engaging community members in decision-making throughout the research process—an approach that is consistent with a processual approach to research ethics—and in developing “locally relevant principles/codes of ethics” that are sensitive to “indigenous values and culture” (Shore 2008, 2; Mohindra, Narayana, and Haddad 2011, 1170). In addition, Nancy Shore et al. (2008, 2) point to the principle of including indigenous knowledge in research and protecting “cultural knowledge”; that is, research ethics extends to epistemological frameworks as well.

However, most existing research ethics guidelines and committees are focused on the protection of individuals, not of communities, in line with the ethical paradigms for research developed in the global North, as discussed earlier. The growth of CBPR has required university and institution-based ethics review boards to consider ethical considerations for the community which have been absent in most national guidelines, such as the Belmont principles for human subjects research issued in the U.S. in 1979 (Shore et al. 2011, 359). Furthermore, researchers have argued that community-based review processes are more appropriate than institution-based RECs to evaluate “considerations of social justice, risks, and benefits” at the community level (Shore et al. 2011, 359). Ethical questions are different for the individual than the community, and community-based review of research ethics is also in keeping with the philosophy of CBPR that prioritizes community input and collaboration (Deeds et al. 2008, 80). There has been a growth of community-institutional partnerships for research, even though in some instances these have not been regulated, as noted in a special issue of the *Journal of Empirical Research on Human Research Ethics* on ethics in CBPR (Shore 2008, 1; Shore et al. 2011, 359, 359). Simultaneously, some researchers advocate that RECs, as well as researchers, receive training concerning ethical issues pertaining to communities and that local RECs include community members or consult with the communities concerned (Deeds et al. 2008, 77, 84).

These approaches raise a host of questions for research ethics guidelines and RECs, such as the central question of how community rights can, indeed, be protected in research and monitored over time, but also questions such as: “When does a group, such as a community, become worthy of ethical consideration?” and “Who consents for the community?” (Deeds et al. 2008, 84). Existing models of research ethics based on the protection of individuals are often inadequate in addressing these questions for RECs as well as for researchers. Several researchers engaged in CBPR, such as Julie Postma (2008, 28), recommend creating a letter of agreement or “principles of participation” at the outset in order to clarify “terms of engagement and expectations” for research partnerships between researchers and community members (see Deeds et al. 2008, 83). Postma, who participated in an environmental justice project with Latino farmworkers in the U.S., draws on the experience of involving community organizations in the research group and creating a community advisory board representing diverse Latino constituencies. There are thus several practical steps and tangible structures that can and should be developed for CBPR and that are very relevant for research ethics in the Palestinian context, where community members generally do not have input into research on themselves.

An ethical approach to CPBR entails its own challenges, some of which also emerge in other research models. Researchers and community members (who may or may not be academics) often have conflicting understandings of research goals and processes. Marginalized populations who have experienced discrimination or negative experiences with researchers may be mistrustful and reluctant to participate in research projects, such as indigenous (tribal), low-income communities in India (Mohindra, Narayana, and Haddad 2011, 1170). In addition to the central issue of power differentials, there are issues of differences in language, communication style, familiarity with research methods and with research ethics review processes; one recommendation to address some of these factors or points of tension is for training workshops and facilitation guidance for both researchers and community participants (Postma 2008, 28). Yet there are still competing frameworks for what research ethics in CBPR means or should look like in practice, as well as in other kinds of research models.

The important point to note is that, however well-intentioned researchers (or REC members) are, CBPR is not a panacea that will resolve all ethical issues. Researchers using a participatory action research model can still have “colonial attitudes,” as noted in studies of research with indigenous communities (Jacklin and Kinoshameg 2008, 55), a point that is worth considering seriously in the Palestinian context. In a study of international collaboration in a CPBR project in Ghana, De Schweinetz et al. (2009, 53) observe that “participatory methods may paradoxically be used to ‘tyrannize’ participants” by legitimizing existing social hierarchies in the community and “decisions of the elite,” depoliticizing “rightfully political issues,” and reinforcing dependence on “outside agencies or facilitators.” Furthermore, CPBR has itself become more mainstream and bureaucratized, and in some cases, linked to government and corporate structures, generating tensions and paradoxes (De Schweinetz et al. 2009, 53).

In other words, CBPR models are not inherently anti-colonial, anti-racist, or democratic, but their ethical approaches depend on the ways in which they are implemented and enacted on the ground. As in other cases, there are micro-ethical questions that arise in participatory research and that RECs, community-based or otherwise, would need to take into account in the review process. For example, Postma (2008, 26) points out that while farmworkers were considered participants in the environmental justice research project, they were not equal partners and were included only in an advisory role. Critiques of CBPR in the global South also observe that “the community” is sometimes viewed as a monolithic or single entity and that researchers look to official bodies or local leaders as representatives, thus strengthening the local status quo and inadvertently, in some instances, reinforcing gender, religious, ethnic, caste, and class hierarchies (De Schweinetz et al. 2009, 61, 63; Osrin et al. 2009, 773).

The politics of representation looms large in relation to the obtaining of informed consent, from individuals as well as communities. Who represents those whom researchers wish to study? How does one get “community consent”? Research models have traditionally emphasized the role of gatekeepers, official or unofficial, who can facilitate access to potential participants (Aluwihare-Samaranayake 2012, 68). Elites and male leaders are often (self-designated) community representatives, but does *not* approaching them for approval resolve the ethical concerns? If researchers challenge the status quo and “entrenched interests,” there may be unintended conflicts and these may affect those who are vulnerable or marginalized (Mohindra, Narayana, and Haddad 2011, 1170). Linda Silka et al. (2008, 5) insightfully observe that unlike tribal, sovereign indigenous nations, many other communities “have no front door” or official gatekeepers with widely accepted or officially recognized authority to approve or discuss research projects. What is also evident in some of the literature is that in certain cases, scholars writing about research ethics in the global South have their own unquestioned assumptions about power dynamics and the social order and perhaps (unwittingly) retain racialized or colonialist perceptions of “other” communities. A more nuanced understanding of the politics and ethical codes of other communities or societies would help inform the negotiation of research ethics in those same contexts.

#### **IV. Ethical Research in Indigenous Communities**

One of the significant shifts in research ethics paradigms has emerged as indigenous communities have become leaders of the “growing international movement to assume ownership and control over research conducted in their communities” (Shore et al. 2008, 2). This shift away from the models imposed from the global North is in response, in large part, to the long history of colonial research *on* indigenous (and poor or marginalized) communities, who have been “researched to death, with no benefit” to themselves, and sometimes in the service of their exploitation and destruction of their societies and cultures. Many in indigenous communities feel that research is “irrelevant to community needs, a threat to local autonomy, and a drain on resources” (Jacklin and Kinoshameg 2008, 53). Indigenous, as well as poor and minority communities, have historically been used as “laboratories” for research, primarily by those who are not from these communities, which led to an exploitative and highly contentious relationship with researchers (Silka et al. 2008, 6).

There is by now a research fatigue in these communities; research is viewed as a burden for those who are over researched “because of their availability or malleability,” and in some cases their subjugation by colonial or racist regimes (Aluwihare-Samaranayake 2011, 73). Writing about indigenous peoples in Canada, Jessica Ball and Pauline Janyst (2008, 37) observe that research has come to be seen as “four letter word” because these groups have been “exhaustively studied and their expectation of realizing positive returns has all but expired.” Linda T. Smith (2012, 1), an indigenous scholar from New Zealand, succinctly observes, “The word itself, ‘research,’ is probably one of the dirtiest words in the indigenous world’s vocabulary.” In *Decolonizing Methodologies: Research and Indigenous Peoples*, Smith (2011, 2) describes “research as a significant site of struggle between the interests and ways of knowing of the West and the interests and ways of resisting of the Other.”

The question of indigeneity in relation to research ethics and knowledge production is crucial in the colonial context of Palestine where a Western research gaze co-exists with a Western-backed regime of displacement, expulsion, confinement, and annihilation of the indigenous/Palestinian population. Globally, new frameworks for research ethics are attempting to counter what Smith, among others, describe as a colonial history of European imperial knowledge production about indigenous peoples. Indigenous groups have challenged



colonialist “claims to discovery and ownership of knowledge” that is in fact the “intellectual property” of native populations (Ball and Janyst 2008, 44). A decolonizing framework is needed to challenge Orientalist knowledge claims and methods of constructing and classifying the “other,” as critiqued in Edward Said’s seminal work. Indigenous or decolonizing research methods and epistemological frameworks are “researching back” or “writing back” to the imperial production of knowledge (Smith 2012, 8). Indigenous or First Nations peoples in North America have been “calling for an end to research conducted ‘on’ Indigenous peoples for the benefit of non-Indigenous scholars and agencies without meaningful engagement of Indigenous peoples” (Ball and Janyst 2008, 33). This shift has been accompanied by the emergence of indigenous researchers who are rethinking questions of knowledge, power, and ethics and offering new paradigms for research ethics (Smith 2012, 10). As Smith (2012, xi-xii) points out, the term “indigenous” is not always used to describe indigenous populations (including by some groups themselves) and various categories are used across the world; the central issue, however, is the shared relationship to colonial power and Western modernity.

Many indigenous communities worldwide have developed guidelines for research ethics, particularly in Canada and Australia, as apparent in the literature, and there are also some local research ethics codes among indigenous communities in India (see Mohindra, Narayana, Haddad 2011). There is no “singular” or universal indigenous framework for research ethics but the priority is that it should be useful to and respectful of indigenous populations (Ball and Janyst 2008, 10). In Canada, for example, there is no single research ethics framework among indigenous groups, although there is a broad consensus on the general principles that should guide research (Ball and Janyst 2011, 34). The overarching framework of indigenous research ethics focuses on restorative justice and self-determination for indigenous peoples and those who have or are living under colonialism; it generally highlights principles such as the “four ‘r’s—respect, relevance, reciprocity, and responsibility,” proposed by aboriginal research programs in Canada (Ball and Janyst 2008, 34). For example, the National Aboriginal Health Organization in Canada has highlighted the principles of “Ownership, Control, Access, and Possession (OCAP)” in research on or with indigenous peoples (Shore et al. 2008, 2). This is similar to the paradigm of CBPR or action research, but it also insists on a decolonizing or anticolonial approach resting on notions of “self-determination and self-governance” (Shore et al. 2008, 2; see also Jacklin and Kinoshameg 2008, 54). Furthermore, a major element of a decolonizing research ethics framework is that any guiding principles should be consistent with the “core values” of the indigenous peoples concerned; in the context of Aboriginal peoples in Australia, national health and medical research guidelines now identify core values that include, in addition to the four principles cited above: equality, survival, protection, spirit, and integrity (Chenhall, Senior, and Belton 2011, 14). The relationships between researchers (indigenous or non-indigenous) and indigenous peoples must also be a central focus of this process of decolonizing research ethics (Ball and Janyst 2008, 35).

In addition to local, regional, and national research ethics guidelines based on indigenous principles and decolonizing paradigms, there are also structures that have been developed for indigenous partnership and community control of research. As in the case of CBPR models of community-based ethics review, these include indigenous ethics review committees that provide advice to any RECs reviewing research involving indigenous peoples (for an example from Australia, see Chenhall, Senior, and Belton 2011, 14). But as some scholars point out, these new principles and processes raise some practical and also tricky ethical questions; for instance, how to involve community members in research if leaders decline to participate in the research or if community members themselves are mistrustful of researchers; how to protect confidentiality if the data is kept by the community; and whether community approval of research findings means that researchers cannot be sure that the research can be disseminated

until the study is complete (Ball and Janyst 2011, 34; Mohindra, Naryana, and Haddad 2011, 1172). There is also sometimes a tension related to the role of indigenous researchers due to their complex “insider/outsider” status related to research on their own communities or the Western academy, and notions of complicity or loyalty can be charged due to the difficult legacy of imperial knowledge production (Ball and Janyst 2008, 37; Smith 2012, 10). Ultimately, scholars (including indigenous scholars) point out that while indigenous research ethics frameworks have been developed globally, there is no easy formula and research ethics principles need to be “culturally and community specific” and responsive to particular expectations (Jacklin and Kinoshameg 2008, 59). This is important to consider when developing or applying research ethics frameworks in Palestine where questions of sovereignty, self-determination, colonialism, and representation in relation to knowledge production and research are pressing.

## **V. Ethical Issues in Research on the Global South and on Vulnerable Populations**

Debates about research ethics related to indigenous populations often overlap with those in the global South and also with vulnerable populations, given that power relations are often skewed and ethical issues complex, if not charged, in all these contexts. One of the major critiques of research ethics models used in the global South, as in the case of research with indigenous populations, is that historically these have been imported from the global North. Amy Rossiter, Richard Walsh- Bowers, and Isaac Prilleltensky (2002, 541-542) argue that in the context of Cuba, there is a tension between a Cuban notion of professional ethics that is rooted in “national, spiritual, and social justice” and North American notions of professional competence and “avoiding wrong-doing.” Cuban psychologists generally view ethics as a “unity of affective and cognitive activities” embedded in a collectivistic social vision focused on democracy and equality, while for Canadian professionals, ethics is “compartmentalized” as a set of codes for “self-regulation” and “cognitive problem-solving,” generally detached from political or economic contexts (Rossiter, Walsh-Bowers, and Prilleltensky 2002, 541-542). The study is careful not to romanticize or overly idealize this cultural contrast, pointing out that Cuban psychologists grappled with the desire to adopt professionalized ethics codes and develop RECs modelled on dominant North American frameworks, while aware that importing models from the North was not necessary (Rossiter, Walsh-Bowers, and Prilleltensky 2002, 544). The researchers also note that the demand for collectivistic solidarity can sometimes undermine “open dialogue,” especially when solidarity is seen as a bulwark against U.S. imperialism and so can also be self-regulating or silencing (Rossiter, Walsh-Bowers, and Prilleltensky 2002, 545, 551). That is, a collectivistic ethical model is not inherently emancipatory. Yet their nuanced analysis also points to the ways in which an “ethics of surveillance” exists in a Canadian professional structure of neo-conservative managerialism and ongoing marginalization of populations by North American capitalism (Rossiter, Walsh-Bowers, and Prilleltensky 2002, 534, 551). In the Palestinian context, these questions are important when discussing research ethics, particularly as neoliberal economic and professional models are also being transplanted and collectivistic and individualist ethics increasingly compete in a post-Oslo moment.

Catherine Riessman (2005), in the article “Exporting Ethics: A Narrative about Narrative Research in South India,” suggests that dialogic research requires an interrogation not just of the researcher’s relationship with the researched but also of the unequal and fraught relationships between the global North and South. A U.S. anthropologist doing research on the meanings and management of infertility in India, Riessman (2005, 473-474) calls for “ethics-in-context” and attention to the “emotionally charged” and also sometimes culturally conflicted

relationships in field work. Informed consent, privacy, and confidentiality can have divergent meanings in various cultural contexts, as Riessman's account of misunderstandings and ethical dilemmas in her research demonstrates. For example, she points to a conflict that emerged between her assumptions that signing an informed consent form was (ethically) necessary, and the refusal of some rural Indian women to sign it due to their suspicions of legal documentation that can be intrusive, if not abusive. In "post-colonial settings," Riessman (2005, 478) reflects, informed consent can have a different meanings and can be seen as an "import from the West" intended primarily to "release the sponsoring agency and funding agency from liability" and not necessarily in the interest of the research subject. Resistance to informed consent, and the underlying legal premise of ownership of data, may be a disruption of power relationships by research participants; it is important to critically reflect on the "conditions of production" of consent, written or otherwise, in research relationships (Riessman 2005, 480). Similarly, a study of public health research in low-income communities in South Asia and Africa points out that being associated too closely with the government, through sponsorship or funding, can be a "liability" for researchers and discourage participation from communities who have historically not benefited from state intervention and in some cases have been harmed (Osrin et al. 2009, 776).

The collision between different research ethics frameworks in North-South research collaboration also generates contradictions and unexpected responses. In a CBPR project in Ghana, involving U.S. and Ghanaian researchers and professionals as well as community members, village residents apparently did not expect equal partnership and were not as concerned with ownership of the research project as were the U.S. and Ghanaian academics (De Schweinetz et al. 2009, 57, 60). This may not actually be surprising, given the long history of Western, imperial research discussed earlier and the "persistent effects of historical power relationships in international CBPR" acknowledged by the authors (De Schweinetz et al. 2009, 62). Village residents in Ghana seemed to accept that their role was simply to provide labor and resources, but they also wanted to see "tangible benefits" from the project, including a school and health clinic (De Schweinetz et al. 2009, 56, 58). The authors situate this "beneficiary role" in the context of economic, technological, and social inequalities that have persisted beyond colonialism. Yet they also under analyse racial politics and neo-colonial interventions in the global South, pointing instead to the belief in "traditional and survival values" in Africa and Asia, in contrast to "secular-rational" values--presumably of the West (De Schweinetz et al. 2009, 61). The point is that while it is evident that communities in the global South, and elsewhere, have a right to benefit from their participation in research, ironically, CBPR in the global South may reproduce dependency models and benefactor-beneficiary hierarchies that actually end up undermining equal partnership and collective decision-making in community research. This is a complex ethical and political issue to be taken seriously in research in Palestine, where foreign funding is pervasive in research projects and development programs.

Other studies also point to the paradoxes generated in research in the global South where monetary incentives or tangible benefits of research are by now expected by community participants but researchers may prioritize other kinds of benefits or be concerned about sustainable support. David Osrin et al. (2009, 777) observe that while rural women in Bangladesh and Nepal wanted travel funds and ambulances for participating in a public health study, researchers were unable to offer such resources and referred the women to providers, hoping also that the resources provided would be ongoing and not temporary. A participatory research project on poor, rural, tribal populations in India also found that the community expected some kind of material benefit, understandably, but researchers clarified before beginning the study that they could not provide this but would instead provide computer and

skills training (Mohindra, Narayana, and Haddad 2011, 1173). While some advise against cash payment to children, for example, in contexts of deep poverty where it might be used for purchasing drugs, others point out that the ethics of payment is complex if children are helping support their families and are taking time off from their paid labour to participate in research (UNICEF 2012, 2). In other cases, the ethical dilemmas arise from a conflict over expectations of intangible rather than tangible benefits in research relationships. For example, Riessman (2005, 479) realized that rural Indian women confused her role as a medical anthropologist with that of a doctor who could offer them medical services, while she herself viewed them as sources of social knowledge. The lessons drawn from these reflections on conflicting views of research is that research ethics and the expectations of (sometimes already heavily) researched and disadvantaged groups can not be understood outside of the deeply unequal, colonial and postcolonial relationships between the global South and the North and the context of global capitalism.

There is some overlap with the ethical concerns discussed above in research in the global South or on indigenous and minority communities, and with those that emerge in doing research with vulnerable persons given the power imbalance in research relationships, but there are also specific concerns that need to be discussed. Aluwihare-Samaranayake (2012, 70) defines vulnerable persons as including:

“those who (a) lack or have an abundance of autonomy or resources, (b) cannot speak for themselves or are institutionalized, (c) engage in illegal activities . . . (d) who may be harmed by the information revealed about them as a result of the research or those (e) who may incur emotional harm through viewing distressing information related to themselves as a result of the research.”

Children and youth, people with psychiatric issues, the elderly, individuals with physical or cognitive disabilities, individuals at risk of sexual or physical abuse, the poor, and individuals in sites of violent conflict or humanitarian crisis would all belong to this category (Aluwihare-Samaranayake 2012, 70; UNICEF 2012). Research on these groups raises tangled ethical questions related to risk, privacy, autonomy, and official consent.

For example, there is a body of literature about ethical concerns in research about children and youth that discusses the complex conflicts that arise in studies of individuals who are vulnerable due to their age. Bethany Deeds et al. (2008) point out that RECs have to balance sometimes conflicting needs of communities and individuals in balancing social justice goals with the privacy of vulnerable subjects. In a CBPR study of adolescents at risk of HIV in the U.S., a tension emerged between research protocols for community involvement and the confidentiality of adolescents. On the one hand, researchers wanted to partner with the community and do the research in community contexts, using culturally sensitive approaches and appropriate language so as not to stigmatize communities, given the controversial nature of HIV/AIDS (Deeds et al. 2008, 80). On the other hand, approaching adolescents in community contexts or public spaces might put these young people at risk by violating their privacy. As the authors point out, such dilemmas point to the need to carefully consider issues of risk and harm at the level of the individual as well as the community, even in community-engaged research. In research on youth and problematic substance abuse, Kathryn Daley (2012) suggests that dealing with sensitive information and emotional situations requires a relational ethical framework and a situational, micro-ethics approach, as discussed earlier. Drawing on Nell Nodding’ theory that ethics must be embedded in “caring” relationships with others in specific situations, she posits that in the practice of research, “caring—with the researcher as care-giver and participant as cared-for—is the most ethical way to negotiate” the ethical dilemmas in research on youth and vulnerable individuals (Daley 2012, 29, 33). While this

model may not be the most appropriate one in all cases, Daley argues like others, that research ethics guidelines do not always account for the complex ethical quandaries that emerge in research practice and that require a flexible, situational ethical response. Similarly, Riessman (2009, 487) argues that “western normative discourse about research ethics with vulnerable populations in clinical and community settings” has been inadequate in accounting for ethical quandaries in research relationships and also proposes a “situated ethics,” one that is presumably culturally sensitive.

A 2012 UNICEF (2) report on ethical principles and dilemmas in research on violence against children points out that there are many gaps in national research ethics guidelines related to research on children, and that the emphases in these research codes tend to be on consent and risk-benefit ratios. There is a lack of “attention to ethical constraints in research with children and young people” and very little ethical guidance (UNICEF 2012, 2, 11). For example, while participatory approaches are valuable in research on children in contexts of violence or crisis, researchers must be trained to cope with sensitive situations and there must be a balance between a focus on distress and empowerment (UNICEF 2012, 21, 22). As Aluwihare-Samaranayake (2012, 69) points out, researchers must balance their interest in obtaining knowledge from vulnerable groups, such as children exposed to abuse or violence, with the distress or trauma which may arise for participants during the research process. At the same time, many note the argument that it is research on vulnerable groups that is often most needed for greater awareness or policy changes and so research ethics protocols must carefully navigate these sometimes competing needs for sensitivity and for knowledge. This is an important issue that needs to be grappled with in the Palestinian context as well, given the interest in studying and documenting youth and those who have suffered traumatic experiences related to war, displacement, incarceration, torture, and violence in its many forms. Scholars who consider themselves activist-researchers or who do research in zones of war and violent conflict have to deal with the risk of physical harm to themselves as well as their ethical obligations to others who are at risk or facing ongoing human rights abuses, for example, in Palestine (de Jong 2012). Furthermore, it is important in research on vulnerable or subjugated populations to not raise “false expectations of change and power dynamics” (UNICEF 2012, 22). In other words, researchers must be careful not to overstate their goals of social change and social justice so as not to promise what they cannot deliver through a research project.

## **VI. Protocols and Methods in relation to Research Ethics**

Drawing on the literature reviewed and the above discussion of a range of research ethics frameworks, dilemmas, and questions, this section offers a brief overview of some specific issues related to research protocols, methods, consent, confidentiality, community input and dissemination of research and a summary of the guidelines offered thus far. These would be useful to consider for research ethics guidelines and RECs in Palestine.

### **1. Protocols**

- Many studies suggest developing a community-based, research ethics review process to ensure that the community can have input into research in which they participate. Nancy Shore et al. (2011 361), drawing on a national (U.S.) study of community-based ethics review processes, identify several criteria that such review processes should focus on, including: the appropriateness of research methods for the community, the use of culturally appropriate recruitment strategies and informed consent, dissemination of findings with the community, fit with the community’s own agenda or priorities, sharing of power and resources with community partners, and risks and benefits to the community. A public

health research project that developed a local code of research ethics with an indigenous population in India pointed out that community meetings to discuss the code provided a context for having a dialogue about ethics and promoting local knowledge but also for building trust with the community (Mohindra, Narayana, and Haddad 2011).

- Communities that are regularly objects of research have also developed their own research partnership guidelines that describe the “philosophy of research and the questions collaborators should answer together to ensure that projects align with the principles” (Silka et al. 2008, 8). These documents are not intended to “censor” research efforts but to ensure that researchers and community members have a shared understanding of research ethics, even if this process is not necessarily always easy or without its own challenges. Including definitions of research terms to make the research process more accessible to non-academics can also be useful (see Appendix for research partnership guidelines developed by a low-income community that became a “laboratory” for U.S. researchers). Furthermore, if communities have low or no literacy, verbal discussion of research discussion and agreement is necessary (Mohindra, Narayana, and Haddad 2011).
- Researchers suggest using memoranda of understanding or letters of agreement with community representatives that can outline the research plans and the involvement of research subjects or partners in all phases of the research. For example, guiding documents for research on indigenous communities in Canada include issues such as: “accountability of all members” of the research project; nature of the data; ownership and storage of and access to data; decision-making processes; and dissemination of findings (Ball and Janyst 2008, 40).
- Compensation for research participation is a complex issue for research ethics, as discussed earlier. It is important to acknowledge that giving or not giving monetary compensation shapes relationships with “gatekeepers” as well as research participants; potential participants should not feel that they are being coerced, nor that their future relationships with the researchers or other community members is contingent on participation (Aluwihare-Samaranayake 2012, 68).

## 2. Methodology

- Research ethics guidelines and RECs, it is suggested, should not dictate research methods, provided they are used respectfully, ethically, and in consultation with the concerned community (Ball and Janyst 2008, 43).
- Some note that RECs, which have traditionally been focused on quantitative research, are not always equipped to assess qualitative research methods. RECs sometimes use the logic of quantitative research to review qualitative research or assume that quantitative models are more ethical; there are different ethical issues that arise in quantitative and qualitative research that deserve careful attention (Chenhall, Senior, and Belton 2011, 17; Juritzen, Grimen, and Heggen 2011, 645-646).
- Whatever the research design and methods, it is important that they are culturally appropriate and that there is sensitivity to issues of social context and language, among other issues (Deeds et al. 2008, 83). Integrating multiple cultural or epistemological perspectives on the research questions, concepts, and methods can be helpful in the research design to take into account the possibility of diverse understandings of the same issues (Riessman 2005, 478).

### 3. Consent and Confidentiality

- While the signing of informed consent forms is often considered the “gold standard” for research ethics review processes in the U.S., and has become an increasingly formalized ritual, many point out that consent actually occurs in research-participant interactions and not (just) in formal paperwork (Juritzen, Grimen, and Heggen 2011, 643; Riessman 2005, 488). The signing of a form may not always indicate actual consent, for it is not a “one-shot agreement” but requires a processual and reflexive approach (Chenhall, Senior, and Belton, Senior, and Belton 2011; Riessman 2005, 475).
- Consent also needs to be sought at the level of community, in addition to the individual, for an ethical research partnership, but the question arises: who represents the community? There needs to be consent from a range of stake holders and it is recommended that researchers organize community meetings where this can be discussed. The question of getting consent from “community representatives” can be a thorny one, as it can mean evading those who have less power in the community or disrupting existing power relationships. Obtaining consent can exclude groups such as women, children, the mentally challenged, and others but getting consent from vulnerable or stigmatized groups or in public spaces is also a sensitive process. David Osrin et al. (2009, 773) recommend documenting the process of obtaining consent and the rationale for choosing those who give consent as one way to at least ensure reflection on the ethics of consent.
- Researchers must ensure that participants are fully aware of what they are consenting to and forms or information sheets but must be clear and appropriate for participants’ reading level (Aluwihare-Samaranayake 2012, 69). It is problematic (and for some, unethical) to obtain written consent from illiterate individuals and researchers suggest providing oral recordings of consent and translating documents, as appropriate (Chenhall, Senior, and Belton, Senior, and Belton 2011, 15). For children or youth, parents and guardians must be competent to give consent and understand their responsibilities (Aluwihare-Samaranayake 2012, 70).
- In virtual research or studies of mobile phone usage, a growing area of research with complex research ethics dilemmas, a traditional signed form is not always possible as identities of participants can be ambiguous (Burden, Schuck, and Aubusson 2012, 18). Both “online pseudonyms and offline identities should be treated as confidential” and researchers should identify themselves to participants in internet research (Burden, Schuck, and Aubusson 2012, 21). These ethical issues are magnified when internet research involves children and youth.
- Issues of confidentiality are difficult in internet research because it is difficult to decide whether online information or discussions are intended to be truly public; one approach is to do a pilot study to understand if participants understand their online data to be “public” or “private” (Burden, Schuck, and Aubusson 2012, 23). However, there is also the issue of ownership of data, so there is a tension between maintaining confidentiality and acknowledging “authorship” (Burden, Schuck, and Aubusson 2012, 21).

### 4. Community Input and Dissemination of Research

- Researchers have to grapple with the question: “which types of problems require community input?” (de Schweinitz et al. 2009, 63). Also, while CBPR research in particular requires a democratic process of decision-making, marginalized communities that would benefit from giving input are also often the ones that have the least resources or time to invest in research partnerships.

- There needs to be flexibility as well as ongoing, honest communication throughout the research process (Jacklin and Kinoshameg 2008, 61).
- Research findings and also writing should be shared with participants to get feedback, in a format that is acceptable and relevant to the community, translating materials where necessary.
- Forms of dissemination of research can include reports and also websites, brochures, and community forums to discuss the findings and implications for communities and individuals.
- In contexts where research findings may be highly contested, due to political subjugation repression, and where the political stakes of doing research are high, such as in research about Palestine, the dissemination of research findings to broad audiences, including to non-academic audiences beyond the local context, becomes even more crucial (de Jong 2012, 200).

## VII. Challenges for Researchers

While research ethics guidelines and the literature on RECs and research ethics has generally focused on the protection of research subjects, at the individual or community level, there is also discussion of the challenges faced by researchers themselves in doing ethical research. For example, researchers may experience a conflict between existing or expected research ethics frameworks and their own ethical orientations, or they may experience a conflict with regard to ethical requirements and their own relationships to the communities concerned (Chenhall, Senior, and Belton 2011; Aluwihare-Samaranayake 2012). In some cases, researchers may become politicized or transformed by the experience of doing research and become involved in political organizing or social movements in solidarity with research participants, such as in Palestine (for example, de Jong 2012). Given the growing engagement in CBPR, researchers also have to “confront institutional and interpersonal challenges” in trying to implement ethical values in practice (Postma 2008, 27). On the one hand, some observe that “good intentions are not enough” and tacit institutional and social norms may persist in research and undermine the equal partnership that researchers desire or generate conflicts in priorities (Postma 2008, 27). Researchers have to acknowledge that it is difficult to achieve the ideal of a truly equal relationship with participants and there is a “constant shift in power balance and dynamics with participants” throughout the research process” (Aluwihare-Samaranayake 2012, 67).

On the other hand, researchers trying to partner with the community also have to “make a leap of faith” in being open to “other ways of knowing” and doing research; Kristen Jacklin and Phyllis Kinoshameg (2008, 62) suggest that rather than viewing community co-ownership and input into research as “giving up power and control” over research, academic researchers will greatly benefit from local or indigenous knowledge. Yet there are indeed practical issues to negotiate in this process, as discussed earlier, and working with the community more closely requires time and energy, as well as the uncertainty about whether research results will ultimately be approved by the community for dissemination (Ball and Janyst 2008, 33; Mohindra, Narayana, and Haddad 2011, 1170). If the research project relies on volunteers from the community, rather than (just) on grant funding, there is the challenge of having fewer resources but simultaneously less dependence on the availability of funds (Silka et al. 2008, 10). There is also the added benefit of helping develop research capacity and skills among community members if they are involved in the research process or participate as research assistants.



Furthermore, the researcher may have to face a range of other kinds of risk, emotional, physical, or financial, that pose their own ethical challenges. It not just research participants but also researchers who have “subjectivities and emotional lives that they bring to research relationships,” as feminist and dialogic or self-reflexive approaches to research have long emphasized (Riessman 2005, 476). There can be ethical distress for the researcher if the research relationships become fraught or there is lack of clarity in the roles of those involved, if there is a challenging physical or political environment or aggression from participants, and if the researcher relives her/his own emotional trauma in the course of the research (Aluwihare-Samaranayake 2012, 72). Some argue that researchers need to grapple with the question of possibly withdrawing from a study if it becomes ethically unsound, and that these risks may need to be addressed in the research proposal to the REC. Aluwihare-Samaranayake (2012, 73) recommends that these risks could be minimized if research ethics education is required for researchers and there is greater knowledge about potential risks or conflicts. While there are no “simple answers” to these ethical dilemmas, researchers need to spend time reflecting on how they might manage potential challenges in their research, and more generally, embark on a “critically conscious ethical research trajectory” (Burden, Schuck, and Aubusson 2012, 24; Aluwihare-Samaranayake 2012, 67).

## VIII. Research Ethics Committees

Given that by now research ethics guidelines have been established in many countries, and RECs have been operating in various national contexts, there is also a body of work that directly addresses the work of RECs and the ways in which they impact research. Since approval from RECs and institutional review boards for the protection of human subjects in research is now mandatory in the global North, and also elsewhere, researchers have to deal with what has become an institutionalized and often bureaucratized apparatus of ethics review. This section addresses the tensions that have arisen due to differences in perception in the role of RECs, which would be important to reflect on as the review process becomes institutionalized in Palestine.

REC members and researchers all invest a considerable amount of time and energy in the ethics review process. However, RECs are sometimes viewed by researchers in North America, Australia, and Europe as a source of concern and frustration due to delays and bureaucratic processes that are seen as hindering, rather than helping, research. In addition, some researchers view RECs as being overly protective toward research participants. While RECs and researchers agree that the primary role of ethics review is to protect participants, studies found that in some instances researchers felt that RECs were being “paternalistic” toward research participants to the point where they were preventing research (Guillemin et al. 2012, 41). In other words, while it is important to ensure that only ethical research is approved, some scholars felt that there was a line between “filtering” unethical research proposal and “gatekeeping” by RECs. Similarly, there have been concerns that RECs evaluate research to make sure it is ethically rigorous without being overly intrusive or prescriptive, for example, by recommending methodological changes beyond the issue of ethical integrity (Guillemin et al. 2012, 41-42). Another concern is that RECs may be protecting the institution from legal risk and harm to reputation more than safeguarding research ethics, a byproduct of the managerial, institutionalized approach to research ethics critiqued by some scholars (Guillemin 2012, 42; Juritzen, Grimen, and Heggen 2011, 645; Rossiter 2002, 541).

One of the serious consequences of these concerns with RECs, and with procedural ethics in some sense, is that researchers sometimes view the research ethics process simply as a hurdle to be overcome, or perhaps even an obstacle to their research, and become demoralized by the

process or “cease to care about ethics” (Guillemin 2012, 44-45). Researchers may decide not to do certain kinds of research if they believe that their research proposals would not get approved by RECs for reasons beyond that of research ethics; this kind of self-regulation or self-censorship due to the power of RECs undermines new research or projects on sensitive issues that are important (Juritzen, Grimen, and Heggen 2011, 643-645). Thus, there are concerns that inappropriate monitoring of research ethics may undermine academic freedom (Juritzen, Grimen, and Heggen 2011, 648). Mistrust or cynicism among researchers creates an adversarial role between researchers and RECs and also frustration with REC members, who are generally researchers themselves, and who in some cases also resent the negative views of RECs among colleagues (Guillemin 2012).

Clearly, RECs are important and necessary for ensuring that research fulfils ethical standards, that it protects individuals as well as communities, and that it is beneficial. At the same time, it is important to note that RECs are not outside of power relations and that they consist, ultimately, of individuals who have to fulfil the mandate of research ethics review in particular institutional settings (Juritzen, Grimen, and Heggen 2011, 641). The literature on RECs offers some suggestions for trying to make the research ethics review process productive and positive:

Ensuring that the review process is timely and efficient;

- a. Having open communication between RECs and researchers and possibly inviting researchers to speak directly to REC members to clarify feedback or misunderstandings to make the process less tense or adversarial;
- b. Avoiding potential conflicts of interest by having REC members from multiple institutions so as to mitigate the issue of institutional protection;
- c. Providing comprehensive training for REC members so that they are aware of the relevant research ethics guidelines, and also of diverse kinds of research models, methods, and contexts.
- d. Studies concur that evaluating research ethics is needed, but that what is also needed is critical reflection and discussion to make sure the research ethics review process fulfils its goals.

## **IX. Conclusion**

The substantial, and growing, body of literature on research ethics and RECs offers numerous insights into various models of research ethics and recommendations for research ethics guidelines and processes appropriate for indigenous populations, vulnerable populations, and communities in the global South. While the literature does not speak directly to the context of Palestine—a glaring absence in existing scholarship—there are many approaches that are relevant to research ethics questions in Palestine and lessons that could be learned from the work of RECs in other locations. In general, the processual and indigenous approaches to research ethics, as well as community-based, participatory research (CBPR) models, provide directions that would be useful. Developing local, community-based review processes and considering community-level, not just individual, consent as well as community input into research projects seem very apt for safeguarding communities in the Palestinian context. There are important debates about each of these approaches, as the literature demonstrates, and also about the role of RECs and the operationalization of research ethics guidelines as they become institutionalized. Research ethics training curricula for Middle East researchers also offer practical guidelines for workshops, multi-day or single-day sessions, that include review of research ethics review history, issues, and protocols (MERETI). These curriculum templates offer ideas and pedagogical strategies, including interactive discussion, multimedia materials,

role plays, mock informed consent and REC review scenarios, and case studies. These models could be adapted to the local context and institutional needs of Birzeit University and the particular needs and challenges of doing research in Palestine in an ethically rigorous way.

## X. References

- Arda, Berna. 2000. "Evaluation of Research Ethics Committees in Turkey." *Journal of Medical Ethics* 26: 459-461.
- Aluwihare-Samaranayake, Dilmi. 2012. "Ethics in Qualitative Research: A View of the Participants' and Researchers' World from a Critical Standpoint." *International Journal of Qualitative Methods* 11(2): 65-81.
- Ball, Jessica and Pauline Janyst. 2008. "Enacting Research Ethics in Partnerships with Indigenous Communities in Canada: 'Do It in a Good Way.'" *Journal of Empirical Research on Human Ethics: An International Journal* 3(2): 33-51.
- Burden, Kevin, Sandy Schuck, and Peter Aubusson. 2012. "m-Research: Ethical Issues in Researching Young People's Use of Mobile Devices." *Youth Studies Australia* 31(3): 17-26.
- Chenhall, Richard, Kate Senior, and Suzanne Belton. 2011. "Negotiating Human Research Ethics: Case Notes from Anthropologists in the Field." *Anthropology Today* 27(5): 13-17.
- Daley, Kathryn. 2012. "Gathering Sensitive Stories: Using Care Theory to Guide Ethical Decision-Making in Research Interviews with Young People." *Youth Studies Australia* 31(3): 27-34.
- de Jong, Anne. 2012. "The Gaza Freedom Flotilla: Human Rights, Activism and Academic Neutrality." *Social Movement Studies* 11(2): 193-209.
- de Schweinetz, Peter et al. 2009. "Evaluating International Collaboration: Differential Perceptions of Partnership in a CBPR Project in Ghana." *Journal of Empirical Research on Human Ethics: An International Journal* 4(4): 53-67.
- Deeds, Bethany et al. 2008. "An HIV Prevention Protocol Reviewed at 15 National Sites: How Do Ethics Committees Protect Communities." *Journal of Empirical Research on Human Ethics: An International Journal* 3(2): 77-86.
- Guillemin, Marilys et al. 2012. "Human Research Ethics Committees: Examining Their Roles and Practices." *Journal of Empirical Research on Human Ethics: An International Journal* 7(3): 38-49.
- Jacklin, Kristen and Phyllis Kinoshameg. 2008. "Developing a Participatory Aboriginal Health Research Project: 'Only if it's Going to Mean Something.'" *Journal of Empirical Research on Human Ethics: An International Journal* 3(2): 53-67.
- Juritzen, Grimen, and Heggen, Truls, Harald Grimen, and Kristin Heggen. 2011. "Protecting Vulnerable Research Participants: A Foucault-Inspired Analysis of Ethics Committees." *Nursing Ethics* 18(5): 640-650.
- Mohindra, K.S., D. Narayana, and Slim Haddad. "Toward Ethically Sound Participatory Research with Marginalised Populations: Experiences from India." *Development in Practice* 21(8): 1168-1175.
- Osrin, David et al. 2009. "Ethical Challenges in Cluster Randomized Controlled Trials: Experiences from Public Health Interventions in Africa and Asia." *Bulletin of World Health Organization* 87: 772-779.
- Postma, Julie. 2008. "Balancing Power Among Academic and Community Partners: The Case of El Proyecto Bienestar." *Journal of Empirical Research on Human Ethics: An International Journal* 3(2): 17-32.
- Riessman, Catherine K. "Exporting Ethics: A Narrative about Narrative Research in South India." *health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*. 9(4): 473-490.

- Rossiter, Amy, Richard Walsh-Bowers and Isaac Prilleltensky. 2002. "Ethics as a Located Story: A Comparison of North American and Cuban Clinical Ethics." *Theory & Psychology* 12(4): 533-556.
- Shore, Nancy et al. 2008. "Introduction to Special Issue: Advancing the Ethics of Community-Based Participatory Research." *Journal of Empirical Research on Human Ethics: An International Journal* 3(2): 1-4.
- . 2011. "Understanding Community-Based Processes for Research Ethics Review: A National Study." *American Journal of Public Health* 101(S1): 359-364.
- Silka, Linda et al. 2008. "Creating Community-Based Participatory Research in a Diverse Community: A Case Study." *Journal of Empirical Research on Human Ethics: An International Journal* 3(2): 5-16.
- Silverman, Henry et al. 2010. "Curriculum Guide for Research Ethics Workshops for Countries in the Middle East." *Developing World Bioethics* 10(2): 70-77.
- Smith, Linda T. 2012 (2<sup>nd</sup> ed). *Decolonizing Methodologies: Research and Indigenous Peoples*. London and New York: Zed Books.
- Sleem, Hany et al. 2010. "Development of an Accessible Self-Assessment Tool for Research Ethics Committees in Developing Countries." *Journal of Empirical Research on Human Ethics: An International Journal* 5(3): 85-96.
- UNICEF. 2012. *Ethical Principles, Dilemmas and Risks in Collecting Data on Violence against Children: A Review of Available Literature*. (By Technical Working Group on Data Collection on Violence against Children). New York: UNICEF.