



## Beyond procedural ethics: Foregrounding questions of justice in global health research ethics training for students

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Interest in global health is growing among students across many disciplines and fields of study. In response, an increasing number of academic programmes integrate and promote opportunities for international research, service or clinical placements. These activities raise a range of ethical issues and are associated with important training needs for those who participate. In this paper, we focus on research fieldwork conducted in lower income nations by students from more affluent countries and the ethics preparation they would benefit from receiving prior to embarking on these projects. Global health research is closely associated with questions of justice and equity that extend beyond concerns of procedural ethics. Research takes place in and is shaped by matrices of political, social and cultural contexts and concerns. These realities warrant analysis and discussion during research ethics training. Training activities present an opportunity to encourage students to link global health research to questions of global justice, account for issues of justice in planning their own research, and prepare for ‘ethics-in-practice’ issues when conducting research in contexts of widespread inequality. Sustained engagement with questions of justice and equity during research ethics training will help support students for involvement in global health research.

**Keywords:** research ethics; global health; justice; equity; students; training

### Introduction

The field of global health is guided by a concern for health equity, and aims to promote the goal of ‘health for all’ (Koplan et al., 2009). Much global health research aims to investigate health issues in low and middle-income countries and to respond to a range of pressing research priorities, including, but not limited to, research on health systems, public health interventions and environmental impacts on health, as well as clinical research on topics relevant to populations in these nations. These research questions are pursued through inquiries carried out in specific political, cultural and social contexts. Global health research initiatives are embedded in particular institutional arrangements and relationships, and may involve investigators or trainees from high-income nations who participate in studies in low or middle-income countries. Given these features, global health research raises a set of ethical issues and concerns that are both common and distinct to research in other settings, including questions related to justice.

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In light of the objectives of global health to address health equity, and structural arrangements within which particular projects are implemented, commentators have emphasised the role of social justice, the 'fair disbursement of common advantages and the sharing of common burdens' (Gostin & Powers, 2006, p. 1054), as a primary value to be pursued in global health research (Benatar & Singer, 2010; Ijsselmuiden, Kass, Sewankambo, & Lavery, 2011). More broadly, global health research by students also raises important questions of justice and equity, including some that are shaped by the student role (Pinto & Upshur, 2009). For example, a primary emphasis of student fieldwork is on learning opportunities for students. This focus, as well as the limited research experience of students, can limit the potential for student research projects to be designed and implemented in ways that optimally address the health needs of local communities. Such projects may, therefore, be less likely to benefit local populations. Justice issues related to student research warrant careful attention, and students would benefit from the opportunity to explore and discuss them.

In this paper, we focus on issues of justice related to global health research fieldwork conducted in low- and middle-income countries by students from wealthy nations. We argue that research ethics training is an important venue for examining these questions. We draw on our own experiences of conducting online, classroom and intensive courses in global health research ethics to illustrate aspects of this discussion. Matthew Hunt has led a summer school in global health research ethics and a seminar series for fellows in the Global Health Research Capacity Strengthening Program in Quebec, Canada, as well as workshops on research ethics in Burkina Faso (<http://www.usi.umontreal.ca/nouvelles.asp?news=590>). Beatrice Godard has taught online courses in global health research ethics and led workshops on this topic in Canada, Ivory Coast and Tunisia. In 2013, Hunt and Godard are co-leading a workshop series for fellows of the Global Health Research Capacity Strengthening Program in Quebec, Canada (<http://www.pifrs-mghrcaps.org/>).

### **Ethics and global health research by students**

Interest in global health is growing among university students across a range of fields (Shah, Nodell, Montano, Behrens, & Zunt, 2011). In response, an increasing number of academic programmes in high-income nations integrate and promote student opportunities for research, service or clinical placements in low- and middle-income countries. Students who participate in global health research fieldwork come from varied disciplines – including, but not limited to: public health, epidemiology, clinical health disciplines, anthropology, sociology and community health – and take part in short research internships or engage in longer periods of research fieldwork as part of their course of study.

Recently, ethics and best practices guidelines have been proposed by the Working Group on Ethics in Global Health Training: the WEIGHT guidelines (Crump, Sugarman, & the Working Group on Ethics Guidelines for Global Health Training, 2011). The primary focus of the guidelines is international clinical electives for health care trainees. However, ethical considerations related to the conduct of global health research by students are also identified. The guidelines assert that for global health experiences that include research, trainees should:

...develop the research plan early and in consultation with mentors, focus on research themes of interest and relevance to the host, understand and follow all research procedures of the host and sending institution, obtain ethics committee approval for the research before initiation of research, and receive appropriate training in research ethics. (Crump et al., 2011, p. 1180)

The proposed steps are important for healthcare trainees who conduct research projects in global health settings, as well as for students from other disciplines.

Questions of ethics for health care trainees participating in international clinical electives have been an increased focus of analysis in the past several years (Pinto & Upshur, 2009; Reisch, 2011; Shah & Wu, 2008,). In a qualitative study of Canadian medical students' experiences of clinical electives in low-resource settings, common ethical issues were identified (Elit et al., 2011). Many of the identified issues are closely related to questions of equity and justice, including: distress and uncertainty when confronted by individuals in great need whom students wished to help but were uncertain how to do so, being treated differently from local students and receiving additional opportunities as a result, and concerns that they were participating in a system of unilateral capacity building with limited benefits for the local community (Elit et al., 2011). To our knowledge there have not been similar empirical investigations focusing on students' experiences of ethical challenges encountered during global health research fieldwork, however, anecdotal evidence suggests that research trainees experience analogous concerns related to justice and equity, notwithstanding the different roles and responsibilities in clinical and research settings.

Many students are drawn to the field of global health research because of an interest to contribute to addressing global inequalities in health (Finch et al., 2011; Lahey, 2012). While many students have this underlying motivation, it is nonetheless pertinent to carefully examine justice and equity issues during research ethics training, especially as these issues are still little addressed in many global health curricula (Lahey, 2012). Critical engagement with questions of justice will support students to analyse and evaluate the ethical dimensions of their own current and future research contributions, and the larger field of global health research. Indeed, such evaluation may prompt students to examine the ethical justification of their own projects, something which they may have otherwise taken for granted, and subject it to due scrutiny. It can also provide an opportunity for students to examine their own motivations and objectives for participating in global health research, and the degree of correspondence between them and the realities of a student global health research project. In the following sections, we argue that considerations of justice and student fieldwork will benefit from exploration at multiple levels, including: situating student research within discourses of global justice, evaluating issues of equity in the design and implementation of research projects, and discussing inequalities encountered during research fieldwork.

### **Helping students to connect global health research to questions of global justice**

In the context of research ethics training, it is helpful to put students' planned research fieldwork within the broader context of global health research and to consider intersections with questions of social justice. Students' attention can be drawn to how justice questions precede the initiation of the project (for example,

which research question will be selected) and continue after it is completed (for example, the possibility for research findings to be put to use locally and how research findings can be disseminated to the local community) – justice questions also surround research in global health in that research activities are situated within social, political and economic contexts of inequality.

As illustrated by the WEIGHT guidelines, multiple questions of justice are associated with the implementation of global health research fieldwork (Crump et al., 2011). The correspondence of research topics to local needs, compliance with local and international ethics standards and procedures, and rigorous scientific and logistical preparation are important considerations. In line with research ethics guidelines, other considerations associated with the principle of justice also need to be addressed, including fairness in the selection and recruitment of participants and a favourable ratio of risk to potential benefits (Emmanuel, Wendler, Killen, & Grady, 2004). Issues of justice are also central to many current debates around ethical aspects of research taking place in low-resource settings, such as expectations for integrated dual research ethics review and oversight of research (Ravinetto et al., 2011), the development of local research capacity (Costello & Zumla, 2000), the provision of fair benefits after the completion of a study (Millum, 2012), researcher responsibilities to respond to situations of injustice in observational research (Lavery et al., 2010a), and responsibilities towards engaging the participation of local communities throughout the process of research development and implementation (Tindana et al., 2007). There are divergent viewpoints around each of these topics. These debates, however, help illustrate how broader questions of global justice infuse the domain of global health research (Pratt & Loff, 2010).

Research ethics training is a natural venue for drawing linkages to global justice. The processes and institutions associated with global health initiatives, including research, are embedded in broader institutional arrangements between nations. This background structure includes histories of colonisation, processes of globalisation, regimes associated with pharmaceutical patents and intellectual property, policies of international organisations (such as the International Monetary Fund), as well as other factors influencing global research priorities. These phenomena and institutions contribute to shaping inequalities in health outcomes between and within nations, and patterns of global health research.

Identifying these connections is important for illuminating the relationship between research practices and justice. Questions can be asked regarding research in global health settings, such as who will derive benefits from the research (Lairumbi, Parker, Fitzpatrick, & English, 2011). These issues are further illustrated by questions related to data sharing, ownership and storage. Discussion of where data or specimens are held, and who ‘owns’ and has access to them, are not only questions of research pragmatics. In global health research, the removal of data and biological samples to other countries – especially to high-income countries – should receive careful attention through the lens of global justice: what are the implications of off-shoring these items or information when it involves a movement from poorer to richer nations, less powerful to more powerful countries, especially where it replicates patterns of domination? What is at stake and what types of justification are required to support these practices? Given the political and historical background, and existing patterns of inequality, these practices require careful scrutiny (Emerson, Singer, & Upshur, 2011; Upshur, Lavery, & Tindana, 2007).

A further opportunity for putting research and research ethics into a global justice perspective is to discuss with students during research ethics training not just the content, but also the development of international research guidelines such as the Helsinki Accord and CIOMS guidelines (Council for International Organizations of Medical Science, 2002; World Medical Association, 2008). In this light, it is pertinent to create opportunities for students to consider the origins and justifications of these guidance documents, as well as the ways that issues of justice have been addressed across successive revisions. If guidelines are presented as ahistorical and incontestable there will be less opportunity to open up discussion around questions of how research ethics principles and guidelines ought to be understood in local cultural and social contexts, and situated within discussions of global justice, or to consider how they have been revised and refined in response to critique, debate and sustained analysis. It has been our experience in running training activities that students often have questions about the processes by which guidelines have been established, and their theoretical and normative foundations.

Students have questioned the universality of these guidelines and their origins within particular philosophical and cultural traditions. These questions are challenging ones to address during a training programme but they represent a line of discussion that can help identify linkages between questions of justice and research, and support critical reflection.

As trainees grapple with these topics they will be better able to situate their own research and activities from the perspective of justice and equity. Focusing on questions of global justice can help draw attention to how particular research projects are part of larger structural and institutional arrangements. It can be hoped that such discussion will sensitise students to particular justice and equity issues, including attention to the potential impacts and legacy of their own research and presence in a community. Students may also be encouraged to look for ways to take up questions of global justice – and to look for common ground with other trainees in order to work collaboratively towards changes in practice and shaping the direction of global health research priorities and practices in the future.

### **Encouraging students to account for equity and justice issues in the design and implementation of their research fieldwork**

Another set of justice considerations relates to the production of research itself, and the nature of student global health fieldwork. Research ethics training represents an important opportunity to raise and respond to justice-oriented questions about how students and supervisors will design and implement fieldwork experiences. This possibility is related to the timing of such training. If done too early in a student's course of study, its application to his or her future research may seem distant or hard to imagine. However, such training should be provided early enough in the process of deliberating over a research question and initiating planning for a research project so that students can identify ethics and justice concerns and adapt their planning accordingly.

Two key justice considerations for global health fieldwork are the principles of responsiveness, that research should respond to local health needs (London, 2008), and fair benefits, that the research conducted has potential to provide benefits to participants and/or local communities (Millum, 2012). In line with the principle of

responsiveness, students should seek to identify a research question that addresses an actual health need in the locale where they will conduct their research. In some circumstances, other considerations may intrude on the selection of the research question including how easy or hard it will be to conduct the research and how effectively the research project will advance the student's career development (Provenzano et al., 2010). These questions are relevant ones for students to consider, however, they should not be allowed to displace the question of whether the research is pertinent in the local setting and has the potential to produce local benefits.

Supervisors and mentors from the student's home university and local researchers in the study setting can help guide students to select a topic that is locally relevant. Incorporating participatory approaches in the research design can also contribute to enhanced likelihood that research will match local needs (Lavery et al., 2010b). During research ethics training, students can also be challenged to think about and discuss the degree to which their research topic corresponds to local needs, other motivations that may have influenced their choice of topic, and what weight these considerations were given in relation to the principle of responsiveness.

Many student global health research projects do target actual needs in the local communities where they will be carried out. It may be more difficult for students, however, to implement research that has the potential to yield tangible, local benefits. Student projects are likely to be less well resourced, shorter in duration than other projects, and smaller in scale. This outcome – lower likelihood of local benefits – will be less likely if student projects are incorporated within larger research projects; however, it is a legitimate concern for all students.

In the context of research ethics training, discussion might focus on how students can seek support from teams and supervisors to develop research projects that have the potential to generate locally applicable results and yield other benefits for the participants. Training programmes and research teams can also examine how they can contribute to the local community, including in the area of developing research capacity, as a means to address the imbalance of benefits. For example, research teams might create opportunities for students and researchers from the local setting to receive additional training so that there is a greater chance of capacity building on all sides.

A third issue of justice that can be particularly challenging for students to fulfil relates to the proposed duty to inform participants and, potentially, host communities of the findings of a research study (Emmanuel et al., 2004). Students may be especially susceptible to encounter obstacles to carrying out this step of their research. In our training sessions students have reported challenges to disseminate findings to the local community and having few opportunities for return trips to the research site for activities including restitution of findings. Depending on the methodological approach, provisional findings might, however, be shared with the community during the initial research trip if data analysis is already advanced. In some circumstances, dissemination activities can be conducted using videoconferences, or local partners can take responsibility for this step of the research. However, high-tech approaches may not be feasible or appropriate in many contexts, and asking local partners to disseminate findings excludes the student from an important component of the research process. Obstacles to disseminating findings to study participants and communities may be a source of frustration for students who feel that this is an important responsibility – indeed, something 'owed' to the local

population. Issues related to responsiveness of research to local needs, the possibility of providing benefits to the local community, and the restitution of findings to the participants and community are important justice-based considerations for student fieldwork in global health.

### **Preparing students to address equity and justice issues they might encounter during fieldwork**

Global health research raises both questions of ‘procedural ethics’ and ‘ethics in practice’ (Guilleman & Gillam, 2004). Procedural ethics encompasses norms, standards and procedures related to the ethical planning and conduct of research, and responsibilities of researchers. Research ethics and research ethics training typically focuses on these considerations. Ethics in practice, in contrast, involves the types of embodied ethical issues that arise in the everyday activities of carrying out a research project and the interactions of researchers with participants, and other people within and around the research process (Guilleman & Gillam, 2004). A wide range of ‘ethics-in-practice’ questions can arise in global health research fieldwork, including several that are uncommon in other contexts of research. While some ‘ethics-in-practice’ issues resemble those arising in other research settings, these issues might take on a different tone or have different implications due to the particular context (Shah et al., 2011). We highlight here issues related to carrying out research in a low-resource setting with limited social supports, and issues that might be encountered in a setting where individual decision-making authority or gender roles are construed differently than in the home country of student researchers. While not the standard set of issues examined in research ethics training or discussed in the research ethics literature, we believe that there is merit in exploring these issues in order to help prepare students to respond to this set of issues that are often experienced as ethically challenging.

Researchers conducting studies in contexts of steep inequalities or underlying injustice may question their responsibilities to participants (Lavery et al., 2010a). A particular set of challenges for global health student researchers relates to conducting research in settings of widespread poverty and limited healthcare resources (Cole, Plugge, & Jackson, 2012; Hetherington & Hatfield, 2012). Raising specific scenarios during training will help students to anticipate and prepare for these possibilities, even if individuals disagree on the best course of action in a particular situation (White & Evert, 2012).

One set of considerations relates to living in settings of poverty, and having personal or project resources that could significantly help individuals in need. In the training we have led, students have reported experiences of struggle and turmoil over whether to use their own money to help research participants who were extremely poor and lacked basic essentials, or could not afford needed healthcare services. For example, a student reported questioning whether she could pay the fees for an emergency surgery that was needed by a research participant who could not afford the cost. Given the importance of these issues, and the specificity of these questions to working in situations of widespread poverty with limited social supports, ethics training is a helpful venue to raise these questions though they might not be addressed in many generic research ethics seminars.

Health professional trainees conducting research fieldwork may experience additional uncertainty regarding whether to use their developing clinical skills and knowledge to assist research participants or their families, outside of those interventions planned for in the research protocol. This might include requests for clinical information or treatment. For example, a health professional trainee who is conducting a household survey on postnatal care in an impoverished rural district might encounter a child with an elevated fever and be asked by the family for assistance. The student may be uncertain how to respond out of concern for biasing the research and acting outside of his or her role as a researcher.

On the other hand, he or she will likely wish to provide assistance to the sick child and worried family. In the context of a robust healthcare system in a country with strong social supports and where referral to other sources of care is available, providing clinical assistance to research participants is likely to be quickly identified as unacceptable and compromising the role of the (student) researcher. The ethical evaluation of such decisions is less clear-cut in a low resource setting where individuals have limited or no access to health services. Identifying these issues in training can help students to design their research protocols to avoid some potential dilemmas of this nature, as well as thinking through possible responses and supports.

Global health trainees travel to another country to conduct their research. Most of them also carry out their studies in a cultural and social environment with which they have limited or partial familiarity or background knowledge. Students should be encouraged to learn about the research site context both to ensure that their research procedures are well aligned with the realities of the setting and community, and also as a means of preparing themselves for living and working in a new cultural and social environment. In the context of research ethics training, students can be prompted to think about situations that may present particular ethical challenges related to conducting research in another cultural context, including those related to social justice.

One prominent example is questions related to gender. Gender roles and expectations vary between cultures. Female researchers may need to navigate particular issues if they are conducting their research in a setting where authority and decision-making in the public sphere is understood to be the reserve of men. Students may also confront situations in which there are cultural values and practices related to participation of individuals in relation to families and communities (Tindana et al., 2011). For example, it may be expected that husbands make decisions for their wives in relation to research participation or the village leaders may play a central role in decision-making related to whether individual members of the community can enrol in a study. Research ethics training can prompt students to learn about local expectations related to decision-making, and to design protocols taking these characteristics into account, while ensuring that research plans are consistent with relevant ethics guidelines.

We have discussed here several ethics-in-practice issues. Students are likely to encounter other issues specific to their research design and research setting. Awareness of this set of issues will be helpful for students. Students will also benefit from learning about avenues for seeking support and guidance during their fieldwork if they experience challenging situations or are confronted by ethics-in-practice questions.



**Suggestions for content and structure of global health research ethics training**

The structures, priorities and processes of global health research are infused with issues of justice and equity at multiple levels (Pratt & Loft, 2010; Pratt et al., 2012). During research ethics training, students can be encouraged to critically assess how the enterprise of global health research relates to questions of global justice, to consider justice issues related to their own project design and implementation, and to anticipate and plan for questions of ‘ethics in practice’ that they might encounter while working in a new social and cultural context, and, potentially, in situations where many are vulnerable and there are few social supports available.

Programmes to provide ethics training for global health research vary in content, format and duration. Sufficient time is required to cover the array of relevant topics, however, a range of mechanisms and modalities might effectively be used to convey the material and engage students. Such training will involve presentation and discussion of the commitments, theories and principles that underpin research ethics and global health. Ethical requirements for conducting research in an international setting will be reviewed and discussed (Emmanuel et al., 2004). As these topics are presented, connections and linkages with global justice can be drawn. For example, topics such as data sharing and data ownership can be examined through the lens of justice. Students will also benefit from being introduced to models and processes for evaluating ethical issues. These models can be implemented and practised through the analysis of case studies. Case studies have limitations as a learning modality since there is much of the social and cultural context that is necessarily taken for granted in the often brief presentation of a case (Dwyer, 2003).

However, case studies remain a very useful method for students to engage with ethical dimensions of global health research by making concepts more tangible and helping them imagine issues that they might encounter. To maximise the benefits of learning through case studies, students might be provided with background readings to be done in advance of the session to allow a greater appreciation for the context and particularities of the case under consideration. For the final session of our workshop series on global health research ethics, we also have students prepare and present case studies based on their own experiences, or drawn from their reading of the literature in their domain of research interest. This activity has generated considerable discussion of ethical issues of particular salience to the students, and helped them analyse challenging situations that they have encountered or are likely to encounter.

Research ethics training can also present an opportunity to examine how students can seek help if they experience difficult issues, including ethical challenges, during fieldwork. Student projects in global health research take different shapes and the types of practical and collegial support available to students varies considerably. As described by Shah and colleagues, students who conduct research in global health settings are likely to experience a ‘greater sense of both “autonomy and isolation” compared to other research contexts’ (Shah et al., 2011, p. 236). In some projects, students work closely with their supervisor throughout the fieldwork phase. They may also receive support from additional mentors who have first-hand knowledge of the research locale. In other contexts, students may be integrated within a well-established and supportive team of researchers in the field site even if their own supervisor is not present in the research locale. The research team may include local researchers and research staff, as well as researchers who come from other regions

and countries. In still other cases, student researchers may be very independent and have few opportunities to ask questions or seek support. Preparing in advance for ethical issues arising in fieldwork will be important for all students. The need is heightened in cases where students will have less supervision and fewer resources to draw upon in the field. In our training activities, we ask students to reflect upon their own projects and list potential ethical issues that they might encounter. We encourage students to review this list with their supervisors and to collaboratively write out a tailored support plan that identifies resources that they can access for help in addressing ethical issues that they might encounter during their research fieldwork.

### Conclusion

Research ethics training provides more than a forum for consideration of the standard set of process-focused ‘how-to’ questions of conducting ethically defensible research. Global health research ethics training can encourage reflection and discussion on issues of justice and equity encountered by students conducting research in global health settings. Critical assessment of justice issues in global health research also draws attention to certain limits to the applicability of principles and recommendations governing research ethics in Western countries for research in other countries, as well as the importance of continued analysis of justice issues in global health research to support refinement of international guidelines. In this sense, foregrounding questions of justice in global health research ethics training for students may help students reflect upon and address justice issues related to their own research, but also support a process of continued international dialogue and partnership development towards advancing the field of global health research ethics through engagement of academics, researchers and policymakers from all regions of the world. Research takes place in, and is shaped by, matrices of political, social and cultural contexts and concerns. These realities warrant analysis and discussion during research ethics training. Engaging with the implications of research activities for social and global justice will help students as they prepare for, and engage in, global health research projects.

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