GLOBAL RESEARCH ETHICS

CASE STUDIES FROM INTERNATIONAL RESEARCH CONTEXTS

CAREN J. FROST, LISA H. GREN,
L. SCOTT BENSON, AND MARGARET CARLSON

Global Research Ethics

Global Research Ethics is a guide for students and their instructors as well as practitioners and researchers to understand topics linked to research ethics from a more global perspective. Research plays a key role in identifying health disparity trends and evaluating interventions to improve the health and well-being of the populations at the individual, local, national, and global levels. Conducting ethically sound research is imperative in these contexts.

This book (a) uses case studies to offer examples of current research ethical dilemmas and (b) considers regulatory and cultural frameworks in a number of country contexts that highlight diverse methods of identifying and managing these ethical dilemmas. Chapters cover different types (groups) of participants, issues in research, and ways of doing research; then each chapter looks at exemplar case studies with at least two analytical commentaries. Case studies include health and social care research, and originate from countries such as Brazil, Chile, South Africa, Botswana, Australia, and New Zealand, as well as the U.S. and U.K. The different viewpoints showcased will allow for dialogue to ensue about the ways in which populations and topics in research need to be conceptualized.

Global Research Ethics is suitable for all undergraduates and postgraduates in research methods courses in the social and health sciences. It provides academic researchers, students, and community partners with guidelines to reflect on as they develop their own research studies.

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Preface

Research plays a key role in identifying health disparities and trends and evaluating interventions to improve the health and well-being of the populations at the individual, local, national, and global levels. Conducting ethically sound research is an international imperative. Although the basic principles when conducting ethical research are shared among countries, there is room for improvement to create open conversations among research communities to improve research practices. Further exploration and collaboration are needed to (a) develop a cohesive view on ethical research and (b) advance conversations and guidelines created to address emerging issues (Bhutta, 2002).

This book aims to be a guide for individuals to understand research and ethics from a more global perspective. From discussions with professionals from all over the world, there is a need for further sharing of information about how to manage cross-cultural ethics issues in research contexts. Community and academic partners at local levels are sometimes not able to conceptualize how to conduct rigorous, non-coercive, and confidential research. This book will use case studies and offer examples of ethical issues and solutions in research to address some situations. It will provide academic researchers, students, and community partners with clear parameters and guidelines to ensure they are conducting research in an ethical manner that fits with global considerations of these issues and structures. There are numerous ways community groups understand ethical frameworks for conducting research. These different views should be a point of dialogue among partners so that the complexity of ethics can be managed together on a research project. Discussants from six continents and various countries will provide the information on global research ethics for this book.

Ethical issues are found continually in the news and this information aids the need for this book and what it hopes to do. For example, human genome research has made headlines over the years and recently it was brought up again outlining the ethical misuse of data sample gathering from Indigenous communities by Western scientists and the mistrust that created. One scientist was trying to change this relationship by a funded program called Summer Internship for Indigenous Peoples in Genomics. Funded by the U.S. National Institutes of Health (NIH), this program hoped to train individuals in genomics so they can "introduce that field's tools to

their communities as well as bring the Indigenous perspective to research" (Wade, 2018). Another topic is euthanasia and the legalization of assisted suicide and the populations it can encompass. In Canada, physicians and other ethicists have proposed the use of euthanasia as an option for children, as well as an option for those suffering from a mental illness (Van Maren, 2018). Another controversial topic of the use of medical cannabis has been spreading throughout Europe with more countries legalizing its use. However, the lack of information and research behind the use of medical cannabis, along with the ethics of using it have created discussions throughout Europe on this topic (Murphy, 2018).

This book links to courses on global research and global ethics for upper-level undergraduate, lower-level graduate students, and community partners. Having access to information about how research is managed in other countries and with individuals and/or communities from those countries will enable researchers in various job roles and collaborating with various communities to have a more comprehensive understanding of how to manage the ethical situations and issues that arise in health sciences, medical, and social sciences research activities.

Each chapter will highlight a specific population that has been the center of several ethical issues and debates. We will begin the book with chapters separately dealing with youth, women, and men, and then the following chapters will target aspects of research about language and participation. The last four chapters call attention to high-profile themes of research: economics and incentives, genetics and bio-specimens, mental health, and use of technology. Each chapter will follow a similar outline containing background on the topic, case studies specific to the issue, and responses from professionals from different communities or countries on the case study and issue at hand. In addition, exercises to use in a classroom setting are provided for each chapter. These exercises could be used as conversation starters to highlight the issues under consideration. An appendix of videos and a list of references at the end of the book can be used to summarize and supplement the information for each chapter.

1 Introduction to Global Research Ethics

Introduction

Over the past 20 years, global, interdisciplinary research has increased and is becoming more prevalent. Many universities have connections with academic settings in other countries and on other continents. Consequently, research ethics parameters need to be reconsidered and reframed based on different cultural understandings of how to interact with human participants in research settings and how to develop cross-national research studies. This book will provide insights into topics linked to global research ethics for work with specific types of populations and on specific research areas that need a more global discussion. This chapter provides the frame for this book, as well as information about the book's structure, which uses case studies and case analyses. This text will be particularly useful in highlighting considerations for global, interdisciplinary work so that research ethics will become a regular and ongoing component for colleagues working transnationally.

The U.S. Department of Health and Human Services defines research as "a systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge" (USDHHS, 2019). Human subject is defined as "a living individual about whom an investigator (whether professional or student) conducting research obtains data through intervention or interaction with the individual, or identifiable private information" (USDHHS, 2019). The National Institutes of Health define ethics as "the norms for conduct that distinguish between acceptable and unacceptable behavior" (Resnik, 2015; BBC, 2014). Ethics help govern research in multiple ways by setting guidelines and rules holding those conducting research responsible for their actions by ensuring their work does not violate the rights of participants (i.e., human subjects). With globalization, research cannot stay within a nation's borders and is best addressed by sharing data, skills, and education with others. According to the Merriam-Webster dictionary, global is defined as relating to or involving the entire world (Merriam-Webster, 2017). Research and ethics reflect this global nature in that nations over the world have come together to produce documents and guidelines to help aid and standardize research going forward. Several of these documents will be mentioned later in this chapter since they helped outline practices over the years and how research is shaped today.

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Human Rights and Research Ethics: The Foundational Documents

The treatment of humans in World War II sheds light on the inhuman medical and research practices that prisoners and other populations were subjected to and called attention to the need to protect human rights. It is well documented that during this time human beings were subjected to experimentation without being allowed to consent to such experimentation and without regard to risks to their physical and emotional well-being. Experimentation was justified with the aims of bettering survival for military personnel, expanding and perfecting the health of some groups over others, and/or advancing pharmaceutical options and specific treatments (USHMM, 2019a). The world was shocked that individuals in power in a modern society could allow and participate in such unethical mistreatment with little or no regard for the rights of human subjects (O'Mathuna, 2006).

Following World War II, 13 trials were conducted between 1945 and 1949 by the Allied Forces to prosecute members and leaders of Nazi Germany who participated in and allowed for mistreatment to occur. Known as the Nuremberg Trials, after the city in which they were held, 185 people were indicted and 23 of these individuals were charged with crimes against humanity, such as medical experimentation (History Channel, 2010). The trials were broken into two parts: the major war criminals' trial and subsequent trials. The major war criminals' trials consisted of indictments of members and leaders of the Nazi Party and the Gestapo (History Channel, 2010). The subsequent trials included charges of crimes against humanity and included trials of German doctors, judges, industrialists, and military officers. During the Doctors' Trial, it was argued these medical professionals did nothing outside of the scope of work that was not already being done elsewhere in the world. The Trials also pointed to the fact that there was no official documentation or law in countries and/or at the global level that stated what could be done during research activities and experimentation using human participants (USHMM, 2019b). These allegations led the way for ethical codes for research and medical practice to be developed.

The Nuremberg Code was developed in 1947 based on information from these trials (Fischer, 2006). This Code was the first set of standards that outlined the rights humans have when participating in research to prevent future abuse, and included concepts of morality, ethics, and legal precautions (USHMM, 2019a). Comprising ten points, a main emphasis of the Nuremberg Code is that research must be voluntary for an individual to participate. An individual could not be forced or coerced into participating, and people should not feel under pressure to participate. Other points more specifically outlined what research was to entail: how it must be useful and must have more benefits than risks to the participant and society (Fischer, 2006). Thus, research and experiments with human participants should be conducted for the good of society, and not for personal study or amusement. In addition, personnel conducting such studies should be scientifically qualified in their scientific discipline of expertise. The Nuremberg Code provided the basis for the further development of standards and protocols for conducting research with human participants, and it has been used as a basis for agreements when participating in research today, especially around informed consent parameters.

After the founding of the United Nations (UN) in 1945, a second foundational document was developed by the UN Commission on Human Rights (UN, 2018). This Commission, headed by Eleanor Roosevelt, created a declaration of rights that was completed in 1948 and was based on the findings from the Nuremberg Trials. Forty-eight of the 58 UN member countries voted in favor of this document depicting the rights all people should have—"the first time countries agreed on a comprehensive statement of inalienable human rights" (UN, 2018). This document, titled the Universal Declaration of Human Rights (UDHR), was created to be a universal set of standards for defining what it meant to be a human being for all people, regardless of gender, race, location, etc. and "remains the primary source of global human rights standards" (Hannum, 1998). Despite the small number of historical voting members, the UDHR has been translated to over 500 languages (see Figure 1.1). Currently, with 192 member states, the UDHR is widely upheld and used, because it was a landmark achievement in defining and standardizing the rights of all humans, is part of the International Bill of Human Rights (UN, 2018).

The UDHR outlines 30 rights that are grouped into seven categories, some of which link to conducting research. These categories cover civil, political, life, liberty, property, speech, privacy, economic, social, and cultural rights (UN, 2018). In addition, several of the UDHR articles reference research specifically. For example, Article 5 states, "no one shall be subjected to torture or to cruel, inhuman, or degrading treatment" (UN, 2018). Articles 18 and 19 highlight rights of freedom of thought and opinion or expression, which are key elements of an informed consent process and discussion in invitations to participate in research studies. Finally, Article

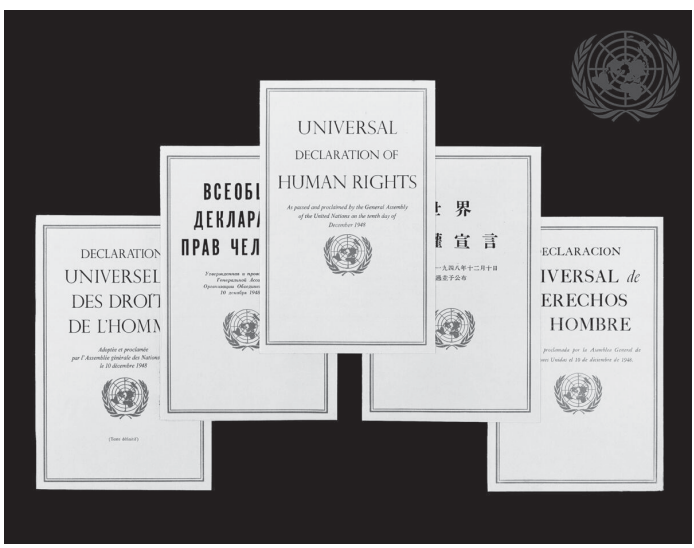

Figure 1.1 Covers of the Universal Declaration of Human Rights

25 states the right to medical care and necessary social services, which should also be represented in an informed consent process.

Although it is not legally binding, the UDHR has been used in the construction of laws, treaties, and constitutions (UN, 2018). The UN uses the UDHR as a basis for wording of the UN Charter, which is, in fact, binding for all 193 member states. The UDHR has been used to build cases against parties that break the rights outlined within it and as an instrument in helping countries define and implement their own human rights agendas (UN, 2018). While not considered international law, the UDHR has been used and upheld in international relations. It is because of its general references and open definitions that it can be widely used and accepted as a standard declaration of rights and is pertinent for research structures (Hannum, 1998).

Several other documents were developed after World War II and should be considered for understanding global research ethics. Assembled in 1945, the World Medical Association (WMA) was concerned by the "treatments" physicians gave to patients and created a code of medical ethics known as the Declaration of Geneva in 1949, which outlined principles a physician should uphold when working with patients (WMA, 2018; Fischer, 2006). Elaborating on this Declaration, the WMA wanted to provide more specific information and interpretation on the responsibilities for a physician when conducting research. Thus, the *Ethical Principles for Medical Research Involving Human Subjects*, later known as the Declaration of Helsinki (DoH) in 1964, was published (Fischer, 2006). The DoH's purpose, like that of the Nuremberg Code, was to prevent any mistreatment of human subjects in research. This document puts the responsibility of the welfare of research participants on the medical provider and researcher; however, it allows for research participant responsibility as well. The three main sections of the DoH are (WMA, 2018):

1. Description of why research involving human participants is needed—this section discusses vulnerable populations, the need to provide special care for those populations when conducting research with them, and the requirement of obtaining consent from all participants;
2. Reiteration of the Nuremberg Code—this section expands on the construct of voluntary participation; stipulates the need to inform participants about the risks, possible benefits, and ability to stop study participation; and outlines the importance of only conducting research with participants who might benefit from it, not just arbitrary individuals to obtain sufficient sample size; and
3. Discussion about how research and medical care are connected and that participants may not understand these connections—this section addresses the use of a placebo to test out possible new methods of treatment and examines the concept of explaining the use of placebo to participants (USDHHS, 2017).

The most important aspect of the DoH is that it indicates the importance of obtaining informed consent for individuals participating in research studies (Fischer, 2006). Informed consent not only applies to adults, but to vulnerable populations such as children, prisoners, people with mental challenges, and military personnel