CONVERGE Ethics and Disaster Research Annotated Bibliography

This annotated bibliography includes resources focused on the ethical conduct of hazards and disaster research. This bibliography is meant to support those interested in learning more about the ethical conduct of research and to complement the CONVERGE Broader Ethical Considerations for Hazards and Disaster Researchers Training Module. These references were compiled through searching Web of Science, PubMed, and Google Scholar databases. If you identify missing references, please send them to converge@colorado.edu, and we will add them to the list.

Citation

Agee, J. (2009). Developing qualitative research questions: A reflective process. *International Journal of Qualitative Studies in Education*, *22*(4), 431-447. https://doi.org/10.1080/09518390902736512

Abstract

The reflective and interrogative processes required for developing effective qualitative research questions can give shape and direction to a study in ways that are often underestimated. Good research questions do not necessarily produce good research, but poorly conceived or constructed questions will likely create problems that affect all subsequent stages of a study. In qualitative studies, the ongoing process of questioning is an integral part of understanding the unfolding lives and perspectives of others. This article addresses both the development of initial research questions and how the processes of generating and refining questions are critical to the shaping of a qualitative study.

Citation

Aijazi, O., Amburgey, E., Limbu, B., Suji, M., Binks, J., Balaz-Munn, C., Ranking, K., & Shneiderman, S. (2021). The ethnography of collaboration: Navigating power relationships in joint research. *Collaborative Anthropologies*, *13*(2), 56-99. https://doi.org/10.1353/cla.2021.0003

Abstract

We came together to write a paper on the devaluation of field researcher labor as an entry point into the broader domain of research ethics to unpack what collaboration may mean in settings of incommensurable inequality. These motivations were grounded in the materialities of our involvement within an international research project focused on post-earthquake reconstruction processes in Nepal since 2015. However, since we started writing this piece, some of us felt that the paper did not adequately reflect their experiences, others felt it put them in the hot seat too quickly, and some thought that it mimicked the faulty modes of collaboration we wanted to unsettle in the first place. Realizing the power dynamics within our own writing collective, we stepped away from a centralized narrative to make room for our diverse, sometimes complementary, sometimes contradictory experiences. The paper is a bricolage of reflections that focus on issues such as the division of labor, coauthorship, and community engagement. We use these reflections as a way to think critically about the current juncture of transnational, collaborative research and propose a series of open-ended reflections that prompt the problematization of the inequities, tensions, and emotional labor inherent in collaborative work.

Citation

Baker, L. R., & Cormier, L. A. (2014). *Disasters and vulnerable populations: Evidence-based practice for the helping professions*. Springer Publishing Company.

Abstract

Vulnerable populations such as children, older adults, and people with disabilities are disproportionately affected by large-scale disasters. This hands-on resource for students and professionals in social work, counseling, nursing, mental health, and other helping professions encompasses the best and most current evidence-based interventions for effectively responding to the needs of vulnerable populations following disasters. Using an all-hazards perspective, the book provides dedicated sections containing population-specific personal preparedness considerations and discusses the role of preparedness in mitigating negative consequences. The resource is unique in its provision of vital information for locating requisite assessment tools, preparedness checklists, and mobile applications offered through national organizations. This book addresses the specific psychosocial needs of vulnerable populations after a disaster. It delivers best practices for crisis intervention with specific populations including children, older adults, people with disabilities, people with mental health issues, and people with substance abuse issues. The authors present a theoretical foundation for understanding disasters, response systems, common guidelines for preparedness, and basic crisis theory. This is a resource that will be valuable not only to practitioners in a great variety of health disciplines, but also to volunteer professionals and paraprofessionals involved in disaster preparedness and response. Case vignettes are included in each chapter to illustrate issues particular to each population. The Key Features of the book are as follows: Offers the highest quality, best available evidence for choosing appropriate interventions; Focuses on vulnerable populations including children, older adults, and people with disabilities, mental health issues, and substance abuse issues; Comprises a practical, hands-on manual for mental health and medical professionals and volunteers regarding disaster preparedness and response; Provides assessment tools and preparedness checklists and forms; and Includes case vignettes to illustrate issues specific to each population.

Citation

Barber, K., & Haney, T. J. (2016). The experiential gap in disaster research: Feminist epistemology and the contribution of local affected researchers. *Sociological Spectrum, 36*(2), 57–74. https://doi.org/10.1080/02732173.2015.1086287

Abstract

In this article, we make the case for a situated knowledge of disasters. By applying a feminist standpoint framework, we argue that an ethic of "objectivity" and a privileging of the unattached researcher creates an experiential gap in the disaster literature whereby researchers who themselves experience disaster are undervalued and underrepresented. We analyze reflexive accounts by disaster researchers to show what epistemological barriers emerge from conventional processes of inquiry and the systematic disadvantaging of local, affected researchers. We also study patterns in articles by "outsider" and "insider" researchers, focusing on differences and similarities in research questions, reflexivity, relationships with and access to participants, and larger theoretical goals. This comparison reveals that the unique position of affected researchers can help to bridge formal knowledge and practical life knowledge, creating new and worthwhile paths to understanding the social effects of disaster.

Citation

Barron Ausbrooks, C. Y., Barrett, E. J., & Martinez-Cosio, M. (2009). Ethical issues in disaster research: Lessons from Hurricane Katrina. *Population Research and Policy Review*, *28*(1), 93–106. https://doi.org/10.1007/s11113-008-9112-7

Abstract

Conducting research in the wake of a catastrophic event imposes the dual responsibilities on researchers of protecting the rights of the survivors as research subjects, while also ensuring research quality and the dissemination and application of findings. This article, based partially on the authors' experiences of conducting research in school districts following Hurricane Katrina, examines the ethical issues that arise when working with survivors, reticent organizations, and institutional review boards. Challenges experienced by researchers concerning access, informed consent, confidentiality, subject compensation, and enlisting the assistance of stressed institutions are described.

Citation

Barzilay, E. J., Schaad, N., Magloire, R., Mung, K. S., Boncy, J., Dahourou, G. A., Mintz, E. D., Steenland, M. W., Vertefeuille, J. F., & Tappero, J. W. (2013). Cholera surveillance during the Haiti epidemic—the first 2 years. *New England Journal of Medicine*, *368*(7), 599-609. https://doi.org/10.1056/NEJMoa1204927

Abstract

Background: In October 2010, nearly 10 months after a devastating earthquake, Haiti was stricken by epidemic cholera. Within days after detection, the Ministry of Public Health and Population established a National Cholera Surveillance System (NCSS).
Methods: The NCSS used a modified World Health Organization case definition for cholera that included acute watery diarrhea, with or without vomiting, in persons of all ages residing in an area in which at least one case of Vibrio cholerae O1 infection had been confirmed by culture.
Results: Within 29 days after the first report, cases of V. cholerae O1 (serotype Ogawa, biotype El Tor) were confirmed in all 10 administrative departments (similar to states or provinces) in Haiti. Through October 20, 2012, the public health ministry reported 604,634 cases of infection, 329,697 hospitalizations, and 7436

deaths from cholera and isolated V. cholerae O1 from 1675 of 2703 stool specimens tested (62.0%). The cumulative attack rate was 5.1% at the end of the first year and 6.1% at the end of the second year. The cumulative case fatality rate consistently trended downward, reaching 1.2% at the close of year 2, with departmental cumulative rates ranging from 0.6% to 4.6% (median, 1.4%). Within 3 months after the start of the epidemic, the rolling 14-day case fatality rate was 1.0% and remained at or below this level with few, brief exceptions. Overall, the cholera epidemic in Haiti accounted for 57% of all cholera cases and 53% of all cholera deaths reported to the World Health Organization in 2010 and 58% of all cholera cases and 37% of all cholera deaths in 2011.
Conclusions: A review of NCSS data shows that during the first 2 years of the cholera epidemic in Haiti, the cumulative attack rate was 6.1%, with cases reported in all 10 departments. Within 3 months after the first case was reported, there was a downward trend in mortality, with a 14-day case fatality rate of 1.0% or less in most areas.

Citation

Beaven, S., Wilson, T., Johnston, L., Johnston, D., & Smith, R. (2019). Research engagement after disasters: Research coordination before, during, and after the 2011–2012 Canterbury earthquake sequence, New Zealand. *Earthquake Spectra 32*(2), 713-735. https://doi.org/10.1193/082714eqs134m

Abstract

This article argues that active coordination of research engagement after disasters has the potential to maximize research opportunities, improve research quality, increase end-user engagement, and manage escalating research activity to mitigate the ethical risks posed to impacted populations. We focus on the coordination of research activity after the 22 February 2011 Mw6.2 Christchurch earthquake by the then newly formed national research consortium, the Natural Hazards Research Platform, which included a social science research moratorium during the declared state of national emergency. Decisions defining this organization's functional and structural parameters are analyzed to identify lessons concerning the need for systematic approaches to the management of post-disaster research, in collaboration with the response effort. Other lessons include the importance of involving an existing, broadly based research consortium, ensuring that this consortium's coordination role is fully integrated into emergency management structures, and ensuring that all aspects of decision-making processes are transparent and easily accessed.

Citation

Black, R. (2003). Ethical codes in humanitarian emergencies: From practice to research? *Disasters, 27*(2), 95–108. https://doi.org/10.1111/1467-7717.00222

Abstract

Notable strides have been made in recent years to develop codes of conduct for humanitarian intervention in conflicts on the part of international NGOs and UN organisations. Yet engagement by the academic and broader research communities with humanitarian crises and ongoing complex political emergencies remains relatively ad hoc and unregulated beyond the basic ethical guidelines and norms developed within universities for research in general, and within the governing and representative bodies of particular academic disciplines. This paper draws on a case study of research on humanitarian assistance to Liberia during that country's civil war from 1989 to 1996. The difficulties faced by humanitarian agencies in Liberia led to the development of two key sets of ethical guidelines for humanitarian intervention: the Joint Policy of Operations (JPO) and Principles and Policies of Humanitarian Operations (PPHO). This paper seeks to address what lessons, if any, these ethical guidelines, together with different experiences of conducting research in war-torn Liberia, can provide in terms of the role of academic researchers - and research itself- in humanitarian crises.

Citation

Boff, G. (2012). Ethics among scholars in academic publishing. In *Proceedings of the Information Systems Educators Conference ISSN* (Vol. 2167, pp. 1435-1444).

Abstract

This paper offers a survey of the contemporary and common-place ethical breaches concerning authorship, research, and publishing in today's scholarly production, as juxtaposed with some of the predominant standards and guidelines that have been developed to direct academic publishing practices. While the paper may suggest the need for an updated and comprehensive set of guidelines for multiple discipline areas, the purpose here is to prepare the theoretical framework for a future computing discipline-specific study of ethical authorship and related concepts in academia.

Citation

Browne, K. E., & Peek, L. J. (2013). Beyond the IRB: An ethical toolkit for long-term disaster research. *International Journal of Mass Emergencies and Disasters*, *31*(3).

Abstract

This article argues for expanding the ethical frame of concern in disaster research from the early phases of site access to longer-term issues that may arise in the field. Drawing on ethical theory, these arguments are developed in five sections. First, we identify the philosophical roots of ethical principles used in social science research. Second, we discuss how ethical concerns span the entire lifecycle of disaster-related research projects but are not fully addressed in the initial protocols for gaining Institutional Research Board (IRB) approval. Third, we introduce the idea of the philosophically informed "ethical toolkit," established to help build awareness of moral obligations and to provide ways to navigate ethical confusion to reach sound research decisions. Specifically, we use the work of W. D. Ross to introduce a template of moral considerations that include fidelity, reparation, gratitude, justice, beneficence, self improvement, and non-maleficence. We suggest that in the absence of a clear framework that researchers can use to think through ethical dilemmas as they arise, Ross' pluralist approach to ethical problem solving offers flexibility and clarity and, at the same time, leaves space to apply our own understanding of the context in question. Fourth, we draw on six examples from our research studies conducted following Hurricane Katrina. Using these examples, we discuss how, in retrospect, we can apply Ross' moral considerations to the ethical issues raised including: (1) shifting vulnerability among disaster survivors, (2) the expectations of participants, and (3) concerns about reciprocity in long-term fieldwork. Fifth, we consider how the ethical toolkit we are proposing may improve the quality of research and research relationships.

Citation

Brown, P., Morello-Frosch, R., Brody, J. G., Altman, R. G., Rudel, R. A., Senier, L., Pérez, C., & Simpson, R. (2010). Institutional review board challenges related to community-based participatory research on human exposure to environmental toxins: A case study. *Environmental Health, 9*(1), 1-12. https://doi.org/10.1186/1476-069X-9-39

Abstract

Background: We report on the challenges of obtaining Institutional Review Board (IRB) coverage for a community-based participatory research (CBPR) environmental justice project, which involved reporting biomonitoring and household exposure results to participants, and included lay participation in research.
M*ethods*: We draw on our experiences guiding a multi-partner CBPR project through university and state Institutional Review Board reviews, and other CBPR colleagues' written accounts and conference presentations and discussions. We also interviewed academics involved in CBPR to learn of their challenges with Institutional Review Boards.
Results: We found that Institutional Review Boards are generally unfamiliar with CBPR, reluctant to oversee community partners, and resistant to ongoing researcher-participant interaction. Institutional Review Boards sometimes unintentionally violate the very principles of beneficence and justice which they are supposed to uphold. For example, some Institutional Review Boards refuse to allow report-back of individual data to participants, which contradicts the CBPR principles that guide a growing number of projects. This causes significant delays and may divert research and dissemination efforts. Our extensive education of our university Institutional Review Board convinced them to provide human subjects protection coverage for two community-based organizations in our partnership.
Conclusions: IRBs and funders should develop clear, routine review guidelines that respect the unique qualities of CBPR, while researchers and community partners can educate IRB staff and board members about the objectives, ethical frameworks, and research methods of CBPR. These strategies can better protect research participants from the harm of unnecessary delays and exclusion from the research process, while facilitating the ethical communication of study results to participants and communities.

Citation

Brun, C. (2009). A geographers' imperative? Research and action in the aftermath of disaster. *The Geographical Journal*, *175*(3), 196–207. https://doi.org/10.1111/j.1475-4959.2009.00329.x

Abstract

After the Indian Ocean tsunami of 2004 a number of academics published texts in attempts to make sense of the disaster. Frustrations and feelings of inability to do something useful to assist were expressed. The academic discussions arising from the disaster may be linked with more general discussions around conducting relevant and responsible research in the social sciences. This paper addresses the role of researchers in the aftermath of the tsunami disaster in Sri Lanka and explores how the debate following the tsunami can move on to refine researchers' roles in geography by way of participatory action research (PAR), a research strategy that has received limited attention in research on disasters. The paper begins by situating the debate in the spatial politics of humanitarian work and academic research. Then discussions that arose among geographers in the aftermath of the tsunami are presented and potentials for conducting responsible research by engaging with the field are introduced. In the final section, starting with the notion of responsible research, how PAR can potentially bring us forward in developing principles and tools for more responsible geographical research in the context of emergencies is discussed.

Citation

Bruno, W., & Haar, R. J. (2020). A systematic literature review of the ethics of conducting research in the humanitarian setting. *Conflict and Health*, *14*(1), 27. https://doi.org/10.1186/s13031-020-00282-0

Abstract

Background: Research around humanitarian crises, aid delivery, and the impact of these crises on health and well-being has expanded dramatically. Ethical issues around these topics have recently received more attention. We conducted a systematic literature review to synthesize the lessons learned regarding the ethics of research in humanitarian crises.
Methods: We conducted a systematic review using the Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA) guidelines to identify articles regarding the ethics of research in humanitarian contexts between January 1, 1997 and September 1, 2019. We analyzed the articles to extract key themes and develop an agenda for future research.
Results: We identified 52 articles that matched our inclusion criteria. We categorized the article data into five categories of analysis: 32 were expert statements, 18 were case studies, 11 contained original research, eight were literature reviews and three were book chapters. All included articles were published in English. Using a stepwise qualitative analysis, we identified 10 major themes that encompassed these concepts and points. These major themes were: ethics review process (21 articles, [40.38%]); community engagement (15 articles [28.85%]); the dual imperative, or necessity that research be both academically sound and policy driven, clinical trials in the humanitarian setting (13 articles for each, [25.0%)]; informed consent (10 articles [19.23%]); cultural considerations (6 articles, [11.54%]); risks to researchers (5 articles, [9.62%]); child participation (4 articles [7.69%]); and finally mental health, and data ownership (2 articles for each [3.85%]).
Conclusions: Interest in the ethics of studying humanitarian crises has been dramatically increasing in recent years. While key concepts within all research settings such as beneficence, justice and respect for persons are crucially relevant, there are considerations unique to the humanitarian context. The particular vulnerabilities of conflict-affected populations, the contextual challenges of working in humanitarian settings, and the need for ensuring strong community engagement at all levels make this area of research particularly challenging. Humanitarian crises are prevalent throughout the globe, and studying them with the utmost ethical forethought is critical to maintaining sound research principles and ethical standards.

Citation

Buchanan, E. A., & Hvizdak, E. E. (2009). Online survey tools: Ethical and methodological concerns of human research ethics committees. *Journal of Empirical Research on Human Research Ethics*, *4*(2), 37-48. https://doi.org/10.1525/jer.2009.4.2.37

Abstract

A survey of 750 university human Research Ethics Boards (HRECs) in the United States revealed that Internet research protocols involving online or Web surveys are the type most often reviewed (94% of respondents), indicating the growing prevalence of this methodology for academic research. Respondents indicated that the electronic and online nature of these survey data challenges traditional research ethics principles such as consent, risk, privacy, anonymity, confidentiality, and autonomy, and adds new methodological complexities surrounding data storage, security, sampling, and survey design. Interesting discrepancies surfaced among respondents regarding strengths and weaknesses within extant guidelines, which are highlighted throughout the paper. The paper concludes with considerations and suggestions towards consistent protocol review of online surveys to ensure appropriate human subjects protections in the face of emergent electronic tools and methodologies.

Citation

Calain, P. (2018). The Ebola clinical trials: A precedent for research ethics in disasters. *Journal of Medical Ethics*, *44*(1), 3–8. https://doi.org/10.1136/medethics-2016-103474

Abstract

The West African Ebola epidemic has set in motion a collective endeavour to conduct accelerated clinical trials, testing unproven but potentially lifesaving interventions in the course of a major public health crisis. This unprecedented effort was supported by the recommendations of an ad hoc ethics panel convened in August 2014 by the WHO. By considering why and on what conditions the exceptional circumstances of the Ebola epidemic justified the use of unproven interventions, the panel's recommendations have challenged conventional thinking about therapeutic development and clinical research ethics. At the same time, unanswered ethical questions have emerged, in particular: (i) the specification of exceptional circumstances, (ii) the specification of unproven interventions, (iii) the goals of interventional research in terms of individual versus collective interests, (iv) the place of adaptive trial designs and (v) the exact meaning of compassionate use with unapproved interventions. Examination of these questions, in parallel with empirical data from research sites, will help build pragmatic foundations for disaster research ethics. Furthermore, the Ebola clinical trials signal an evolution in the current paradigms of therapeutic research, beyond the case of epidemic emergencies.

Citation

Centers for Disease Control and Prevention [CDC]. (2020, March 2). *How Tuskegee changed research practices.* Research Implications. https://www.cdc.gov/tuskegee/after.htm.

Abstract

N/A

Citation

Chan, E. Y. Y., Wright, K., & Parker, M. (2019). Health-emergency disaster risk management and research ethics. *The Lancet*, *393*(10167), 112–113. https://doi.org/10.1016/S0140-6736(18)33126-X

Abstract

Medical care and health responses in emergency contexts often rely on best-fit interventions rather than best practices to protect communities in suboptimally functioning systems and complex contexts.4,5 Unlike health emergency actions that are focused on the response, the health-EDRM approach emphasises emergency preparedness and disaster risk reduction and can take account of the limitations of the response-focused research landscape.4,6 A greater emphasis on prevention can provide opportunities for research infrastructure building in normal times to support any emergency-related research attempts. Issues such as decision making about research participation, determination of duties and roles at the research interface, treatment and public health, management of expectations on the front line, and participant protection from stigmatisation, discrimination, and exclusion are questions hotly debated in the bioethics community.5,7 In global health emergencies, the implementation of research plans is often the biggest challenge. [...]any preventive, forward-looking approach to emergency research should involve diverse and informed voices within the local community and encourage regular discussion, debates, and periodic reviews of latest methodology and guideline developments in emergency contexts, alongside practical ethics and research methodology training for researchers, funders, ethics committee members, and publishers.5 Experience sharing will enable the identification of models of good ethical practice and address the latest challenges of ethical problems associated with an increasingly complex world.

Citation

Childress, J. F., Faden, R. R., Gaare, R. D., Gostin, L. O., Kahn, J., Bonnie, R. J., Kass, N. E., Mastroianni, A. C., Moreno, J. D., & & Nieburg, P. (2002). Public health ethics: Mapping the terrain. *The Journal of Law, Medicine & Ethics*, *30*(2), 170-178.

Abstract

This paper provides a rough conceptual map of the terrain of public health ethics. It first defines public health and identifies several "general moral considerations" that variously support and constrain the pursuit of public health. It then sketches a framework for resolving conflicts among these considerations, with particular attention to screening programs. Finally, it examines areas of overlap and tension between public health and paternalism, and between public health and human rights

Citation

Chung, B., Jones, L., Campbell, L. X., Glover, H., Gelberg, L., & Chen, D. T. (2008). National recommendations for enhancing the conduct of ethical health research with human participants in post-disaster situations. *Ethnicity & Disease*, *18*(3), 378–383.

Abstract

The intricacies and time- sensitivity of conducting high- quality and clinically relevant health-related human subject research in post-disaster situations challenges traditional approaches to ensuring optimal protection that study participants are protected from exploitation and harm. This article briefly reviews the ethics and guidelines for conducting research in post-disaster periods and offers recommendations to improve human subjects research conducted in situations defined by the National Response Framework as 'disasters' and 'emergencies.'

Citation

Citraningtyas, T., MacDonald, E., & Herrman, H. (2010). A Second Tsunami?: The ethics of coming into communities following disaster. *Asian Bioethics Review*, *2*(2), 108–123. https://muse.jhu.edu/article/416386/summary

Abstract

Introduction: Disasters are often followed by a convergence of individuals and organisations, such as government and aid workers, media personnel and researchers, into affected communities. External aid agents can be crucial to providing rescue, emergency healthcare, and necessities for the survival of affected communities in the direct aftermath of a disaster. Other parties such as media and government personnel as well as researchers can play a crucial role in assisting the community and collecting and disseminating much-needed information. At the same time, a sudden, large-scale interaction with outside forces can be intrusive and cause problems for affected communities. Following the Indian Ocean Tsunami in 2006, the wave of national and international individuals and agencies that arrived in some tsunami-affected areas was so large and difficult to manage that it was said to create a subsequent human-made disaster, which some activists have referred to as “a second tsunami”.

Citation

Collogan, L. K., Tuma, F., Dolan-Sewell, R., Borja, S., & Fleischman, A. R. (2004). Ethical issues pertaining to research in the aftermath of disaster. *Journal of Traumatic Stress*, *17*(5), 363–372. https://doi.org/10.1023/B:JOTS.0000048949.43570.6a

Abstract

In January 2003, The New York Academy of Medicine and the National Institute of Mental Health sponsored a meeting entitled “Ethical Issues Pertaining to Research in the Aftermath of Disaster.” The purpose of the meeting was to bring together various experts to examine evidence concerning the impact of research on trauma-exposed participants, review the applicable ethical principles and policies concerning protection of human subjects, and offer guidance to investigators, IRBs, public health and local officials, and others interested in assuring that research in the aftermath of a disaster is conducted in a safe and ethical manner. This article summarizes the group's key findings and outlines potential considerations for those working in this field.

Citation

DePrince, A. P., & Chu, A. T. (2008). Perceived benefits in trauma research: Examining methodological and individual difference factors in responses to research participation. *Journal of Experimental Research on Human Research Ethics*, *3*(1), 218–219. https://doi.org/10.1525/jer.2008.3.1.35

Abstract

This study examined methodological and individual difference factors in relation to perceived benefits and cost-benefit ratios among adult participants in trauma-related research. In two samples (*N*'s = 72 and 118), ethnically-diverse community participants completed trauma-related questionnaires plus an in-depth interview. In separate community (*N* = 213) and undergraduate (*N* = 130) samples, participants completed trauma-related questionnaires, but no interviews. Participants rated their perceptions of the research process using the Response to Research Participation Questionnaire (RRPQ). Cost-benefit ratios were favorable in all samples. The research procedures (questionnaires only versus questionnaires plus interviews) explained unique variance in RRPQ scale scores and cost-benefit ratios, as did trauma-related distress. Implications of these findings for developing trauma research protocols are discussed.

Citation

Dhungana, N. (2022). Aiming at a moving target: Methodological reflections on the study of politics of citizen-centric governance in post-earthquake Nepal. *Disaster Prevention and Management: An International Journal*, *31*(1), 31-40.

Abstract

Purpose – The growing prominence of disaster research has also prompted vibrant discussions about the motivation and ethical conduct of disaster researchers. Yet, the individual researchers' aspirations and aims, together with the challenging and changing circumstances under which one undertakes disaster research have received relatively scant attention. Drawing on the author's personal experience of becoming a disaster researcher under the unexpected humanitarian crisis following the 2015 Nepal earthquakes, this paper seeks to contribute to the debates surrounding the role of reflexivity and ethical sensitivity in doing disaster research under the climate of uncertainty.
Design/methodology/approach – The paper draws on the author's reflections and vignettes to highlight the author's experience of becoming a disaster researcher, and my trajectory of navigating the complex terrain of fieldwork.
Findings – The paper underscores how the process of becoming a disaster researcher was closely intertwined with and shaped by my concerns and care for the disaster-affected communities. The paper argues that doing contextually relevant and ethically sensitive research is not a static target. It demands constant reflexivity and improvisation, in response to the unpredictable real-world conditions of disasters. Instead of aiming to tame such uncertainty, disaster researchers may benefit from appreciating and embracing uncertainty as a major facet of its epistemological distinctiveness.
Originality/value – The paper contributes to the ongoing efforts in advancing methodological reflection and innovation in disaster research. In so doing, the paper is expected to aid early-career researchers who are often faced with ethical and practical dilemmas of doing fieldwork.

Citation

Donner, W. & Diaz, W. (2018). Methodological issues in disaster research. In H. Rodríguez, J. Donner, J. E. Trainor (Eds.), *Handbook of Disaster Research*. (2nd ed). Cham, Switzerland: Springer. https://search-ebscohost-com.colorado.idm.oclc.org/login.aspx?direct=true&db=nlebk&AN=1636914&site=ehost-live&scope=site.

Abstract

This timely Handbook is based on the principle that disasters are social constructions and focuses on social science disaster research. It provides an interdisciplinary approach to disasters with theoretical, methodological, and practical applications. Attention is given to conceptual issues dealing with the disasters and to methodological issues relating to research on disasters. These include Geographic Information Systems as a useful research tool and its implications for future research. This seminal work is the first interdisciplinary collection of disaster research as it stands now while outlining how the field will continue to grow.

Citation

Eckenwiler, L., Pringle, J., Boulanger, R., & Hunt, M. (2015). Real-time responsiveness for ethics oversight during disaster research. *Bioethics*, *29*(9), 653–661. https://doi.org/10.1111/bioe.12193

Abstract

Disaster research has grown in scope and frequency. Research in the wake of disasters and during humanitarian crises - particularly in resource-poor settings - is likely to raise profound and unique ethical challenges for local communities, crisis responders, researchers, and research ethics committees (RECs). Given the ethical challenges, many have questioned how best to provide research ethics review and oversight. We contribute to the conversation concerning how best to ensure appropriate ethical oversight in disaster research and argue that ethical disaster research requires of researchers and RECs a particular sort of ongoing, critical engagement which may not be warranted in less exceptional research. We present two cases that typify the concerns disaster researchers and RECs may confront, and elaborate upon what this ongoing engagement might look like - how it might be conceptualized and utilized - using the concept of real-time responsiveness (RTR). The central aim of RTR, understood here as both an ethical ideal and practice, is to lessen the potential for research conducted in the wake of disasters to create, perpetuate, or exacerbate vulnerabilities and contribute to injustices suffered by disaster-affected populations. Well cultivated and deployed, we believe that RTR may enhance the moral capacities of researchers and REC members, and RECs as institutions where moral agency is nurtured and sustained.

Citation

Ellis, B. H., Kia-Keating, M., Yusuf, S. A., Lincoln, A., & Nur, A. (2007). Ethical research in refugee communities and the use of community participatory methods. *Transcultural psychiatry*, *44*(3), 459-481. https://doi.org/10.1177/1363461507081642

Abstract

This article describes the distinct challenges associated with conducting ethical research with refugees. A case example of an ongoing study of stigma and access to mental health treatment among Somali refugee adolescents resettled in the USA is presented. In developing the study, standard research paradigms were critically examined in order to take account of the unique aspects of Somali culture and experience. Community participatory methods were adopted to uphold both ethical and methodological rigor in the research. A participatory approach for developing ethical protocols within different refugee communities is recommended.

Citation

Falb, K., Laird, B., Ratnayake, R., Rodrigues, K., & Annan, J. (2019). The ethical contours of research in crisis settings: Five practical considerations for academic institutional review boards and researchers. *Disasters*, *43*(4), 711–726. https://doi.org/10.1111/disa.12398

Abstract

The number of research studies in the humanitarian field is rising. It is imperative, therefore, that institutional review boards (IRBs) consider carefully the additional risks present in crisis contexts to ensure that the highest ethical standards are upheld. Ethical guidelines should represent better the specific issues inherent to research among populations grappling with armed conflict, disasters triggered by natural hazards, or health-related emergencies. This paper seeks to describe five issues particular to humanitarian settings that IRBs should deliberate and on which they should provide recommendations to overcome associated challenges: staged reviews of protocols in acute emergencies; flexible reviews of modification requests; addressing violence and the traumatic experiences of participants; difficulties in attaining meaningful informed consent among populations dependent on aid; and ensuring reviews are knowledgeable of populations' needs. Considering these matters when reviewing protocols will yield more ethically sound research in humanitarian settings and hold researchers accountable to appropriate ethical standards.

Citation

Fernandez, C. V., Kodish, E., & Weijer, C. (2003). Informing study participants of research results: An ethical imperative. *IRB: Ethics & Human Research*, *25*(3), 12-19. https://doi.org/10.2307/3564300

Abstract

N/A

Citation

Ferreira, R. J., Buttell, F., & Cannon, C. (2018). Ethical issues in conducting research with children and families affected by disasters. *Current Psychiatry Reports*, *20*(6), Article 42. https://doi.org/10.1007/s11920-018-0902-2

Abstract

We review topical evidence on ethical issues in conducting disaster research with children and families affected by natural disasters, with an emphasis on analyzing specific vulnerabilities associated with children and families affected by disasters, identifying significant findings and trends of ethical guidelines and approaches, and discussing key observations into ethical research in a disaster setting. Current evidence indicates that there is a wide range of research methods for child disaster studies. Vulnerability as a concept in child disaster studies is more prevalent with several scholars underscoring the need for an ethical approach to disaster research.

Citation

Ferreira, R. J., Buttell, F., & Ferreira, S. (2015). Ethical considerations for conducting disaster research with vulnerable populations. *Journal of Social Work Values and Ethics*, *12*(1), 29-40.

Abstract

in disasters the past decades, particularly in the United States. Due to the increased frequency of disasters, the field of disaster research has seen a corresponding increase in empirical studies involving human subjects. A large number of these studies include vulnerable populations. Study of these populations requires additional precautionary disaster research practices in order to align with ethical standards for research. This article has a dual purpose: Part I provides a better understanding of the vulnerability of populations associated with disaster research; Part II offers a framework for best practices in conducting disaster research with vulnerable populations.

Citation

Fleischman, A. R., & Wood, E. B. (2002). Ethical issues in research involving victims of terror. *Journal of Urban Health*, *79*(3), 315–321. https://doi.org/10.1093/jurban/79.3.315

Abstract

Although research after an episode of terror can provide important information to improve the health and well-being of present and future victims, there are unique ethical challenges that need to be addressed. Man-made disasters have profound effects on victims, rescue workers, and their families and on others in the community; this may impair their ability to provide voluntary and uncoerced decisions about research participation. Because such potential participants in research may be vulnerable and also subject to being overburdened with redundant research, they deserve special consideration. We propose specific recommendations to assist investigators, institutional review boards (IRBs), public health officials, and political leaders to help serve the interests of future participants in terror-related research.

Citation

Fothergill, A., & Peek, L. (2015). *Children of Katrina*. University of Texas Press.

Abstract

The vulnerability of children was starkly apparent in Hurricane Katrina, the most disruptive and destructive disaster in modern U.S. history. A dozen children and youth in Louisiana perished in the disaster. An untold number of children lost loved ones, were orphaned, or were left homeless. Over 5,000 children were reported missing, many of whom were separated from their family members for weeks or even months after the storm. Over 370,000 school-age children were displaced immediately following Katrina, while 160,000 remained dislocated for years. *Children of Katrina* examines what happened to children and youth in Hurricane Katrina and how their lives unfolded in the years after the catastrophe and displacement. They wanted to know: What happened to these children? What did they need during the emergency response and recovery periods? Who helped them? How did they help themselves and other children as well as adults? How did their lives unfold following the catastrophe and displacement? To answer these questions, the authors spent seven years using ethnographic methods to study and analyze the experiences of children and youth in the aftermath of Katrina.

Citation

Gaillard, J. C., & Gomez, C. (2015). Post-disaster research: Is there gold worth the rush? *Jàmbá: Journal of Disaster Risk Studies*, *7*(1), 6. https://doi.org/10.4102/jamba.v7i1.120

Abstract

Excerpt: "Towards a code of ethics for post-disaster research: If Killian (1956) raised some of these issues in his pioneer exploration of field studies in disasters, and Kelman (2005) more recently put forward some salient points in disaster research at large, very few academic discussions have since occurred with regard to the ethical and conceptual legitimacy of rushing to places affected by disasters in the immediate aftermath of the event for conducting various kinds of research. Psychology and biomedical sciences are the limited exceptions to the rule in the context of their narrow fields (Collogan et al. 2004; O'Mathúna 2010; Sumathipala et al.2007). Yet the field of disaster studies at large has grown huge, and related publications have soared over the past few decades."

Citation

Gaillard, J. C., & Peek, L. (2019). Disaster-zone research needs a code of conduct. *Nature*, *575*(7783), 440–442. https://doi.org/10.1038/d41586-019-03534-z

Abstract

This article calls for a code of conduct in large scale disasters that affect large numbers of researchers. It highlights several ethical dilemmas and power imbalances that have emerged in the context of recent major events.

Citation

Gibbs, L., Block, K., MacDougall, C., Harms, L., Baker, E., Richardson, J., Ireton, G., Gallagher, H. C., Bryant, R., Lusher, D., Pattison, P., Watson, J., Gillett, J., Pirrone, A., Molyneaux, R., Sexton-Bruce, S., & Forbes, D. (2018). Ethical use and impact of participatory approaches to research in post-disaster environments: An Australian bushfire case study. *Biomed Research International*, *2018*, 5621609. https://doi.org/10.1155/2018/5621609

Abstract

This paper presents a case study of Beyond Bushfires, a large, multisite, mixed method study of the psychosocial impacts of major bushfires in Victoria, Australia. A participatory approach was employed throughout the study which was led by a team of academic investigators in partnership with service providers and government representatives and used on-site visits and multiple methods of communication with communities across the state to inform decision-making throughout the study. The ethics and impacts of conducting and adapting the approach within a post-disaster context will be discussed in reference to theories and models of participatory health research. The challenges of balancing local interests with state-wide implications will also be explored in the description of the methods of engagement and the study processes and outcomes. Beyond Bushfires demonstrates the feasibility of incorporating participatory methods in large, post-disaster research studies and achieving rigorous findings and multilevel impacts, while recognising the potential for some of the empowering aspects of the participatory experience to be reduced by the scaled-up approach.

Citation

Gilligan, J. M. (2019). Expertise across disciplines: Establishing common ground in interdisciplinary disaster research teams. *Risk Analysis*. https://doi.org/10.1111/risa.13407

Abstract

Hazards and disasters arise from interactions between environmental and social processes, so interdisciplinary research is crucial in understanding and effectively managing them. Despite support and encouragement from funding agencies, universities, and journals and growing interest from researchers, interdisciplinary disaster research teams face significant obstacles, such as the difficulty of establishing effective communication and understanding across disciplines. Better understanding of interdisciplinary teamwork can also have important practical benefits for operational disaster planning and response. Social studies of science distinguish different kinds of expertise and different modes of communication. Understanding these differences can help interdisciplinary research teams communicate more clearly and work together more effectively. The primary role of a researcher is in *contributory expertise* (the ability to make original contributions to a discipline); but *interactional expertise* in other disciplines (the ability to understand their literature and communicate with their practitioners) can play an important role in interdisciplinary collaborations. Developing interactional expertise requires time and effort, which can be challenging for a busy researcher, and also requires a foundation of trust and communication among team members. Three distinct aspects of communication play important roles in effective interdisciplinary communication: *dialects*, *metaphors*, and *articulation*. There are different ways to develop interactional expertise and effective communication, so researchers can pursue approaches that suit their circumstances. It will be important for future research on interdisciplinary disaster research to identify best practices for building trust, facilitating communication, and developing interactional expertise.

Citation

Guillemin, M., & Gillam, L. (2004). Ethics, reflexivity, and “ethically important moments” in research. *Qualitative inquiry*, *10*(2), 261-280.

Abstract

Ethical tensions are part of the everyday practice of doing research—all kinds of research. How do researchers deal with ethical problems that arise in the practice of their research, and are there conceptual frameworks that they can draw on to assist them? This article examines the relationship between reflexivity and research ethics. It focuses on what constitutes ethical research practice in qualitative research and how researchers achieve ethical research practice. As a framework for thinking through these issues, the authors distinguish two different dimensions of ethics in research, which they term procedural ethics and “ethics in practice.” The relationship between them and the impact that each has on the actual doing of research are examined. The article then draws on the notion of reflexivity as a helpful way of understanding both the nature of ethics in qualitative research and how ethical practice in research can be achieved.

Citation

Haire, B. (2018). Aspects of disaster research ethics applicable to other contexts. *Journal of Medical Ethics*, *44*(1), 9–10. https://doi.org/10.1136/medethics-2016-103843

Abstract

In his article 'The Ebola Clinical Trials: a precedent for research ethics in disasters', Philippe Calain constructs a compelling case as to why and how experiences from the recent Ebola epidemic should be used to develop a framework for disaster research ethics. In particular, Calain proposes a useful model for assessing whether or not an unproven intervention could be suitable for human use in a disaster context, and makes a powerful argument against the separation of patient care from research goals. In this commentary, I argue that the separation of patient care goals from research goals is also unhelpful in the context of other forms of participant disadvantage even when that disadvantage is less severe than an ongoing public health emergency. I contend that recognising that research in disadvantaged populations is an intervention that could and should aim to produce positive outcomes for participants, just as it should in disaster contexts, therefore seems a well-justified lesson that can be extrapolated from the experience of the Ebola epidemic.

Citation

Hewitt, J. (2007). Ethical components of researcher researched relationships in qualitative interviewing. *Qualitative Health Research, 17*(8), 1149-1159.

Abstract

Qualitative interviews are widely and often uncritically adopted for health care research, with little justification of therapeutic value. Although they might provide valuable insights into the perspectives of participants, they represent only a version of reality, rather than "truth" per se. Qualitative research is vulnerable to bias through the attitudes and qualities of the researcher, social desirability factors, and conditions of worth. Exploitation, through role confusion, therapeutic misconception, and misrepresentation are particular risks for health care-related research. Ethical codes, biomedical principles and care philosophies provide little contextual guidance on the moral dilemmas encountered in the practice of research. If nurse researchers are to navigate the moral complexities of research relationships, then sensitivity to risk to participants must be of continual concern, from conception of the study to the reporting of outcomes. Examination of the self through critical reflection and supervision are therefore necessary components of ethical research.

Citation

Hamideh, S. (2020). Opportunities and challenges of public participation in post-disaster recovery planning: Lessons from Galveston, TX. *Natural Hazards Review*, *21*(4), 05020009.

Abstract

While public participation can improve recovery planning, post-disaster environments pose unique challenges and opportunities that can enhance or undermine participation depending on the recovery policies and features of the planning process. This paper presents findings of archival research and in-depth interviews in a qualitative case study of Galveston (Texas) following Hurricane Ike to examine the challenges and successes of participatory recovery planning in Galveston and the factors that shape these outcomes. Seizing heightened participation momentum after a disaster by engaging residents in a transparent process provides optimism and an opportunity for recovery champions to gain support for their ideas. However, planning while unprepared, homogeneity of participants, and skipping deliberation may limit voices of the marginalized residents in decisions and undermine implementation of the proposals. Under-represented socially vulnerable groups should be included in all stages of recovery planning through deliberate outreach strategies tailored to their circumstances. Supported by professional planners and technical experts, involved stakeholders should engage in deliberation rather than mere input solicitation to increase the effectiveness of post-disaster participatory planning.

Citation

Hulley, S.B., Cummings, S.R., Browner, W.S., Grady, D.G., & Newman, T.B. (2007). *Designing clinical research.* (3rd ed.). Philadelphia, PA: Lippincott Williams & Wilkins.

Abstract

Designing Clinical Research has been extensively revised and continues to set the standard as a practical guide for doctors, nurses, pharmacists, and other health professionals involved in all forms of clinical, translational, and public health research. It presents advanced epidemiologic concepts in a reader-friendly way, and suggests common sense approaches to the challenging judgments involved in designing, funding, and implementing.

Citation

Hunt, M., Tansey, C. M., Anderson, J., Boulanger, R. F., Eckenwiler, L., Pringle, J., & Schwartz, L. (2016). The challenge of timely, responsive and rigorous ethics review of disaster research: Views of research ethics committee members. *PLoS ONE*, *11*(6), e0157142. https://doi.org/10.1371/journal.pone.0157142

Abstract

Research conducted following natural disasters such as earthquakes, floods or hurricanes is crucial for improving relief interventions. Such research, however, poses ethical, methodological and logistical challenges for researchers. Oversight of disaster research also poses challenges for research ethics committees (RECs), in part due to the rapid turnaround needed to initiate research after a disaster. Currently, there is limited knowledge available about how RECs respond to and appraise disaster research. To address this knowledge gap, we investigated the experiences of REC members who had reviewed disaster research conducted in low- or middle-income countries.

Citation

Jacobsen, K., & Landau, L. B. (2003). The dual imperative in refugee research: Some methodological and ethical considerations in social science research on forced migration. *Disasters*, *27*(3), 185–206. https://doi.org/10.1111/1467-7717.00228

Abstract

Social scientists doing fieldwork in humanitarian situations often face a dual imperative: research should be both academically sound and policy relevant. We argue that much of the current research on forced migration is based on unsound methodology, and that the data and subsequent policy conclusions are often flawed or ethically suspect. This paper identifies some key methodological and ethical problems confronting social scientists studying forced migrants or their hosts. These problems include non-representativeness and bias, issues arising from working in unfamiliar contexts including translation and the use of local researchers, and ethical dilemmas including security and confidentiality issues and whether researchers are doing enough to 'do no harm'. The second part of the paper reviews the authors' own efforts to conduct research on urban refugees in Johannesburg. It concludes that while there is no single 'best practice' for refugee research, refugee studies would advance its academic and policy relevance by more seriously considering methodological and ethical concerns.

Citation

Jesus, J. E., & Michael, G. E. (2009). Ethical considerations of research in disaster-stricken populations. *Prehospital and Disaster Medicine*, *24*(2), 109–114. https://doi.org/10.1017/s1049023x00006634

Abstract

Recently, emphasis has been placed on improving and expanding research in disaster response and the treatment of disaster-stricken populations. However, research in these settings presents unique ethical challenges with which the scientific and biomedical ethics communities continue to struggle. At the core of the controversy is the question of how best to balance the critical need for research with the equally important obligation to respect and protect the interests of research participants within the unique stress of a disaster. This concern stems from the potential of increased vulnerability of individuals stricken by disaster over and above their usual vulnerability to risk and exploitation as research subjects. Ethical principles that must be considered in these situations are the same as those that are important when conducting any human research: respect for persons, non-maleficence, beneficence, and justice. This paper explores the ethical challenges that accompany inadequate resources and personnel, the potential vulnerability of research participants, the dual role of physician-researcher, and the importance of the public's perception and trust are explored. It then proposes a number of potential avenues through which to conduct ethically justifiable research that could answer many of the pressing questions in disaster medicine and response.

Citation

Kass, N. E. (2001). An ethics framework for public health. *American Journal of Public Health,*
91(11), 1776-1782. Retrieved from:
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1446875/pdf/0911776.pdf

Abstract

Public health as an organized discipline began more than 100 years ago, with the goal of improving the health, primarily, of populations rather than of individuals. Given its population-based focus, however, public health continually faces dilemmas concerning the appropriate extent of its reach and at what point the work of public health professionals is infringing on individual liberties in ethically troublesome ways. Nonetheless, there have been few attempts to articulate an ethics of public health. Bioethics, as a discipline, helps health care professionals identify and respond to moral dilemmas in their work. In this article I suggest that the contexts out of which bioethics emerged—medical care and human research— were oriented toward a different set of concerns than those typically arising in public health. While the founders of bioethics articulated principles equally relevant for public health, the more specific action guides and codes of healthcare ethics that have followed are an imperfect fit for public health. Codes of medical and research ethics generally give high priority to individual autonomy, a priority that cannot be assumed to be appropriate for public health practice. A framework of ethics analysis geared specifically for public health is needed, both to provide practical guidance for public health professionals and to highlight the defining values of public health, values that differ in morally relevant ways from values that define clinical practice and research. A first attempt at such a framework is offered here.

Citation

Kaufman, C. E., & Ramarao, S. (2005). Community confidentiality, consent, and the individual research process: Implications for demographic research. *Population Research and Policy Review*, *24*(2), 149-173. https://doi.org/10.1007/s11113-004-0329-9

Abstract

Institutional review boards are increasingly meticulous about informed consent and risks and benefits to study participants. Concurrently, heated debate in a number of fields has advanced the notion of *community risk* and benefit. When research is conducted in communities, and the results may "do harm to" communities socially, economically, or medically, should informed and voluntary consent be obtained from communities as well? We argue that for demographers – by definition interested at the phenomena at the population level – concern for individuals *as a part of communities* is critical to the research process. Questions of community consent, confidentiality, and participation will be pushed to the fore as demography delves into new areas and methods of investigation. This paper provides a brief overview of the historical development of ethics in human subjects research and the subsequent ties to community-level concerns. Drawing on current examples from a variety of settings, we explore definitions of community, the scope and viability of community participation in research, and the implications of these for demographic enquiry. We find that in contrast to substantive debates, little attention has been given to ethical issues in the demographic research process. Research accountability to communities, including the documentation of community risks and benefits, and community representation and consultation in the research process are recommended.

Citation

Katapally, T. R. (2019). The SMART framework: Integration of citizen science, community-based participatory research, and systems science for population health science in the digital age. *JMIR mHealth and uHealth, 7*(8), e14056. https://doi.org/10.2196/14056

Abstract

Citizen science enables citizens to actively contribute to all aspects of the research process, from conceptualization and data collection, to knowledge translation and evaluation. Citizen science is gradually emerging as a pertinent approach in population health research. Given that citizen science has intrinsic links with community-based research, where participatory action drives the research agenda, these two approaches could be integrated to address complex population health issues. Community-based participatory research has a strong record of application across multiple disciplines and sectors to address health inequities. Citizen science can use the structure of community-based participatory research to take local approaches of problem solving to a global scale, because citizen science emerged through individual environmental activism that is not limited by geography. This synergy has significant implications for population health research if combined with systems science, which can offer theoretical and methodological strength to citizen science and community-based participatory research. Systems science applies a holistic perspective to understand the complex mechanisms underlying causal relationships within and between systems, as it goes beyond linear relationships by utilizing big data–driven advanced computational models. However, to truly integrate citizen science, community-based participatory research, and systems science, it is time to realize the power of ubiquitous digital tools, such as smartphones, for connecting us all and providing big data. Smartphones have the potential to not only create equity by providing a voice to disenfranchised citizens but smartphone-based apps also have the reach and power to source big data to inform policies. An imminent challenge in legitimizing citizen science is minimizing bias, which can be achieved by standardizing methods and enhancing data quality—a rigorous process that requires researchers to collaborate with citizen scientists utilizing the principles of community-based participatory research action. This study advances SMART, an evidence-based framework that integrates citizen science, community-based participatory research, and systems science through ubiquitous tools by addressing core challenges such as citizen engagement, data management, and internet inequity to legitimize this integration.

Citation

Katapally, T. R. (2020). A global digital citizen science policy to tackle pandemics like COVID-19. *Journal of Medical Internet Research, 22*(5), e19357.

Abstract

The coronavirus disease (COVID-19) pandemic is an extremely complex existential threat that requires cohesive societal effort to address health system inefficiencies. When our society has faced existential crises in the past, we have banded together by using the technology at hand to overcome them. The COVID-19 pandemic is one such threat that requires not only a cohesive effort, but also enormous trust to follow public health guidelines, maintain social distance, and share necessities. However, are democratic societies with civil liberties capable of doing this? Mobile technology has immense potential for addressing pandemics like COVID-19, as it gives us access to big data in terms of volume, velocity, veracity, and variety. These data are particularly relevant to understand and mitigate the spread of pandemics such as COVID-19. In order for such intensive and potentially intrusive data collection measures to succeed, we need a cohesive societal effort with full buy-in from citizens and their representatives. This article outlines an evidence-based global digital citizen science policy that provides the theoretical and methodological foundation for ethically sourcing big data from citizens to tackle pandemics such as COVID-19.

Citation

Kelman, I. (2005). Operational ethics for disaster research. *International Journal of Mass Emergencies and Disasters*, *23*(3), 141–158.

Abstract

Operational ethics for disaster research is suggested as an important area for further investigation. The main questions are suggested as:

1. Could carrying out disaster research interfere with disaster and risk management activities?
2. Could publishing disaster research interfere with disaster and risk management activities?
3. Should researchers take responsibility for the operational outcomes of their research?

The example of technical rescue illustrates how these questions might be addressed in order to better understand operational ethics for disaster research. Experiences from field work on active volcanoes are presented as a research area where operational ethics have been applied, although improvements are needed. Researcher good governance is an approach which consolidates many of the issues discussed. Although disaster researchers might feel that no further governance steps are necessary, these questions should be openly debated.

Citation

Kelman, I. (2015). Ethics of disaster research. In M. Wyss & S. Peppoloni (Eds.), *Geoethics* (pp. 37–47). *Elsevier*. https://doi.org/10.1016/B978-0-12-799935-7.00004-6

Abstract

Disaster research explores how to reduce vulnerability and disaster impacts (predisaster activities) alongside response to and recovery from disasters (postdisaster activities). Because vulnerability and disasters directly affect people and communities, disaster research is fraught with difficulties and frequently makes the difference between life and death. This chapter explores the ethics of disaster research by examining how that research might interfere with disaster-related activities and how to deal with the outcomes from disaster research. No clear-cut solutions are available. Instead, it is important to continue disaster research while being aware of the implications so that detrimental effects could be avoided while augmenting the positive consequences.

Citation

Kendra, J., & Gregory, S. (2019). Ethics in disaster research: A new declaration. In J. Kendra, S. G. Knowles, & T. Wachtendorf (Eds.), *Disaster research and the second environmental crisis: Assessing the challenges ahead* (pp. 319–341). Springer International Publishing. https://doi.org/10.1007/978-3-030-04691-0_16

Abstract

The opening chapter in this volume portrayed the growing urgency of disaster research, as the nature and scope of hazards shift. People already familiar with their local environment may find that a changing climate changes their risk for certain kinds of hazards (Relf, G., Kendra, J. M., Schwartz, R. M., Leathers, D. J., & Levia,

D. F. (2015). Slushflows: Science and planning considerations for an expanding hazard. Natural Hazards, 78(1), 333–354). People moving from place to place in search of better jobs or housing may move into a hazard milieu that is new to them. Political transformations with an authoritarian bent will probably increase vulnerability amongst populations already at greater risk for experiencing a disaster and for recovering more slowly, such as those in poor housing, those with chronic illnesses, and those with Functional and Access Needs. Robust research is needed, but some critics have emerged to challenge the practice and propriety of disaster research, especially quick-response research. This chapter argues for an affirmative right to conduct research.

Citation

Kilpatrick, D. G. (2004). The ethics of disaster research: A special section. *Journal of Traumatic Stress*, *17*(5), 361–362. https://doi.org/10.1023/B:JOTS.0000048961.75301.74

Abstract

This issue of the Journal of Traumatic Stress contains a special section addressing the important topic of ethical issues involved in conducting research after disasters and terrorism. Included in this Special Section are revised versions of papers originally commissioned at a meeting sponsored by the New York Academy of Medicine and the National Institute of Mental Health. The objective of this meeting, the persons who attended it, and recommendations from attendees are described in the paper titled "Ethical Issues Pertaining to Research in the Aftermath of Disaster" authored by Collogan, Tuma, Dolan-Sewell, Borja, and Fleischman (2004, this issue).

Citation

Klitzman, R. L. (2012). US IRBs confronting research in the developing world. *Developing World Bioethics*, *12*(2), 63-73. https://dx.doi.org/10.1111%2Fj.1471-8847.2012.00324.x

Abstract

Increasingly, US-sponsored research is carried out in developing countries, but how US Institutional Review Boards (IRBs) approach the challenges they then face is unclear. Methods: I conducted in-depth interviews of about 2 hours each, with 46 IRB chairs, directors, administrators and members. I contacted the leadership of 60 IRBs in the United States (US) (every fourth one in the list of the top 240 institutions by National Institutes of Health (NIH) funding), and interviewed IRB leaders from 34 (55%). Results: US IRBs face ethical and logistical challenges in interpreting and applying principles and regulations in developing countries, given economic and health disparities, and limited contextual knowledge. These IRBs perceive wide variations in developing world IRBs/RECs' quality, resources and training; and health systems in some countries may have long-standing practices of corruption. These US IRBs often know little of local contexts, regulations and standards of care, and struggle with understandings of other cultures' differing views of autonomy, and risks and benefits of daily life. US IRBs thus face difficult decisions, including how to interpret principles, how much to pay subjects and how much sustainability to require from researchers. IRB responses and solutions include trying to maintain higher standards for developing world research, obtain cultural expertise, build IRB infrastructure abroad, communicate with foreign IRBs, and 'negotiate' for maximum benefits for participants and fearing 'worst-case scenarios'. Conclusions: US and foreign IRBs confront a series of tensions and dilemmas in reviewing developing world research. These data have important implications for increased education of IRBs/RECs and researchers in the US and abroad, and for research and practice.

Citation

Kwok, L. S. (2005). The white bull effect: Abusive coauthorship and publication parasitism. *Journal of Medical Ethics*, *31*(9), 554-556. https://doi.org/10.1136/jme.2004.010553

Abstract

Junior researchers can be abused and bullied by unscrupulous senior collaborators. This article describes the profile of a type of serial abuser, the White Bull, who uses his academic seniority to distort authorship credit and who disguises his parasitism with carefully premeditated deception. Further research into the personality traits of such perpetrators is warranted.

Citation

Langat, P., Pisartchik, D., Silva, D., Bernard, C., Olsen, K., Smith, M., Sahni, S., & Upshur, R. (2011). Is there a duty to share? Ethics of sharing research data in the context of public health emergencies. *Public Health Ethics*, *4*(1), 4-11.

Abstract

Making research data readily accessible during a public health emergency can have profound effects on our response capabilities. The moral milieu of this data sharing has not yet been adequately explored. This article explores the foundation and nature of a duty, if any, that researchers have to share data, specifically in the context of public health emergencies. There are three notable reasons that stand in opposition to a duty to share one's data, relating to: (i) data property and ownership, (ii) just distribution of benefits and burdens and (iii) the contemporary ethos of science. We argue each reason can be successfully met with corresponding rationale in favour of data sharing. Further support for data sharing has been echoed in policies of health agencies, funding bodies and academic institutions; in documents on the ethical conduct of biomedical research; and in discussions on the nature of public health. From this, we ascertain that sharing data is the morally sound default position. This article then highlights the key roles reciprocity and solidarity play in supporting the practice of data sharing. We conclude with recommendations to regard public health research data as a common-pool resource in order to build a framework for stable data sharing management.

Citation

Lavin, R. P., Schemmel-Rettenmeier, L., & Frommelt-Kuhle, M. (2012). Conducting research during disasters. *Annual Review of Nursing Research*, *30*(1), 1–19. https://doi.org/10.1891/0739-6686.30.1

Abstract

The potential for man-made or natural disasters is a reality that exists within the confines of the global setting. Man-made and/or natural disasters, although devastating to the human population, offers researchers the ability to explore and advance current preparedness, response, and recovery practices. When conducting research, consideration must be given to the ethical treatment of vulnerable populations and the protection of privacy for those affected by the disaster.

Citation

Legerski, J. P., & Bunnell, S. L. (2010). The risks, benefits, and ethics of trauma-focused research participation. *Ethics & Behavior*, *20*(6), 429-442. https://doi.org/10.1080/10508422.2010.521443

Abstract

With the rising interest in the field of trauma research, many Institutional Review Boards, policymakers, parents, and others grapple with the impact of trauma-research participation on research participants' well-being. Do individuals who participate in trauma-focused research risk experiencing lasting negative effects from participation? What are the potential benefits that may be gleaned from participation in this work? How can trauma research studies be designed ethically, minimizing the risk to participants? The following review seeks to answer these questions. This review indicates that most studies in this area have found that only a minority of participants experience distress when participating in trauma-focused research. Furthermore, these negative feelings tend to dissipate quickly over time, with the majority of participants self-appraising their participation as positive, rewarding, and beneficial to society. Design characteristics that may serve to minimize participants' risk of experiencing distress are discussed, as well as implications for public policy and future research.

Citation

Levine, C. (2004). The concept of vulnerability in disaster research. *Journal of Traumatic Stress*, *17*(5), 395–402. https://doi.org/10.1023/B:JOTS.0000048952.81894.f3

Abstract

The concept of vulnerability in research derives from a specific set of historical circumstances relating to abuses in biomedical research. Now so many people and groups have been labeled vulnerable that the concept has lost much of its force. In disaster research, participants should not be automatically considered vulnerable unless they are legally designated as such, for example, children. Instead specific aspects of the research should be thoroughly examined. Examples are the potential for the participants to be pressured to participate in several protocols, political or social turmoil surrounding the disaster, and cognitive impairments or mental health problems. In addition to a careful consent process, there should be procedures in place to provide assistance to participants who experience serious distress.

Citation

Lowlander Center. (2013). *A working guide to participatory action research as a tool for participatory engagement and problem-solving*.

Abstract

N/A

Citation

Mackenzie, C., McDowell, C., & Pittaway, E. (2007). Beyond ‘do no harm’: The challenge of constructing ethical relationships in refugee research. *Journal of Refugee Studies*, *20*(2), 299–319. https://doi.org/10.1093/jrs/fem008

Abstract

This paper highlights some of the central ethical challenges involved in undertaking social science research with refugees in conflict and crisis situations. It focuses on two main sets of challenges: first, the difficulties of constructing an ethical consent process and obtaining genuinely informed consent; and second, taking fully into account and responding to refugee participants' capacities for autonomy. The authors also discuss the challenges involved in applying the central normative principles governing ethics review processes—the principles of beneficence, integrity, respect for persons, autonomy and justice—to the context of refugee research. It is argued that researchers should seek ways to move beyond harm minimization as a standard for ethical research and recognize an obligation to design and conduct research projects that aim to bring about reciprocal benefits for refugee participants and/or communities. Some of the methodological issues raised by this analysis are discussed in the conclusion.

Citation

Merriam, S. B., Johnson-Bailey, J., Lee, M. Y., Kee, Y., Ntseane, G., & Muhamad, M. (2001). Power and positionality: Negotiating insider/outsider status within and across cultures. *International Journal of Lifelong Education, 20*(5), 405-416.

Abstract

Early discussions of insider/outsider status assumed that the researcher was predominately an insider or an outsider and that each status carried with it certain advantages and disadvantages. More recent discussions have unveiled the complexity inherent in either status and have acknowledged that the boundaries between the two positions are not all that clearly delineated. Four case studies - a Black woman interviewing other Black women, Asian graduate students in the US interviewing people from ‘back home’, an African professor learning from African businesswomen, and a cross-cultural team studying aging in a nonWestern culture - are used as the data base to explore the complexities of researching within and across cultures. Positionality, power, and representation proved to be useful concepts for exploring insider/outsider dynamics.

Citation

Missbach, A. (2011). Ransacking the field? *Critical Asian Studies*, *43*(3), 373–398. https://doi.org/10.1080/14672715.2011.597334

Abstract

After the end of almost thirty years of armed conflict in 2005 and following a devastating tsunami in 2004, Aceh has become a “social laboratory” for foreign researchers who study Indonesia's northern-most province from every angle. Over the last five years, this effort has resulted in the publication of a considerable number of articles in major journals. For some foreign researchers, Aceh became a fast track accelerating their careers. Yet, how much did local Acehnese researchers benefit from being at the center of this scholarly attention, and how much were they able to participate in academic debates? To answer these questions, this article examines the involvement of Acehnese scholars in the process of knowledge production in and about contemporary Aceh. One of the key findings is that local researchers are often involved in data collection, but left out from its analysis and interpretation due to a general lack of structural conditions for publishing, such as under-funding, lack of access to major academic literature, and language barriers. Embedding this inquiry about research cooperation and competition in wider debates about representation and academic development support, this article stresses critical evaluations of current academic ventures. Moreover, Aceh as a post-conflict/tsunami site illustrates the enormous difficulties that developing countries such as Indonesia face in tertiary education and academic research. Long-standing structural imbalances responsible for uneven research outcomes cannot disappear overnight or only as a result of foreign educational initiatives. Nevertheless, this article introduces a specific example of short-term academic collaboration named Aceh Research Training Institute (ARTI)—a flicker of hope in an otherwise rather unpromising situation.

Citation

Mitchell, M. X. (2017, October 12). History, ethics, and the environmental archive. *Somatosphere*. http://somatosphere.net/2017/history-ethics-and-the-environmental-archive.html/

Abstract

Most historical work contemplating the ethics of archival practices has focused on biological archives, which historians have recognized as ethically complicated sites. As the Marshallese case illustrates, however, where environmental science was predicated on dispossession, violence, and the infliction of suffering, environmental archives may raise similar and additional ethical dilemmas. Not least, environmental archives raise questions concerning conflicting ontologies and belief systems. As historians of science have explored, scientific archives often incorporate scientific researchers' underlying assumptions. Environmental archives of the twentieth century United States, for example, typically incorporate assumptions that there is an inherent distinction between human bodies and the environment, between data and referents, and between past and present. These assumptions do not necessarily hold in the Marshallese worldview, where even data about one's ancestral atoll may be seen as special or sacred. An environmental archive may be much more than a simple reminder of a dark past; It can be a site of ongoing harm in the present. How, then, should historians engage with archival materials and with communities who see environmental data in a different light—as a present-day connection to a sacred person or place or a memory of a grievous injury?

Citation

Morris, N. (2015). Providing ethical guidance for collaborative research in developing countries. *Research ethics, 11*(4), 211-235. https://dx.doi.org/10.1177%2F1747016115586759

Abstract

Experience has shown that the application of ethical guidelines developed for research in developed countries to research in developing countries can be, and often is, impractical and raises a number of contentious issues. Various attempts have been made to provide guidelines more appropriate to the developing world context;

however, to date these efforts have been dominated by the fields of bioscience, medical research and nutrition. There is very little advice available for those seeking to undertake collaborative social science or natural science research in developing countries and what is there tends to be held within disparate sources. Charting the development of a set of ethics documentation for future use by the Ecosystem Services for Poverty Alleviation (ESPA) programme research community, this paper outlines past and present attitudes towards ethics procedures amongst this community and suggests ways in which ethics procedures might be made more relevant and user-friendly to researchers working in this area.

Citation

Nakiire, L., Mwanja, H., Pillai, S. K., Gasanani, J., Ntungire, D., Nsabiyumva, S., Mafigiri, R., Muneza, N., Ward, S. E., Daffe, Z., Ahabwe, P. B., Kyazze, S., Ojwang, J., Homsy, J., McIntyre, E., Lamorde, M., Walwema, R., Makumbi, I., Muruta, A., & Merrill, R. D. (2020). Population movement patterns among the Democratic Republic of the Congo, Rwanda, and Uganda during an outbreak of Ebola virus disease: Results from community engagement in two districts —Uganda, March 2019. *MMWR. Morbidity and Mortality Weekly Report, 69*(1), 10-13. https://doi.org/10.15585/mmwr.mm6901a3

Abstract

N/A

Citation

Newman, E., & Kaloupek, D. G. (2004). The risks and benefits of participating in trauma-focused research studies. *Journal of Traumatic Stress: Official Publication of The International Society for Traumatic Stress Studies*, *17*(5), 383-394.

Abstract

Concern about minimizing harm and maximizing benefit has been particularly acute with regard to the scientific study of individuals exposed to potentially traumatic events such as terrorist attack or disaster. This review outlines conceptual and practical issues and summarizes available evidence regarding potential risks and benefits of participation in trauma-related research. Current, limited evidence suggests that most individuals make favorable cost–benefit appraisals regarding their participation. Although a subset of participants report strong negative emotions or unanticipated distress, the majority of these do not regret or negatively evaluate the overall experience. Continuing efforts are needed to identify individuals at risk for unfavorable reactions to research participation. A systematic empirical approach to evaluating participant experience in all human research is recommended.

Citation

Newman, E., Willard, T., Sinclair, R., & Kaloupek, D. (2001). Empirically supported ethical research practice: The costs and benefits of research from the participants' view. *Accountability in Research, 8*(4), 309-329. https://doi.org/10.1080/08989620108573983

Abstract

Concern about minimizing harm and maximizing benefit has been particularly acute with regard to the scientific study of individuals exposed to potentially traumatic events such as terrorist attack or disaster. This review outlines conceptual and practical issues and summarizes available evidence regarding potential risks and benefits of participation in trauma-related research. Currently, limited evidence suggests that most individuals make favorable cost–benefit appraisals regarding their participation. Although a subset of participants report strong negative emotions or unanticipated distress, the majority of these do not regret or negatively evaluate the overall experience. Continuing efforts are needed to identify individuals at risk for unfavorable reactions to research participation. A systematic empirical approach to evaluating participant experience in all human research is recommended.

Citation

Norris, F. H., Friedman, M. J., Watson, P. J., Byrne, C. M., Diaz, E., & Kaniasty, K. (2002). 60,000 disaster victims speak: Part I. An empirical review of the empirical literature, 1981–2001. *Psychiatry*, *65*(3), 207-239. https://doi.org/10.1521/psyc.65.3.207.20173

Abstract

Results for 160 samples of disaster victims were coded as to sample type, disaster type, disaster location, outcomes and risk factors observed, and overall severity of impairment. In order of frequency, outcomes included specific psychological problems, nonspecific distress, health problems, chronic problems in living, resource loss, and problems specific to youth. Regression analyses showed that samples were more likely to be impaired if they were composed of youth rather than adults, were from developing rather than developed countries, or experienced mass violence (e.g., terrorism, shooting sprees) rather than natural or technological disasters. Most samples of rescue and recovery workers showed remarkable resilience. Within adult samples, more severe exposure, female gender, middle age, ethnic minority status, secondary stressors, prior psychiatric problems, and weak or deteriorating psychosocial resources most consistently increased the likelihood of adverse outcomes. Among youth, family factors were primary. Implications of the research for clinical practice and community intervention are discussed in a companion article (Norris, Friedman, and Watson, this volume).

Citation

Norris, F., Galea, S., Friedman, M., & Watson, P. (2006). *Methods for disaster mental health research*. New York, NY: Guilford Press.

Abstract

N/A

Citation

North, C. S., Pfefferbaum, B., & Tucker, P. (2002). Ethical and methodological issues in academic mental health research in populations affected by disasters: The Oklahoma City experience relevant to September 11, 2001. *CNS Spectrums*, *7*(8), 580–584. https://doi.org/10.1017/S1092852900018186

Abstract

Empirical data from research studies are vital to guiding mental health interventions following disasters. However, few data are available for this purpose. Important advances in policy and procedures for the conduct of organized research emerged from the Oklahoma City bombing, yielding cooperative working relationships among researchers and culminating in the ethical attainment of informative research data. However, the academic community was again caught off guard after the September 11, 2001, terrorist attacks. Suggestions to surmount these obstacles include incorporating research infrastructures into disaster preparedness plans in advance; organizing the community of researchers; and working closely with major funding organizations. Methodological issues pertaining to measurement of psychopathology include the importance of obtaining diagnostic data; interpreting the meaning of symptoms in the absence of a psychiatric disorder; differentiating preexisting symptoms from those that emerged after the disaster, and optimal timing of postdisaster assessment.

Citation

Nuffield Council on Bioethics. (2020). *Research in global health emergencies: Ethical issues.* London, WC: Nuffield Council on Bioethics.

Abstract

N/A

Citation

O'Brien, M. H. (1993). Being a scientist means taking sides. *BioScience*, *43*(10), 706-708. https://doi.org/10.2307/1312342.

Abstract

N/A

Citation

Office for Human Research Protections [OHRP]. (1979). *Belmont Report*. OHRP. 1-10. https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/read-the-belmont-report/index.html.

Abstract

The *Belmont Report* was written by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. The Commission, created as a result of the National Research Act of 1974, was charged with identifying the basic ethical principles that should underlie the conduct of biomedical and behavioral research involving human subjects and developing guidelines to assure that such research is conducted in accordance with those principles. Informed by monthly discussions that spanned nearly four years and an intensive four days of deliberation in 1976, the Commission published the *Belmont Report*, which identifies basic ethical principles and guidelines that address ethical issues arising from the conduct of research with human subjects.

Citation

O'Mathúna, D. (2015). Research ethics in the context of humanitarian emergencies. *Journal of Evidence-Based Medicine*, *8*(1), 31–35. https://doi.org/10.1111/jebm.12136

Abstract

Research is needed to make responses to disasters and humanitarian emergencies more evidence-based. Such research must also adhere to the generally accepted principles of research ethics. While research into health interventions used in disasters raises distinctive ethical concerns, seven ethical principles developed for clinical research are applied here to disaster research. Practical examples from disaster settings are used to demonstrate how these ethical principles can be applied. This reveals that research ethics needs to be seen as much more than a mechanism to obtain ethical approval for research. Research ethics involves ethical principles and governance frameworks, but must also consider the role of ethical virtues in research. Virtues are essential to ensure that researchers do what they believe is ethically right and resist what is unethical. Research ethics that truly protects participants and promotes respect needs to include training in ethical virtues to ensure disaster research is carried out to the highest ethical standards. This article is based on a presentation at the Evidence Aid Symposium on 20 September 2014, in Hyderabad, India.

Citation

O'Mathúna, D. P. (2010). Conducting research in the aftermath of disasters: Ethical considerations. *Journal of Evidence-Based Medicine*, *3*(2), 65–75. https://doi.org/10.1111/j.1756-5391.2010.01076.x

Abstract

Disaster research focuses on the impact disasters have on people and social structures. Planning for and responding to disasters require evidence to guide decision-makers. The need for such evidence provides an ethical mandate for the conduct of sound disaster research. Disaster research ethics draws attention to ethical issues common to all research involving human subjects. However, disaster research involves a number of distinctive factors, including the degree of devastation affecting participants and the urgency often involved in initiating research projects. Such factors generate ethical issues not usually encountered with other types of research, and create tensions that must be taken into account in designing and conducting disaster research so that it attains the highest ethical standards. An overview of general research ethics issues is presented here in the context of disaster research. As with all research involving humans, protection of participants and minimizing harm is the highest ethical priority. Other ethical issues include formal ethical approval, informed consent, balancing burdens and benefits, participant recruitment, coercion, the role of compensation, and conflicts of interest. Using examples from specific studies, some of the distinctive features of disaster research ethics are discussed. These include cross-cultural collaboration and communication, vulnerability of participants arising from the degree of devastation, avoiding exploitation of disaster victims, and protecting researchers. The article concludes with some of the major challenges facing disaster research ethics and how they might be addressed.

Citation

Packenham, J. P., Rosselli, R. T., Ramsey, S. K., Taylor, H. A., Fothergill, A., Slutsman, J., & Miller, A. (2017). Conducting science in disasters: Recommendations from the NIEHS working group for special IRB considerations in the review of disaster related research. *Environmental Health Perspectives*, *125*(9). https://doi.org/10.1289/EHP2378

Abstract

Research involving human subjects after public health emergencies and disasters may pose ethical challenges. These challenges may include concerns about the vulnerability of prospective disaster research participants, increased research burden among disaster survivors approached by multiple research teams, and potentially reduced standards in the ethical review of research by institutional review boards (IRBs) due to the rush to enter the disaster field. The NIEHS Best Practices Working Group for Special IRB Considerations in the Review of Disaster Related Research was formed to identify and address ethical and regulatory challenges associated with the review of disaster research. The working group consists of a diverse collection of disaster research stakeholders across a broad spectrum of disciplines. The working group convened in July 2016 to identify recommendations that are instrumental in preparing IRBs to review protocols related to public health emergencies and disasters. The meeting included formative didactic presentations and facilitated breakout discussions using disaster-related case studies. Major thematic elements from these discussions were collected and documented into 15 working group recommendations, summarized in this article, that address topics such as IRB disaster preparedness activities, informed consent, vulnerable populations, confidentiality, participant burden, disaster research response integration and training, IRB roles/responsibilities, community engagement, and dissemination of disaster research results. https://doi.org/10.1289/EHP2378

Citation

Parker, M., & Kingori, P. (2016). Good and bad research collaborations: researchers' views on science and ethics in global health research. *PLoS ONE, 11*(10), e0163579. https://doi.org/10.1371/journal.pone.0163579

Abstract

There has been a dramatic rise in the scale and scope of collaborative global health research. A number of structural and scientific factors explain this growth and there has been much discussion of these in the literature. Little, if any, attention has been paid, however, to the factors identified by scientists and other research actors as important to successful research collaboration. This is surprising given that their decisions are likely to play a key role in the sustainability and effectiveness of global health research initiatives. In this paper, we report on qualitative research with leading scientists involved in major international research collaborations about their views on good and bad collaborations and the factors that inform their decision-making about joining and participating actively in research networks. We identify and discuss eight factors that researchers see as essential in judging the merits of active participation in global health research collaborations: opportunities for active involvement in cutting-edge, interesting science; effective leadership; competence of potential partners in and commitment to good scientific practice; capacity building; respect for the needs, interests and agendas of partners; opportunities for discussion and disagreement; trust and confidence; and, justice and fairness in collaboration. Our findings suggest that the sustainability and effectiveness of global health research collaborations has an important ethical or moral dimension for the research actors involved.

Citation

Patino, C. M., & Ferreira, J. C. (2016). Developing research questions that make a difference. *Jornal Brasileiro de Pneumologia*, *42*(6), 403-403. https://doi.org/10.1590/s1806-37562016000000354

Abstract

N/A

Citation

Peek, L., Abramson, D., Cox, R.S., Fothergill, A., & Tobin, J. (2018). Children and disasters. In H. Rodríguez, J. Donner, J. E. Trainor (Eds.), *Handbook of Disaster Research*. (2nd ed). (pp. 243-262). Cham, Switzerland: Springer.

Abstract

This chapter reviews available literature on children and disasters, with an emphasis on the recent dramatic expansion in this area of study. The overarching goal is to provide an overview of the substantive contributions of scholarship on children and disasters. Through this process, our specific objective is to identify major empirical, theoretical, and methodological trends and patterns. After reading the chapter, our hope is that others will understand the major contributions of this area of study—both for the field of disaster research and practice, and for the social sciences more generally—while also recognizing the need for new lines of inquiry and approaches. We begin by defining key concepts that frame this chapter and by describing our approach to reviewing the literature. Next, we offer a summary of publication patterns associated with children and disasters; here we underscore the growth in this subfield and highlight how a relatively limited number of large-scale catastrophic events have served to spur research in this area. We then turn to six major waves of research that have been most prevalent over time. These include contributions to enhanced understanding of (1) the effects of disaster on children's mental health and behavioral reactions; (2) disaster exposure as it relates to physical health and well-being; (3) social vulnerability and sociodemographic characteristics; (4) the role of institutions and socio-ecological context in shaping children's pre- and post-disaster outcomes; (5) resiliency, strengths, and capacities; and (6) children's voices, perspectives, and actions across the disaster lifecycle. We also emphasize advancements in methods, theory, policy, and practice, and offer suggestions for future directions in research.

Citation

Peek, L., Champeau, H., Austin, J., Mathews, M., & Wu, H. (2020). What methods do social scientists use to study disasters? An analysis of the social science extreme events research network. *American behavioral scientist*, *64*(8), 1066-1094. https://doi.org/10.1177/0002764220938105

Abstract

Methods matter. They influence what we know and who we come to know about in the context of hazards and disasters. Research methods are of profound importance to the scholarly advancement of the field and, accordingly, a growing number of publications focus on research methods and ethical practices associated with the study of extreme events. Still, notable gaps exist. The National Science Foundation-funded Social Science Extreme Events Research (SSEER) network was formed, in part, to respond to the need for more specific information about the status and expertise of the social science hazards and disaster research workforce. Drawing on data from 1,013 SSEER members located across five United Nations (UN) regions, this article reports on the demographic characteristics of SSEER researchers; provides a novel inventory of methods used by social science hazards and disaster researchers; and explores how methodological approaches vary by specific researcher attributes including discipline, professional status, researcher type based on level of involvement in the field, hazard/disaster type studied, and disaster phase studied. The results have implications for training, mentoring, and workforce development initiatives geared toward ensuring that a diverse next generation of social science researchers is prepared to study the root causes and social consequences of disasters.

Citation

Peek, L., & Fothergill, A. (2009). Using focus groups: Lessons from studying daycare centers, 9/11, and Hurricane Katrina. *Qualitative research*, *9*(1), 31-59. https://doi.org/10.1177/1468794108098029

Abstract

The purpose of this article is to examine focus groups as a qualitative research method. We describe and evaluate the use of focus groups based on three separate research projects: a study of teachers, parents, and children at two urban daycare centers; a study of the responses of second-generation Muslim Americans to the events of September 11; and a collaborative project on the experiences of children and youth following Hurricane Katrina. By examining three different projects, we are able to assess some of the strengths and challenges of the focus group as a research method. In addition, we analyze the design and implementation of focus groups, including information on participant recruitment, the most effective group size, group composition and issues of segmentation, how to carry out focus groups, and the ideal number of groups to conduct. We pay particular attention to the ways in which focus groups may serve a social support or empowerment function, and our research points to the strength of using this method with marginalized, stigmatized, or vulnerable individuals.

Citation

Peek, L., Tobin, J., Adams, R., Wu, H., & Mathews, M. (2020). A framework for convergence research in the hazards and disaster field: The natural hazards engineering research infrastructure CONVERGE facility. *Frontiers in Built Environment*, *6*, 110.

Abstract

The goal of this article is twofold: to clarify the tenets of convergence research and to motivate such research in the hazards and disaster field. Here, convergence research is defined as an approach to knowledge production and action that involves diverse teams working together in novel ways – transcending disciplinary and organizational boundaries – to address vexing social, economic, environmental, and technical challenges in an effort to reduce disaster losses and promote collective well-being. The increasing frequency and intensity of disasters coupled with the growth of the field suggests an urgent need for a more coherent approach to help guide what we study, who we study, how we conduct studies, and who is involved in the research process itself. This article is written through the lens of the activities of the National Science Foundation-supported CONVERGE facility, which was established in 2018 as the first social science-led component of the Natural Hazards Engineering Research Infrastructure (NHERI). Convergence principles and the Science of Team Science undergird the work of CONVERGE, which brings together networks of researchers from geotechnical engineering, the social sciences, structural engineering, nearshore systems, operations and systems engineering, sustainable material management, and interdisciplinary science and engineering. CONVERGE supports and advances research that is conceptually integrative, and this article describes a convergence framework that includes the following elements: (1) identifying researchers; (2) educating and training researchers; (3) setting a convergence research agenda that is problem-focused and solutions-based; (4) connecting researchers and coordinating functionally and demographically diverse research teams; and (5) supporting and funding convergence research, data collection, data sharing, and solutions implementation.

Citation

Qureshi, K. A., Gershon, R. R. M., Smailes, E., Raveis, V. H., Murphy, B., Matzner, F., & Fleischman, A. R. (2007). Roadmap for the protection of disaster research participants: Findings from the world trade center evacuation study. *Prehospital and Disaster Medicine, 22*(6), 486–493. https://doi.org/10.1017/S1049023X00005306

Abstract

Introduction: This report addresses the development, implementation, and evaluation of a protocol designed to protect participants from inadvertent emotional harm or further emotional trauma due to their participation in the World Trade Center Evacuation (WTCE) Study research project. This project was designed to identify the individual, organizational, and structural (environmental) factors associated with evacuation from the World Trade Center Towers 1 and 2 on 11 September 2001. Methods: Following published recommended practices for protecting potentially vulnerable disaster research participants, protective strategies and quality assurance processes were implemented and evaluated, including an assessment of the impact of participation on study subjects enrolled in the qualitative phase of the WTCE Study. Results: The implementation of a protocol designed to protect disaster study participants from further emotional trauma was feasible and effective in minimizing risk and monitoring for psychological injury associated with study participation. Conclusions: Details about this successful strategy provide a roadmap that can be applied in other post-disaster research investigations.

Citation

Reid, K. (2018, November 9). 2013 Typhoon Haiyan: Facts, FAQs, and how to help. *World Vision*. https://www.worldvision.org/disaster-relief-news-stories/2013-typhoon-haiyan-facts

Abstract

Super Typhoon Haiyan, also known as Super Typhoon Yolanda, made landfall in the Philippines on Nov. 8, 2013, as a Category 5 storm. It laid waste to the Visayas group of islands, the country's central region and home to 17 million people. Haiyan was the most powerful storm in 2013 and one of the most powerful typhoons of all time. With wind speeds sustained at more than 150 mph, Haiyan was classified as a super typhoon. However, its massive storm surge was even more destructive. Local officials estimated that Tacloban City on the island of Leyte was 90% destroyed. The typhoon's fury affected more than 14 million people across 44 provinces, displacing 4.1 million people, killing more than 6,000 people and leaving 1,800 missing. In addition, Typhoon Haiyan damaged 1.1 million houses, destroyed 33 million coconut trees (a major source of livelihoods), and disrupted the livelihoods of 5.9 million workers. Overall damage is estimated at $5.8 billion.

Citation

Resnik, D. B., Elliott, K. C., & Miller, A. K. (2015). A framework for addressing ethical issues in citizen science. *Environmental Science & Policy*, *54*, 475-481. https://doi.org/10.1016/j.envsci.2015.05.008

Abstract

The collaboration between laypeople and professional scientists known as "citizen science" is an important trend in research and data gathering. Citizen science offers important benefits to science and society. For example, citizens can help scientists with data collection and provide advice on research design and implementation. Citizens can also gain a better understanding of scientific concepts and methods. Additionally, citizens can help scientists better understand and address issues of concern to their families and communities. However, citizen science also raises ethical issues that should be addressed when projects begin and throughout the course of scientific investigation. To promote ethical research, scientists should develop guidelines for involvement of citizens in research, communicate effectively with participants and local communities at the outset of their involvement in research projects, carefully oversee their work, develop appropriate publication practices, and provide lay-volunteers with education and training on the responsible conduct of research. Researchers also need to be cognizant of clarifying these roles and responsibilities as well as promoting appropriate and safe citizen participation and transparency of the study methods, data analysis, and communication of results.

Citation

Resnik D. B., Miller Aubrey K., Kwok Richard K., Engel Lawrence S., & Sandler Dale P. (2015). Ethical issues in environmental health research related to public health emergencies: Reflections on the GuLF STUDY. *Environmental Health Perspectives*, *123*(9), A227–A231. https://doi.org/10.1289/ehp.1509889

Abstract

Health research in the context of an environmental disaster with implications for public health raises challenging ethical issues. This article explores ethical issues that arose in the Gulf Long-term Follow-up Study (GuLF STUDY) and provides guidance for future research. Ethical issues encountered by GuLF STUDY investigators included a) minimizing risks and promoting benefits to participants, b) obtaining valid informed consent, c) providing financial compensation to participants, d) working with vulnerable participants, e) protecting participant confidentiality, f) addressing conflicts of interest, g) dealing with legal implications of research, and h) obtaining expeditious review from the institutional review board (IRB), community groups, and other committees. To ensure that ethical issues are handled properly, it is important for investigators to work closely with IRBs during the development and implementation of research and to consult with groups representing the community. Researchers should consider developing protocols, consent forms, survey instruments, and other documents prior to the advent of a public health emergency to allow for adequate and timely review by constituents. When an emergency arises, these materials can be quickly modified to take into account unique circumstances and implementation details.

Citation

Resnik, D. B. (2015). What is ethics in research & why is it important. *National Institute of Environmental Health Sciences*. https://www.niehs.nih.gov/research/resources/bioethics/whatis/index.cfm

Abstract

N/A

Citation

Rosenstein, D. L. (2004). Decision-making capacity and disaster research. *Journal of Traumatic Stress*, *17*(5), 373–381. https://doi.org/10.1023/B:JOTS.0000048950.36359.a2

Abstract

The extent to which victims of a disaster are able to make capacitated and voluntary decisions to enroll in research is an important and virtually unexplored question. Although there are no compelling data to suggest that experiencing a severe trauma, in and of itself, renders all or even most individuals incapable of making autonomous decisions, the assessment of decision-making capacity (DMC) for research participation warrants serious consideration. This paper provides a framework for and procedural approach to the assessment of DMC in research with individuals exposed to disaster. Particular attention is paid to the implementation of additional safeguards to protect subjects who are vulnerable by virtue of impaired DMC. Recommendations are offered to clinical investigators, ethical review boards, and policymakers with regard to the design, review, and conduct of research in the aftermath of disaster.

Citation

Ross, W. D. (2002). *The right and the good*. Oxford University Press.

Abstract

The Right and the Good is a classic of 20th-century philosophy by the great scholar Sir David Ross, which is now presented in a new edition with a substantial introduction by Philip Stratton–Lake, a leading expert on Ross. Ross's book was originally published in 1930, and is the pinnacle of ethical intuitionism, which was the dominant moral theory in British philosophy for much of the 19th and early 20th century. The central concern of the book is with rightness and goodness, and their relation to one another. Ross argues against notable rival ethical theories. The right act, he holds, cannot be derived from the moral value of the motive from which it is done; furthermore, rightness is not wholly determined by the value of the consequences of one's action, whether this value is some benefit for the agent, or some agent-neutral good. Rather, the right act is determined by a plurality of self-evident prima facie duties. Ross portrayed rightness and goodness as simple non-natural properties. Philip Stratton provides a substantial introduction to the book, in which he discusses its central themes and clears up some common misunderstandings. A new bibliography and index are also included, along with editorial notes that aim to clarify certain points and indicate where Ross later changed his mind on particular issues. Intuitionism is now enjoying a considerable revival, and this new edition provides the context for a proper modern understanding of Ross's great work.

Citation

Ruggles, S., Adolph, K., Chen, R., Entwisle, B., Gornick, J., & Gutmann, M. (2016). *Public access to NSF-Funded research data for the social, behavioral, and economic sciences*. https://www.nsf.gov/sbe/reports/Public_Access_NSF_Workshop_Report_Final_Briefs.pdf

Abstract

N/A

Citation

Samdami, M. (2002). *Research ethics in complex emergencies.* Fletcher School of Law and Diplomacy, Fall, Medford.

Abstract

Situations involving conflict and forced migration have become increasingly commonplace in today's world. The need to understand the causes, consequences, and characteristics of these situations is creating a burgeoning field of research. But given the nature of complex emergency settings, traditional research guidelines may be inappropriate. The research and policy community has recognized this problem and has begun to address issues surrounding the ethics of doing research in emergency settings and among conflict-affected and displaced populations. The Roundtable on the Demography of Forced Migration, under the aegis of the Committee on Population of the National Research Council, held a workshop to examine some of these issues. This report to the roundtable summarizes the workshop presentations and discussion.

Citation

Schiermeier, Q. (2018). Tsunami scientists clash with Indonesian government over rules on foreign research. *Nature*, *562*(7727), 317–318. https://doi.org/10.1038/d41586-018-07030-8

Abstract

Two weeks after an earthquake and subsequent tsunami killed more than 2,000 people on the Indonesian island of Sulawesi, some foreign researchers say that red tape is slowing down or preventing investigative work of the devastated coastlines.But the Indonesian government says that it has sped up the time it takes to process permits for researchers in the wake of the tsunami, and that the requirements it imposes on international researchers have been in place for years.

Citation

Sim, J., & Waterfield, J. (2019). Focus group methodology: Some ethical challenges. *Quality & Quantity*, *53*(6), 3003-3022. https://doi.org/10.1007/s11135-019-00914-5

Abstract

Focus group methodology generates distinct ethical challenges that do not correspond fully to those raised by one-to-one interviews. This paper explores, in both conceptual and practical terms, three key issues: consent; confidentiality and anonymity; and risk of harm. The principal challenge in obtaining consent lies in giving a clear account of what will take place in the group, owing to unpredictability of the discussion and interaction that will occur. As consent can be seen in terms of creating appropriate expectations in the participant, this may therefore be hard to achieve. Moreover, it is less straightforward for the participant to revoke consent than in one-to-one interviews. Confidentiality and anonymity are potentially problematic because of the researcher's limited control over what participants may subsequently communicate outside the group. If the group discussion encourages over-disclosure by some participants, this problem becomes more acute. Harm in a focus group may arise from the discussion of sensitive topics, and this may be amplified by the public nature of the discussion. A balance should be struck between avoiding or closing down potentially distressing discussion and silencing the voices of certain participants to whom such discussion may be important or beneficial. As a means of addressing the above issues, we outline some strategies that can be adopted in the consent process, in a preliminary briefing session, during moderation of the focus group, and in a subsequent debriefing, and suggest that these strategies can be employed synergistically so as to reinforce each other.

Citation

Substance Abuse and Mental Health Services Administration. (2016). *Disaster technical assistance center supplemental research bulletin: Challenges and considerations in disaster research*. SAMHSA; 2016:2-11. https://www.hsdl.org/?abstract&did=798614.

Abstract

This issue of SAMHSA [Substance Abuse and Mental Health Services Administration] Disaster Technical Assistance Center's 'Supplemental Research Bulletin,' 'Challenges and Considerations in Disaster Research,' addresses the ethical and operational concerns in research design, participant recruitment, data collection, and data interpretation during disaster research. The purpose of this issue is for researchers to learn about and anticipate procedural challenges that can only be overcome by prior planning, including having a research team properly trained in and prepared for the unique aspects of disaster research (Lavin et al., 2012).

Citation

Sumathipala, A., & Siribaddana, S. (2005). Research and clinical ethics after the tsunami: Sri Lanka. *Lancet*, *366*, 1418-1420. https://doi.org/10.1016/S0140-6736(05)67581-2

Abstract

In late 2004, the *Journal of Traumatic Stress* published a special section about the ethics of disaster research, addressing ethical issues related to conducting research after disasters and terrorist attacks, and based on a meeting organised by The New York Academy of Medicine and the US National Institute of Mental Health. 1 Four areas of critical importance to development, evaluation, and conduct of research protocols after a disaster were identified: decisional capacity of potential participants, vulnerability of research participants, risks and benefits of research participation, and informed consent. The participants at the meeting were mental health professionals, trauma researchers, public-health officials, ethicists, representatives of institutional review boards, as well as family members and emergency personnel from the Oklahoma City and World Trade Center attacks. The attendees agreed that research after a disaster is important and can be done ethically. However, they felt that specific research proposals should be scrutinised by a single body to assess disaster-related research, as was the case after the Oklahoma City bombing, when a good deal of research was reviewed centrally and approved by a special process put in place with the approval of the state Governor.

Citation

Tansey, C. M., Anderson, J., Boulanger, R. F., Eckenwiler, L., Pringle, J., Schwartz, L., & Hunt, M. (2017). Familiar ethical issues amplified: How members of research ethics committees describe ethical distinctions between disaster and non-disaster research. *BMC Medical Ethics, 18*(1), 44. https://doi.org/10.1186/s12910-017-0203-z

Abstract

Background: The conduct of research in settings affected by disasters such as hurricanes, floods and earthquakes is challenging, particularly when infrastructures and resources were already limited pre-disaster. However, since post-disaster research is essential to the improvement of the humanitarian response, it is important that adequate research ethics oversight be available.
Methods: We aim to answer the following questions: 1) what do research ethics committee (REC) members who have reviewed research protocols to be conducted following disasters in low- and middle-income countries (LMICs) perceive as the key ethical concerns associated with disaster research?, and 2) in what ways do REC members understand these concerns to be distinct from those arising in research conducted in non-crisis situations? This qualitative study was developed using interpretative description methodology; 15 interviews were conducted with REC members.
Results: Four key ethical issues were identified as presenting distinctive considerations for disaster research to be implemented in LMICs, and were described by participants as familiar research ethics issues that were amplified in these contexts. First, REC members viewed disaster research as having strong social value due to

its potential for improving disaster response, but also as requiring a higher level of justification compared to other research settings. Second, they identified vulnerability as an overarching concern for disaster research ethics, and a feature that required careful and critical appraisal when assessing protocols. They noted that research participants' vulnerabilities frequently change in the aftermath of a disaster and often in unpredictable ways. Third, they identified concerns related to promoting and maintaining safety, confidentiality and data security in insecure or austere environments. Lastly, though REC members endorsed the need and usefulness of community engagement, they noted that there are significant challenges in a disaster setting over and above those typically encountered in global health research to achieve meaningful community engagement.
Conclusion: Disaster research presents distinctive ethical considerations that require attention to ensure that participants are protected. As RECs review disaster research protocols, they should address these concerns and consider how justification, vulnerability, security and confidentially, and community engagement are shaped by the realities of conducting research in a disaster.

Citation

Taylor, H. A. (2016). Review and conduct of human subjects research after a natural or man–made disaster: Findings from a pilot study. *Narrative Inquiry in Bioethics*, *6*(3), 211-222. http://doi.org/10.1353/nib.2016.0061

Abstract

The conduct of human subjects research in the wake of natural and man–made disasters is essential in order to further our understanding of the mental and behavioral health effects of such events on individuals and communities. The results of post–disaster research can better prepare public health systems to consider and address individual and community mental and behavioral health needs. In–depth interviews (n = 17) explored the ethical concerns and challenges encountered by investigators and IRBs in their review and conduct of post–disaster research. A variety of review mechanisms are described as well as the concerns of investigators and IRBs about the vulnerability of subjects and the challenges of conducting research in a community affected by disaster.

Citation

Van Brown, B. L. (2020). Disaster research “methics”: Ethical and methodological considerations of researching disaster-affected populations. *American Behavioral Scientist*, *64*(8), 1050-1065. https://doi.org/10.1177/0002764220938115

Abstract

How we do research directly affects what we know about the subject matter under study. While the study of disaster events continues to grow, rigorous inquiry on disaster research methodology is limited because it is confounded by the disruption a disaster presents. Yet it is precisely at that point that special methodological problems emerge. The methodological—and inherently ethical—challenges disaster researchers face became apparent to me during my own fieldwork on domestic violence organizations and their recovery trajectory following Hurricanes Katrina and Rita in 2005. In this article, I explore methodological and ethical issues that lay beneath “studying” people in the wake of disaster events and argue that ethical concerns should have the same, if not greater, primacy as methods; a dual consideration I refer to as “methics.” My findings support this argument and add to the growing chorus advocating for a paradigm shift in disaster research methods.

Citation

White, R. F. (2007). Institutional review board mission creep: The common rule, social science, and the nanny state. *The Independent Review, 11*(4), 547-564. https://www.jstor.org/stable/24562415

Abstract

In this article, I scrutinize the process by which scientific research on human subjects is regulated by Institutional Review Boards (IRBs). At the outset, let us agree that at least some biomedical scientific research on human subjects must be externally monitored and that whether the government should sometimes be involved in that process is at least an open question. We simply cannot forget the lessons learned from Nuremberg and Tuskegee. My argument, however, is that although the IRB process may have been at least marginally well suited to serve its original mission (to protect federally funded biomedical research subjects from physical harm), that process has become buried in an avalanche of new and unrelated socially constructed mandates. Today, the IRB process consumes an inordinate amount of time, energy, and resources in attempting to prevent a growing host of imagined harms, minor harms, or highly unlikely harms. Consequently, IRBs no longer serve their original mandate well. Worse, they have surreptitiously undermined legitimate and useful social science education, and freedom of inquiry. Despite a growing body of scholarly criticism, seasoned with IRB horror stories, the beat goes on ("Communications Scholars' Narratives" 2005).

Citation

World Health Organization. (2020). *Ethical standards and procedures for research with human beings*. Retrieved from https://www.who.int/ethics/research/en/#:~:text=Research%20ethics%20govern%20the%20standards,and%20welfare%20of%20research%20participants.text=Discussion%20of%20the%20ethical%20principles,are%20central%20to%20ethical%20review

Abstract

Research ethics govern the standards of conduct for scientific researchers. It is important to adhere to ethical principles in order to protect the dignity, rights and welfare of research participants. As such, all research involving human beings should be reviewed by an ethics committee to ensure that the appropriate ethical standards are being upheld. Discussion of the ethical principles of beneficence, justice and autonomy are central to ethical review. WHO works with Member States and partners to promote ethical standards and appropriate systems of review for any course of research involving human subjects. Within WHO, the Research Ethics Review Committee (ERC) ensures that WHO only supports research of the highest ethical standards. The ERC reviews all research projects involving human participants supported either financially or technically by WHO. The ERC is guided in its work by the World Medical Association Declaration of Helsinki (1964), last updated in 2013, as well as the *International Ethical Guidelines for Biomedical Research Involving Human Subjects* (CIOMS 2016).

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