Webinar

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# Research ethics in crisis situations

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Register at changer-project.eu



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Why research at any time?





#### **Evidence and Humanitarian Crises**

"Recent humanitarian disasters, due to natural and man-made hazards or a combination of the two, reinforce the need for more effective, efficient, humane responses at the local, national and international levels."

"The patchwork of practices and preferences is often anecdotal, based on the history and perceptions of [various groups] ... rather than on the use of evidence-based interventions and practices."

Jillson et al. *BMC Health Services Research* 2019;19:274

Photograph Dónal O'Mathúna



#### Why Humanitarian Research?







evidence-based approaches to building resilience and responding to humanitarian crises:

A DFID Strategy Paper

Promoting innovation and



"We don't really know which interventions are most effective in reducing risk, saving lives and rebuilding livelihoods after crises... At present, humanitarian decisions are often based on poor information" (DFID, 2012, p. 5).

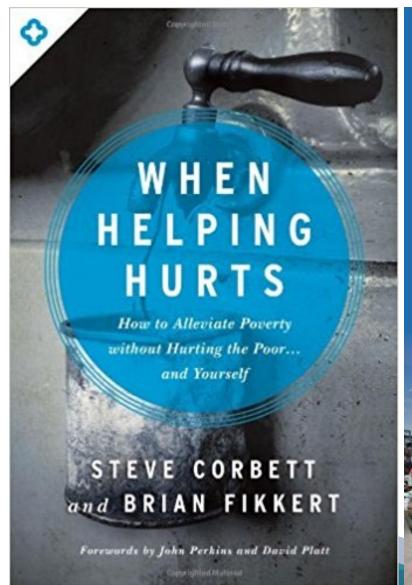
http://www.alnap.org/resource/9823\_aspx

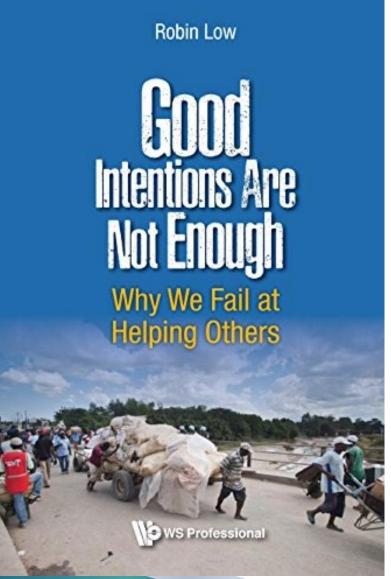


## **Ethical Imperative for Research**

Those in need deserve help.
Those with the resources should help.

But ...







#### **Ethical Imperative for Research**

For humanitarian health settings:

the "ethical imperative to collect good data in such settings to ensure the most effective interventions are being delivered and best possible health outcomes achieved within the constraints of those settings is

strong" (p. 2293).

Blanchet et al. Evidence on public health interventions in humanitarian crises. *Lancet* 2017;390:2287-2296.



Photograph courtesy of Pretesh Kiran

## Why collect data during war?



To document and promote awareness of the health impacts of war



To ensure appropriate distribution of resources to address health needs of affected populations



To inform the development of new interventions and altering/adapting existing interventions



To assess the efficacy and safety of interventions



#### Research during war

"Documenting the ... effects falls to those of us who are entrusted with the public's health worldwide—the physicians and health scholars who use science to bear witness to the harms of war... [It] is on a scaffolding of documentation that we change the world's perspective on the harms incurred by actions like war, with the goals of preventing or halting such conflicts in the long-term. This calls for a redoubling of effort to study and write about the harms of war."

Galea S. Physicians and the Health Consequences of War. *JAMA Health Forum.* 2022;3(3):e220845. doi:10.1001/jamahealthforum.2022.0845



#### On-going research collaboration

PI: Emily Anderson, Loyola University Chicago

Co-I: Dónal O'Mathúna, The Ohio State University

Talina Perez, MA bioethics student OSU

Loyola research assistance:

Sydney Gordon, MSW/MPH student

Yaryna Pikulytska, MD, MA, Loyola Bioethics doctoral student, Ukraine

Iryna Stelmakh, MD, MA, Loyola Bioethics doctoral student, Ukraine

Sarah Kumi, MD/MPH student, Loyola SSOM

Elizabeth Robinson, M2, Loyola SSOM

Funded by NIH Fogarty International Center D43TW011506-04S1



## Preliminary results

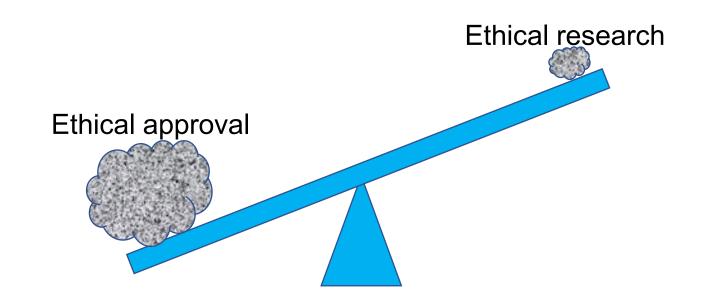
Final interviewees: 18 researchers from the US, Europe, and Africa Conducted research in Africa, Europe, Middle East, and South America

#### Developing themes:

- Issues in ethics review
- Questioning the social value of the research
- Challenges to research implementation
- Risks to participants
- Risks to researchers
- Issues in reporting







O'Mathúna DP. The dual imperative in disaster research ethics. In: *SAGE Handbook of Qualitative Research Ethics*, eds. Iphofen R, Tolich M. 2018; 441-454.



#### Hence...

"Discussions of ethics have become ubiquitous in the research community... However, researchers complain that institutional review boards have lost sight of their original purpose of protecting human subjects, focusing instead on bureaucratic minutiae."

Jones DS, Grady C, Lederer SE. Ethics and clinical research—The 50th anniversary of Beecher's bombshell. *New England Journal of Medicine* 2016;374:2393-2398

Especially challenging during crises.



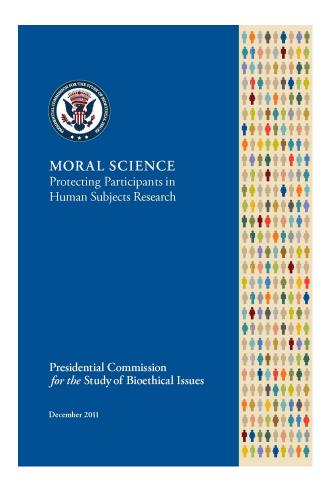
#### Going beyond ethics approval processes

"What I believe is lacking in the approach to research ethics found in much of the literature, codes of practice, and university training is how to positively encourage ethical conduct. Developing an understanding of what to do is always a more challenging prospect than issuing edicts about what is not right. This demands that any discussion about research ethics is located in the complex and ambiguous context in which it takes place" (p. 3).

Bruce Macfarlane, Researching with Integrity (Taylor & Francis, 2008).







"a focus on the internal ethical motivation of individual investigators, not only the rules and regulations that externally motivate investigators toward compliance" (p. 32).

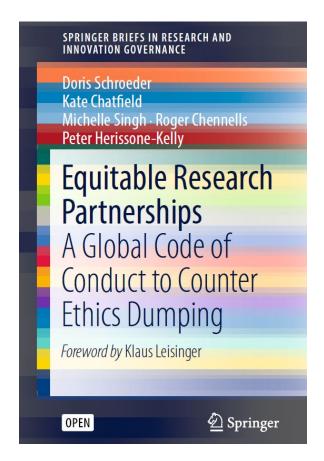
https://bioethicsarchive.georgetown.edu/pcsbi/node/558.html



#### Values and Character

Table 2. Four values that underpin ethical research (Schroeder et al., 2019).

Fairness	Respect
Fairness can have a number of interpretations (Pogge, 2006) but the most relevant in the context of ethics dumping is <i>fairness</i> in exchange. Is the balance of benefits and burdens equitably distributed?	People's customs and cultures may be different. Researchers must ensure that their own behaviour does not cause offence. They may also need to accept a way of approaching a matter that they personally disagree with.
Care	Honesty
Researchers should demonstrate care by taking responsibility for the welfare of those who contribute to their research or might suffer as a result of it. This will entail the tailoring of procedures, such as informed consent, to meet local requirements (language, literacy etc.). Care also requires that time and effort is invested to achieve quality research.	Researchers should be truthful about all aspects of their work and strive for transparency in their activities. This includes not omitting important information. The value of honesty also links research ethics with research integrity, which includes issues such as credit for contributions, manipulation of data, or misappropriation of research funds.



Chatfield et al. *Research*Ethics 2021;17(1):23-44.



What should we do?

We didn't expect this.

Responding to changing context and issues.

Balancing rigor with safety and practicalities.

Questioning the value of the research.







Henry Beecher: Informed consent is important, but the most reliable

safeguard to ethical research involving humans is:

"the presence of an intelligent, informed, conscientious, compassionate, responsible investigator."

Beecher HK. Ethics and clinical research. *New England Journal of Medicine* 1966;274:1354-1360.

Reprinted in Harkness J, Lederer SE, Wikler D. Laying ethical foundations for clinical research. *Bulletin of the World Health Organization* 2001;79(4):365-372.

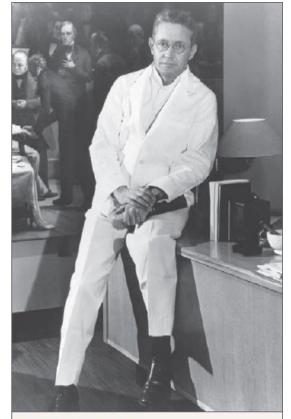


Figure 2. Henry Beecher.

Courtesy of Massachusetts General Hospital, Archives and Special Collections.



## 3. Dealing with risks and safety

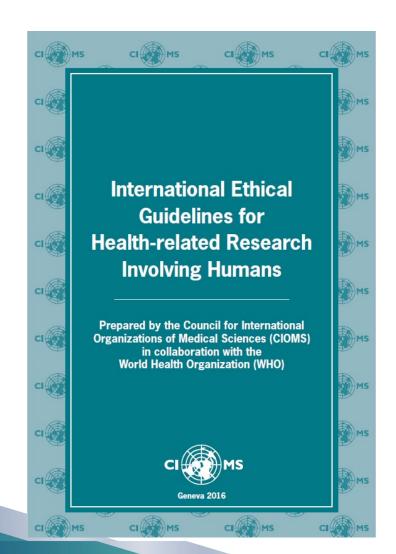
"But still, while we make them participants for research, we are increasing the risk. We are increasing the chances of them to be a target because they are talking with strangers. We are talking with white people. Maybe they are informants, and informants are murdered very easily in territories of war, and we don't have that on mind, you know, when we, when we do IRBs." Research participant



#### CIOMS Guidelines

#### Guideline 7:

Researchers, sponsors, health authorities and relevant institutions should engage potential participants and communities in a meaningful participatory process that involves them in an early and sustained manner in the design, development, implementation, design of the informed consent process and monitoring of research, and in the dissemination of its results.





## Community engagement



https://www.sciencemag.org/news/2017/03/san-people-africa-draft-code-ethics-researchers#

Schroeder D, Chatfield K, Edwards S. The unexpected power of research ethics. Research Ethics 2020; 16(1-2), doi: 10.1177/1747016120906643

## 4. Urgency and ethics



Section 8. "While new knowledge and interventions may be urgently needed during public health emergencies, it remains essential to uphold the ethical principles in this Declaration during such emergencies."

https://www.wma.net/policiespost/wma-declaration-of-helsinki/





WHAT WE DO POLICY PUBLICATIONS NEWS & PRESS WHO WE ARE JUNIOR DOCTORS MEMBERS' AREA

Policy / Current Policies / WMA Declaration of Helsinki - Ethical Principles for Medical Research Involving Human Participants



WMA DECLARATION OF HELSINKI – ETHICAL PRINCIPLES FOR MEDICAL RESEARCH INVOLVING HUMAN PARTICIPANTS



Adopted by the 18<sup>th</sup> WMA General Assembly, Helsinki, Finland, June 1964 and amended by the:

29th WMA General Assembly, Tokyo, Japan, October 1975

35<sup>th</sup> WMA General Assembly, Venice, Italy, October 1983

41st WMA General Assembly, Hong Kong, September 1989

48th WMA General Assembly, Somerset West, Republic of South Africa, October 1996

52<sup>nd</sup> WMA General Assembly, Edinburgh, Scotland, October 2000

53<sup>rd</sup> WMA General Assembly, Washington DC, USA, October 2002 (Note of Clarification added)

55<sup>th</sup> WMA General Assembly, Tokyo, Japan, October 2004 (Note of Clarification added)

59th WMA General Assembly, Seoul, Republic of Korea, October 2008

64th WMA General Assembly, Fortaleza, Brazil, October 2013

and by the 75<sup>th</sup> WMA General Assembly, Helsinki, Finland, October 2024

3rd April 2025

**Policy Types** 

Declaration

Archived Versions

» DoH-Jun1964

» DoH-Oct1975

» DoH-Oct1983

» DoH-Sept1989







https://en.wikipedia.o wiki/Eurocopter\_MH-65\_Dolphin



## Questions for Humanitarian Research Ethics



Siriwardhana C, Lignou S, Doherty S, O'Mathúna D; http://bit.ly/2eVKd36



#### Ethics in the Field



Narratives from:
Afghanistan, Iraq,
Israel, Myanmar,
Palestine, Sudan,
and Ukraine

"Their series of essays fosters a deeper understanding of the moral and ethical dimensions of their collective work and the risks they take to do it. The risks they take to write."

Kim Thuy Seelinger in: Anderson & O'Mathúna, Hastings Center.

https://www.thehastingscenter.org/caring-for-patients-in-armed-conflict-narratives-from-the-front-lines/



Healthcare Under Fire: Stories from Healthcare Workers During Armed Conflict

Symposium Editors: Dónal O'Mathúna, PhD, Thalia Arawi, PhD, and Abdul Rahman Fares, PhD(c)

→ More Information

Journal version: <a href="https://muse.jhu.edu/issue/50783">https://muse.jhu.edu/issue/50783</a>

Open access version with teaching guide:

https://nibjournal.org/voices/voices-armed-conflict/

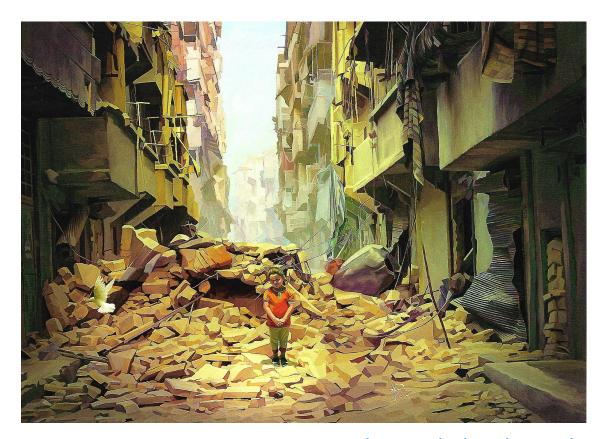
#### **Humanities and Ethics**





'You use a glass mirror to see your face; you use works of art to see your soul.'

George Bernard Shaw (1921) Back to Methuselah



Upcoming Hope 2 by Imad Abu Shtayyah Used with permission





#### The Partnership































#### THANK YOU!





CHANGER Website

Embassy of Good embassy.science/wiki/Initial 6845c6e83b11

ger-eu-project/

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