





# Ethics and Disasters: From Where We Are to Where We Need To Go

# **Dublin City University, Ireland**

## 3 – 4 October 2016



COST Action IS1201: Disaster Bioethics (http://DisasterBioethics.eu)









# Disaster

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Dear Conference Delegates,

On behalf of the COST Action on Disaster Bioethics and Dublin City University (DCU), I would like to welcome you to the conference on "Ethics and Disasters: From Where We Are to Where We Need To Go". This conference is the culmination of four years' work by the members of COST Action IS1201. For those of you who are not familiar with COST Actions, these are networks funded by the COST Association and supported by the EU Framework Programme Horizon 2020. Our COST Action has existed since October 2012 and has over 130 members from academia, non-governmental organisations and international organisations. Twenty-eight COST countries officially participate in the Action, with additional collaborators from four continents outside Europe. Over its four years it has produced academic, news media and social media publications. You will hear several presentations over these two days that provide insight into some of our work. The Action has held two ethics training schools with training materials it developed and continues to refine. The Action has also contributed to ethics guideline initiatives with the World Health Organisation (WHO), the International Committee of the Red Cross, UNICEF and UNISDR, and the United Nations office for disaster risk reduction (DRR).

The Action was initiated when scholarly engagement with ethical issues in disasters was relatively new. A sign of growing interest in the topic is that our recent meetings increasingly involve others not involved in the Action who work on disaster ethics. This conference is no different, and we are delighted to have keynote lectures, oral presentations and posters from some who are meeting with us for the first time. We believe this field has much more work that can be done, and we welcome the opportunity to develop new collaborative links with many of you. While the conference looks back, we also want to look to the future, to develop new relationships and also new initiatives that we can develop together to continue the work the Action has begun.

As the final event of our Action, we want this meeting to be a celebration of the work that has happened over the four years. At the same time, it is a celebration of the many friendships which we have also developed. We have had meetings from Dublin to Tel Aviv, from Malta to Tartu. We have come to enjoy being together, and working with one another. While our Action draws to a close, I know that our friendships and collaboration will not. Whether this is your first meeting, or you are a regular with us, we have two days of challenging and invigorating discussions ahead of us. And of course, a healthy serving of Irish food and a few pints!

Many people have contributed to this event. A special thanks goes to Mary Comiskey and the STEP Research Administration Unit Team at DCU who have worked very hard to organise the many aspects of this conference. I also want to thank our funders, the COST Association, the Wellcome Trust, Fáilte Ireland, and DCU.

Ceád mile fáilte roimhe go léir to dtí Éireann agus Ollscoil Chathair Bhaile Átha Cliath.

Vonal O'Mathina

Dónal O'Mathúna, PhD Chair, COST Action IS1201 Disaster Bioethics Dublin City University, Ireland

## **Conference Information**

#### **Campus Map**



The venues for the Conference are:

- Stokes Building (Research & Engineering Building
- School of Nursing
- Nano-Bioanalytical Research Facility (NRF)
- Biomedical Diagnostics Institute

#### Accessibility

For bus times to and from DCU please see <u>Dublin Bus</u>. The nearest bus stop for DCU can be located on Ballymun Road. Buses 4, 9, 11 and 13 are serviced from this stop.

#### Taxis

VIP Taxis - 01 478 3333

Cabs 2000 - 01 890 0900

#### **Conference Dinner**

Conference dinner will be held at <u>The Church</u>, Dublin on the 3<sup>rd</sup> October 2016. Transport from DCU to the restaurant will depart at 18:30 sharp from outside The Helix.

## Acknowledgements

The Ethics and Disasters: From Where we are to Where we need to go Conference is pleased to acknowledge generous sponsorship from:











## **Conference Programme**

Monday, 3 October 2016				
08:00-09:00	REGISTRATION - Stokes Building Foyer			
09:00-09:30	WELCOME AND OPENING REMARKS – Room S209, Stokes Building, 2 <sup>nd</sup> Floor Dr. Dónal O'Mathúna, Chair of COST Action IS1201, Dublin City University, Ireland Prof. Vojin Rakić, Head of the European Division of the UNESCO Chair in Bioethics and Director of the Center for the Study of Bioethics, University of Belgrade, Serbia			
09:30-10:30	KEYNOTE 1: When Patients Fear their Doctors and Vice Versa: Ebola Dilemmas Dr. Mercedes Tatay and Dr. Philippe Calain, Médecins Sans Frontières, Switzerland Chair: Prof. M. Murat Civaner, Uludag University, Turkey			
10:30-11:00	Coffee Br	Coffee Break and Poster Session - Stokes Building Foyer		
11:00-11:20 11:20-11:40	ORAL PAPERS SESSION 1: Governance Issues - Room S209, Stokes Building, 2 <sup>nd</sup> Floor         Chair: Prof. Ana Borovečki, University of Zagreb, Croatia         Disaster Justice and Good Governance of Nuclear Energy Technologies         Dr. Behnam Taebi, Delft University of Technology, The Netherlands         Taking Stock of Governance in the Sendai: The Way Ahead?         Dr. Karen da Costa, University College London, UK and Dr. Emmanuel Raju,			
11:40-12:00	University of Copenhagen, Denmark "Where We Need to Go" – An Operational Response to Insights from COST Action IS1201 Mr. David R Curry, GE2P2 Global - Governance, Evidence, Ethics, Policy, Practice, USA			
12:00-13:00	Stokes Building (2 <sup>nd</sup> Floor) Room S208 Working Group 1: Healthcare Ethics	School of Nursing (2 <sup>nd</sup> Floor) Room H206 Working Group 2: Bioethics, Culture, & Moral Theory	School of Nursing (3 <sup>rd</sup> Floor) Room H306 Working Group 3: Research Ethics	Nano- Bioanalytical Research Facility (NRF) Boardroom (Ground Floor) Working Group 4: Ethics & Governance
13:00-14:00	Lunch	and Poster Session	- Stokes Building Foy	

Monday, 3 C	october 2016 (continue	d)		
14:00-15:00	Stokes Building (2 <sup>nd</sup> Floor) Room S208 Working Group 1: Healthcare Ethics	School of Nursing (2 <sup>nd</sup> Floor) Room H206 Working Group 2: Bioethics, Culture, & Moral Theory	School of Nursing (3 <sup>rd</sup> Floor) Room H306 Working Group 3: Research Ethics	Nano- Bioanalytical Research Facility (NRF) Boardroom (Ground Floor) Working Group 4: Ethics & Governance
	ORAL PAPERS SESSION 2: Humanitarian Ethics - Room S209, Stokes Building, 2 <sup>nd</sup> Floor Chair: Dr. Marcin Waligora, Jagiellonian University, Poland			
15:00-15:20	Ethical Challenges of Providing End-of-Life Care in an Ebola Treatment Unit (2014- 2015) Prof. Heather Draper, University of Birmingham, UK			
15:20-15:40	<b>Complex Relational Ethics of Teamwork in Humanitarian Medical Aid Projects</b> Prof. Matthew Hunt, McGill University, Canada			
15:40-16:00	<b>Transgression and desire in the gesture of care - A humanitarian story</b> Ms. Anaïs Rességuier, Sciences Po Paris, France			
16:00-16:20	Case studies for Training in Ethical Issues Encountered in International Disasters Ms. Catherine Hale, University of Birmingham, UK			
16:20-16:45	Delegates will transfer on foot from the Stokes Building for Dr. Sheri Fink's Keynote Lecture in The Helix Gallery (2 <sup>nd</sup> Floor)			
16:45-17:45	KEYNOTE 2: Healthcare Ethics in Emergencies: From Katrina to Ebola and Beyond Dr. Sheri Fink, Author of <i>Five Days at Memorial</i> Chair: Dr. Dónal O'Mathúna, Dublin City University, Ireland			
17:45-18:30	Wine Reception and Book Signing with Dr. Sheri Fink - The Helix Gallery (2nd Floor)			
18:30	Bus leaves from outside The Helix to The Church Restaurant (http://www.thechurch.ie/)			
19:00	Conference Dinner in The Church Restaurant			

## **Conference Programme**

Tuesday, 4 October 2016				
09:00-10:00	<b>KEYNOTE 3: Global Justice and Disasters: A View from Low and Middle-Income</b> <b>Countries Room S209, Stokes Building, 2<sup>nd</sup> Floor</b>			
	<b>Prof. Anant Bhan</b> , International AIDS Vaccine Initiative India and Yenepoya University, India Chair: Dr. Ayesha Ahmad, University College London, UK			
	ORAL PAPERS SESSION 3: Equity and Justice - Room S209, Stokes Building, 2 <sup>nd</sup> Floor Chair: Dr. Signe Mezinska, University of Latvia, Latvia			
10:00-10:20	Applied Ethics and Allocation of Foreign Aid: Disparity in Pretensions and Practice Prof. Jónína Einarsdóttir and Dr. Geir Gunnlaugsson, University of Iceland, Iceland			
10:20-10:40	Gender and Disability in Disaster Contexts: Towards Humanitarian Responsiveness Dr. Ayesha Ahmad, University College London, UK Prof. Jackie Leach Scully, Newcastle University, UK; Prof. Lisa Eckenwiler, George Mason University, USA; Prof. Matthew Hunt, McGill University, Canada			
10:40-11:10	Coffee Break - Stokes Building 2 <sup>nd</sup> Floor Coffee Dock Poster Session - Stokes Building Foyer			
	ORAL PAPERS SESSION 4: Biomedical Ethics - Room S209, Stokes Building, 2 <sup>nd</sup> Floor Chair: Prof. Péter Kakuk, University of Debrecen, Hungary			
11:10-11:30	Ethics and Biobanks for International Disaster Research Prof. Bernice Elger, University of Basel, Switzerland			
11:30-11:50	Constructing Different Meanings of Antimicrobial Resistance: How to Deal with (fear of) Stigmatization in Antimicrobial Resistance Research Involving Refugees Ms. Alena Kamenshchikova, University of Tartu, Estonia			
11:50-12:10	Ethical Framework for Off-Label Use of Medication in a Disaster Setting Based on Clause 37 of the World Medical Association Declaration of Helsinki (2013) Dr. Shlomit Zuckerman, Inbal Governmental Insurance Company, Israel and Prof. Eugenijus Gefenas, Vilnius University, Lithuania			
12:10-13:00	Stokes Building (2 <sup>nd</sup> Floor)School of Nursing (2 <sup>nd</sup> Floor)School of Nursing (3 <sup>rd</sup> Floor)Stokes Building (3 <sup>rd</sup> Floor)Room S208Room H206Room H306BDI BoardroomWorking Group 1: Healthcare EthicsWorking Group 2: Bioethics, Culture, & Moral TheoryWorking Group 3: Research EthicsWorking Group 3: Governance			
13:00-14:00	Lunch - Stokes Building Stokes Building 2 <sup>nd</sup> Floor Coffee Dock			

## **Conference Programme**

Tuesday, 4 October 2016 (continued)			
14.00 14.20	ORAL PAPERS SESSION 5: Other Ethical Issues - Room S209, Stokes Building, 2 <sup>nd</sup> Floor Chair: Dr. Daniel Messelken, University of Zurich, Switzerland		
14:00-14:20	Ethics of Visual Identification of the Dead in Disasters Dr. Vina Vaswani, Dublin City University, Ireland and Yenepoya University, India		
14:20-14:40	From Moral Theories to Decision-Making in Disaster Settings: Specifying the Role of Compromise Dr. Péter Kakuk, University of Debrecen, Hungary		
14:40-15:00	Coffee Break - Stokes Building Stokes Building 2 <sup>nd</sup> Floor Coffee Dock		
15:00-16:00	KEYNOTE PANEL DISCUSSION: Disaster Ethics and International Organisations Room S209, Stokes Building, 2 <sup>nd</sup> Floor		
	Prof. Virginia Murray, Public Health England and UNISDR, UK;		
	Dr. Carla Saenz, Pan American Health Organization;		
<b>Prof. Leslie Swartz</b> , Lead Research Partner, Southern African Federation Disabled, and Stellenbosch University, South Africa.			
	Chair: Prof. Heather Draper, University of Birmingham, UK		
16:00-17:00	Management Committee Meeting: Finishing up and Planning Post-Action Room S209, Stokes Building, 2 <sup>nd</sup> Floor Chair: Dr. Dónal O'Mathúna, Chair of COST Action IS1201, Dublin City University, Ireland		

## Dr. Dónal O'Mathúna Dublin City University, Ireland



**Dónal O'Mathúna, PhD** is Senior Lecturer in Ethics, Decision-Making & Evidence at the School of Nursing & Human Sciences, Dublin City University, Ireland. He is Chair of COST Action IS1201: Disaster Bioethics, a network of academic and NGO members addressing disaster ethics), supported by the EU Framework Programme, Horizon 2020. He is also Convenor of Cochrane Ireland, a branch of the Cochrane Collaboration which promotes developments in systematic reviewing and evidence-based practice on the island of Ireland. He is actively involved in systematic reviews and research into Disaster Bioethics. The latter has led to a number of

presentations and peer-reviewed articles on the ethical issues that arise for healthcare practitioners and researchers during disasters. He is co-editor of *Disaster Bioethics: Normative Issues when Nothing is Normal* (Springer, 2014). He has worked with the World Health Organisation and UNICEF on ethical issues in disasters. He is also interested in the role of emotions in teaching and training in ethics, especially in moral perception and how narratives help to engage people with ethical issues.

#### Professor Vojin Rakić University of Belgrade, Serbia



Vojin Rakić, PhD, full Professor, is Founding Director of the Center for the Study of Bioethics, Head of the Serbian Unit of the UNESCO Chair in Bioethics and Chair of the Cambridge Working Group for Bioethics Education in Serbia. Vojin Rakić is also Head of European Division of the UNESCO Chair in Bioethics. He has a PhD in Political Science from Rutgers University in the United States (1998). He completed his

elementary and high school in the Netherlands, graduated philosophy in Serbia, and has MA degrees in European Studies and Political Science from the Central European University in Prague and from the Department of Political Science of Rutgers University. Vojin Rakić was a senior research fellow at the Center for Higher Education Policy Studies at the University of Twente in the Netherlands (1999-2001). Between 2001-2003 he was a U.N. Special Adviser to the Government of Serbia. Since 2003 he works as a university professor in Belgrade. In 2009 Rakić was also a Visiting Scholar at the European University Institute in Florence, Italy. Vojin Rakić publishes primarily in English. His publications include various books and edited collections (recently: an edited volume published by Routledge), as well as numerous articles from the domain of (bio-)ethics, and political philosophy (recent publications: articles in the Journal of Medical Ethics, American Journal of Bioethics, Cambridge Quarterly of Health Care Ethics, American Journal of Bioethics: Neuroscience, Medicine, Health Care and Philosophy and Journal of Evolution & Technology).

#### **Keynote Biographies**

## Dr. Mercedes Tatay Médecins Sans Frontières, Switzerland



**Mercedes Tatay MD, DTM&H** is the International Medical Secretary of Médecins Sans Frontières (MSF) since February 2016. A specialist in infectious diseases and tropical medicine, Dr. Tatay joined MSF in 1998 and has worked in a number of conflict and epidemic settings, including in Tanzania, Sierra Leone, Burundi, Zambia, CAR, Liberia, Afghanistan, Niger, Ivory Coast, Uganda, Sudan and the Democratic Republic of Congo. This allowed her to develop expertise in operational management and medical programme planning in complex humanitarian emergency contexts. Dr. Tatay became Head

of Emergency Programs with MSF France, and from 2003 to 2007 she oversaw humanitarian interventions in Iraq, Jordan, Sudan, Chad, CAR, Pakistan, Sri Lanka, Indonesia, Lebanon, Haiti, Nigeria, Ivory Coast, Liberia, Angola, DRC, Philippines and Niger among others (conflicts, epidemics and natural disasters).

Later on, Dr. Tatay practised as an infectious diseases physician in two university teaching hospitals infectious diseases and tropical medicine departments in France until 2015. In 2015, she worked as a consultant for WHO in infection prevention and control as well as in field coordination during the Ebola outbreak response in Sierra Leone. She also took coordination responsibilities as part of the UN Country team leadership. Her teaching experience includes clinical seminars and trainings on infectious diseases, applied epidemiology, operational management emergency response and humanitarian medicine.

## Dr. Philippe Calain Médecins Sans Frontières, Switzerland



Philippe Calain MD, PhD, MSc, DTM&H is director of research at the Research Unit on Humanitarian Stakes and Practices (UREPH), MSF Switzerland. As medical doctor, he specialized in infectious diseases, virology and tropical medicine. After several years of clinical activities in Belgium and Switzerland, he joined the Department of Microbiology at the University of Geneva, where he received a doctorate in biology in 1995. He was appointed as a virologist at the US-CDC from 1995 until 1997. He later worked in Rwanda (ICRC), Afghanistan

(MSF), and Laos (WHO). He served as an external member of the WHO Research Ethics Review Committee in 2010-2013. He has published peer-reviewed papers on humanitarian ethics, public health ethics, global health governance, public health surveillance, and extractive industries.

#### **Keynote Biographies**

Dr. Sheri Fink New York Times, USA



**Sheri Fink M.D., Ph.D.** is the author of the New York Times bestselling book, *Five Days at Memorial: Life and Death in a Storm-Ravaged Hospital* (Crown, 2013) about choices made in the aftermath of Hurricane Katrina. She is a correspondent at the *New York Times*, where her and her colleagues' stories on the West Africa Ebola crisis were recognized with the 2015 Pulitzer Prize for international reporting, the George Polk Award for health reporting, and the Overseas Press Club Hal Boyle Award. Her story "The Deadly Choices at Memorial," co-

published by ProPublica and the New York Times Magazine, received a 2010 Pulitzer Prize for investigative reporting and a National Magazine Award for reporting. A former relief worker in disaster and conflict zones, Fink received her M.D. and Ph.D. from Stanford University. Her first book, *War Hospital: A True Story of Surgery and Survival* (PublicAffairs), is about medical professionals under siege during the genocide in Srebrenica, Bosnia-Herzegovina. *Five Days at Memorial* was the winner of the National Book Critics Circle Award for nonfiction, the PEN/John Kenneth Galbraith Award for nonfiction, the Ridenhour Book Prize, the J. Anthony Lukas Book Prize, the Los Angeles Times Book Prize, the Southern Independent Booksellers Alliance Book Award, the American Medical Writers Association Medical Book Award, and the NASW Science in Society Journalism Book Award.

## Prof. Anant Bhan International AIDS Vaccine Initiative India and Yenepoya University, India



**Dr. Anant Bhan** is a trained medical doctor with a masters' degree in bioethics from the University of Toronto. He is a researcher in the fields of Global Health, Health Policy and Bioethics. He recently joined the International AIDS Vaccine Initiative (IAVI) at their India Regional Office in New Delhi as Senior Manager where he focuses on health systems, primary health care, maternal, newborn and child health, and India-Africa health sciences collaborations. He is also Adjunct Professor in the Department of Community Medicine, Yenepoya Medical College and the Centre for Ethics, Yenepoya University, Mangalore, India. In the past, he has worked for NGOs and a government public health training institution in India, as well as a consultant to a project on Ethical, Social

and Cultural issues in health biotechnology based at the University of Toronto. Anant has published extensively in various national and international medical journals in the field of global/public health and bioethics, as well as contributed to popular mass media. He is on the Editorial Board of 'Public Health Ethics' (www.phe.oxfordjournals.org), a quarterly journal of Oxford University Press and also

## **Keynote Biographies**

Review on the International Advisory Board of the Bioethics serves Asian (http://www.asianbioethicsreview.com). He is also a member of the Ethics Working Group of the US NIH-funded HIV Prevention Trials Network (http://www.hptn.org/hptnresearchethics.htm). Anant has been a resource person for trainings in global health, research methodology, research ethics and public health ethics, and also serves as guest faculty in various educational institutions in India and abroad. He currently is a member of four ethics committees in India (two of which he also serves as the chairperson of), and has been as a reviewer for multiple journals, conference scientific committees and international grant competitions. Anant is also a member of the Working Group set up to revise the 2002 CIOMS International Ethical Guidelines for Biomedical Research involving Humans, and the Steering Committee of the Global Forum on Bioethics in Research. He is also a member of the Board of the International Association of Bioethics.

#### **Panelist Biographies**

## Prof. Virginia Murray Public Health England and UNISDR, UK



**Professor Virginia Murray** was appointed as Consultant in Global Disaster Risk Reduction for Public Health England in April 2014. This appointment is to take forward her work as vice-chair of the UN International Strategy for Disaster Reduction (ISDR) Scientific and Technical Advisory Group and as the Chair of the Science & Technology Organising Committee for the UNISDR Science and Technology Conference on the implementation of the Sendai Framework for Disaster Risk Reduction 2015-2030 January 27-29 2016 and

with the support of COST Bioethics programme included a side event on ethics for DRR. Prior to this she was appointed as Head of Extreme Events and Health Protection, Public Health England in January 2011. With the Extreme Events team, she helped to develop evidence base information and advice on flooding, heat, cold, volcanic ash, and other extreme weather and natural hazards events. Appointed as Visiting Professor in Health Protection, MRC-HPA Centre for Environment and Health, Imperial College and King's College, London (2004) and Honorary Professor at University College London (2013), she has published widely.

#### Dr. Carla Saenz Pan American Health Organization



**Carla Saenz PhD** is in charge of the Regional Program on Bioethics at the Pan American Health Organization (PAHO), which is the World's Health Organization's Regional Office for the Americas. She gives technical cooperation on bioethics, which includes support for the incorporation of ethics in national and regional plans, policies and regulations, and the development of capacity on the different areas of bioethics in Latin America and the Caribbean. Dr. Saenz is also responsible for PAHO's Ethics Review Committee (PAHOERC), which reviews all human subject research conducted with PAHO's involvement. Dr. Saenz holds a PhD in Philosophy

from the University of Texas at Austin. Prior to joining PAHO, she was at the Department of Bioethics at Clinical Center at the National Institutes of Health (NIH), where her research focused on population-based bioethics, and served as a Visiting Professor in the Philosophy Department at the University of North Carolina at Chapel Hill, where she was affiliated to UNC's Parr Center for Ethics. Dr. Saenz has authored several publications on different areas of bioethics, and has recently coedited the book *Public Health Ethics: Cases Spanning the Globe* and been responsible of the development of PAHO's zika ethics guidance.

#### **Panelist Biographies**

#### Prof. Leslie Swartz Stellenbosch University, South Africa



Leslie Swartz PhD trained as a clinical psychologist and obtained his PhD in psychology at the University of Cape Town, South Africa. He is currently Distinguished Professor of Psychology at Stellenbosch University. His fields of interest include mental health and disability issues in low-income contexts, and he has published widely on these topics. He is Editor-in-Chief of African Journal of Disability and Associate Editor of Transcultural Psychiatry and International Journal of Disability, Development and Education. He was Lead Research Partner on the Southern African Federation of the Disabled Research Project, training disability activists in southern Africa in basic research skills. Recent work has focussed on disability and access to health care in a number of African countries, disability and physical activity in poorly-resourced contexts, and language issues in access to mental health care.

## DISASTER JUSTICE AND GOOD GOVERNANCE OF NUCLEAR ENERGY TECHNOLOGIES

#### Dr. Behnam Taebi, Delft University of Technology and Harvard University

Radiation risks associated with nuclear technology are different than other technological risks in that, first, there are larger uncertainties associated with radiation impacts (i.e. there is no safe level of radiation and health impacts of accumulated low-dose radiation might only manifest themselves after a long time) and, second, major nuclear disasters could have devastating impacts far beyond national and generational borders. This creates several problems of justice with regard to nuclear technology, which should play a role in different stages of disaster mitigation, preparation, response and recovery. This paper aims to conceptualize *disaster justice* for nuclear energy technology through the lenses of *ethics of risk* and *good governance*.

While the notion of good governance has mostly been discusses in relation to developing countries, various cases of *bad* or *poor governance* – such as the Fukushima-Daiichi disaster - showed its broader relevance. Current discussions on good governance often neglect its normative dimension. I aim to spell out these normative issues for nuclear technology by focusing on distributive and procedural justice. As regards distributive justice, questions will be addressed such as: (why) is it morally justified that radiation workers, people in the vicinity of reactors and others are exposed to different levels of radiation? What is the proper unit of *distribution*? How should we deal with the intergenerational distributions? As regards procedural justice, I will focus on the role of scientific uncertainties and controversies in decision-making. Could *citizen science* contribute to more reliable and *transparent* information and more *accountable* local/national governments and corporations?

#### Biography



**Behnam Taebi Ph.D** is an assistant professor of philosophy at Delft University of Technology, The Netherlands, and an associate with the Harvard Kennedy School's Belfer Center, USA. His research interests are in energy ethics, responsible innovation and ethics of engineering. He studied Material Science and Engineering (2006) and received his Ph.D. in Philosophy of Technology (2010). He is the coordinating editor of a volume on *The Ethics of Nuclear Energy* (Cambridge University Press, 2015) and a special issue of *Journal of Risk Research* (2015) on "Socio-Technical Challenges of Nuclear Power Production" and is currently writing a monograph on *Ethics and Engineering* (under contract with Cambridge University Press). Taebi is a member of a task group of the International Commission of Radiological Protection (ICRP) that is

working on the protection of the public and the workers for (near) surface disposal of radioactive waste.

## TAKING STOCK OF GOVERNANCE IN THE SENDAI: THE WAY AHEAD?

#### Dr. Karen da Costa - University of Copenhagen, Denmark

We consider the critique made to the Hyogo Framework for Action (HFA) 2005-2015, notably relating to governance including accountability. We identify how have these notions been addressed by the Sendai Framework for Disaster Risk Reduction (SFDRR) 2015-2030. We furthermore consider whether the way they have been addressed is a way forward to reducing disasters.

Against the background of increasing impacts of disasters, 2015 was pivotal for the adoption of new international frameworks, notably the SFDRR; the Sustainable Development Goals, and the Paris Agreement on Framework Convention on Climate Change.

Our paper focuses on the SFDRR that was negotiated in Sendai in Japan in March 2015. The SFDRR aims to target and address disaster risk with four priority areas. It is also a renewed commitment from the HFA, the previous international framework on disaster risk reduction. The SFDRR was meant to learn from the HFA, and indeed it places greater emphasis on 'disaster risk governance' than ever before. However it appears that the large question of implementation remains a challenge, which closely relates to governance including accountability.

Our paper contributes to highlighting the role of accountability as a crucial feature of governance in disasters. It also identifies possible ways ahead, in terms of strengthening governance and accountability in disasters, through, among others: strong political will; tackling corruption; greater stakeholders' participation and capacity development.

#### Biography



**Karen da Costa** holds a Ph.D. (2011) in International Studies from the Graduate Institute of International and Development Studies, University of Geneva. She also holds the European Masters (2003) in International Humanitarian Assistance, Network on Humanitarian Assistance (NOHA) from the Ruhr-University of Bochum. Her research interests relate to international human rights law, including the impact of natural disasters on the enjoyment of human rights. She is currently Research Associate in International Law, at Faculty of Laws, University College London. Her previous work experience includes positions as University Fellow at the Irish Centre for Human Rights, National University of Ireland, Galway; Legal Consultant for the International Federation of the Red Cross and Red Crescent Societies, and Human Rights Officer at the United Nations

Operation in Côte d'Ivoire. Her book 'The Extraterritorial Application of Selected Human Rights Treaties' (2013) has been published by Brill/Martinus Nijhoff Publishers/Graduate Institute of International and Development Studies Series.

## "WHERE WE NEED TO GO" – AN OPERATIONAL RESPONSE TO INSIGHTS FROM THE IS1201 COST ACTION

#### Mr. David R Curry, GE2P2 Global - Governance, Evidence, Ethics, Policy, Practice, USA

Much has been learned from the COST Action – about disasters; about research and evidence generation involving and carried out in the context of disasters; and about the ethical challenges facing those who respond, those who study, and those affected by disasters.

Using a case study approach, the paper will examine an operational response to the insights gained in the Action: an ongoing initiative to form and operate an independent, global, virtual ethics and research services organization to deliver responsive and cost-effective guidance and consultation for research and evidence generation involving vulnerable populations — especially populations in disaster and humanitarian contexts.

Discussion will include what such an organization requires:

- Building and maintaining a global network of "talent" to deliver such ethics and research consultation. This network need to involved field practitioners, scientists, researchers, ethicists, domain and cultural context experts, scholars in the social and bio sciences and the humanities, knowledge management/big data/ICT experts, and others.
- Building processes, protocols and policies to assure consistent, coherent (and ethical) performance.
- Building solid teams around certain focus areas, such as research involving children and adolescents, research involving humanitarian contexts, etc.
- Building a portfolio of supporting services such as ethics training, systematic reviews, help desk capability and more to deliver a full solution.

In short, such an organization needs to be a hybrid between an NGO and a consulting firm, operate at global scale, and able to address a complex ecology of research disciplines, geographies, cultures, and organization types.

#### Biography



**David R. Curry, MS** serves as President and CEO of *GE2P2 Global – Governance, Evidence, Ethics, Policy, Practice*, comprising a non-for-profit foundation and a public benefit company with a common purpose: to advance ethical and scientific rigor in research and evidence generation for governance, policy and practice in human rights action, humanitarian response, health, education, heritage stewardship, and sustainable development – serving governments, international agencies, INGOs, civil society organizations (CSOs), commercial entities, consortia and alliances. He is also Executive Director of the Center for Vaccine Ethics and Policy, anchored at NYU School of Medicines Division of Medical Ethics. The Center has a number of focus areas, including the ethics

and policy around utilization of vaccines and essential medicines in humanitarian contexts. David was lead investigator/author on the R2HC/Wellcome Trust/DFID commissioned project to develop an ethical framework for research on health interventions in humanitarian contexts.

## ETHICAL CHALLENGES OF PROVIDING END OF LIFE CARE IN AN EBOLA TREATMENT UNIT (2014-2015)

#### Prof. Heather Draper, University of Birmingham, UK

#### Method

Twenty British military medical and medical support personnel who deployed to Sierra Leone (between October 2014 and April 2015) were interviewed about the ethical challenges faced. A largely conventional approach to content analysis was taken using the data to draw conclusions about themes in the participants' thinking.

#### Problem and findings

End of life care caused particular ethical difficulties, even though most participants were accustomed to dealing with the dying and dead. Specific issues included: uncertainty about the course of the disease in individuals (patients who were recovering died unexpectedly/ patients thought to be 'hopeless' survived) – this resulted in, amongst other things, a 'hybrid' approach to palliation; the trade-off between infection control and providing 'normal' end of life care and comfort; moving dying patients long distances to receive palliative care; preparation of the dead for burial.

#### Discussion and conclusions

The duty to care for patients ('normal' professional obligations) was constrained by public health measures (containment) and the need to protect staff from infection (obligations to employees/self/colleagues). End of life care, where human <u>contact</u> seems especially important, was particularly impacted. Meaningful end of life <u>care</u> is difficult to provide during a mass outbreak of a highly infectious and serious disease.

#### Originality

This was first large-scale Ebola outbreak; original date reported; end of life care provision in humanitarian disaster response is little discussed in bioethics. The difficulties of providing meaningful care need to be taken into account when deciding how to prioritise end of life care in a disaster response.

#### **Biography**



**Heather Draper PhD** is Professor of Biomedical Ethics, Institute of Applied Health Research, at the University of Birmingham, UK. Her paper will be drawing on the analysis of data collected as part of an ESRC funded project 'Military healthcare professionals experiences of ethical challenges whilst on Ebola humanitarian deployment (Sierra Leone)', which she led in 2015. She is also Vice Chair of this COST Action IS1201.

## THE COMPLEX RELATIONAL ETHICS OF TEAMWORK IN HUMANITARIAN MEDICAL AID PROJECTS

#### Prof. Matthew Hunt, McGill University, Canada

International humanitarian non-governmental organizations are key contributors to relief and reconstruction efforts during crises, including in contexts of disaster, war or disease outbreak. Provision of care and implementation of public health interventions in these settings raises a range of vexing ethical challenges. An issue that remains under examined to date is the ethics of teamwork in humanitarian medical organizations. Such teams are typically international and interdisciplinary, and gradients of power and privilege (for example between expatriate and local staff) may be significant. Challenges may also arise around different sets of professional expectations, moral commitments and cultural norms within teams. In this presentation, I draw on secondary analysis of over 70 in-depth interviews with expatriate and national health professionals who participated in the response to humanitarian crises. These interviews reveal how the structure of teams can be a source of ethical challenges at multiple levels, ranging from how decisions are made and who is involved in them, to who will be evacuated during an emergency. At the same time, humanitarian health teams are frequently identified as a crucial source of support for humanitarian workers facing ethical challenge. Critical analysis of these features of humanitarian teams - both as sources of ethical challenge and sources of ethical support - can help make these relational dynamics visible, and render them more accessible for discussion and reflection.

#### **Biography**



**Matthew Hunt, PT, PhD** is the Director of Research and an Associate Professor in the McGill University School of Physical and Occupational Therapy, Canada, and an Associate Member of the McGill Biomedical Ethics Unit. Previously, he has worked as a physiotherapist in Montreal, North Africa and the Balkans.

Matthew's research interests are at the intersections of ethics, global health and rehabilitation. He currently leads research projects related to oversight of research in situations of disaster; needs of persons with disability during crises; and ethics of humanitarian healthcare and public health responses. Matthew also heads a capacity building project for

rehabilitation providers in Haiti and co-directs the Humanitarian Health Ethics Network (<u>humanitarianhealthethics.net</u>).

# TRANSGRESSION AND DESIRE IN THE GESTURE OF CARE. A HUMANITARIAN STORY

#### Ms. Anaïs Rességuier, Sciences Po Paris, Center for Political Research, France

This presentation seeks to give some insights on the gesture of care (or help), in particular in the context of humanitarian action. It is inspired by a specific situation encountered by a humanitarian actor in a detention center. From this story, it draws a number of fundamental elements to the gesture of care, in particular the importance of transgression and desire. On this basis, it then proposes a model to approach practices of care and distinguishes between the "heart of care" and the "tools of care". It then draws conclusions for ethics from this analysis.

These theoretical elaborations seek to contribute practically to the humanitarian sector. More specifically, it wishes to respond to the particular trend the sector is engaged in today toward a profound increase in technicisation, bureaucratization, and improvement in effectiveness and efficiency. Though this increased capacity can be celebrated, it has also raised new issues. Indeed, the sector today is being criticized for having become too rigid, standardized, and mechanistic. Numerous experts on humanitarianism today see this evolution as one of the greatest dangers the sector is now facing - a danger that impacts both beneficiaries and humanitarians. One of the objectives of the theoretical developments on ethics and the gesture of care proposed in this paper is precisely to respond to this current trend.

#### Biography



Anaïs Rességuier is a philosopher conducting research on humanitarianism and on caring and helping practices more generally. She is now finishing her PhD thesis at the Center for Political Research at Sciences Po Paris. Her thesis consists of a philosophical reflection on caring and helping gestures with a particular focus on humanitarian practices. It proposes a model to approach these gestures and to avoid the various pitfalls they entail. After a Master (MA) in Philosophy at the Sorbonne University and a Master (MSc) in Forced Migration at the University of Oxford, she worked with Hugo Slim at the University of Oxford on a project on Humanitarian Ethics conducted in collaboration with various humanitarian organisations.

## CASE STUDIES FOR TRAINING IN ETHICAL ISSUES ENCOUNTERED IN INTERNATIONAL DISASTERS

#### Ms. Catherine Hale, University of Birmingham, UK

A short presentation (20) mins with 5 mins for Q & A) on the outputs from Working Group 1, on the generation of new and novel detailed learning and teaching materials about 'Disaster bioethics', covering a broad range of ethical problems encountered in international disasters.

The presentation would include:

- An overview of the process and strategy in generating new teaching and learning materials for use by the international community
- Assessment of pre-existing ad-hoc materials to avoid duplication
- Precis of the challenges and strengths of international collaboration in order to generate outputs
- Justification of 'problem case based method' chosen
- Methods of generation of case construction
- Showcase breadth and type of disaster bioethics cases produced
- Explanation of detailed development of cases with leaners' questions and suggested answers for tutors/facilitators
- Detailed example of one case with learners' questions and suggested answers

What next? Where/how best to make accessible to the international community materials generated and how best to generate and develop further learning and teaching materials.

#### Biography



**Catherine Hale Barrister-at-law**, MSc, PGCE, LLB (Hons), is Senior Lecturer in Medical Law and Ethics, Institute of Clinical Sciences at the University of Birmingham, UK. Upon completing her MSc in Health Care Ethics in 2000 she obtained a full-time lectureship in Medical Law and Ethics at the University of Birmingham and is now a Senior Lecturer within the Medicine, Ethics, Society and History (MESH) group. During her career at the University of Birmingham she has taught and administered a wide variety of programmes particularly within the Medical School and continues to specialise in medical law, combining

her previous clinical experience especially as a transplant co-ordinator, with her considerable teaching and legal expertise. Catherine is an Associate of the Integrated Studies Unit, within the Department of Primary Care and General Practice, which specialises in how to communicate with patients effectively in clinical practice. She is also a member of the Institute of Medical Law, Law School, University of Birmingham, an Associate of The Institute of Clinical Leadership, University of Warwick and Consultant to the Ministry of Defence.Catherine is an influential legal expert on issues related to health care, particularly current or topical ethical issues. As a regular speaker at external events and media commentator she has provided lectures and commentary on key health

## **Oral Abstracts**

care and legal issues. She is a key player in the medical undergraduate curriculum having both extensive management committee membership and teaching responsibilities. Her role within the Medical School is to not only give students an understanding of their legal obligations but also to equip them with the ethical reasoning skills and personal qualities in order to achieve appropriate standards of conduct.

Catherine's ethical and legal research interests include prescribing, discrimination in health care, professional roles and end of life issues. She is currently working in collaboration with Dundee Medical School and colleagues at Birmingham to undertake research into ethical issues encountered by medical students in their elective placements. She is also drafting a paper commissioned by the British Journal of Nursing on Ethical and Legal Issues for Physician Assistants

## APPLIED ETHICS AND ALLOCATION OF FOREIGN AID: DISPARITY IN PRETENSIONS AND PRACTICE

#### Prof. Jónína Einarsdóttir, University of Iceland, Iceland

We explore the applied ethics of development aid and humanitarian assistance, and juxtapose these with claimed objectives and factors that influence the choice of recipients. Despite some diversity among donors, ethical considerations appear not to be a prominent factor for allocation of aid. Although recipients' need is not entirely ignored, donors' self-interest and herd behaviour, and recipients' merits and voting in the United Nations, play crucial roles in allocation decisions. Likely to be shunned are complex emergencies and fragile states, the overlapping settings for action of development and humanitarian aid. Donors should take to heart and put into practice that allocation of aid is an ethical endeavour that should rest on proper needs assessment, established objectives and adopted agreements.

See: Einarsdóttir J, Gunnlaugsson G (2016). Applied Ethics and Allocation of Foreign Aid: Disparity of Pretensions and Practice. Development Policy Review, 34 (3): 345--363.

#### **Biography**



Jónína Einarsdóttir has PhD in Anthropology from Stockholm University. She is Professor of Anthropology and responsible for MA programme in Development Studies at the Faculty of Social and Human Sciences. She is vice-chairman for the Research Committee for The School of Social Sciences, University of Iceland and a member the Programme and Research Council for the Nordic Africa Institute in Uppsala. Einarsdóttir has conducted extensive fieldwork in Guinea-Bissau and Iceland, and had shorter assignments in Mozambique and Malawi. In Guinea-Bissau,

Einarsdóttir has studied maternal grief, child death, infanticide, breastfeeding and child trafficking. In Iceland, Einarsdóttir has done research on ethical questions related to treatment of extremely preterm infants and the implications of their birth on the daily life of their families, domestic violence and punishment of children, as well as the 20th century customs to send urban children to stay and work on farms during the summertime. Failed states, aid and health care systems, as well as cholera and Ebola are themes of interest.

## GENDER AND DISABILITY IN DISASTER CONTEXTS: TOWARDS HUMANITARIAN RESPONSIVENESS

#### Dr. Ayesha Ahmad, Institute for Global Health, University College London, U.K.

In this paper, we address the under-examined needs of vulnerable populations in disaster contexts experiencing health injustice due to inequalities related to gender and disability.

International Humanitarian Organizations increasingly recognize that responsiveness in the provision of humanitarian services demands careful attention to the particular needs of certain groups.

Within an already vulnerable population, gender and disability are key features, separately and as they intersect, that require further recognition by humanitarian health efforts in terms of how they shape individual needs due to an increased likelihood of being harmed or wronged.

Guidance documents (e.g. Humanitarian Disability Charter, International Federation of Red Cross and Red Crescent Societies document on gender based violence in disasters) demonstrate a commitment to equity and justice in these areas, and represent important advances. Following Kurasawa's concept of global justice and human rights work as social labor, or practices, we wish to investigate the moral experience of humanitarian health worker trying to respond to the needs of specific populations in humanitarian contexts, particularly in relation to gender and disability as independent and interesting variables. We draw on our previous work to identify key areas in gender and disability that our collaboration proposes to examine in further work after the COST Action is completed.

#### References:

 Humanitarian Disability Charter http://humanitariandisabilitycharter.org
 International Federation of Red Cross and Red Crescent Societies http://www.ifrc.org/Global/Documents/Secretariat/201511/1297700 GBV in Disasters EN LR2.pdf

#### Biography



**Ayesha Ahmad PhD** is a lecturer in Medical Ethics and Law at St George's University of London, UK, an Honorary Lecturer at the Institute for Global Health, University College London and Guest Lecturer in Transcultural Psychiatry, Queen Mary University of London. During the COST Action, she has co-chaired the Working Group for Culture and Gender in Disasters, Conflict, and Humanitarian Crises. She is currently working on a funded research project investigating trauma therapeutic approaches to gender based violence using traditional story-telling in Afghanistan and developing medical education on humanitarian action and ethics. Her particular areas of interest are trauma and mental health

during chronic conflict, culture and clinical ethics, and humanitarian responses to gender based violence.

#### ETHICS AND BIOBANKS FOR INTERNATIONAL DISASTER RESEARCH

#### Prof. Bernice Elger, University of Basel, Switzerland

In disasters that involve infectious diseases and radiation, collections of biological samples are essential to permit the development of research activities that need to be carried out simultaneously to save lives. However, the examples of the Ebola outbreak in 2014, Chernobyl and Fukushima show that public health activities involving a sample biobank are delayed and/or made difficult because various competing actors take their "own" samples and establish separate collections in their home countries. This means that Ebola samples are at present spread out over many countries. Such fragmentation reduces the possibilities to carry out the best possible research as the numbers in many of the collections remain low and sample collection is not standardized following evidence based Standard Operation Procedures (SOPs). In the case of Chernobyl, a biobank has only been established more than ten years after the disaster which makes it very difficult to calculate radiation doses and to calculate cancer risks. Similarly, in Fukushima there is at present no systematic collection of samples. As disasters are unforeseen, it is important to establish in advance an ethical approach how to enable harmonized sample collections during the medical response to the disasters. Indeed, part of the medical approach is in general the taking of at least one blood sample and there are no additional risks to victims if samples are stored systematically while the benefits are high. In this presentation we will show barriers and facilitators to sample collections during past disasters and propose steps to establish a publish health framework how to ensure now that in the next disasters sample collection will take place ethically and efficiently. The presentation will discuss the relevance and appropriateness of the revised version of the CIOMS guidelines that was open to consultation in 2016, in particular of the newly introduced section on "Research in disaster situations". We will present a public health disaster biobank framework and defend essential components of biobanks for international disaster research.

#### **Biography**



**Bernice Elger PhD** is head of the Institute for Biomedical Ethics at the University of Basel and associate professor at the Center for Legal Medicine at the University of Geneva where she is head of the Unit for Health Law and Humanitarian Medicine. She studied medicine and theology in Germany, France, Switzerland and the US and obtained her specialty degree in internal medicine (FMH) in Switzerland. As part of her work at the Center for Legal Medicine at the University of Geneva, she has worked in prison medicine for 15 years. She has been member of the advisory committee of the Chernobyl Biobank for many years and wrote her habilitation thesis

on ethical and legal issues of biobanks.

## CONSTRUCTING DIFFERENT MEANINGS OF ANTIMICROBIAL RESISTANCE: HOW TO DEAL WITH (FEAR OF) STIGMATIZATION IN ANTIMICROBIAL RESISTANCE RESEARCH INVOLVING REFUGEES. MAASTRICHT, THE NETHERLANDS.

#### Ms. Alena Kamenshchikova, University of Tartu, Estonia

Ever-increasing level of antimicrobial resistance around the world is a threatening issue for global health. Inappropriate use of antibiotics and human mobility are recognized to be two of the major causes of antimicrobial resistance development. Refugees who arrived to Europe crossing different countries and regions are one of the most vulnerable groups for infectious diseases and antimicrobial resistance development consequently. However, antimicrobial resistance research in healthy refugees provokes different sensitive outputs among microbiologists, public health professionals and refugees. Current study focuses on a role of (fear of) stigmatization in antimicrobial resistance research in refugees providing different meanings of antimicrobial resistance by Syrian refugees, microbiologists, and public health professionals from Maastricht, the Netherlands. In total 18 people were interviewed in depth, from Medical Microbiology department at Maastricht University; Sexual Health, Infectious Diseases and Environmental Health Department at South Limburg; and Asylum Seeker center. Three groups of meanings were indicated: antimicrobial resistance as (1) a public health threat; (2) as a threat to individual health; and (3) antibiotics were understood as a universal treatment that can heal one's body from variety of conditions. It was suggested, that patterns of stigma in antimicrobial resistance research can emerge within presentations of research when refugees are a priory determined and separated as a carrier of resistant microorganisms. Conclusively, to make ethically responsible antimicrobial resistance research in refugees and avoid stigmatization, three groups of meanings have to be equally addressed, and refugees must not be presented as a single potential carrier of resistant microorganisms.

#### Biography



Alena Kamenshchikova, second year MA Philosophy, University of Tartu, Estonia. In 2014 she graduated as a Bachelor in Sociology from Tomsk State University, Russia, with a thesis focusing on standardized practices in daily medical work. In the period from January – April 2014 she did an exchange program with M.Sc. Global Health at Maastricht University, the Netherlands. Since 2015 she has been working as a junior research fellow in the Center for Policy Analysis and Studies of Technologies, Tomsk State University, Russia. In the summer of 2016, she did her research internship at the Department of Health, Ethics &

Society, Maastricht University, The Netherlands. Sphere of research interests: standardization in healthcare, global justice, disaster ethics and refugee health.

## ETHICAL FRAMEWORK FOR OFF-LABEL USE OF MEDICATION IN A DISASTER SETTING BASED ON CLAUSE 37 OF THE WORLD MEDICAL ASSOCIATION DECLARATION OF HELSINKI (2013)

#### Dr. Shlomit Zuckerman, Inbal Governmental Insurance Company, Israel and Prof. Eugenijus Gefenas, Vilnius University, Lithuania

Off-label use of medications in the clinical settings is known to be globally widespread. In the developed world, pediatric and psychiatric use, as well as antibiotics and pain killers are commonly prescribed off-label, oftentimes despite a lacking strong scientific support. While off-label prescribing in disaster settings is vast, it brings to the table substantial ethical concerns. Therefore, application of an ethical framework for this common practice in disasters is imperative.

The proposed paper - evolving from the work of working group 3 (research ethics) of the COST Action 1201S- analyzes the plausibility of clause 37 of the World Medical Association Declaration of Helsinki (2013) Ethical Principles for Medical Research Involving Human Subjects as an ethical framework for the practice of off-label use in disaster setting and its subsequent research arm.

We begin by discussing two other possible frameworks for off-label use in a disaster setting: the principlism perspective and the Goals of Public Health Emergency Preparedness and Response (PHEPR) model. We then move to investigate the set of criteria required by clause 37 for appropriate use of unproven intervention and its application to off-label use in a disaster setting. We conclude that this model is best suitable for our purpose. In particular we discuss the requirement for conduct of subsequent research arm for the evaluation of safety and efficacy of the intervention, the documentation of new information and its appropriate publicizing of as the unique contribution of the proposed model. Finally, we discuss its limitation.

#### Biography



**Shlomit Zuckerman, PhD LL.B** received a BSc. in Biology (*Cum Laude*) and LL.B in Law from the Hebrew University in Jerusalem. She practiced law for three years as a federal prosecutor and legal advisor at the City of Jerusalem Legal Division, where she specialized in litigation, labour, institutional and environmental Law. In 2009, she received a PhD in Empirical Bioethics from Case Western Reserve University in Cleveland, Ohio, U.S. Since returning to Israel she has been teaching medical ethics and health law at the Universities of Haifa, Tel Aviv and Jerusalem and the

Academic College of Tel Aviv Yaffo. Since early 2015 she has been working as a medical risk manager and research coordinator at Inbal Governmental Insurance Company in Israel. Her current research interests include health care decision making, ethics, law and risk management in the public health, disaster ethics and standards of care in the face of scarce resources.

## **ETHICS OF VISUAL IDENTIFICATION OF THE DEAD IN DISASTERS**

#### Dr. Vina Vaswani, Dublin City University, Ireland and Yenepoya University, India

Our body represents our identity. Our face establishes our individuality. Hence photographs form an important tool to identify a person. Identity is a greatly discussed topic is social sciences, psychology, anthropologists and forensic medicine, albeit from a different lens.

In developing countries, soon after the disaster, the waiting mobs and relatives of the deceased press for bodies to be released as soon as possible. It is customary in developing countries to have relatives identify the body by visualization.

Identification by visual recognition is a crucial tool, but it should be carried out with caution. Visual identifications in Bali bombings in 2002, Tsunami 2005, Hurricane Katrina, 2005 have resulted in many misidentifications, thereby putting the families to additional grief.

Ethical issues: When the relatives identify the deceased, the emotional stress associated with identifying can be traumatic. In resource-limited settings, visual identification is used as the popular method because of its utilitarian value. But visual identification results in significant misidentifications. For those whose bodies remain misidentified, are also deprived of last rites. Last rites are important for family members, as the family comes to terms, and the process of grieving is regarded upon as healing process for the family and community. Although The International Committee for Red Cross advises comparison of Ante mortem data with post mortem data and DNA typing to establish identification, lack of training and resource limitation is the limiting factor.

#### Biography



**Dr. Vina Vaswani MD, M Phil, MA** is Professor & Head of the Department of Forensic Medicine and Toxicology, Yenepoya University, Mangalore, India. After completing MD in Forensic Medicine in 1996 has been involved in undergraduate and postgraduate teaching at medical schools in South India. Dr. Vina completed M Phil in Hospital and Health Systems Management, in 2006. In 2008, she completed her Master's in Bioethics as a student of Erasmus Mundus initiative of the European Union. Upon returning to her university, she has been handed additional responsibility of Director at the Centre for Ethics, since 2011. She runs two

postgraduate diplomas - one in bioethics and one in clinical ethics. Besides this she envisaged an environmental ethics course for medical graduates. Vina is currently registered for PhD in Disaster Ethics, under the supervision of Prof. Dr. Bert Gordijn and Prof. Dr. Anne Scott, at the Dublin City University.

## FROM MORAL THEORIES TO DECISION-MAKING IN DISASTER SETTINGS: SPECIFYING THE ROLE OF COMPROMISE

#### Dr. Péter Kakuk, University of Debrecen, Hungary

According to some scholars, the emergence of bioethics in the 1970's saved the life of ethics, as a segment of moral philosophy, as academic ethics was brought back to our everyday social sphere. Although the success of bioethics fuelled a renewed interest in ethical theories, but in a fresh and challenging context of everyday conflicts, dilemmas, and issues that were usually originate from health care or hospital environments. Contrary to this applied focus of much of today's ethical theorizing one would scarcely find a similar academic interest in the role and concept of compromise in the ethics of decision-making in health care. Compromise is usually regarded as a valuable concept in business, in politics, in law, but not in morality. We are successors of a philosophical tradition that sees compromise in moral issues as wrong, as it forms a danger to our moral life, as it is simply a betrayal of principles and moral theories, and as to practice compromise is to demolish our moral integrity. With reference to the work Martin Benjamin - who confronted this tradition, and introduced a positive concept of moral compromise into ethics - my paper focuses on the concept of integrity preserving compromise and its potential role in ethical decision-making in disaster settings. I summarize the major elements of the dominant view of compromise in ethics and assess its relation to ethical theorizing (theories, codes, principles). After explicating the concept of integrity preserving compromise I try to assess the potential roles it might have in situations where nothing is normal.

#### **Biography**



Péter Kakuk PhD studied philosophy at the University of Debrecen and Health Care Ethics and Law at the University of Manchester. He has a PhD in Health Sciences. Currently, he is Assistant Professor in the Department of Behavioural Sciences at the University of Debrecen, where he is teaching medical ethics and bioethics. He is member of the Hungarian Medical Research Council's Scientific and Research Ethics Committee and President elect of the European Society for Philosophy of Medicine and Health Care.

His primary research interests are related to bioethics, ethics of genetics, research ethics and scientific integrity.

## KEYNOTE PANEL DISCUSSION: DISASTER ETHICS AND INTERNATIONAL ORGANISATIONS

The panel will be composed of representatives from international organisations actively involved with disasters and disaster responses (defined very broadly). The aim of this panel is to promote a forwarding looking discussion about disaster ethics from two perspectives. One is for panellists to present the types of disaster ethics issues identified, perceived or anticipated by their organisations, and the second is to make practical proposals for how others, like those in the audience, could contribute to helping these organisations address or prepare for ethical issues in disasters. The overall objective for this broader discussion is to allow practical proposals to develop about how the field of disaster bioethics could and should develop so that it can make significant impacts on the well-being of those hit by disasters, epidemics, etc.

Practically speaking, each panellist will be given up to 10 minutes to address both perspectives based on each organisation's work and experiences. After all panellists have presented, each panellist will be given the opportunity to respond to one point raised by the other panellists. Then the discussion will be opened to the audience to respond to the disaster ethics issues identified and/or react to the proposals suggested by the panellists. Members of the audience will be asked to state their comments and questions in concise and focused ways to allow the broadest participation possible.

## **Poster Titles**

No.	Poster Title	Presented By
1.	A systematic review of Ebola treatment trials to assess the extent to which they adhere to ethical guidelines	Thomas Richardson, University of Birmingham, UK
2.	Medical Intelligence, Security and Global Health: Ethical Challenges for Disaster Response	Gemma Bowsher King's Centre for Global Health, Conflict and Health Research Group, Kings College London
3.	Research in Disaster Settings: A Systematic Qualitative Review of Ethical Guidelines	Signe Mezinska University of Latvia, Riga
4.	Exploring the Intersections between Bioethics and Human Rights in a Humanitarian Medical Aid Organisation working in the Gaza Strip	Hanna Gouta Kings College London
5.	Policy-brief offering recommendations for ethical review in public health emergencies	Janaina Sallas, Pan American Health Organization/ World Health Organization
6.	Presenting a Case Repository of Disaster Research Ethical Issues	Kristóf János Bodnár, Eugenijus Gefenas, Péter Kakuk University of Debrecen, Hungary
7.	Disaster Bioethics: A COST Action Network Addressing Ethical Issues in Disasters	Donal O'Mathuna, Dublin City University
8.	Post-Research Ethics Audit (PREA) for Health Research in Humanitarian Crises	Donal O'Mathuna, Dublin City University
9.	Ethics Case Studies to Build People's Resilience for Disasters	Donal O'Mathuna, Dublin City University

## A SYSTEMATIC REVIEW OF EBOLA TREATMENT TRIALS TO ASSESS THE EXTENT TO WHICH THEY ADHERE TO ETHICAL GUIDELINES

#### Thomas Richardson, University of Birmingham, UK

#### Objective

To determine to what extent studies met criteria specified in the three frameworks for ethical trial conduct.

#### Methods

Data sources: Databases were searched using a specific search strategy. A grey literature search and citation search were also carried out.

Eligibility criteria: Studies were included where the intervention was used to treat Ebola in human subjects regardless of study design, comparator or outcome measured.

#### Results

Included studies: Sixteen studies were included. Data was extracted on information relating to ten ethical areas of interest.

Synthesis of results: Eight studies were judged to fully comply with the criteria. The other eight studies had at least one criteria where not enough information was available. Two studies had ethical concerns relating to at least one ethical criteria.

Description of the effect: One study did not apply for ethical approval as the authors argued that treating approximately one hundred patients consecutively for compassionate reasons did not constitute a clinical trial. In another study the risk-benefit ratio of the drug does not appear to be favourable.

#### Conclusions

Deviating from standard research expectations in disasters to an appropriate extent is accepted. However, guidelines should be adapted to better define the boundaries between using medicines for compassionate use versus in a clinical trial. Greater support should be offered for local research ethics committees to provide robust ethical review. Systematic reviews should be undertaken in future epidemics of novel infectious diseases to assess if comparable findings arise.

## MEDICAL INTELLIGENCE, SECURITY AND GLOBAL HEALTH: ETHICAL CHALLENGES FOR DISASTER RESPONSE

#### Gemma Bowsher, King's Centre for Global Health, Conflict and Health Research Group, Kings College London

Medical intelligence, security and global health are distinct fields that often overlap, especially as the drive towards a global health security agenda gathers pace. The deployment of securitisation discourses alongside the involvement of national and international intelligence organisations presents unique bioethical challenges in complex disaster settings.

The recent Ebola outbreak is one such event that demonstrates the problematic ethical dimensions introduced by an increasingly normative paradigm of threat that sees global health objectives subsumed by national strategic interests. A critical analysis of this epidemic response reveals the tension between operational benefits and ethical concerns in politically defined states of exception; tensions which linger in the discourses surrounding Zika and even the ongoing refugee crisis.

Undertaking a pragmatic approach to disaster response in a security paradigm, we attempt to define a framework that illustrates how medical intelligence can be incorporated into foreign policy action in order delineate the boundaries and scope of this growing field whilst seeking to maintain a space for ethical action.

## **RESEARCH IN DISASTER SETTINGS: A SYSTEMATIC QUALITATIVE REVIEW** OF ETHICAL GUIDELINES

#### Signe Mezinska, University of Latvia, Riga

#### Background

Conducting research during or in the aftermath of disasters poses many specific practical and ethical challenges. This is particularly the case with research involving human subjects. The extraordinary circumstances of research conducted in disaster settings require appropriate regulations to ensure the protection of human participants.

The goal of this study is to systematically and qualitatively review the existing ethical guidelines for disaster research by using the constant comparative method.

#### Methods

We performed a systematic qualitative review of disaster research ethics guidelines to collect and compare existing regulations. Guidelines were identified by a tree-tiered search strategy: 1) searching databases (PubMed and Google Scholar), 2) an Internet search (Google), and 3) a search of the references in the included documents from the first two searches. We used the constant comparative method for analysis of included guidelines.

#### Results

Fourteen full text guidelines were included for analysis. The included guidelines covered the period 2000-2014. Qualitative analysis of the included guidelines revealed two core themes: vulnerability and research ethics committee review. Within each of the two core themes, various categories and subcategories were identified.

#### Conclusions

Some concepts and terms identified in analyzed guidelines are used in an inconsistent manner and applied in different contexts. Conceptual clarity is needed in this area as well as empirical evidence to support the statements and requirements included in analyzed guidelines.

## EXPLORING THE INTERSECTIONS BETWEEN BIOETHICS AND HUMAN RIGHTS IN A HUMANITARIAN MEDICAL AID ORGANISATION WORKING IN THE GAZA STRIP

#### Hanna Gouta, Kings College London, UK

**Purpose:** This research explores how humanitarian workers providing medical aid in the Gaza Strip perceive and experience bioethics and human rights, and investigates how the two concepts interact with each other in this setting.

**Methods:** Qualitative research methods were used to capture the accounts of humanitarian workers of Palestinian Health Aid<sup>1</sup>, a medical aid organisation working in Gaza. Semi-structured interviews were conducted with seven members of the organisation and their narratives investigated using thematic analysis. Participant's referred to concrete examples throughout the interviews generating rich data, and two case-studies on the organisation's programmes were discussed in each interview to provide participant's with the opportunity to reflect on ethical and human rights issues in greater detail.

**Results:** Participants encountered complex ethical challenges in providing assistance and engaged in ethical deliberation in the face of these dilemmas. In some cases, these responses were related to normative frameworks in bioethics and human rights. However for the most part it was demonstrated that ethical decision-making is context-dependent and differs between the participants. It was also found that human rights and bioethics converge in medical humanitarianism over the protection of individuals however how they achieved this in practice differs between the two norms.

**Conclusion:** These results have implications for the development of frameworks for humanitarian workers. Such frameworks need to recognise that norms are dynamic and are reworked on the ground to meet the needs in a given setting. Approaches thus need to engage with the dynamic nature and lived reality of humanitarian aid.

<sup>&</sup>lt;sup>1</sup> A pseudonym to maintain the organisations anonymity

## POLICY-BRIEF OFFERING RECOMMENDATIONS FOR ETHICAL REVIEW IN PUBLIC HEALTH EMERGENCIES

#### Janaina Sallas, Pan American Health Organisation/World Health Organisation

Introduction: Emergencies of new pathogens are not new, but in nowadays, they attract attention because of impacts in public health. Ebola, Zika virus are some examples of emergencies in public health that challenging decision-makers, researchers and populations. Development of new technologies and knowledge is critical to address these public health emergencies, but must forwarding with ethics guidelines. Brazilian regulations and standards of research ethics are available since 1980, however recommendations in how to proceed in public health emergencies doesn't exist (1,2,3). The necessity of establishing ethical review guidelines on research in emergency situations is crucial to ensure and safeguard individuals involved and society in general. Evidence Informed Policy Network by World Health Organization stimulates production of policies-brief based on evidence to support options and decision to solve local problems (4,5). There are some discussions about how realize ethical review in public health emergencies (4,5,6,7,8,9) however there aren't procedures oriented to local strategy. **Objective**: develop ethical review guidelines on research in emergency situations based on evidences to support targeted at filling this gap with decision-makers and also encourage dialogue between actors involved. Methods: exploratory study, observational methods. Results: options identified were development of new guidelines; training of Institutional Review Board/National Research Ethics Committee members and adaptation of Brazil Platform. Conclusions: the options aren't new considering routine process of protocol's ethical review, however approximation of evidences - ethical review and decision-makers is.

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## PRESENTING A CASE REPOSITORY OF DISASTER RESEARCH ETHICAL ISSUES

#### Kristóf János Bodnár, Eugenijus Gefenas, Péter Kakuk

In 2016, as members of the Research Ethics Working Group, we were trying to collect, survey, and systematise information (from published papers to personal recollections) about as many research conducted in disaster setting as possible. The purpose of this project was to map and typologize these disaster-related researches in virtue of the bio- and research ethical issues, questions, or problems involved in those. As a result, our aim was to create a case-repository demonstrating 'typical' research ethical issues pertaining in such contexts, thus attempting to support various stakeholders of disaster research: students, field workers, volunteers and other professionals.

In our poster, on the one hand, we will provide the audience with those cases we have collected and constructed during this process, and on the other, we will present briefly the overall purpose and method of this project, by outlining the prospective outcome of it, i.e. demonstrating the actual form this case-repository will be made available for the target audience in the near future.

#### **E**THICS CASE STUDIES TO BUILD PEOPLE'S RESILIENCE FOR DISASTERS

#### Dónal O'Mathúna, Dublin City University, Ireland; Heather Draper, University of Birmingham, UK; Kadri Simm, University of Tartu, Estonia; and members of COST Action IS1201: Disaster Bioethics

Case studies are an important tool for examining situations which challenge our ability to determine what is right and wrong. Disaster planning includes the need to make ethical decisions such as how limited resources will be distributed. Disaster responders, especially healthcare professionals, are confronted by many ethical dilemmas. Research has identified ethical dilemmas as a regular source of stress and anxiety in responders, often resulting in their unwillingness to return to the field. Other research has found that healthcare professionals usually receive little training to prepare for ethical decision-making in disasters. Training in ethical decision-making through ethics case studies may help to build resilience among those responding to and impacted by disasters.

One aim of the Disaster Bioethics COST Action IS1201 is to improve ethical decision-making in disasters and develop training materials that promote ethical resilience among responders (http://DisasterBioethics.eu). Funded by the European Cooperation in Science and Technology (COST) from 2012 to 2016, the Action has been officially joined by 28 COST countries (mostly European) and members from Africa, Asia, North America and New Zealand. Through this network, ethical dilemmas in disasters were collected and developed into pedagogical case studies. These were piloted in summer schools organised by the Action and in other training programmes for disaster healthcare responders. Feedback from the participants has been collected and used to adapt the case studies. This poster will provide examples of the case studies and the questions used to stimulate ethical reflection, as well discuss the evidence collected during their evaluation.

Presented originally at the United Nations International Strategy for Disaster Reduction (UNISDR) Science and Technology Conference on the implementation of the Sendai Framework for Disaster Risk Reduction 2015-2030 in Geneva, Switzerland (27-29 January 2016).

## DISASTER BIOETHICS: A COST ACTION NETWORK ADDRESSING ETHICAL ISSUES IN DISASTERS

#### Dónal O'Mathúna, Dublin City University, Ireland and members of COST Action IS1201: Disaster Bioethics

Ethical decisions are made throughout disaster risk reduction planning and in disaster responses. Statements like the Sendai Framework stress the importance of making disaster risk reduction more "people-centred," which concurs with the aims of bioethics. To support ethical decision-making regarding disasters, the Disaster Bioethics COST Action IS1201 brings together ethicists, humanitarian responders, international agencies and policy-makers to examine ethical issues in disasters and develop relevant training materials and ethical guidelines. Funded by the European Cooperation in Science and Technology (COST) from 2012 to 2016, the Action has 28 COST countries (mostly European) officially participating as well as members from Africa, Asia, North America and New Zealand (http://DisasterBioethics.eu).

The network has working groups focused on four topics: disaster research ethics, healthcare ethics in disasters, moral theory and culture in disasters, and disasters ethics governance. Research ethics is of particular relevance in the context of the Sendai Framework. Research, data collection, evaluation of policies, and other evidence-generating activities should be conducted within ethical parameters. The Action has examined such issues in various contexts, and contributed to ethical guideline development with WHO, UNESCO and other international organisations. The impact of research on vulnerable groups, especially women, children and migrants, has received special consideration.

Overall, Action IS1201 aims to improve ethical decision-making for disasters by understanding the ethical concerns and dilemmas in disasters, critically analysing the issues, and strengthening ethical resilience through training materials and ethics guidelines. This poster will describe how this has been done and provide examples of the networks outputs.

Presented originally at the United Nations International Strategy for Disaster Reduction (UNISDR) Science and Technology Conference on the implementation of the Sendai Framework for Disaster Risk Reduction 2015-2030 in Geneva, Switzerland (27-29 January 2016).

## POST-RESEARCH ETHICS AUDIT (PREA) FOR HEALTH RESEARCH IN HUMANITARIAN CRISES

#### Dónal O'Mathúna, Dublin City University, Ireland; Chesmal Siriwardhana and Shannon Doherty, Anglia Ruskin University, UK; and the PREA Consortium

The Sendai Framework calls for research and other projects that generate evidence for effective and sustainable disaster risk reduction strategies. All such activities require careful attention to ethical issues. Health research conducted in humanitarian crises faces the usual ethical challenges of ensuring that respect for persons, informed consent, justice and other ethical principles are protected and promoted, while minimising harms of various types. The humanitarian context raises additional challenges from the interaction of different cultures, while the sudden onset of disasters raises concerns about ethical oversight being bypassed or rushed. When women, children, migrants and other vulnerable groups (of special concern in the Sendai Framework) are included in research projects, additional ethical questions arise.

The evidence for the effectiveness of research ethics procedures themselves is limited, especially in disasters. The post-research ethics audit (PREA) aims to explore the ethical challenges experienced during health research in humanitarian crises. The project will gather empirical data from researchers, participants, research ethics committees and others on the ethical issues experienced during disaster research. The first phase is an online survey of researchers and ethics committees involved in disaster research. This poster will present preliminary survey findings and a detailed description of PREA. Using the survey results, in-depth interviews will be conducted with participants experienced humanitarian crisis research. A web-based, globally accessible knowledge platform will be developed and openly available to describe the ethical challenges of health research in humanitarian crises and to share lessons learned from previous experiences of addressing these challenges.

Presented originally at the United Nations International Strategy for Disaster Reduction (UNISDR) Science and Technology Conference on the implementation of the Sendai Framework for Disaster Risk Reduction 2015-2030 in Geneva, Switzerland (27-29 January 2016).