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in Science and Technology
- COST -**

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Secretariat

COST 4136/12

MEMORANDUM OF UNDERSTANDING

Subject : Memorandum of Understanding for the implementation of a European Concerted Research Action designated as COST Action IS1201: Disaster Bioethics: addressing ethical issues triggered by disasters

Delegations will find attached the Memorandum of Understanding for COST Action as approved by the COST Committee of Senior Officials (CSO) at its 185th meeting on 6 June 2012.

MEMORANDUM OF UNDERSTANDING
For the implementation of a European Concerted Research Action designated as
COST Action IS1201
DISASTER BIOETHICS: ADDRESSING ETHICAL ISSUES TRIGGERED BY
DISASTERS

The Parties to this Memorandum of Understanding, declaring their common intention to participate in the concerted Action referred to above and described in the technical Annex to the Memorandum, have reached the following understanding:

1. The Action will be carried out in accordance with the provisions of document COST 4154/11 “Rules and Procedures for Implementing COST Actions”, or in any new document amending or replacing it, the contents of which the Parties are fully aware of.
2. The main objective of the Action is to build an interdisciplinary network of scholars, relief agencies and policy-makers to improve ethical decision-making for disasters by identifying ethical issues in disaster preparation and response, proposing guidelines, and developing training materials and other ethics resources.
3. The economic dimension of the activities carried out under the Action has been estimated, on the basis of information available during the planning of the Action, at EUR 44 million in 2012 prices.
4. The Memorandum of Understanding will take effect on being accepted by at least five Parties.
5. The Memorandum of Understanding will remain in force for a period of 4 years, calculated from the date of the first meeting of the Management Committee, unless the duration of the Action is modified according to the provisions of Chapter V of the document referred to in Point 1 above.

A. ABSTRACT AND KEYWORDS

Disasters overwhelm local and often national capacity to respond effectively. Significant imbalances result between needs and available resources. Disasters have become more frequent and more costly, trends predicted to continue. As a result, disaster risk reduction and management are important priorities for national, European and global agencies. Ethical decisions must be made throughout disaster planning and in responses. High level statements stress the importance of disaster ethics to put people first in disasters. Yet few resources are available for disaster ethics decision-making. Policy makers, humanitarian agencies and individual responders seek ethical guidance and training materials to better address the challenging and distressful ethical dilemmas in disasters. Evidence-based knowledge is required to promote high-quality ethical decision-making.

This Action aims to improve ethical decision-making for disasters by gathering knowledge of the ethical dilemmas and issues, carefully examining them, and developing training materials and published resources to address disaster ethics. These outputs will assist policy-makers, humanitarian organisations, healthcare professionals, researchers and the public. The Action will benefit European citizens, organisations and States who already provide extensive resources for disaster relief. Thereby, the Action will benefit those affected by disasters which disproportionately impact lower income countries and the more vulnerable within those regions.

Keywords: disaster ethics, bioethics, humanitarian ethics, emergency, public policy

B. BACKGROUND

B.1 General background

Disasters are situations that by definition overwhelm the local, and often national, capacity to respond. In these cases, an imbalance between needs and resources is generated. According to the United Nations International Strategy for Disaster Reduction (UNISDR), 2010 was the deadliest year in decades for disasters: 373 natural disasters killed 300,000 people, impacted 200 million more, and cost over US\$100 billion (<http://www.unisdr.org/archive/17613>). Foremost amongst these were the Haitian earthquake that killed over 222,000 people and a heat wave in Russia that killed 56,000 people. 2011 was the costliest year ever for disaster damages, estimated at between US\$350 and \$380 billion, largely due to the Japanese earthquake (<http://www.unisdr.org/archive/24588>). The frequency and cost of disasters are expected to increase significantly in future years (Oxfam 2009 <http://www.oxfam.org/sites/www.oxfam.org/files/forecasting-disasters-2015.pdf>).

Disasters involve many, complex issues with ethical dilemmas prominent. In October 2011, at the second meeting of the European Forum for Disaster Risk Reduction (EFDRR; <http://www.unisdr.org/europe>) held in Macedonia, the Council of Europe committed itself to a new framework for disaster risk reduction. In this, ethics was held to be crucial to putting people first in disaster risk reduction. The first recommendation was to address the ethical aspects of disaster risk reduction through the application of ethical principles.

While high-level statements on disaster ethics exist, many are highly aspirational and require further exploration to permit practical application. Ethical decisions must be made in disaster preparation, and also during responses. But these decisions are highly complex, involve much uncertainty and risk, and in disasters are made in the midst of chaotic and often dangerous situations. They require choosing ‘lesser evils’, rather than ideal solutions. In spite of these challenges, few tools and little training are currently available on disaster bioethics. Governmental agencies and international organizations are seeking ethics guidelines, while individual responders are looking for training programmes to help them cope with and respond to ethical dilemmas.

This COST Action will allow development of a network to address the ethics of disasters. This initiative will address urgent problems and dilemmas that have significant implications for EU Member States given the level of funding and resources committed to disaster relief. The EU's humanitarian aid office, ECHO, allocated more than €900 for emergency relief in 2009 (<http://europa.eu/pol/hum/>). Other European-based non-governmental organisations (NGOs) and individuals are involved in providing aid. Europe is headquarters to many international organisations involved in disasters and global bioethics, including the World Health Organization (WHO), International Federation of Red Cross and Red Crescent Societies (IFRC), Médecins Sans Frontières (MSF) and the United Nations Educational, Scientific and Cultural Organization (UNESCO). It is appropriate, therefore, that European researchers, in collaboration with others around the world, take steps towards an integrated and coordinated approach to disaster bioethics. This Action will allow scholars, humanitarian organisations and policy-makers to grapple with the challenging and complex ethical issues faced during disasters.

This initiative is best addressed as a COST Action for a number of reasons. First, it will further develop a group of interested researchers, organizations and policy-makers who have established links and are already engaged in identifying core ethical issues. The Action will establish a clear programme of work, a structure for the network and a platform from which related research projects can be initiated. Second, relatively little research has been conducted on disaster bioethics. A network of those interested in the topic will allow the development of innovative research projects. Third, disasters raise ethical challenges for individuals and societies, often involving people from different cultures, and focused on health needs. These areas fit precisely into the focus of the ISCH domain of COST. In addition, the field of bioethics uses diverse philosophical and social science methods to address questions best facilitated by a broad network of individuals such as COST funds. The nature of disasters requires an international and pan-European response involving cooperation between COST and non-COST researchers and international organisations and policy-makers such as this Action has brought together.

In recent years, Europe has not seen the scale of destruction visited upon places like Haiti and the countries impacted by the 2004 Indian Ocean tsunami. However, Europe has a humanitarian responsibility to help others prepare for disasters. The 2011 Great East Japan earthquake and 2005 Hurricane Katrina are reminders that high-income countries are not immune from disasters' devastating effects. Europe is impacted by disasters regularly, such as Winter storm Xynthia in 2010 that killed 53 people in France and more in neighbouring countries, leading to damages valued in billions. The L'Aquila earthquake in Italy in 2009 left 308 dead, 1600 injured and 60,000 people displaced. This Action will develop resources to help European governments, organizations and individuals so they can provide the maximum assistance when faced with disasters.

B.2 Current state of knowledge

Widespread agreement exists that ethical issues occur throughout disaster management and response. The International Federation of Red Cross and Red Crescent Societies (IFRC) has a Code of Conduct for disaster responders dating from 1994 (<http://www.ifrc.org/en/publications-and-reports/code-of-conduct/>). In 2006 the World Medical Association issued a *Statement on medical ethics in the event of disasters* (<http://www.wma.net/en/30publications/10policies/d7/index.html>). Some qualitative research conducted by Canadian and Australian researchers has identified ethical dilemmas facing healthcare responders and researchers. These situations can lead to moral distress, which sometimes incapacitates responders, hinders them returning to the field, or leads to long-term psychological problems (Alexander & Klein, *Prehospital and Disaster Medicine* 2009;24:87-94). Canadian research found that volunteers are provided little ethics guidance or training (Schwartz et al. *AJOB Primary Research* 2010;1:45-54). The challenge for healthcare professionals trained in and with experience from high income contexts arriving in a low income, resource scarce disaster setting is enormous.

Disaster relief workers in particular, and humanitarian aid workers in general, are increasingly called upon to make evidence-based decisions. More disaster research is being conducted to provide such evidence. As with any area of research involving human subjects, ethical issues arise. Previous reviews of disaster responses have identified unethical research practices (Sumathipala & Siribaddana, *Lancet* 2005;366:1418-20). In a small number of cases, international controversy has arisen. In other cases, disaster survivors have been left with a negative view of research, which has hampered efforts to conduct further important research (Pittaway et al. *Journal of Human Rights Practice* 2010;2:229-251).

While the importance of disaster research cannot be denied, no internationally agreed guidelines or codes exist for research in disaster settings. A working group set up after the 2004 Indian Ocean Tsunami has developed draft guidelines for disaster research (Sumathipala et al. *Asian Bioethics Review* 2010;2:124-142). Médecins Sans Frontières (MSF) has developed processes to ethically review their disaster research projects (Schopper et al. *PLoS Medicine* 2009;6:e1000115). The problem is exacerbated by the fact that international humanitarian law applies only to war-zones. Indeed, one of the most urgent and hitherto unaddressed issues is the legal status of disaster relief teams in terms of fundamental issues such as licensure, informed consent, neutrality and accountability.

People involved in the initiatives mentioned above have participated in developing this Action. The participants link research and work in the field, which will lead to outputs that will be pragmatic and of relevance in the field and for policy-makers. The network will engage with alumni from the Emergency Management and Disaster Medicine (EMDM) Academy (www.dismedmaster.com) which includes about 400 doctors from 67 different nations around the world. The EMDM Academy (www.emdmacademy.org) includes 16 educational and research centres which produce research and education in the field of disaster medicine. Other network members are involved with the International Federation for Emergency Medicine in developing ethics guidelines. The network already includes representatives from a number of international humanitarian organisations. By having these organisations directly involved in the Action, the potential to influence international policy and ethical guidelines will be strengthened. The Action plans to expand its network to include those who have been through disasters, responders, and researchers from around the world.

Bioethics as an academic discipline and a part of clinical practice is already quite established through EU research, but this project would extend this into a novel area. Recent FP7 Security Calls on disaster response include examination of ethical issues. However, the ethical issues have been one piece of a larger issue (for example, http://www.cssc.eu/projects_details.php?project_id=4&stato=0). In this Action, disaster ethics will be the central focus. Considering the number of projects dealing with disasters and their risks in the FP7 framework, Europe is well advanced in this general field. However, bioethics funding has been directed more to new technology and disease-specific issues. This network will allow Europe to become a global leader in disaster bioethics.

B.3 Reasons for the Action

This COST Action will bring together those with experience of responding to disasters to engage with bioethics experts and policy-makers. International humanitarian organisations regularly publish reports on their activities and challenges. This Action will identify where ethically relevant analyses have already been undertaken on the most significant ethical issues in disasters. One of the criticisms made about current ethics training is that it is more applicable to higher-income settings than to low-income settings where disasters frequently occur. Innovative, disaster-focused, ethics training materials are needed which take account of careful theoretical reflection as will occur in this Action.

The Action will benefit survivors of, responders to, and researchers of disasters, as well as those funding and coordinating disaster responses. The outputs of the Action will be proposals for ethics guidelines, policy proposals, training materials, academic publications and research proposals. Resources will be made available publicly, developed into disaster bioethics curricula, and distributed to engage with policy development. The positions developed for workshop and conference presentations will be published to encourage wider debate and further scholarship. These meetings will provide opportunities for early stage researchers to engage with those with more experience and from different backgrounds and disciplines.

B.4 Complementarity with other research programmes

Disaster Bioethics is of relevance to the FP7 Security and Health programmes. However, the field is at a very early stage of development. For this reason, COST is more suitable to allow a network to develop, from which proposals for research projects will develop. Other networks are developing, such as the Canadian one mentioned above. A workshop on disaster ethics was held in London in January 2012. Some of the participants in this proposal were present and interacted with other researchers and NGOs. Another of the Action's participants has applied to the German funding body, Minerva (<http://www.minerva.mpg.de>), to establish a centre for multidisciplinary research on disaster and humanitarian medicine which will examine ethical issues. The whole field is at an early stage of development, making this an opportune time to initiate this Action.

C. OBJECTIVES AND BENEFITS

C.1 Aim

The main aim of the Action is to improve ethical decision-making for disasters by gathering knowledge of the ethical dilemmas encountered in disaster settings and by developing training materials and resources for tackling these dilemmas that will assist policy-makers, humanitarian organisations, healthcare professionals, and researchers.

C.2 Objectives

By developing a network of ethics researchers, disaster responders and policy-makers, this Action will produce substantial benefits for European society and beyond. In particular, it will:

- Create and develop an interdisciplinary network of scholars, relief agencies and policy-makers to address Disaster Bioethics
- Engage with practitioners and policy-makers to identify ethical issues and ensure that ethical principles are promoted in disaster responses and that ethics training is incorporated into disaster preparations

- Enhance the protection of and respect for disaster survivors by promoting ethical decision-making, behaviour and character development among all involved with disasters
- Develop training materials aimed at reducing the moral distress of responders entering disaster settings
- Stimulate active scholarly discussion of and interest in research into Disaster Bioethics and pursue funding for such activities

C.3 How networking within the Action will yield the objectives?

Interaction and dialogue facilitated by COST are the primary means by which this Action will achieve its objectives. This will be facilitated in the Action through the following means.

- Organise annual workshops to allow co-production of knowledge between academics, professionals, humanitarian organisations and policy-makers to consolidate insight into the ethics of disasters and to develop various resources

These workshops will allow network participants to present their on-going scholarly engagement with Disaster Bioethics. Presentations from early stage researchers will be encouraged at each workshop. Arising from the discussions at the workshops, various Action resources will be published, including publications, policy-proposals and training materials. Each meeting will also be used to identify specific ethical topics that need to be researched or analysed in more detail.

- Facilitate Short Term Scientific Missions (STSM)

The specific ethical issues identified in workshops will become the subject of STSMs. Examples could include principles for triage, vulnerability in disaster research, ways of balancing speed with careful planning, mechanisms for ethical review of disaster research, to name a few. The Action will develop an efficient mechanism by which teams will develop at workshops and apply for an STSM. Each mission will meet for in-depth analysis of specific issues and lead to a presentation at the next workshop and contribute to a publication or guideline development. These missions will ensure early stage researchers have opportunities to interact with senior scholars.

- Disseminate the resources produced by the Action

A website will be developed to facilitate resource dissemination. Publications will be made available on an open-access basis to maximise exposure for the materials. Other workshop presentations will be published in two edited volumes, one on research ethics in disaster contexts and the other on ethical decision-making for healthcare practitioners during disasters. The Action proposers have experience publishing edited volumes.

- Organise summer schools on disaster bioethics

The resources developed by the Action will be formulated into curricular materials for a disaster bioethics summer school. A series of case studies will be developed for this. The summer school will be organised in conjunction with the Faculty of the EMDM Academy, already involved with the network. Early stage researchers will be given the opportunity to teach in the summer school to assist their development as academics. The first of these training schools will be focused exclusively on early stage researchers.

- Propose ethical guidelines for those addressing medical and healthcare needs during disasters and engaging in research during disasters

Proposals will be developed for use by other organisations in developing ethical guidelines for their members and activities. Policy-makers and representatives of international organisations will provide input into how best the Action can assist policy-makers and international organisations as they develop such guidelines. The resources and expertise developed within the Action will be actively brought to the attention of policy-makers addressing disaster preparedness. Methods of evaluating the impact of guidelines will be developed also.

- Develop research proposals on high priority disaster bioethics topics for submission to relevant funding agencies

The Action will identify topics for further research and seek funding for them. The network will assist in bringing together research teams that can engage in such research. The Action will encourage application to various research funding agencies to allow such research to be carried out. Each research team will be encouraged to include early stage researchers.

C.4 Potential impact of the Action

The Action aims to impact ethical decision-making at many levels and thus to have a significant impact in disaster planning and response. Disasters are expected to increase in frequency and destructiveness, leading to massive needs. The resources from this Action should improve ethical decision-making to ensure disaster planning and responses are ethically appropriate. The Action will benefit responders and researchers going into the field by helping them become better prepared to address ethical dilemmas and therefore be more efficient in the field. Disaster researchers will benefit from having ethical guidelines for their projects, which will also assist agencies and policy-makers overseeing or approving such research. International agencies coordinating disaster responses and risk reduction will be able to use the resources from the Action to assist in their planning and policies. This will benefit EU member states and citizens, along with the recipients of European assistance. Ultimately, those who suffer the devastating effects of disasters will benefit through having responders who are better prepared to manoeuvre through the ethical dilemmas they face.

C.5 Target groups/end users

This COST Action targets academic and non-academic end users. Various academic research centres and researchers will be brought together through the Action. These come from a wide range of countries across Europe, and include some non-COST countries. The academic projects will be targeted towards early stage researchers and ensure gender balance is taken into account. Concerns about ethics and gender will also be examined. The Action will produce information that is useful for policy-makers and international relief agencies.

Other non-academic end users include healthcare humanitarian organisations and disaster responders. Given that many individuals may find themselves faced with disasters, the resources available on the Action website will include some targeted at the general public. An explicit effort will be made to have the resources available in a number of languages.

D. SCIENTIFIC PROGRAMME

D.1 Scientific focus

Bioethics research is characterised by multi-disciplinary methods and active involvement between professionals including those affected by disasters. These approaches will be emphasised within this Action. Those already involved in the Action are actively involved in research projects and policy development within their own institutions and organisations. The results of this research will feed into the work of the Action. During meetings, the resulting feedback and discussions will be incorporated into the on-going projects.

The first step in bioethics is identification of ethical issues. Those who took the initiative to propose this Action are in dialogue with Canadian researchers who have been conducting qualitative research involving healthcare responders to disasters. Their research has identified the urgent need to address ethical issues, and some of the specific dilemmas that can arise (Schwartz et al. *AJOB Primary Research* 2010;1:45-54). During Year 1 of the Action, the focus will be on identifying ethical issues as revealed in various research projects around the world. A systematic search of published literature, organisational reports and government agencies will be conducted. The Action network will use its broader contacts and networks to identify such issues and proposals made to address them. A strength of the Action is the involvement of international humanitarian organisations. Their extensive networks within the humanitarian community will enable the Action to identify relevant reports, and also gain access to, and engage with those who have extensive field experience and who will be able to identify significant ethical dilemmas that require further analysis. This will provide an important means of checking that most major ethical dilemmas have been identified.

Years 2 and 3 will focus on analysis of the identified ethical issues. Smaller research teams will be formed to focus on specific issues, with STSMs used to provide concentrated time for discussions. One of the methods used widely in bioethical research is casuistry. This involves the analysis of case studies to identify general principles and develop paradigm cases. These allow the presentation of various perspectives with a goal of finding common grounds for resolution. The Action will also test and validate the relevance of the key principles in the field and involve disaster affected people. At the very least, this method will allow the views of different actors to be presented, presumptions to be identified, and active dialogue to occur on the substantive issues.

During this phase, each STSM will develop a case focused on the issue it examined that will assist discussions at workshops. These will be elicited from those with field experience, bioethics expertise, and policy background. In bringing together people with diverse backgrounds, a variety of perspectives will be heard at the workshops. The discussions will lead to the identification of substantive issues that require further ethical analysis in STSMs. The workshops will also allow the development of paradigm cases which are both realistic and able to stimulate deep ethical reflection. These will be fed into the materials being developed for incorporation into the training programmes and guidelines.

The third phase of the Action, Year 4, will be focused on guideline development. The in-depth discussions in Years 2 and 3 will be brought together to focus on general principles for disaster responders, researchers and policy-makers. The different working groups discussed below will target the different audiences. The multi-disciplinary composition of the Action will assist here. Some of those involved in proposing this Action have had considerable experience developing and promoting the UNESCO Universal Declaration on Bioethics and Human Rights (2005). This will provide guidance as the cases and detailed discussions are developed into guideline proposals. The involvement of international agencies within the Action will be of considerable value in this phase also.

Many ethical issues in disasters involve cultural issues that need to be addressed also. One of the participants who helped to prepare this Action has had a prominent role in the Working Group on Disaster Research and Ethics (WGDRE). This group was constituted after the 2004 Indian Ocean Tsunami in response to ethical concerns about some disaster research. This researcher is based in a COST country, but has close ties to an Asian network addressing disaster bioethics. This will enable the Action to have wider collaboration with Asian researchers and scholars, and assist in including various cultural perspectives. The Action proposers have collaborative links with South Africa, which has a reciprocal agreement with COST. The involvement of these researchers will add another important cultural dimension to the Action.

D.2 Scientific work plan methods and means

Bioethics is an interdisciplinary field, providing a range of methodological and analytical tools that are well-suited to an issue as complex as disaster bioethics (Ives & Draper, *Bioethics* 2009;23:249-58). To allow focused work on each of the objectives, four Working Groups (WGs) will be established. Each WG will ensure that particular deliverables are produced.

Working Group 1: Healthcare ethics

Healthcare needs are a priority in responding to disasters. However, as noted in Section D.1, medical, nursing and other healthcare professionals encounter significant ethical dilemmas. This WG will identify the significant ethical issues in providing disaster healthcare, engage in ethical reflection on those issues (particularly through focused STSMs), and develop principles for ethics guidelines and other resources for healthcare professionals. Issues that require further ethical analysis include working in dangerous and vulnerable environments, approaches to triaging casualties, working outside one's professional scope of practice, conflicts between different professionals, dealing with cultural differences in decision-making, and many others. For example, triage decisions should be based on needs, but this can lead to people of certain age, gender or disabilities being treated differently; another question is whether amputations be done for short-term benefit when long-term rehabilitation is unlikely to be available, severely impairing amputees' quality of life and livelihoods; ethical issues in palliative care during disasters require consideration.

This WG will also carefully analyse approaches to ethical decision-making. Ethics training from high-income settings can create problems when applied in low-income or disaster settings. Healthcare professionals are confronted with having to make decisions when all options violate some ethical principle. This can be the source of moral distress, which adds another burden to responders which can become debilitating. This has led to the call for alternative approaches to ethical decision-making in ‘non-ideal’ situations (Tessman L. *Hypatia* 2010;25:797-824). This has much relevance for disasters, but requires extensive and careful analysis to develop practical approaches. WG1 will examine such non-ideal moral theories and their relevance for disaster bioethics, and develop theoretical approaches that are practically useful.

Working Group 2: Bioethics, culture and moral theory

Disasters often strike in one culture and lead to responses from other cultures. Ethical dilemmas arise when important values and beliefs are viewed and prioritised differently in different cultures. For example, fairness is an ethical principle valued across cultures, but viewed and implemented differently in different cultures. Gender issues will be examined in particular as these can generate challenging ethical issues. The Action’s network includes participants with experience in gender issues. As another example, burial practices are very important culturally, but may be resource intensive. Those from another culture may seek to expedite burials or use mass graves for pragmatic purposes. Cultural issues are involved here, but so too are ethics. The distress caused by preventing the usual burial and grieving process, or interfering with identification of the dead, can influence the recovery of a community (Morgan et al. *PLoS Medicine* 2006;3:e195). This research also found that the health risk from large numbers of dead bodies after a natural disaster is negligible, exemplifying how evidence is important in ethical decision-making.

This WG will gather information on significant cultural challenges in disaster settings. The Action benefits from having participants who have wider networks in Europe, Asia, Africa and North America. Further connections will be established through the international organisations involved in the Action. From this review, the main ethical issues will be identified and analysed in STSMs. From these deliberations, proposals will be developed for ways of addressing cultural differences and the resulting ethical challenges.

Another aim of WG2 is to address the role of ethical theory in disaster bioethics. Ethical decisions are strongly influenced by ethical theories, but each has strengths and limitations, especially when applied in disaster settings (Agency for Health Care Research and Quality 2006 <http://www.ahrq.gov/research/mce/>). In disaster planning, consequentialist approaches can conflict with duty-based approaches. Conflicts can occur within one approach, where duties to patients or society may conflict with duties to family or self. This WG will investigate broad ethical concepts and theories and their place in disaster bioethics. It will aim to make proposals on a theoretical framework in which cultural differences and community norms are addressed and respected while ways of resolving differences are pursued. An algorithm for disaster bioethics that is theoretically sound and practically useful will be developed within WG2.

Working Group 3: Research ethics

Evidence-based approaches to disaster planning and responding are increasingly being demanded. However, the evidence is lacking for many decisions, or is of poor quality. As noted in the Mid-Term Review of the UNISDR Hyogo Framework for Action, ‘much of the existing operational research related to emergencies and disasters lacks consistency, is of poor reliability and validity and is of limited use for establishing baselines, defining standards, making comparisons or tracking trends’ (UNISDR 2011 *Hyogo Framework for Action: Building the Resilience of Nations and Communities to Disasters 2005-2015 Mid-Term Review*, p.46). More research is needed in disaster settings, but this means that research ethics must be addressed.

This WG will identify where work has occurred in disaster research ethics, engage in ethical reflection on the main ethical issues, and make proposals for ethics guidelines and resources to assist those commissioning, conducting or overseeing disaster research. As mentioned above, one of the participants in the action has extensive experience in disaster research ethics through the post 2004 tsunami Asian Working Group on Disaster Research and Ethics (WGDRE). These guidelines are in draft format and require further development. WG3 will examine specific research ethics issues in detail during STSMs. These will include such issues as: conflict of interest, informed consent, vulnerability of disaster survivors, seeking approval for and initiating research shortly after a disaster strikes, and the importance of completing required follow up and pursuing timely publication. WG3 will examine the MSF model for research ethics review and other proposals to identify strengths and weaknesses in the various alternatives.

Guidelines for intervention research ethics exist, but other research methods are used frequently in disaster settings. For example, social science research methodologies raise similar but also distinctive ethical issues. For example, interview research has often viewed interviewees as collaborators, rather than research subjects. This has created dilemmas over ‘ownership’ of data, and expectations among participations that research projects will lead to significant benefits. Such methodologies have received less explicit analysis in disaster settings, and will be examined by WG3 also.

Working Group 4: Ethics and governance

Ethics and governance are closely linked, especially in international policy and law. Governance addresses a broader range of issues, which includes ethics. Together, these promote good policies and high standards in disaster risk reduction and disaster risk management. Disaster preparedness and responses raise many ethical issues, such as vulnerability, susceptibility and community resilience, inequalities of disaster risks and impacts, accountability, balancing sustainability and development, and how people’s rights are respected. Planning involves priority setting which involves ethical decision-making. The UNISDR Hyogo Framework notes that policies for disaster preparedness must be implemented in an ethical fashion ([http://unocha.romenaca.org/Portals/0/Docs/Disaster-Preparedness-for-Effective-Response\[1\].pdf](http://unocha.romenaca.org/Portals/0/Docs/Disaster-Preparedness-for-Effective-Response[1].pdf)). For example, UNISDR has identified vulnerability as a key principle in setting priorities. Some of the most vulnerable people during disasters are children in schools and patients in hospitals, which has made the planning and building of safe schools and hospitals a high priority (<http://www.unisdr.org/we/campaign/schools-hospitals>). This WG will examine the interplay of ethics and governance in setting such priorities and the standards by which initiatives will be measured.

WG4 will, like the others, begins with a systematic review of existing reports and policies in this area and identify specific issues which require further ethical analysis. STSMs will be developed to allow focused, in-depth investigations into specific issues. Having international organisations in the Action will facilitate the identification of issues requiring analysis, and provide an avenue by which conclusions and recommendations from the Action can be brought to the attention of policy-makers.

Such work fulfils one of the requirements identified in the Chair's Summary from the May 2011 Global Platform for Disaster Risk Reduction. According to this, political entities should: 'Actively engage and support scientific and technical communities to inform decision-making.' (<http://www.unisdr.org/we/inform/publications/19947>). In other words, policy-makers at the highest levels will benefit from the type of outputs this Action will provide.

E. ORGANISATION

E.1 Coordination and organisation

The Action will be carried out by the participating COST Countries in accordance with the usual COST structure. This will involve a Management Committee (MC) directed by a Chair, and four Working Groups (WGs). Representatives of early stage researchers will be invited to the MC and all efforts will be made to encourage gender balance in the MC.

The MC will be responsible for coordinating the Action. A Steering Group (SG) will be appointed to support the MC in managing the day-to-day activities of the Action, in conjunction with the COST office. The SG will be composed of the MC Chair, Vice-Chair, WG chairs, and an STSM Coordinating Officer. If deemed necessary, additional appointments will be made to SG, such as a summer school Director or editorial board Chair. The SG will report to the MC at its annual meeting. The SG will meet quarterly, or as deemed necessary by the MC Chair. Such meetings will take place virtually where possible, using video-conferencing or web-based facilities.

The Action will hold an annual workshop/conference to give researchers the opportunity to present their on-going work in the area. Each workshop will focus on a particular ethical challenge, although opportunities to present on any disaster bioethics topic will be available. Presentations relevant to the workshop topic will be invited from appropriate experts, disaster response organisations or policy-makers. A proportion of the presentations will be reserved for early stage researchers. Time for active engagement between practitioners and bioethicists will ensure ethical rigour and practical relevance. At the end of Year 4, this event will be a major international conference to show-case the Action's work and ensure the initiative is continued.

The MC and WGs will hold meetings in conjunction with the annual workshop. The WGs may organise other meetings during the year as the need arises to allow their work to progress.

Smaller research teams will be developed within the Action to address specific topics. These teams will organise Short-Term Scientific Missions (STSMs) to permit intensive collaboration on their topics. Each team will appoint a host institution to coordinate the details of each STSM. Significant efforts will be made to encourage early stage researchers to be actively involved in these missions.

E.2 Working Groups

As described in D.2, this Action will contain four WGs:

- Working Group 1: Healthcare ethics
- Working Group 2: Bioethics, culture and moral theory
- Working Group 3: Research ethics
- Working Group 4: Ethics and governance

Each WG will have a chair and vice-chair, selected by and reporting to the MC. Each WG chair will be a member of the SG to ensure close collaboration between all the WGs. The chair and vice-chair of each WG will coordinate its activities and ensure outputs are produced. They will prepare a report to be given at each annual workshop and a Final Report at the conclusion of the Action. Active involvement of early stage researchers will be encouraged in all WGs, which should make every effort to achieve gender balance. The structures of the WGs may be modified during the Action by the MC if needed to facilitate delivery of the Action's objectives.

E.3 Liaison and interaction with other research programmes

Relatively little research and few initiatives exist in disaster bioethics, although during Year 1 of the Action, an extensive search will be made for activity in this area. Identified research programmes will be interacted with to identify areas of mutual collaboration and avoid unnecessary duplication of effort. As mentioned in Section D.1, the Action's proposers are already cooperating with Canadian, Asian and South African researchers in this field. International organisations with an active stake in disaster bioethics have participated in and encouraged development of this Action. This Action will bring together many European researchers with an active interest in this new and emerging research area.

E.4 Gender balance and involvement of early-stage researchers

This COST Action will respect an appropriate gender balance in all its activities and the Management Committee (MC) will place this as a standard item on all its agendas. The Action will also be committed to involve early stage researchers considerably. This item will also be placed as a standard item on all MC agendas. Examination of gender-related aspects of disaster ethics will be encouraged.

Gender balance and early stage researcher involvement will be promoted in all activities of the Action, including the composition of the MC, SG and WGs. When selecting presenters for workshops and conferences, and teams for STSMs, these issues will be given careful attention. New and innovative approaches to gender balance, such as those developed by the FP7 project GENDERA (<http://www.gendera.eu/>), will be pursued to ensure best practice is followed.

A training school and workshop for early stage researchers will be organised at the end of Year 1. In addition to allowing early stage researchers to present their work, this school will provide practical training in research funding applications and publishing peer-reviewed articles, skills which are not as commonly addressed in bioethics training as they would be in other sciences. Early stage researchers will be involved in planning this school to ensure the programme is developed according to their perceived needs.

F. TIMETABLE

The duration of the Action will be four years. An inaugural meeting will be held at the start of Year 1 to establish the MC, SG and WGs. These will establish the definitive work plan of the Action and timelines in accordance with COST guidelines.

The following table shows the timetable for the main Action activities. STSMs will be organised on an on-going basis as the research teams organise themselves. Each research team will establish a strategy for their work which will be proposed to the SG and adopted or modified before approval. The MC will review the progress made by each of these teams at the annual meeting. At the mid-term meeting of the Action, the structure and productivity of all WGs will be evaluated to determine if revisions are necessary.

	Year 1		Year 2		Year 3		Year 4	
	Early	Late	Early	Late	Early	Late	Early	Late
Inaugural MC meeting	X							
MC meeting		X		X		X		X
Annual Conference		X		X		X		
SG meeting	X	X	X	X	X	X	X	X
WG meetings		X		X		X		X
Early stage research training		X						
Disaster bioethics Summer School				X		X		
International conference								X
Final Report								X

G. ECONOMIC DIMENSION

The following COST countries have actively participated in the preparation of the Action or otherwise indicated their interest: CH, EE, HR, IE, IL, IT, LT, NL, SE, TR, UK. On the basis of national estimates, the economic dimension of the activities to be carried out under the Action has been estimated at 44 Million € for the total duration of the Action. This estimate is valid under the assumption that all the countries mentioned above but no other countries will participate in the Action. Any departure from this will change the total cost accordingly.

H. DISSEMINATION PLAN

H.1 Who?

The Action's dissemination plan will target the following audiences:

- Bioethics researchers and disaster researchers in universities and other research organisations both within Europe and beyond
- Humanitarian organisations responding to disasters with aid or personnel
- Healthcare professionals and researchers planning to work in the aftermath of disasters
- Policy makers in COST Countries and international organizations involved in disaster response planning
- The general public through the Action website

Given that each of these audiences will have different interests and requirements, a variety of dissemination strategies are planned as detailed below in H.2. The MC will develop a strategic plan for dissemination and encourage dissemination by all Action participants. The plan will be evaluated and may need to be updated as the Action progresses.

H.2 What?

All members of the Action will promote its activities on their websites and give due credit to the network when giving presentations. They will be encouraged to pursue media coverage where appropriate, especially given the public interest in this topic. The role of COST is facilitating this work will be referenced.

The Action will develop its own website to promote activities and disseminate resources in an open-access format. The website will be overseen by the SG, with all WGs expected to regularly provide materials based on their on-going work. The website will have a private component to facilitate the work of the Action, but much of it will be publicly available. One area will contain the training tools and other resources developed to assist the public and professionals. Forums will also be established to permit discussion of ethical cases and topics. These will aim to facilitate public awareness of and discussion about disaster ethics which is a high priority for UNISDR and other international disaster risk reduction agencies. The website will allow people to comment on the ethical cases and issues so that everyone can learn from the experiences of those who have been through a disaster or involved in responding to one.

For academic audiences, the Action aims to publish two academic volumes during its time. One of these will focus on healthcare ethics in disasters and the other on disaster research ethics. Contributions will be developed from presentations made at various Action meetings, especially the themed annual workshop. Action participants will be encouraged to publish peer-reviewed journal articles and make presentations at scientific meetings. Early stage researchers will be provided peer review and editorial assistance by others within the Action to facilitate publication.

The annual workshop will be held as a satellite meeting to a major conference where possible. For example, some researchers involved in the Action are also involved in the European Society for Philosophy in Medicine & Healthcare (<http://espmh.org/>). The European Society for Emergency Medicine has a section in Disaster Medicine and could be another venue for a satellite conference. Holding the conference in association with such meetings will allow opportunities for future dissemination.

Dissemination aimed at policy-makers is another aim of the Action. Those from the international humanitarian organisations involved in the Action will be able to report into their organisations via their internal channels. Participants in the Action will be encouraged to organise meetings with these and other organisations to help in policy and guideline development.

H.3 How?

The website will be used to provide material written for the general public as well as researchers and professionals. The website will also be used to make announcements related to events being organised by the Action or of interest to those engaged with disaster bioethics. As relevant funding opportunities are identified, and research projects develop, information on these will be circulated through the website. In this way, the website will become a significant information hub for those interested in disaster bioethics.

The publications and presentations arising from the Action will be a means of informing academics about the Action and the benefits of COST. These will contribute to one of the Action's objectives of stimulating scholarship and research into disaster bioethics.

The dissemination strategy will be broad, requiring diverse methods. The aim is to provide knowledge that helps the public, disaster responders, researchers and policy-makers. For this reason, a variety of methods will be used, with regular attention paid to new methods – such as the role of social media, Twitter, etc. and whatever innovative approaches will be available by the time the Action comes to completion.
