

Creating and enhancing **TRUST**worthy responsible and equitable partnerships in international research

eNewsletter 2018, Issue 5

"TRUST Global Code of Conduct to be a reference document applied by all research projects applying for H2020 funding"

Speech by Dr. Wolfgang Burtscher, Deputy Director-General of the Directorate-General for Research and Innovation of the European Commission Final TRUST event at the European Parliament in Brussels

"I am very pleased to be here at this conference. I would like to take this opportunity to thank the organisers, the partners, the Co-ordinator of this great research project. You have done an excellent job. I would also like to extend my thanks to the European Parliament for providing the opportunity to present the impressive results of the TRUST project.

Now, it is true that being open to the world, for both research and innovation, is one of the cornerstones of Horizon 2020, the EU's Research and Innovation Framework Programme, because it provides huge opportunities in scientific and technological terms. However, we are also aware that the globalization of research and innovation activities has a less appealing side too. Operating at a global level increases the risk that improper practices are carried out in countries with more permissive regulatory frameworks and lacking adequate oversight mechanisms.

This leads in many cases to the exploitation of research participants and local communities. (...)

When low and middle income countries are involved, the focus should be on empowering local communities. Researchers conducting research in such countries should consider how their activities respond to local needs and establish fair benefit-sharing measures. This includes, whenever possible, effective capacitybuilding. With Horizon 2020, the European Commission was amongst the first research

funders to actively deter ethics dumping, by mandating that funding cannot be granted for activities carried out outside the European Union if such activities are prohibited in Member States.

This concretely means that the projects must comply not only with the laws of the country where the research is conducted but also with EU ethical and legal standards. (...)

We should be clear that there can be no compromises when it comes to ethics. Justice, responsibility and sound judgement should be the guiding principles for research in third countries. Researchers should be conscious of their responsibility to uphold high standards of research and ethics. At the same time, they should keep an open mind, respecting the specificities of each cultural context.

In this context, the work of TRUST, which constitutes a Horizon 2020 success story, demonstrates that, in order to actively combat ethics dumping, a coordination of stakeholder efforts is required. Moreover, following the example of TRUST, such efforts should be based on a bottom-up approach that empowers local communities involved, as equal partners. (...)

I have had a very close look at the Global Code of Conduct that you have proposed, and I really find it impressive. We have decided that in order to take a concrete step forward, we will put it on our so-called participant portal of



Dr. Wolfgang Burtscher

Horizon 2020 as a reference document to be consulted and applied by all relevant research projects, and to serve as an education tool for the younger generation of researchers. We are sure that this participant portal is highly visited. Over the last four years, we have had over 170,000 applications for funding under Horizon 2020 so I really think that this is an appropriate tool for making your code known to the research community.

The real value added of these guidelines will be clear when each and every one of us, when doing, reviewing and monitoring research, insists on the application of the principles enshrined in your document."



The TRUST project

The TRUST Project is an EU funded project which aims to **catalyze a global collaborative effort to improve adherence to high ethical standards around the world**.

In an interdisciplinary collaboration between multi-level ethics bodies, policy advisors, policy makers, civil society organisations, funding organisations, industry, and academic scholars from a range of disciplines, this project combines long-standing, highly respected efforts to build international governance structures with new exciting network opportunities in **Europe**, **India, Sub-Saharan Africa, China and Russia**.

Read more at www.trust-project.eu/

Major TRUST event successfully held at European Parliament

On June 29, 2018, TRUST co-hosted its main dissemination event with the European United Left/Nordic Green Left European Parliamentary Group.

The event was a major success.

The following is a summary of the key messages and achievements.

We would like to let quotes from delegates speak for themselves.



TRUST Team at final event

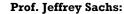
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Joyce Adhiambo Odhiambo, PHDA:

"We want respect from researchers. Is that too much to ask?"



"The world is unfair. We are talking about R&D in an unfair world... The Code of Conduct is exquisitely clear that it is unethical to do research in one place for the sake of another."



© Amy Azra Dean



Prof. Doris Schroeder, UCLan:

"We believe that it is important that equitable research relationships are not governed by something complicated that is unrelated to morality in normal life."



Dr Michael Makanga, EDCTP:

"Research which is unethical in Europe is unethical in Africa."



Prof. Klaus Leisinger, FGVA:

"If we use this Global Code, we avoid many problems."

South African San Council:

"What does the San community want? We don't want to be exploited anymore. We want to be respected. We want justice."

Leana Snyders,

TRUST major event continued...



Dafna Feinholz, UNESCO:

"Research and innovation are needed to face humanity's challenges. But they need to be done in an ethical manner."



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Dorian Karatzsas, EC

"We heard that ethics is out of range outside of Europe. Through Commission leadership, this was not accepted."





Dr Mahnaz Vahedi, TDR:

"My message here is that ethics dumping can be mitigated when ethics committees in resource-poor settings are equipped to review a broader spectrum of research projects, from clinical trials to any other research, such as implementation research."



© Stelios Kouloglou

Speaker panel

Dr Leonardo Simão, EDCTP

"Sometimes the government institutions are weak, they are not well trained, they don't have that maturity which is necessary to guide such a sensitive process. But also there are lack of resources, like computers, offices; a lot of work is done on paper, which takes a lot of time."



Dr Vasantha Muthuswamy, FERCI:

"TRUST efforts and values were included in the new [Indian] National Ethical Guidelines for Biomedical and Health Research" Dr François Bompart, DNDi:

"Two European countries, the UK and France, have set up state of the art systems to protect healthy volunteers, and we feel that national healthy volunteer registries, which are part of the EU global health agenda, could go a long way towards ensuring the best global level of protection for healthy volunteers around the world."



Dr. Wolfgang Burtscher

"Finally, as a concrete step forward, I would like to inform you that the Code developed by TRUST will be soon included in the Participant Portal of Horizon 2020 as a reference document to be consulted and applied by all relevant research projects and serve as an education tool for the younger generation of researchers."



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SPECIAL THANKS to Stelios Kouloglou, MEP for a successful TRUST event at the European Parliament in Brussels.

💟 TRUST on Twitter

Follow us on Twitter: <u>@TRUST Project</u> is tweeting about the project news, events and outcomes, while keeping up to date with actors and projects around the world addressing the global challenges of our times.

TRUST YouTube channel!

Follow us on YouTube! TRUST has a number of informative documentaries –

click here to watch!

FGVA sponsors dance, music and rap competition for the San Code of Research Ethics

The <u>Foundation Global Values Alliance</u>, a TRUST partner, sponsored a dance, music and rap competition in South Africa.

The TRUST jury was looking for artistic representation of the San Code of Research Ethics – and in particular the values of Fairness, Respect, Care and Honesty.

Five teams competed, each representing a San community or organization. Singlehandedly and with great enthusiasm the teams went ahead and wrote or composed lyrics and music to promote the values of the San Code of Research Ethics.

The winner of the competition is the team called !Khwa ttu kids. <u>!Khwa ttu</u> is a San training and education center outside Cape Town. It is a centre of San culture and heritage that provides tailor-made training for young San of Southern Africa.

The video "We are the San" of the !Khwa ttu kids won the first prize because "its story is beautifully told, the dancers and singers are unusually talented and the serious topic is explained with a joyful spirit" said the TRUST jury.

In the video the !Khwa ttu kids very artistically illustrate the changes their culture has undergone in modern times. They call upon researchers to involve the San in a meaningful, careful and respectful way in research. The story is sung to modern music in their indigenous mother tongue !Xun with English subtitles. The video can be accessed <u>here</u>.

Upon announcement of the winner the team leader of the !Khwa ttu kids couldn't help herself but jumped a meter high in happiness and pride.

The jury nominated three winners in total. Watch out for the runners-up video and the 3^{rd} in place – they will be announced soon!



lst in place: "We are the San" by the !Khwa ttu kids.

The jury and the TRUST team concluded after the competition: "What we got was so much more than a code with music, we got powerful messages in highly creative videos filmed in amazing scenery."

Al Jazeera The Stream reports on San Code of Research Ethics

TRUST is very proud to have been part of the Al Jazeera English programme called The Stream.

On August 16, 2018, The Stream screened an episode about the topic: *Is there an ethical way to research indigenous communities?*

The Stream is a social media community with its own daily television program, focusing on stories that are ongoing, global, and sourced from social media. Al Jazeera broadcasts in over 130 countries.

TRUST coordinator Prof. Doris Schroeder was contacted by Al Jazeera in preparation for the show. The TRUST material provided substantiated the live discussion with three debate participants.

The program started with a TRUST video showing San leader Andries Steenkamp, who emphasized how important it is that researchers respect community structures. He asked researchers to come through the door, not the window.

Reverend Mario Mahongo's request that indigenous peoples should not be treated like museums, but as partners in research, continued the TRUST path of the program.

Throughout, the four TRUST values Fairness, Respect, Care and Honesty, were visible in large capital letters on the walls of the Washington the Stream studio.

How the San feel exploited by researchers was illustrated with another TRUST video by quoting #Khomani San community member Jan van der Westhuizen talking about lack of benefit sharing.

The show finished by showing the beginning of the video "We are the San" by !Khwa ttu kids – winner of the dance,



Al Jazeera The Stream: Is there an ethical way to research indigenous communities?

music and rap competition mentioned above.

The TRUST team is very proud that the show relied heavily on project outcomes as well as the San Code of Research Ethics.

The show was re-screened three times and is available on <u>YouTube</u>.

Global Code of Conduct in the News

News about the Code gathers momentum

News has been spreading fast about the new Global Code of Conduct for Research in Resource-Poor Settings (GCC). Coverage has included high profile media and research platforms. Full articles are also here: http://www.globalcodeofconduct.org/engagement/





Global efforts are required to eradicate ethics dumping

Transnational research is vital to academic pursuits but it shouldn't be carried out at the cost of vulnerable people in resource-poor countries, says Kate Chatfield





Guest blog: Four universal values for a fresh new ethical framework and a global code of ethics

Professor Doris Schroeder and Dr Kate Chatfield discuss a fresh new ethical framework and a global code of ethics, which was recently adopted by the European Commission fo



Fighting Ethics Dumping through Equitable Partnerships

The Guardian Doris Schroeder



Fri 31 Aug 2018 07.30 BST

Ethics dumping: the exploitative side of academic research

A new EU code makes equitable partnerships in resource-poor settings a condition for funding

Doris Schroeder, University of Central Lancashire and Co-ordinator of the TRUST project 27 July 2018

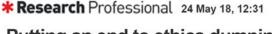
nature

Linda Nordling 3rd July 2018



Europe's biggest research fund cracks down on 'ethics dumping'

The practice of conducting ethically dubious research in foreign countries is under fresh scrutiny.



Putting an end to ethics dumping

Doris Schroeder explains how a recently published global code of conduct for research in resource-poor settings could help end the practice of scientists going abroad to do research that would not be permitted at home.

EN

English

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A global code of conduct to counter ethics dumping

News from around the world

Partners for Health and Development in Africa, **PHDA** Council on Health Research for Development, **COHRED**

Forum for Ethics Review Committees in India, FERCI

The South African San Institute Trust, SASI

United Nations Educational, Scientific and Cultural Organization,

Institut National de la Sante et de la Recherche Medicale, **INSERM**

Springer Nature creates a new role to lead on research integrity

As one of the largest publishers of academic research, Springer Nature has developed a new position of Research Integrity Director.

<u>'Helicopter research': who benefits</u> <u>from international studies in</u> <u>Indonesia?</u>

Research study on Indonesia's Bajau people highlights important issue of the 'helicopter research'.

South Africa pushes science to improve daily life

Sweeping policy changes aim to refocus research efforts on poverty, unemployment, drought and other national problems.

The challenge of harmonising

research ethics standards Canada needs national-level collaboration to harmonise ethics reviews across institutions.

Culling wildlife for the sake of research

A case in which the University of Florida killed birds to protect crop research raises

questions on the ethics of field studies' potential side effects.

Europe's plans for responsible science

The upcoming Horizon Europe program needs to include sustained support for RRI.

The mice with human tumours: Growing pains for a popular cancer model

Researchers had high hopes for patientderived xenografts. Now they are contending with limitations in the clinic and the lab.

Publications:

National Health and Medical Research Council (2018)

Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders, Commonwealth of Australia: Canberra [Available <u>here</u>]

Iphofen, Ron and Tolich, Martin (2018):

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The SAGE Handbook of Qualitative Research Ethics, SAGE Publications Ltd. [Available <u>here</u>]

UPCOMING EVENTS

Zurich, Switzerland, 14-15 January 2019 21st International Conference on Animal Testing and Ethics

Brisbane, Australia, 6-7 May 2019 <u>6th World Congress on Advanced</u> <u>Clinical Trials and Clinical Research</u>

Barcelona, Spain, 23-24 May 2019 21st International Conference on Scientific Method and Research Ethics

Birmingham, UK, 30-31 May 2019 5th Annual Conference of the Centre for the Study of Global Ethics

Hong Kong, 2-5 June 2019 6th World Conference on Research Integrity

Hamilton, New Zealand, June 2019 <u>NAISA Conference – Native American</u> <u>and Indigenous Studies Association</u>

Oxford, UK, 1-2 July 2019 Clobal Health and Bioathics

TRUST

PROJECT CO-ORDINATOR

Centre for Professional Ethics, University of Central Lancashire, UCLan

PARTNERS

ACF, Action Contre la Faim, UCT, University of Cape Town, Department of Environmental and Geographical Sciences SIGNOSIS, Signosis SPRL FGVA, Stiftung Globale Werte Allianz EDCTP, European & Developing Countries Clinical Trials Partnership WITS, University of the Witwatersrand Johannesburg, School of Law



UNESCO

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