

Save the Date! – TRUST final event 29 June 2018 European Parliament

On June 29, 2018, TRUST is holding the project's final event "ETHICS DUMPING – Looking for Justice" at the European Parliament in Brussels.

Among the confirmed speakers are Prof. Jeffrey Sachs, Irina Bokova, Robert-Jan Smits, Prof. Klaus Leisinger and Dr. Leonardo Simão.

Professional moderation by Vivienne Parry, MBE, BBC journalist and Board of UK Research and Innovation.

At the event, TRUST outputs will be related to broader goals, such as the Sustainable Development goals and the European commitment to be *Open to the World*.

A detailed programme and registration details will be available in spring 2018 on the [TRUST project website](#).



TRUST on Twitter

Follow us on Twitter: [@TRUST_Project](#) 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 book: Ethics Dumping – now on Springer Open Access

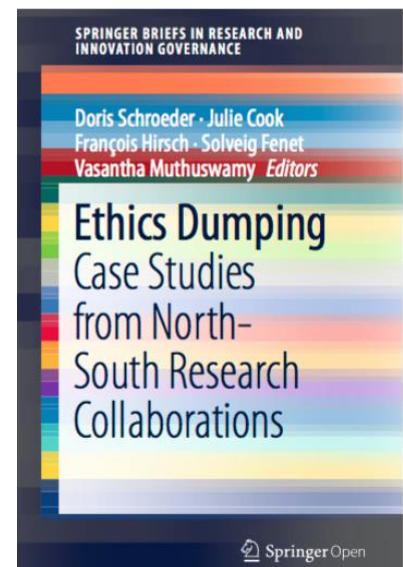
Editors: Prof. Doris Schroeder, Julie Cook, Dr François Hirsch, Solveig Fenet, Dr Vasantha Muthuswamy

Undertaking international cooperation in research and innovation responsibly requires equitable and respectful relationships between countries and among research and innovation partners.

- From the Foreword by Louiza Kalokairinou and Isidoros Karatzas

TRUST is very proud to present its first book publication *Ethics Dumping – Case Studies from North-South Research Collaborations*. As Louiza Kalokairinou and Isidoros Karatzas from the European Commission point out in the foreword: "(...), it is of particular importance to examine case studies, as they may elucidate ethical issues relevant to real-life recent research and innovation activities involving low and middle income countries, which may contribute to avoiding the duplication of past mistakes and injustices." This book provides a collection of up-to-date ethics dumping cases, collected and analysed in a joint effort by the TRUST team.

The editors hope that the book presents ethics dumping case studies that researchers may not



be aware of and thus contribute to much needed awareness raising in the context of North-South research partnerships.

Click [here](#) to access the book.



The TRUST project

The TRUST Project is an EU funded project which aims to catalyse 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/

TRUST MEETINGS

TRUST Funder workshop in London

On June 12-13, 2017, TRUST co-hosted a two-day workshop in London with the Wellcome Trust to meet representatives from different funding organisations and pharmaceutical companies.

TRUST considers Funders to play an important role in promoting fair research relationships, thus the workshop had a dual purpose: 1) to seek input and expertise from funding agents to feed directly into the development and improvement of the main TRUST tools and goals, and 2) to inform first-hand about TRUST activities and developments thus far.

The stakeholder group attending the workshop, included representatives from *funder groups* (WHO-TDR, Calouste Gulbenkian Foundation, Wellcome Trust, MRC-UK, and European Commission) and *industry platforms* (DNDi, Sanofi, Roche, GlaxoSmithKline and Boehringer Ingelheim)

The main ethical challenges raised by the representatives were: Ensuring double ethics review; how to obtain consent from minors; illiteracy; post-trial access; community engagement; as well as the exact roles and responsibilities of research actors in North-South collaborations.

TRUST project coordinator Prof. Doris Schroeder presented the idea of the Global Code of Conduct as well as the efforts undertaken so far. The code will be web-based, concise, clear, non-technical, intercultural and organised using the four TRUST values: Respect, Fairness, Care and Honesty.

Professor of Law, Dr Pamela Andanda from the University of the Witwatersrand (WITS) presented highlights from completed reports on ethics compliance, tools and strategic approaches that fed into the development of the second main tool of TRUST: the Compliance and follow-up tool for North-South collaborations.

TRUST member and Director of COHRED (Africa), Jacintha Toohey, presented a draft online version of the Fair Research Contracting (FRC) web tool, the third main tool of TRUST. In an interactive

and encouraging review session, all participants were asked to provide feedback through conducting a pilot assessment by logging onto the latest web-version of COHRED's FRC tool via their smartphones and tablets.

All three tools have been developed through the TRUST team: extensive analysis of existing ethics codes and literature review; broad collection of case studies of exploitation in North-South collaborative research; direct consultation with vulnerable research populations (sex workers and the San indigenous people in the Kalahari); and consultation with ethics committee members in India and Kenya. The steps are being documented in different TRUST Deliverables that can be accessed via the [project website](#).

The guests from the different funding and industry organizations appreciated the efforts and provided valuable feedback on the tools for further consideration by the TRUST Team.



Details on the workshop can be accessed via the [TRUST Deliverable Funder Platform Report](#) on the project website.



Dr Michelle Singh (3rd from l.) with representatives from the funder panel



Prof. Klaus Leisinger (front) with representatives from the industry panel



TRUST Funder Workshop participants, Wellcome Trust London

TRUST MEETINGS continued...

The San Code of Research Ethics

On October 17-18, 2017, SASI hosted a consolidation and dissemination workshop with delegates from all San groups in Upington, South Africa.

The overall goal of this workshop was to discuss ideas and strategies that can ensure the success of the San Code of Research Ethics beyond TRUST.

Focus of the discussions were awareness raising of the code amongst the different communities as well as a potential action plan in order to implement an incorporation strategy in future research requests.

Director of the South African San Institute, Hennie Swart, led the workshop interactively. Scope and meaning of the code were reiterated, culminating into a discussion about the code in practice.

Another major outcome of the workshop was the successful gathering of ideas to further the code. The results will be analysed for possible future implementation.

The San Code of Research Ethics is an important outcome of TRUST and available on the [project website](#).

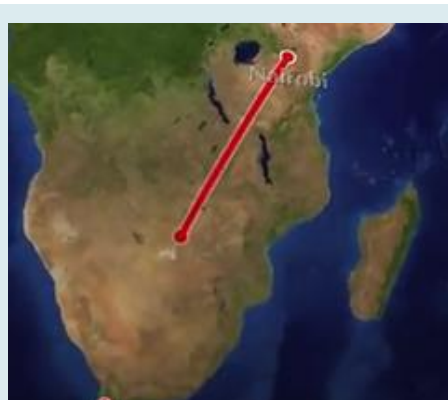


San stakeholders at the workshop 'Consolidating and Disseminating the San Code of Research Ethics' in Upington, South Africa.



Workshop participants interactively discussing the code in practice.

#Khomani San elder Petrus Vaalbooi contributing to the discussion.



TRUST YouTube channel!

TRUST has a new documentary! This 4th video is an outcome of the 3rd TRUST meeting in Kimberley in February 2017, where San elders and representatives met with Kenyan peer educators for sex workers to communalities. In this clip some of the participants explain their understanding of honesty.

Click [here](#) to watch!

TRUST Partner FERCI co-hosted 17th FERCAP International Conference and 5th FERCI National Conference

On November 19-22, 2017, TRUST partner FERCI co-hosted this year's 17th FERCAP International Conference and 5th FERCI National Conference in India's capital Delhi.

With the topical theme "Strengthening International Research Collaboration through Good Ethical Practice", this conference made a significant contribution to the current debate of improving research ethics. In total, more than 70 presentations and discussion sessions addressed matters related to this topic.

The TRUST project was well represented at this conference and members of the team were honoured to share details of the project activities to date. At the opening of the conference, President of FERCI, and TRUST member, Dr Vasantha Muthuswamy, delivered a warm welcoming speech to delegates.

Prof. Klaus Leisinger, from Foundation Global Value Alliance, delivered a thought-provoking keynote presentation, entitled 'Elements of an Enlightened Corporate Performance'. The pledge to "leave no one behind" is at the heart of the 2030 Agenda. With a focus on the pharmaceutical industry, Prof. Leisinger spoke about how corporate management must reflect upon the responsibility of leaving no one behind with regard to access to medicines programmes and the handling of intellectual property for life-saving innovative drugs, especially in the context of clinical trials in low-income countries.

Pamela Andanda, Professor of Law at the University of the Witwatersrand, Johannesburg, delivered an inspiring talk about the development of one of the three TRUST tools, the compliance and follow-up tool. This tool is being designed primarily for use by ethics committees and funders to provide them with a means of monitoring researcher compliance with ethical requirements over the course of a research study. At present, compliance and follow-up for research studies in LMICs is mostly a haphazardous activity. We are hoping that the TRUST tool will help to resolve this problem thereby contributing to improved ethical compliance globally.

Dr Kate Chatfield, from the University of Central Lancashire, UK, delivered two



TRUST delegates: Prof. Pamela Andanda, Dr Vasantha Muthuswamy, Prof. Klaus Leisinger, Dr Nandini Kumar and Dr Kate Chatfield.



Right: FERCI president Dr Muthuswamy and FERCI Vice president Dr Kumar



Left: Prof. Andanda

presentations on behalf of the TRUST project. Firstly, Dr Chatfield spoke about selected extracts from the forthcoming Springer publication, *Ethics Dumping: Case Studies from North-South Research Collaborations Equitable Research Partnerships*. This book, compiled by the TRUST consortium, details cases of exploitation in LMICs in many types of research including animal studies, social science, genetic studies, clinical studies and agricultural research.

In her second presentation, Dr Chatfield was given the opportunity to describe the TRUST development of a new Global Code of Conduct for North-South collaborative research. The Code is another main TRUST output, primarily intended for funders to ensure high ethical standards of their funded activities.

Dr Nandini Kumar, TRUST member and

FERCI Vice President presented the brand new Indian guidelines for ethical conduct in research. These guidelines are leading-edge in many ways, having incorporated lessons from earlier TRUST activities to strengthen the previous Indian guidelines and to help avoid ethics dumping. (Please click [here](#) for more information about the new ethics guidelines.)

The TRUST contributions stimulated a-high level of interest and discussion. The aims of the project were well-received and the objectives are now eagerly anticipated by representatives from ethics committees across Asia.

Dr Vasantha Muthuswamy, president of FERCI, complimented the TRUST contributions by saying the "presence of all of you at the Conference added real value to this conference theme".

News from around the world

[Nine things we now know about the European open science cloud](#)

On 28 and 29 November, data experts, policymakers and scientists gathered in Brussels, Belgium, to discuss the way forward. Horizon went along and this article reports about the things learned.

[Call for papers – Special Issue to honor Professor John Robertson](#)

To honor him and his legacy the Journal of Law and the Biosciences is soliciting papers for an honorary special issue. Papers should be submitted before **January 15, 2018**.

[Academics back authorship statements to stamp out 'abuse'](#)

Two-thirds of researchers have been slighted by seniors on authorship issues, Times Higher Education poll reveals.

[Online Course: Responsible Research & Innovation \(RRI\) for Researchers](#)

Research Transfer and entrepreneurship courses at Universitat Oberta de Catalunya.

[Fraud Scandals Sap China's Dream of Becoming a Science Superpower](#)

The New York Times article about China's increased number of retracted papers due to faked peer reviews.

[Call for papers - Women in science, medicine, and global health](#)

The Lancet wants to reach researchers who are working to address barriers for women in science medicine and global health.

[Bioethics: Justice in genomics](#)

Rosario Isasi examines a study on the societal impact of grand sequencing projects. Nature article about the book *The Postgenomic Condition*.

Publications:

Reardon, Jenny (2017):
The Postgenomic Condition. Ethics, Justice and Knowledge after the Genome. The University of Chicago Press.
[[Available here](#)]

Mitra, James (2016):
The New Health Bioeconomy. R&D Policy and Innovation for the Twenty-First Century. [[Available here](#)]

UPCOMING EVENTS

Singapore, 1-2 March 2018
[Singapore Research Ethics Conference 2018](#)

Montreal, Canada, 24-25 May 2018
[ICABEAW 2018: 20th International Conference on Animal Biotechnology, Ethics and Animal Welfare](#)

Birmingham, UK, 31 May–1 June 2018
[The 4th Annual Conference of the Centre for the Study of Global Ethics](#).

Oxford, UK, 20-23 June 2018
[14th International Conference on Clinical Ethics Consultation \(ICCEC\)](#)

Stellenbosch, South Africa, 3-5 October 2018
[6th International Conference on Ethics Education](#)

Jerusalem, Israel, 27-29 November 2018
[UNESCO Chair in Bioethics 13th World Conference](#)

New Delhi, India, 4-7 December 2018
[14th World Congress of Bioethics](#)



Very Happy New Year to All our Readers

TRUST

PROJECT CO-ORDINATOR

Centre for Professional Ethics, University of Central Lancashire, [UCLan](#)

PARTNERS

Partners for Health and Development in Africa, [PHDA](#)
Council on Health Research for Development, [COHRED](#)

Forum for Ethics Review Committees in India, [FERCI](#)
United Nations Educational, Scientific and Cultural Organization,
[UNESCO](#)

The South African San Institute Trust, [SASI](#)
Institut National de la Sante et de la Recherche Medicale, [INSERM](#)

[ACE](#), Action Contre la Faim,

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[SIGNOSIS](#), Signosis SPRL

[FGVA](#), Stiftung Globale Werte Allianz

[EDCTP](#), European & Developing Countries Clinical Trials Partnership

[WITS](#), University of the Witwatersrand Johannesburg, School of Law



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