



TRUST

Equitable Research Partnerships

Cape Town Plenary Meeting Report

Kalk Bay, 28 February - 2 March 2017

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Project full title:	Creating and enhancing TRUST worthy, responsible and equitable partnerships in international research
Project acronym:	TRUST
Type of funding scheme:	Coordination and support action
Work programme topics addressed:	Reducing the risk of exporting non ethical practices to third countries, GARRI-6-2014
Project web-site:	www.trust-project.eu/
GRANT AGREEMENT No:	664771
Name of the Coordinator:	Prof. Doris Schroeder (dschroeder@uclan.ac.uk)

Citation suggestion: Van Niekerk, J. Wynberg, R. and Chatfield, K. (2017). Cape Town Plenary Meeting Report, TRUST Project, www.trust-project.eu



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Acronyms and Abbreviations

ACF	<i>Action Contre La Faim</i>
ARC	Agricultural Research Council
BioPANZA	Bio Products Advancement Network South Africa
COHRED	Council on Health Research for Development
CRISPR	Clustered Regularly Interspaced Short Palindromic Repeats
DEA	Department of Environmental Affairs
DST	Department of Science and Technology
EDCTP	European and Developing Countries Clinical Trials Partnership
EU	European Union
FERCI	Forum for Ethics Review Committees in India
FGVA	Foundation Global Values Alliance
INSERM	French National Institute of Health and Medical Research
LMIC	Low and Middle Income Country
NRF	National Research Foundation
PHDA	Partners for Health and Development in Africa
SASI	South African San Institute
SGC	Science Granting Council
UCLan	University of Central Lancashire
UCT	University of Cape Town
UNESCO	United Nations Educational, Scientific and Cultural Organization
WITS	University of the Witwatersrand
WP	Work Package

Background

This report describes the third plenary meeting of the TRUST project, co-organised by the University of Cape Town and the University of Central Lancashire. At this meeting, project partners came together with project advisors and an additional fourteen invited guests. Guests included representatives from groups who have been vulnerable to exploitation in research and those in a position to influence policy including funding agencies, national governmental departments and science councils. A primary aim of the meeting was to obtain input from research councils and policy advisors within the realms of agriculture and the bio-economy in relation to North South exploitation in research.



Project partners, advisors and invited guests in Kalk Bay

Present at this meeting

From the TRUST Project

Prof Pamela Andanda, Dr Kate Chatfield, Dr Roger Chennells, Dr David Coles, Julia Dammann, Amy Dean, Dr Dafna Feinholz, Solveig Fenet, Dr Francois Hirsch, Dr Joshua Kimani, Prof Olga Kubar, Dr Nandini Kumar, Prof Klaus Leisinger, Prof. David Morton, Dr Ngayya Munuo, Dr Vasantha Muthuswamy, Prof Miriam Shuchman, Dr Michelle Singh, Hennie Swart, Elena Tavlaki, Jacintha Toohey, Jaci van Niekerk, Dr Jane Wathuta, Paul Woodgate and Assoc Prof Rachel Wynberg.

Invited guests

Catherine, John, Josephine, Joyce, Rosemary (peer educators for sex worker cohorts in Nairobi), Leana Snyders (Director, South African San Council (SASC)), Collin Louw (Secretary, SASC), Mario Mahongo (Acting Chairman, SASC), Ben Durham (Chief Director, Department of Science and Technology, South Africa), Natalie Feltman (Director, Department of Environmental Affairs, South Africa), Dr Sepo Hachigonta (Director, National Research Foundation, South Africa), Dr Lyn Horn (Senior Manager, University of Cape Town, South Africa), Dr Isiah Mharapara (Executive Director, Agricultural Research Council, Zimbabwe), Rosemary Wolson (Intellectual Property Manager, Council for Scientific and Industrial Research, South Africa).

Day 1: 28 February 2017

Message from Prof Doris Schroeder

The first day began with a welcome message from the coordinator of the TRUST project, Prof Doris Schroeder from the University of Central Lancashire (UCLan). Unfortunately, Prof Schroeder was unable to attend the meeting in person. Nevertheless, her thoughts and guiding hand were present both at the start and throughout the meeting.



In the opening message, Prof Schroeder thanked everyone who had participated in the workshops and filming in Kimberley in the preceding week. She also sent thanks to Francesca Cavallaro and Julia Dammann for producing the latest TRUST newsletter and wished everyone good luck with the meeting, as well as with the launch of the San Code of Research Ethics.

The second TRUST documentary

Dr Roger Chennells from the South African San Institute (SASI) and Dr Joshua Kimani from Partners for Health and Development in Africa (PHDA) fed back on the previous week's meeting in Kimberley between San representatives and Kenyan sex worker peer educators - utilising Open Space Technology¹.

The official purpose of the Kimberley meeting was two-fold:

1. Engagement between two vulnerable research communities, establishing what they could learn from each other.
2. Collaboration for documentary film clips to be made by Amy Dean from UCLan, adding peoples' words to the core values captured in the San Code of Research Ethics, namely, ***honesty, respect, justice and fairness*** and ***care***.

Roger reported that many insights and new knowledge emerged from the Kimberley meeting. He remarked that it was touching to listen to the lived experiences of research communities, adding that one needed to understand what people feel in order to have fair research partnerships. Feelings of vulnerability, loss of power and marginalisation could be the same for many other groups. He noted that there were differences between the groups too, for instance, a sex worker could possibly stop being a sex worker, but a San person could not stop being 'San'. Roger screened a short video of the meeting, where both groups discussed the San Code of Research Ethics.

¹ Open Space Technology is a leadership practice that allows for the creation of inspired meetings and events. For more, see: <http://openspaceworld.org/wp2/what-is/>

Dr Joshua Kimani from PHDA commented that he was initially not sure whether the two communities would find common ground. In the end, it transpired that they had much in common, engaging in lengthy discussions.



Joshua added that due to economic circumstances, many sex workers were unable to change jobs. He expressed some doubt about enforcing ethical codes for research in situations where they are out of context and applied in different communities. The San code, for example, could not be directly applied by sex workers in Kenya.

A number of the sex worker peer educators responded to Roger and Joshua, expressing their wish to develop a Research Ethics Code for sex workers and explaining that they were vulnerable on multiple fronts. For example, they were practising something illegal; they were often exposed to violence; and the very people who were supposed to protect them - the police – sometimes demanded bribes. Furthermore, they were poor and regularly in financial need; in their work they faced competition from sex workers from other countries; many of them were illiterate; and they frequently did not understand what research was being undertaken and why.

Questions and Comments

- When developing a code for sex workers, how about speaking to sex workers from the global North? There could also be resonance with sex workers from South and Central America.
- Why were these two communities selected by TRUST? **Response:** When TRUST was formed, these two cases were already well developed. Also, when considering 'helicopter' type research, these two communities are representative of groups affected by such research.

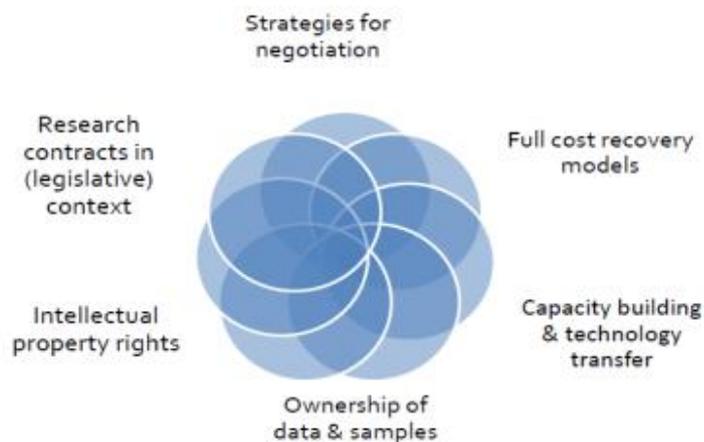
A web tool for fair research contracts

Jacintha Toohey from the Council on Health Research for Development (COHRED) demonstrated use of the mock-up web tool for fair research contracts and outlined COHRED's future plans. The COHRED web tool is a decision-making tool aimed at researchers. The team at COHRED started working on it in January 2016, releasing the first version in May 2016. This was further developed into the third version and circulated for comment and feedback at the end of 2016.



The web tool will be hosted on the COHRED website. On the landing page, there are six tool boxes which when clicked, each reveal short descriptions. At the bottom of the screen, key words and key questions also lead to short explanations. Each category is colour coded.

FAIR RESEARCH CONTRACTING

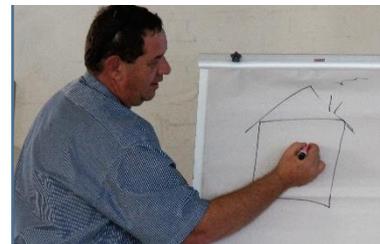


Looking ahead, September 2018 is the final date for completion of the tool. Until then, COHRED will seek and incorporate feedback from the TRUST partners on the categories depicted on the left.

The San Code of Research Ethics

On behalf of the San, Hennie Swart from SASI confirmed that the San Research Ethics Code was ready to be launched. He used a metaphor, often cited by Andries Steenkamp, the San leader who passed away in 2016, of a house with a door and a window. In the past researchers had conducted research with the San, 'without entering through the door, rather entering through the window', meaning that they did not obtain consent for their research through the correct channels.

Hennie Swart (SASI) explains how researchers must enter via the front door, not the window



Leana's message to researchers: "Knock on the door, you will be given the San Code and then we can take it further."

Leana Snyders, director of the San Council, spoke about the correct process to follow, commenting that the San Code would have been a useful document to have 20 years earlier. Ms Snyders commented that research involving the San would only work if the correct entities were consulted and if the San Code of Research Ethics was followed. A review panel – consisting of community representatives, the San Council and experts in particular fields (for example, genomics) would assess each application. Previously, researchers expected approval within a very short time period, now they had to respect San processes.



Left to right: Julia Dammann (SASI), Leana Snyders, Mario Mahongo, Collin Louw (San Council), Joshua Kimani (PHDA) explain the San Code of Research Ethics

The group expressed the need to distribute the San Code widely; TRUST partners were urged to distribute the code via their websites and copies would be sent to university ethics committees amongst other things.

Questions and Comments

- For researchers, cultural contexts and self-reflection are vital. Research with the San should be directly relevant to San needs and interests.
- TRUST could act as an interface for introducing tools to governments, which might then institutionalise them. For instance, the South African National Ethics Committee could be utilised as a platform for the San Code.
- World Health Organization regional meetings for ethics committees were recommended as appropriate platforms for sharing the San Code.
- If no benefits to the San were specified in a proposal, should the research be allowed to go ahead? **Response:** Benefits do not need to be monetary. The San community would like research projects to yield community development benefits. San youth could act as translators for example and build capacity in that way, or researchers could return summaries of their projects in accessible formats.

Ensuring compliance across borders

Prof Pamela Ananda from the School of Law at the University of the Witwatersrand (WITS) spoke about ensuring compliance with legal instruments and ethics guidelines across borders. She reported that the main challenge for ensuring compliance with legal instruments and ethics guidelines across borders is the existence of varying ethics review practices across regions and countries.



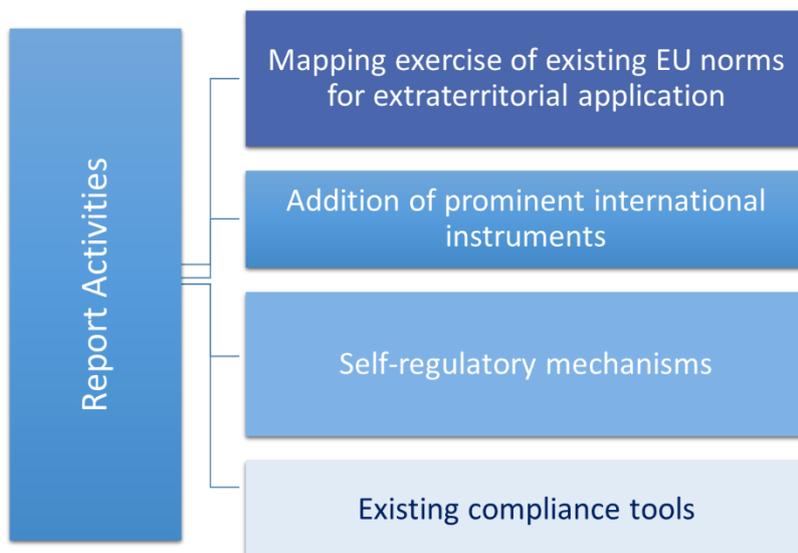
The varying practices in themselves were not a problem but they could lead to ethics dumping. That is the reason why Work Package 4 focuses upon ensuring compliance with ethical guidelines, laws and codes across borders.

Prof Ananda (WITS): “The main challenge for ensuring compliance across borders is the existence of varying ethics review practices”

The three deliverables in the Work Packages all focus on compliance and follow up:

- National and international compliance tools (Deliverable 4.1)
- Compliance failures (Deliverable 4.2)
- Strategic approaches to compliance failures in low and middle income countries (Deliverable 4.3)

NATIONAL AND INTERNATIONAL COMPLIANCE TOOLS



The team had completed the mapping of compliance tools and were working on compliance failures. The WITS presentation focused on the issue of ensuring compliance from the perspective of the available tools and the challenges, gaps and failures in ensuring compliance when using these tools. Prof Ananda stressed that compliance in this context meant compliance with laws, institutional policies and ethics guidelines.

The overarching criterion: All research MUST, irrespective of type and where it is conducted, comply with fundamental ethical principles to avoid ‘ethics dumping’. Prof Ananda gave an example of an anthropologist wanting to job shadow medical personnel, but refusing to seek ethics clearance from the medical faculty. This researcher’s involvement may not have caused physical harm, but could have breached privacy and confidentiality, which may additionally lead to reputational damage.

The WITS team encountered some challenges with Deliverable 4.1 since some compliance tools were binding, whilst others were non-binding. An example of a compliance failure could be lack of coordination between ethics committees. Prof Ananda added that all research that is funded by an EU framework programme, must comply with EU standards for research, even when the research is conducted beyond the European Union (EU) borders. In practice however, the application of EU norms and rules implies a form of external governance that may be deemed to interfere with the sovereignty of non-EU Member-States.

TYPES OF LEGAL INSTRUMENTS RELEVANT TO RESEARCH ETHICS



EXISTING COMPLIANCE TOOLS



Using community advisory boards as a compliance tool:

- Ensures the implementation of the research protocol and social value of the research.
- Negotiates the availability of the products of research to the local communities to ensure benefit sharing.
- Enables local capacity building.

Dr Jane Wathuta, also based at WITS, reported on Deliverable 4.2. Compliance gaps, failures and challenges in adherence with ethical standards in international collaborative research. Jane commented that these could be individual or institutional.



Jane Wathuta: 'Failures, challenges and gaps in social science research' arise from:

- A different professional culture
- Power dynamics and misunderstandings regarding ethics guidelines
- Divergent regulatory structures
- New areas of human research that fall outside traditional governance standards' boundaries



Factors leading to compliance gaps, failures and challenges in adherence with ethical standards include:

- Lack of early engagement with all collaborating partners to define goals, expectations, contributions, roles, responsibilities and supportive action where partners are disadvantaged or in lower resourced settings.
- Poor effort of partners to consider the legal obligations of researchers in their local context in varying jurisdictions.
- Lack of respect for partner’s local ethics regulatory authorities.

Questions and Comments

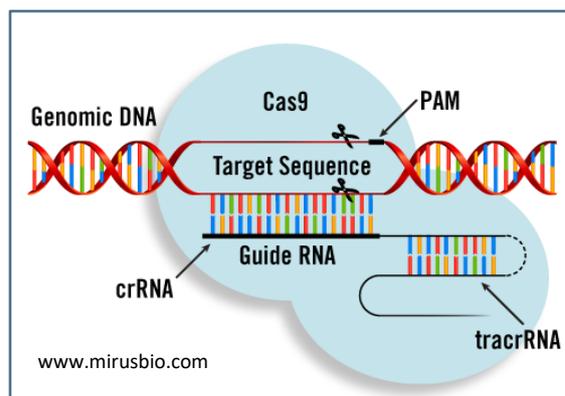
- There are differing views of misconduct. Published articles may have to be retracted if misconduct is proven.
- There is a need to avoid ‘ethics silos’ – there should be consistency in the approach to ethics.
- How do you define a ‘compliance failure’? What makes something a compliance failure? **Response:** There are tools for monitoring compliance, for example auditing or a review process. There might not be a formal complaint, but someone might have flagged an action as leading to compliance failure.

Inserm activity report

Dr Francois Hirsch from the French National Institute of Health and Medical Research (Inserm) described the Inserm ethics committee and its interaction with the new genome editing technology, CRISPR (clustered regularly interspaced short palindromic repeats).

Some issues raised about CRISPR:

- What are the novel questions raised by this technology?
- Does the rapidity of its development raise specific issues?
- Does the ease of its use in laboratories call for specific regulations?



Dr Hirsch noted that different issues were at stake with CRISPR. In humans, use of this technology raises the issue of 'off-targeting' and 'germline modifications'. Its use in animals, particularly in the so-called 'harmful species' such as mosquitoes, raises the question of irreversible consequences to biodiversity.

Inserm recommends that research aimed at evaluating the efficacy and safety of CRISPR technology in experimental models should be promoted and the potential unwanted side-effects of the gene-drive should be evaluated before its use in real life. The institute further recommends that the ban on all modifications of the germlines in human reproduction should be respected and suggests that those concerned should participate in national or international events that address the issues of freedom of research and medical ethics.



Dr Francois Hirsch and Solveig Fenet represent Inserm in Kalk Bay

Dr Hirsch reported on a number of activities and publications:

- The Inserm Ethics Committee met in Paris in March 2016, at a workshop titled: Fostering Responsible Research with CRISPR-Cas9.
- At a meeting in Vienna in September 2016: CRISPR and Malaria, participants from Gabon were invited as they were already facing the impact of CRISPR.
- Inserm participated in an External Experts Meeting in Buenos-Aires in November 2016: Fostering Global Responsible Research with CRISPR-Cas9.
- The next External Experts Meeting on Fostering Global Responsible Research with CRISPR-Cas9 would take place in India in April 2017.
- A meeting on Ethics and CRISPR: An African Perspective was in preparation, it would be led by the Inserm Ethics Committee in partnership with:

- European and Developing Countries Clinical Trials Partnership (EDCTP)
- The World Health Organization
- The Wellcome Trust
- The UNESCO Chair, Vienna (tbc)
- Médecins Sans Frontières (tbc)
- The University of Tübingen (tbc)
- Inserm released a White Paper entitled: *Fostering Responsible Research with Genome Editing Technologies: A European Perspective* in June 2016.
- Dr Hirsch co-authored a correspondence piece in *Nature: CRISPR-Cas9: A European Position on Gene Editing*, published in January 2017.
- A suggestion from Inserm is a possible TRUST Policy Brief on Ethics and CRISPR led by Inserm.

In the second Inserm presentation, [Solveig Fenet](#) fed back on the TRUST International Case Study Competition. Focussing on ‘ethics dumping’, ten cases had been selected in June 2016. The best of these would be published in a Springer Briefs Book and on the TRUST website.

Inserm was also involved in the production of a report titled: *Ethics dumping: data and sample sharing - towards a sustainable sharing of data and samples collected during trials implemented in resource-limited countries* (available on the Inserm website). The report highlights the need for equitable relations in scientific research while fostering international collaboration. It stresses the need to protect the interests of study participants by sharing the knowledge generated by the data and/or biological samples they provided. It further stipulates that consent obtained from illiterate populations needed to be contextualised.

Ms Fenet provided an update on international texts on ethics in biomedical research:

- Council for International Organizations of Medical Sciences
- The World Medical Association Declaration of Taipei on Ethical Considerations regarding Health Databases and Biobanks (2016)
- Guideline on Good Clinical Practice (2016)

In closing, she described three types of informed consent: specific informed consent; broad informed consent; and an informed opt-out procedure for research with health-related data.

UNESCO activity report

Dr [Dafna Feinholz](#) from UNESCO reported on the compilation of an inventory of stakeholders.

Stakeholders were categorised as follows:

- | | |
|--------------------------|-------------------------------|
| ● Ethics committees | ● Academia |
| ● Vulnerable populations | ● Civil Society Organisations |
| ● Policy makers/advisors | ● Industry and researchers |

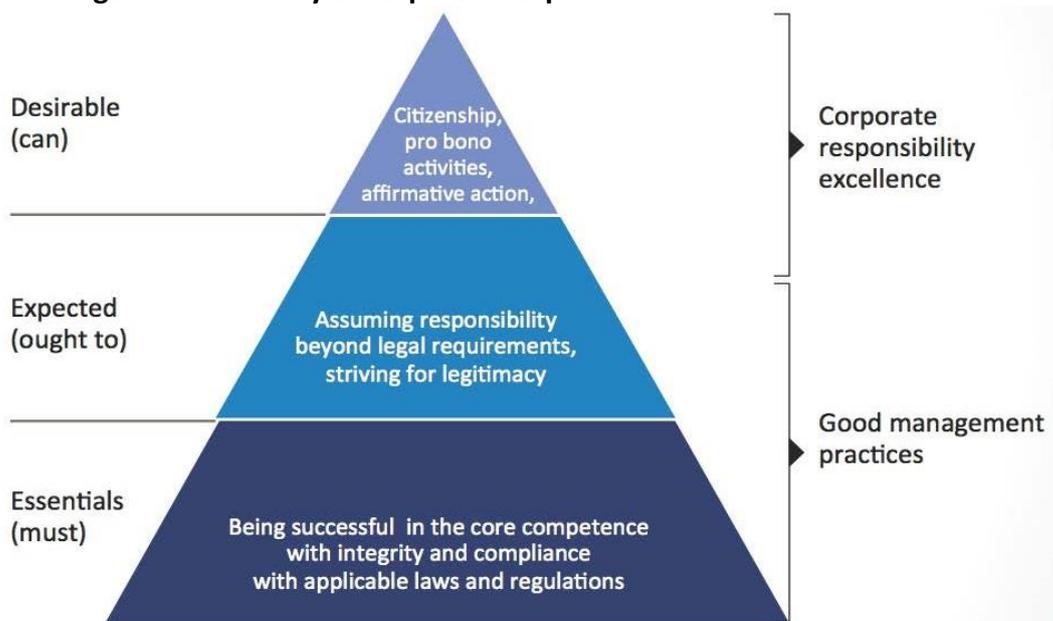


Dr Dafna Feinholz (UNESCO) with TRUST advisor Prof Miriam Shuchman

At the end of 2016, UNESCO sent out personalised emails to the 130 contacts listed in the inventory, informing them of TRUST’s activities and providing links to the main project outputs. Thus far, UNESCO had received numerous responses, many of them praising the project’s work and asking to get involved through, for example, training. Dr Feinholz promised that UNESCO would continue close communication in order to keep up the momentum. As for the next steps of engagement, UNESCO would work towards increasing the outreach, thus creating support for the project’s mission globally.

Pharmaceutical research partnerships

Prof Klaus Leisinger from the Foundation Global Values Alliance (FGVA) delivered a talk about equitable research partnerships in pharmaceutical research. He used the diagram below to explain the **generic hierarchy of corporate responsibilities**:



Prof Leisinger stressed that it is important to differentiate between technology-inherent² and technology-transcending³ risks. He listed the values of the San Research Ethics Code - respect, honesty, justice and fairness and care – stating that, according to the political theorist Michael

² Risks that originate from the technology itself: here we have well-documented principles and practices of proper risk assessment. Such risk assessments allow governments, communities, and business to make informed decisions about the benefits and risks inherent in using a particular technology to solve a specific problem. Risks disallowed in industrial countries should not be exported to Lower and Middle Income Countries (LMICs).

³ Technology-transcending risks emanate from the political and social context in which a technology is used. For example, productivity enhancing high-yielding seed varieties usually deepen income and wealth disparities as rich farmers can afford to be early innovators whilst in many cases small-scale farmers do not have sufficient access to agricultural extension services, fertilizer and water.

Walzer, one could distinguish between values or moral concepts that are ‘thick’ and those that are ‘thin’⁴. According to Prof Leisinger, respect, honesty, care and justice/fairness could be regarded as ‘thin’ in the context of the SAN Code, which expresses what these values mean in a specific context, i.e. research activities.

To illustrate ‘thin’, which in the context of pharmaceutical research relates to access, representation etc., Prof Leisinger raised the following question: Once a trial is over, should the pharmaceutical company provide the participants with the drug (when proven to be effective)? Most pharmaceutical companies would say “No – this is not our business model”, however some companies are more forward thinking and already have clinical trial drug access programmes in place.

Mechanisms to mitigate the risk of ethics dumping – preliminary conclusions:

Although some groups might call for new guidelines and new codes of conduct, the multitude of existing declarations, codes and guidelines suggests that there are already sufficient frameworks in place. The ethical framework for clinical research is clearly defined and guidelines to educate and train researchers and research ethics committee members are easily accessible.

A review of academic and NGO literature suggests that a number of issues ought to be considered:

- *Ex ante* due diligence
- Human resource issues (selection and development of staff involved)
- *Ex post* compliance monitoring
- Post trial access to innovative medicines for Phase III trial participants with chronic diseases



From the left: Dr David Coles (UCLan), Prof David Morton (Advisor) and Prof Klaus Leisinger (FGVA)

⁴ According to Michael Walzer the first, *thick* type of moral argument is culturally connected, referentially entangled, detailed and specific; the second, or *thin* type, is abstract, ad hoc, detached and general. Available at: <https://www.questia.com/library/5776261/thick-and-thin-moral-argument-at-home-and-abroad>

Day 2: 1 March 2017

The second day of the workshop began with a round of introductions as a number of new participants, external to the main TRUST team, had joined the meeting. The new arrivals were mostly representing policy-makers from South Africa and Zimbabwe. The TRUST project coordinator, Prof Doris Schroeder, sent a welcome message to the group and described the mission of the TRUST project as shown in the graphic on the right



Doris also outlined the major outputs of the project, namely:

- A Global Code of Conduct for North-South Collaborations
- A Fair Research Contract web tool
- A Compliance and Follow-up tool

Partnerships for competitive international research collaboration

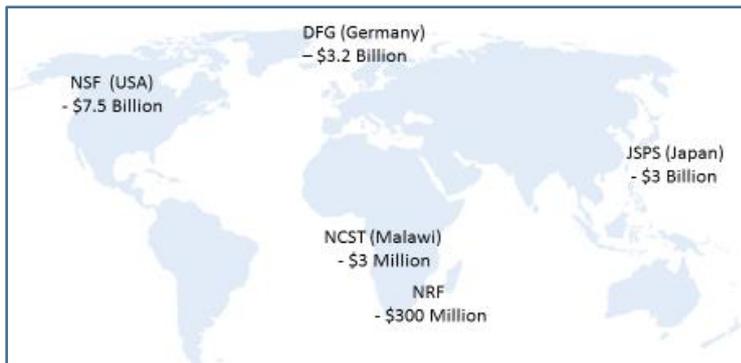
Dr Sepo Hachigonta, Director of Multilateral and Strategic Initiatives at the National Research Foundation (NRF), presented a funder's view of partnerships for competitive international research collaboration.

According to Dr Hachigonta, Science Granting Councils (SGCs) are essential actors in national systems of innovation. Some of their functions include:

- Disbursing funds for research and development in science, technology, engineering, mathematics and humanities.
- Promoting competitive research excellence.
- Building human capacity through:
 - Scholarships and bursaries
 - Exposure of students to research and infrastructure
 - Providing opportunities for staff to participate in opportunities abroad
- Contributing to identifying, developing and monitoring national research agendas and priorities.
- Providing advice on science, technology and innovation policies.
- Managing bilateral and multilateral science and technology agreements.
- Assessing the communication, uptake and impact of publicly funded research.
- Conducting research and innovation.

When considering a global overview of SGCs, there is a need to collaborate in order to survive in the funding space. Furthermore, many issues are cross cutting, for example, with issues around water and energy.

A GLOBAL OVERVIEW OF SCIENCE GRANTING COUNCILS



The NRF has many strategic partnerships, with a central focus on Africa and a strong drive towards the knowledge economy. Researchers are encouraged to work beyond South Africa's borders and the NRF also has a strong focus on bringing in the private sector.

Guiding principles for internationalisation include excellence and inclusivity; competitiveness; innovation; and truly global and effective partnerships.

The NRF has become increasingly coordinated and networked; has increased knowledge sharing; has had greater impact of funded projects; has increased visibility of the role of SGCs at national level; and has adopted innovative models of funding. Another achievement has been the joint leveraging of resourcing opportunities to support long-term multilateral and trilateral forms of collaborative engagements in the Global South (with a focus on the African continent).

However, some challenges remain:

- Mutual benefits.
- Collaborative agreements are secondary to science, technology and innovation policies or political ends.
- Limited knowledge exchange/sharing among SGCs.
- Poor coordination and duplication of roles among various science, technology and innovation actors, particularly national and sector agents.
- Weak partnerships with industry and other private sector actors.
- Lack of co-investment funds.

Questions and Comments

- How do you ensure that PhD candidates give back to the communities they work with? **Response:** When we speak of impact, we try to get proof of interaction with society or research participants.
- Can you give an example of legal challenges related to research? **Response:** Agreements might be signed with another country, but it may be hard to honour such agreements because budgets and activities might change for many reasons.
- Can you tell us a bit more about the process you have to go through to get money from the government? **Response:** The main sources of funds are the Department of Science and Technology and the Treasury. Over the past few years, the budget has not increased much.

Ensuring fair contracts for technology transfer

Rosemary Wolson, intellectual property manager at the Council for Science and Industrial Research (CSIR) spoke about fair contracting in the realm of technology transfer.

Ms Wolson briefly introduced the CSIR, which has a main campus in Pretoria and other facilities around the country. The institution celebrated 70 years of operation in 2015, has a total of 2,663 staff and an operating income of R2.36 billion (154 million Euros).

The CSIR has the following research impact areas:

Industry	Built environment
Health	Natural environment
Energy	Defence and security

Impact pathways:



Knowledge transfer – in support of decision-making, capability development

Technology transfer – licensing of intellectual property, new enterprises

Skills development and transfer – training, lecturing

Scientific and engineering contribution to knowledge base – publications

Ms Wolson made some general observations about contracting, highlighting that there was often a need for a trade-off between thoroughness and efficiency and that regulatory as well as cross-border issues could result in contracting becoming a complicated and burdensome process. Partners often had different needs and perspectives, also employing different cultural lenses. She further outlined the need for trust, trusted intermediaries and when necessary, dispute resolution mechanisms which function on a practical level, helping parties to come to terms rather than split apart. It is important for institutions to develop appropriate capacity to manage these issues proactively.

In terms of bioprospecting R&D, the CSIR has a long history dating back to the 1960s. The CSIR works with a range of knowledge holders, including traditional healers. They work with organisations such as the Traditional Healers' Trust, as well as with individual healers or other indigenous knowledge holders, with whom they enter into collaborations and benefit-sharing agreements.

'Socially responsible licensing' can be defined as: Intellectual property management strategies and associated business models to attract investment for addressing situations where the private sector would not otherwise invest in an unmet market need in the developing world.

The technology transfer function is responsible for taking the products of the institution's R&D efforts to market. While the typical tech transfer model is commercially focused, institutions are increasingly recognising the need for alternative approaches in certain cases, to address market failures and ensure that access to and benefits from the technologies

concerned can be more widely spread. A technology transfer office can achieve this by engaging in equitable licensing practices. These include developing appropriate intellectual property strategies, and incorporating relevant licence provisions to ensure that licensees commercialise in line with the equitable licensing objectives. Ms Wolson outlined options for reducing intellectual property barriers by selective patent filing. For instance, when filing a patent, one could opt not to file in (certain) low and middle income countries (LMIC); entities in such countries could then, in theory, produce the invention without a license.

Ms Wolson stressed that one must be sure that this will in fact achieve one's objectives, as unintended consequences could ensue. For example:

- Companies in high income countries might be deterred from taking up the technology altogether.
- Interest from LMIC licensees might be reduced if they require patent protection (in places where there is innovative capacity).
- The technology might not be able to be implemented in practice where access to other technologies and/or to know-how is required to practise the invention.

She suggested that it was best to decide on a case-by-case basis: *Will intellectual property protection assist in transferring the technology to those who need it?*

Concerns about equitable licensing

- Quality and liability
 - Risks - especially high in healthcare arena
- Product diversion
 - 'Leakage'
 - Illegal exports into countries where the exported technology will compete unfairly with a licensee's legitimate rights
- Lack of capacity to exploit the technology
 - Need for know-how, capital investment in infrastructure
- Competition/anti-trust
- Prior consent may be required from inventors to give up (some) benefit sharing

Questions and Comments

- The CSIR has a small section on peace – can you elaborate? **Response:** This is part of our Defence, Peace, Safety and Security unit. Historically, the CSIR had a strong focus on defence. This is now balanced out with work relating to peace, safety and security.
- When working with organisations such as the Traditional Healer's association you mentioned, how do you determine that such an organisation is really representative? **Response:** We work with more than one organisation and according to the Biodiversity Act it is imperative to use due diligence to find out who the rightful holders of indigenous knowledge are. While we use our best efforts to do so, it can be a burdensome process which falls outside our core competence. Arguably,

identification of additional knowledge holders is more effectively managed at a national level.

A global code of conduct

Dr Kate Chatfield from UCLan and Dr Michelle Singh from EDCTP discussed one of the three tools which TRUST is developing – a Global Code of Conduct for North-South collaborations in research.

Kate described a heavy reliance on Northern approaches assuming:

- Well-functioning ethics committees.
- A critical, or at least neutral, attitude towards researchers.
- Alternative ('standard') access to medical care or other benefits.
- High literacy or the view that imposing alternatives on non-literate participants are not stigmatising.

Additionally, there was a related, often uncritical, acceptance of the 'Georgetown Mantra' (beneficence, non-maleficence, autonomy and justice)⁵ in Northern approaches, whilst values such as community, solidarity, empathy or care were not acknowledged.

As part of the preparation of the global code, Prof Doris Schroeder and Dr Kate Chatfield compiled an exploitation risk matrix, based on the values agreed upon in Nairobi: fairness and justice, respect, honesty and care.

One of the earliest activities of the TRUST project was to collect case examples of exploitation in collaborative research through an open call and extensive literature searches. Further cases from India were presented and discussed by research ethics experts at a meeting in Mumbai in March 2016 and TRUST members also consulted the San and sex workers in Nairobi, thereby gathering many examples. The culmination of this activity was identification and analysis of 88 risks for exploitation in North-South collaborative research which were mapped against the TRUST values of respect, honesty, justice and fairness and care.

The risk matrix maps risks of exploitation by:

- Individual
- Institution
- Local community
- Animals
- Environment

Following this mapping exercise, the team matched research ethics principles (from existing codes), to each risk in order to:

- Give more credibility to the dissemination of the Global Code of Conduct as the risk matrix will link to existing guidelines.
- Identify gaps, where risks exist without relevant guidelines.

⁵ Also known as the 'four principles of bioethics', see for example, <https://medanth.wikispaces.com/Bioethics>

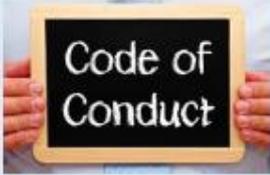
They found that eight risks identified by the TRUST project for exploitation in North-South collaborative research needed attention in the context of a Global Code of Conduct, as they were not yet covered by major existing guidelines.

The TRUST consortium recognises that a global code of conduct for North-South collaborations cannot possibly summarise all existing codes, they were thus busy developing a two-part code; with Part 2 having 4 elements.

PART 1:

Addressing the honour of the researcher and creating equity in approach; for example via a signed Declaration of Honour by the researcher... (“I sign on my honour that I will protect the values of justice, care, honesty, respect”).

PART 2: A FOUR-PART CODE

<p>Easily understood generally shared values</p> 	<p>Mapped against research ethics principles</p> 
<p>Support for researchers with existing codes and laws</p> 	<p>Open narrative shared at least with funder</p> 



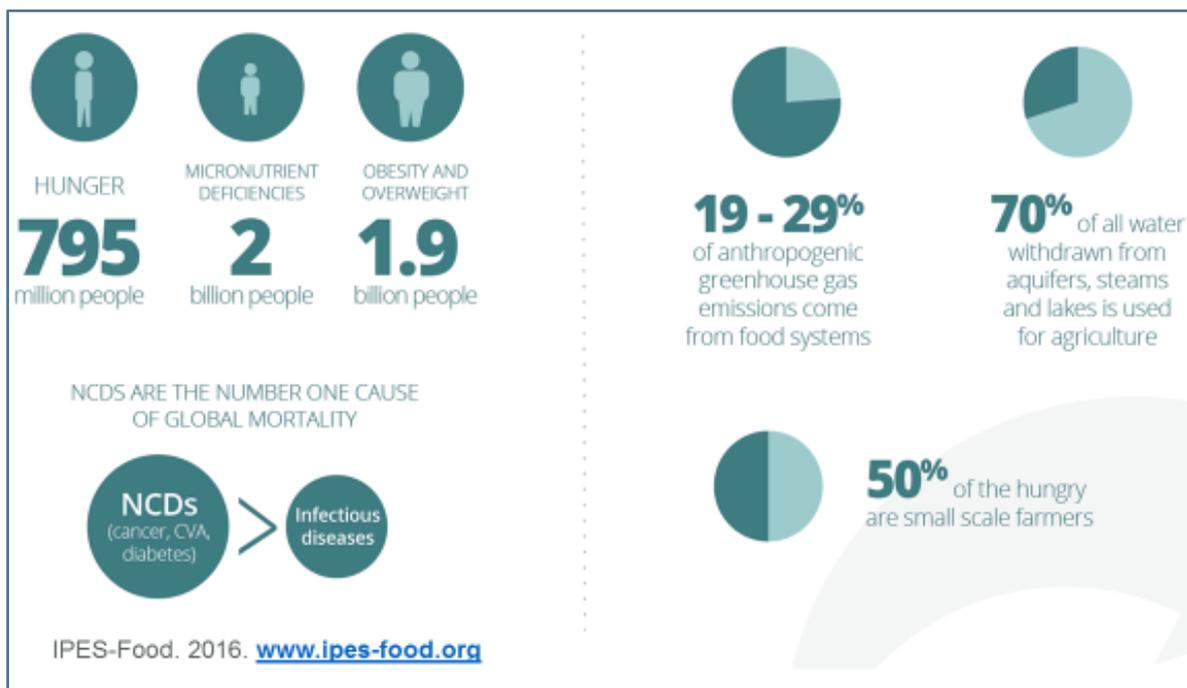
Jacintha Toohey (COHRED) and Dr Michelle Singh (EDCTP)

Why global research ethics must take note of agricultural research



Associate Prof Rachel Wynberg, Research Chair on the Bio-economy based at UCT, presented statistics and figures that demonstrate how serious problems in food systems manifest in health issues such as obesity and non-communicable or 'lifestyle' diseases. Whereas food systems were reducing hunger in some parts of the world, the focus on quantity rather than quality was leading to micronutrient deficiencies and related disease burdens. Nutrition is often interpreted narrowly around single nutrient supplementation rather than looking at root causes or improving the diversity of diets.

Agriculture has an extremely worrying environmental footprint where it is responsible for 19-29% of greenhouse gas emissions and 70% of global water extraction. Further, it is responsible for land degradation, biodiversity loss and chemical pollution (see figure below).

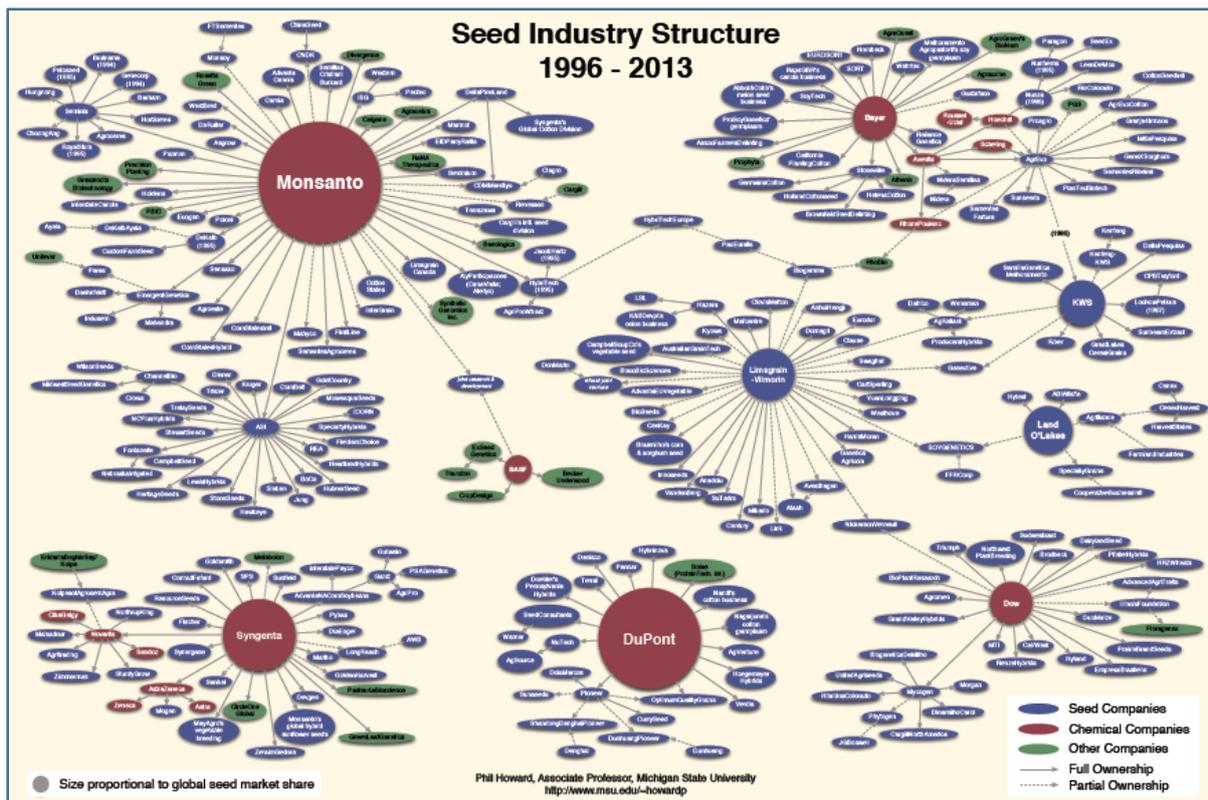


Green Revolution thinking:

- Input-intensive crops
- Wide applicability vs localised approaches
- Staple crop breeding vs minor species
- Technological innovation vs social innovation
- Value chain approach vs horizontal knowledge-building

Industrial agriculture has an input-responsive crop focus, a model in which rice, maize and wheat make up more than 50% of plant-based food intake – despite the fact that more than 7000 plants provide food for humans. In many LMICs, agricultural production is also largely based on Green Revolution thinking (see box).

Dramatic changes over the past 30 years have profoundly affected both agriculture and food markets. At the same time, consolidation of seed companies has increased (see graphic below), strongly linked to the intellectual property protection of seed.



Regarding trends in agricultural research, there has been a huge shift to digital sequence information, away from plants themselves. Farmers' knowledge is used less and private sector interest in agricultural research has escalated with an associated decline in public sector research. The primary focus of research and policy programmes is upon improving the productivity of industrial agriculture and technological innovation for input-responsive crop breeding. Prof Wynberg questioned whether these were the right indicators.

The shift towards private sector priority setting is particularly acute for universities. Over the last 30 years, cuts in government funding have put a strain on higher education and agricultural research budgets, with private funding often filling the void. This leads researchers to follow the agendas set by private sector funders. What remains of public sector research has largely supported this agenda, continuing to focus on a small number of tradable crops and often focusing on technological innovation (particularly for input-responsive crop breeding) to drive productivity increases.

Dominant actors are able to bring their power to bear in various ways. With reduced public sector research funding and influence on research trajectories, input agribusinesses are able to take centre-stage in framing the problems and providing the solutions. In this way they are able to secure demand for their products, while ensuring continued power and influence. Research for smaller, more vulnerable populations such as small-scale farmers, growing a diversity of crops, is typically ignored in the current research model.

The primary focus of research and policy programmes is upon improving the productivity of industrial agriculture and technological innovation for input-responsive crop breeding. Prof Wynberg questioned whether these were the right indicators.

What role for ethical research partnerships?

- Determining the right performance indicators (for example: nutrition, diversity, environmental stewardship).
- Framing the problems and solutions from the bottom up (for example, what are the needs and interests of the farmer and the consumer?).
- Redesigning research funding models to suit local contexts and needs.
- Bringing agricultural research back into the public sector.

Turning the tide on research partnerships – the case of agriculture

Dr Isiah Mharapara from Zimbabwe's Agricultural Research Council (ARC) spoke about partnerships in agricultural research.

Dr Mharapara said that partnerships were like friendships – although they may be based on satisfying the business needs of the players; they were contractual, time bound and have deliverables. With most partnerships, one partner initiates the linkage and someone pays or invests for the roll out. According to Dr Mharapara, the partner with the funding tends to dictate the rules of the game and one party usually benefits more than the other.

Dr Mharapara asserted that agricultural research in Africa has largely been based on foreign principles and understanding, meaning that the continent's own crops, fruits, insects, fish and animals had been ignored. Through the introduction of 'Western' tillage systems and cash crops such as tobacco, as well as genetically engineered crops, Africa has failed to develop that which is best adapted to local conditions. According to Dr Mharapara, a lack of financial resources has meant that African nations are vulnerable to exploitation. This has resulted in damage to ecological systems, loss of soils, fertility, biodiversity and natural resilience, as well as erosion of indigenous knowledge.

Why should the tide turn on research partnerships?

- Some past partnerships have been inappropriate, inequitable, unbalanced or unfair.
- In some cases partnerships were totally absent, top-down, or dictatorial.
- Partnerships should be agreed by all those involved or affected.
- All partners need to declare their interest in the partnership.
- There is a need for making partnerships more flexible.
- Partners should operate from a consultative framework.

Enhancing partnership contributions:

- Know, appreciate and respect partners' values and capacity.
- Communicate processes, procedures and results effectively (simplicity is key).
- Prioritise the improvement of locally adapted resources and systems through appropriate science and technology.
- Operate through an inclusive, consultative, robust and agreed process.

- Develop and share an agreed research partnership framework.

In closing, Dr Mharapara said that Africa needed to invest in R&D, but this had to be in line with an appropriate vision and should not be dictated by those intent on establishing markets for their agricultural products in Africa.

Questions and Comments

- When the agenda is set by a funder, is it an example of ‘going back’?
- What are the ethical requirements of setting the research agenda?

Imperatives for fairness in biotechnology

Ben Durham from the Department of Science and Technology (DST) gave a presentation about South Africa’s Bio-economy Strategy.

According to Mr Durham, ‘bio-economy’ refers to bio-based science and innovation activities and processes that translate into socio-economic outputs. He outlined some of the strategic objectives of the Bio-economy Strategy (see table below).

Bio-economy Strategy Objectives (indicators)		
Economic indicators	R&D indicators	Transformation indicators
Bio-economy contribution to gross domestic product Number of jobs in the Bio-economy Products/services commercialised High tech exports Value of high tech exports Number of biotechnology companies	Number of publications Number of patents Number of Masters and Doctoral students Absorption of Masters and Doctoral graduates into the National System of Innovation	Number of PDI-derived innovation projects supported Proportion of PDI ownership of biotechnology ventures Proportion of PDI Masters and Doctoral students
PDI = previously disadvantaged individuals		

Mr Durham stated that the South African context is one of huge unemployment and inequality; however, science in South Africa could be described as world class, with South African researchers amongst the most efficient in the world (in terms of publications or citations per dollar). Five South African universities are ranked in the top 500 universities globally according to the University Ranking by Academic Performance report of 2015-2016 and South Africa ranked 54th in the Global Innovation Index in 2016.

Mr Durham stressed that if investment in science were to increase, research had to be relevant to national challenges and priorities, such as:

- Transformation
- Research excellence
- Contribution to national priorities (for example the Bio-economy Strategy)

- New knowledge - addressing national challenges
- Attracting Foreign Direct Investment
- Innovation potential (job creation)

Questions and Comments

- What was the DST’s response to South African students’ protests around free tertiary education and decolonisation of the curriculum? **Response:** Mr Durham answered in his own capacity, saying that education for all should not be free, as it would then be undervalued.

Implementing benefit sharing in practice – the case of the biodiversity economy

Ms Natalie Feltman, Director of the Bioprospecting and Biodiversity Economy at the Department of Environmental Affairs (DEA) reported on South Africa’s biodiversity economy.



In an overview of the bioprospecting sector, Ms Feltman reported that both farmers and wild harvesters supplied raw materials, with a focus on plant materials. The majority of indigenous plant materials (70%) are exported in raw or unprocessed forms. The development and sale of domestic products based on indigenous plants amounted to R2.08 billion (136 million€) per annum, with consumers willing to pay a premium for goods containing indigenous resources.



Ms Feltman underlined key challenges that inhibit growth in the biodiversity economy, such as:

- Limited supply of raw materials due to low levels of cultivation.
- Low levels of local value addition and product development.
- Limited local and international awareness of indigenous plant resources, other than the 'top' five: rooibos, buchu, honeybush, *Aloe ferox* and *Pelargonium sidoides*.
- Difficult access to markets for products containing indigenous resources.
- Complex, costly and cumbersome national and international regulatory environment.
- In terms of transformation, lack of participation of communities and traditional knowledge holders in the sector.

In response to the challenges above, Ms Feltman outlined key initiatives aimed at driving growth in the biodiversity economy:

- A mass cultivation drive would see 25 key plant species grown commercially.
- Management plans would be drawn up for seven high value wild harvested species.
- A coordinating and facilitating BioPANZA (Bio Products Advancement Network South Africa) would be initiated to harness existing initiatives and address the innovation chasm.
- Amendments to national legislation will be fast-tracked to bring it in line with the Nagoya Protocol.
- The bioprospecting, access and benefit-sharing permitting system would become more streamlined.

Questions and Comments

- How do you go about M&E (monitoring and evaluation) and verification? **Response:** These are built into our progress plans, we have an M&E department.
- It would be good to develop communities of practice for each relevant species.
- National legislation cannot be enforced beyond borders.
- Benefit sharing could encompass participating in research, joint innovation and joint R&D.

Video screening: from a research contract to a San Code of Ethics

In the next item on the agenda, SASI screened the short film: Protecting San Indigenous Knowledge – From a Research Contract to a San Code of Ethics (available at <http://trust-project.eu/>) where the San leaders, representatives and community members explain how their original Research Contract developed into the San Code of Research Ethics.

Questions and Comments

- How do you control individuals from accessing the San without prior informed consent? **Response:** The traditional leaders are informed about the San Code, which helps to prevent this kind of access.
- How is the San Council formed? **Response:** There are three San communities in South Africa; each of these elects their own representatives or leaders; 50% or more are female.

- What has government done for the San? **Response:** The San do work with certain government departments, but actually government has done little for the San.

What role can TRUST most usefully play in policy making?

A discussion unfolded about the San Code of Research Ethics and the role TRUST could play in making the Code 'official'. It was suggested that the code needed to be marketed well. One way of ensuring this would be to get a number of top universities to workshop the Code and then endorse it. The San Code is not unique as the needs and concerns expressed in it are universal.

The role of researchers was discussed, highlighting the need for self-reflection and awareness of cultural contexts. Research should be directly relevant to community needs and interests.

*Comment from the group:
"No researcher should be able to say in the future 'we didn't know'".*

Another suggestion was to identify the ethics committees in each country where TRUST is represented. The San Code could then be taken up at different levels and also fed into other guidelines in other countries. One person suggested making use of creative forms of dissemination, for example, cartoons for children.

The value of research could be discussed with communities, research should not be a one-way process and expectations from both sides needed to be heard. Community engagement should happen throughout the research process and include ethics committees.

Proposals for taking the Code forward:

- The San Code could be translated into Kiswahili.
- The San Code could be used to facilitate discussion - noting that process is important and that ownership was necessary.
- Members of ethics committees could introduce the San Code and invite feedback.
- TRUST should highlight issues of vulnerability, exploitation and stigmatisation sensitivity.

Day 3: 2 March 2017

The first item on Day 3's programme was discussion of the TRUST Project's mid-term review, planned for 17 March 2017. This was followed by a presentation/training opportunity from one of the TRUST advisors.

Animal welfare in research

One of the TRUST advisors, veterinarian [Prof David Morton](#), gave a presentation on the use of animals in experimentation. Prof Morton began by saying that in research, choice usually exists on a spectrum, human volunteers can consent to partake in research and whilst some people had little choice, animals had no voice and therefore no choice. He asked: "Who consents on behalf of the animals?"

Research with animals is frequently conducted in countries in the global South as it is cheaper and regulation is less strict. Whilst this was a legitimate choice, he warned researchers to be mindful of data integrity and ask whether the standard of science is the same. From an ethical viewpoint, it would not be right to have to repeat work. Researchers should also beware of reputational risks, for example, if the application of double standards were detected, the work may not be published as it might not be deemed legal in a Northern country.

When considering burdens, risks and harms to animals, the level of care is very important. This relates to the attitude of the care and veterinary staff, as well as researchers. Prof Morton mentioned that the training of animal carers for laboratory animals differs greatly between countries. He stressed that as far as benefits were concerned, there were none that accrued to the animals who were being experimented upon.

The three 'Rs' of minimal harm – to minimise the harm caused:

- [Replace](#) (with a cell culture or computer model for example)
- [Reduce](#) (number of animals)
- [Refine](#) experiment (cause less harm, 'humane endpoint'?)

Even so, the question remains whether the research should be done? In that case, Prof Morton suggests one does a harm: benefit evaluation.

Publications to search for gathering case material:

- Published material (note: authors may have been turned down elsewhere)
- NGO materials
- Unpublished material from LMICs
- Journals – guidelines

Finding legislation, guidelines or codes:

- Institutional mission statements
- Training requirements and syllabi
- Ethics review processes

In terms of codes of conduct, Prof Morton stated that compliance with ethical animal research is hindered by the lack of an international framework, in other words there was no equivalent of the Declaration of Helsinki (which applies to research on humans and is focussed on the experience of the participants and not on any research outcomes) for animals.

For Prof Morton, the bottom line is that any research that is outsourced to Southern nations ought to be looked at in a particular way. He recalled an example of research on animals that embodied minimal risk and maximum care: the work of the Russian physiologist Ivan Pavlov.

In preparation for the London meeting

In preparation for the next TRUST Plenary meeting, scheduled for June 2017 in London, [Paul Woodgate](#) from the Wellcome Trust, Dr Michelle Singh, Prof Klaus Leisinger and Dr Kate Chatfield made some brief remarks.

Launch of the San Code

The group departed for the Company Gardens in the centre of Cape Town for the official launch of the San Code of Research Ethics. Appendix 2 provides a summary of the launch.



The TRUST group in Cape Town's Company Gardens

Appendix 1: Programme

Day 1 – 28 Feb 2017, internal

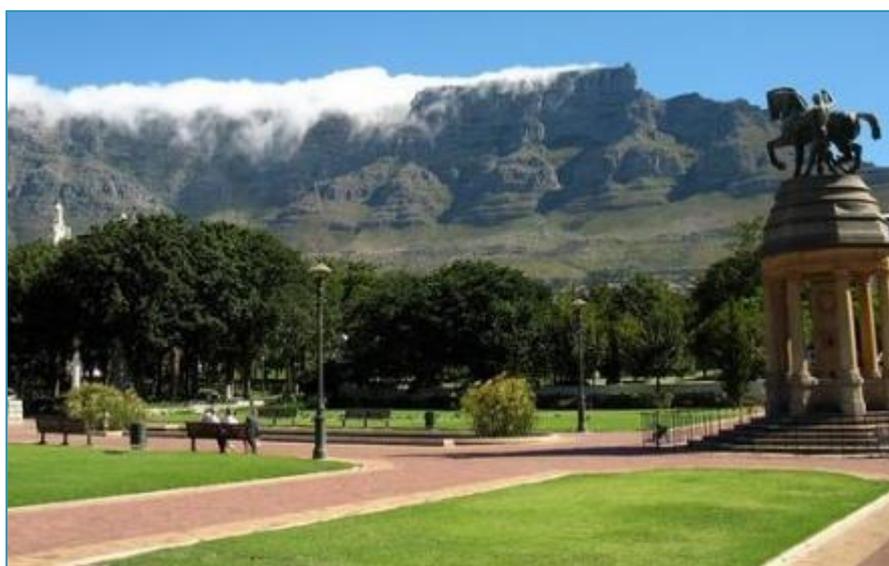
11.00 – 11.10	Welcome and aims of the day	Dr Kate Chatfield on behalf of Prof Doris Schroeder
11.10 – 11.30	The 2 nd TRUST Documentary – an overview	PHDA, UCLan, SASI
11.30 – 11.50	Questions and Discussion	
11.50 – 12.10	A demonstration of the web tool for fair research contracts as submitted on 28 February as deliverable and a sketch of future work plans	Jacintha Toohey
12.10 – 12.30	Questions and Input from Group	
12.30-13.30	Lunch	
13.30 – 13.50	The San Code of Ethics	SASI
13.50 – 14.10	Questions and Discussion	
14.10 – 14.30	Ensuring compliance with legal instruments and ethics guidelines across borders	Prof Pam Andanda and Dr Jane Wathuta
14.30 – 14.45	Inserm – Short Activity Report with questions	Inserm
14.45 – 15.00	UNESCO – Short Activity Report with questions	UNESCO
15.00 – 15.40	Questions and Input from Group	
15.40 - 16.00	Tea break	
16.00 – 16.15	Equitable Research Partnerships in Pharmaceutical Research – an Update	Prof Klaus Leisinger
16.15 – 16.30	Questions and Input from Group	
16.30 – 16.45	Planning for Day 2	Dr Kate Chatfield
From 16.45	Individual meetings of work package leaders with their teams organised as necessary by WP leaders	
19.00	Group dinner	

Day 2 – 1 Mar 2017 with externals

9.20 – 9.30	Welcome and Aims of the Day	Prof Rachel Wynberg, Dr Kate Chatfield
9.30 – 9.45	Introduction of all Participants	All
9.45 – 10.05	Partnerships for Competitive International Research Collaboration	Dr Sepo Hachigonta, NRF
10.05 – 10.25	Ensuring Technology Transfer and Fair Research Contracts	Rosemary Wolson, CSIR
10.25 – 10.45	Questions and Discussion	
10.45 - 11.05	A Global Code of Conduct for North-South Collaborations in Research	Dr Kate Chatfield, UCLan, Dr Michelle Singh, EDCTP
11.05-11.15	Input, especially from external guests	
11.15-11.30	Tea break	
11.30 – 11.45	Why Global Research Ethics must take note of Agriculture Research	Prof Rachel Wynberg, UCT
11.45 – 12.05	Turning the Tide on Research Partnerships – the Case of Agriculture	Dr Isiah Mharapara, ARC Zimbabwe
12.05 – 12.25	Imperatives for Fairness in Biotechnology	Ben Durham, DST
12.25 – 13.00	Questions and Discussion	
13.00-14.00	Lunch	
14.00 – 14.20	Implementing Benefit Sharing in Practice: the Case of the Biodiversity Economy	Natalie Feltman, DEA
14.20 – 14.35	A Brief Overview of the San Code of Ethics	SASI
14.35 - 14.50	Video-Screening – From a Research Contract to a San Code of Ethics	SASI
14.50 – 15.20	Questions and Discussion	
15.20 - 15.40	Tea break	
15.40 – 16.10	What role can TRUST most usefully play in policy making? A group discussion	Prof Rachel Wynberg as facilitator
16.10 – 16.30	Wrap up and Close of Meeting	Dr Kate Chatfield

Day 3 2 March 2017

9.30 – 11.45	Management Meeting to include:	
	TRUST mid-term review, 17 th March 2017	Dr Kate Chatfield
	How to gather case material on animal welfare in research? How to gather legislative material on local governance, including compliance mechanisms, on animal welfare in research A policy brief on international standards and harmonization?	Prof David Morton
	Planning for London meeting	Paul Woodgate, Dr Michelle Singh, Prof Klaus Leisinger, Dr Kate Chatfield
	Other management business	Signosis
11.45	Leaving for Cape Town	



12.30 Lunch in the Café at the Company Gardens, Cape Town

13.30 – 14.00 Launch of San Research Ethics Code, Company Gardens Cape Town.
Close of meeting and good-bye to externals.

Appendix 2: San Code of Research Ethics Launch



From the left: Joran Useb (San from Namibia), Leana Snyders (SASC), Roger Chennells (SASI), Mario Mahongo (SASC), Colin Louw (SASC)

[Melanie Gosling](#) reports on the launch of the San Council's code of ethics for researchers.

The South African San Council has launched a code of ethics to guide researchers to stop intrusive and sometimes exploitative research in San communities. The council said that after more than a century of being questioned, photographed, measured and 'sampled' by researchers from around the world and having San indigenous knowledge pilfered for commercial gain, it was time to say, 'Enough.' While the council is not saying there must be an end to research, it is saying that it must be on their terms.

The code of ethics was launched in Cape Town on Thursday 2 March during a conference of TRUST, an international network set up in 2015 to ensure that researchers stick to high ethical standards. TRUST is funded by the European Union's Horizon 2020 Programme.

The council said before researchers could work among the San, they must agree to embrace the four pillars of the code: respect, honesty, justice and fairness and care. The code is also designed to ensure the sharing of any benefits from researchers using San traditional knowledge for commercial developments in the pharmaceutical industry, in cosmetics and in food and beverages.

Leana Snyders, director of the San Council, said at the conference there had been 'an influx' of researchers in the Kalahari in recent years. "They don't all respect personal boundaries. They don't think they need to respect us. So we said: 'Look, we must get this thing under control.' One of our respected leaders Andries Steenkamp said: 'Researchers must not come in through the window. Only skelms (bad people) come into your house through the window. They must knock on the front door and wait to be let in.' That's what this code is about. It's for us to decide to open the door. It's to stop exploitation," Snyders said.

The code was drawn up by three South African San groups: the Khomani, the !Xun and the Khwe. Roger Chennells, a Cape Town lawyer who has represented the Kalahari San since the 1990s and helped develop the code, said it was about creating equitable research partnerships. “There has been a lot of research done on San communities and it was always on the terms set by the researcher. There was some genetic research done on San in Namibia recently where the researcher had got consent through a translator from four old people for some complicated genetic research. It was published with some really pejorative stuff in it. The old people’s consent did not cover what the researchers did,” Chennells said.

The code also focuses on the sharing of skills between researchers and San communities and the transfer of the results of the research in an accessible form. Mario Mahongo, acting chair of the South African San Council, said San communities hoped researchers all over the world would respect what they were doing and adhere to the code. “We are not standing with hands cupped, begging from the research community, but we are saying our young people also need to learn, so they must benefit. For instance, use them as translators,” Mahongo said.

In a short movie shown at the conference, San community member Jan van der Westhuizen spoke about how foreign researchers had gleaned information about medicinal plants from his forefathers. This, he said, had been used to manufacture medicines used by people all over the world. “Yet my forefathers died in poverty. And so it goes on.”

Snyders said researchers would have to apply to work with San communities through the council and follow a process and protocols to ensure the interests of both the researchers and the San were met. “In future, we hope to have a review panel made up of members of the San community and experts to vet research proposals,” Snyders said.

Hennie Swart, director of the South African San Institute, said they would also like to see research conducted that they themselves had asked for.

Published originally on GroundUp.

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