



# TRUST

Equitable Research Partnerships

## ***TRUST 1<sup>st</sup> Kimberley meeting, 21-22 March 2016.***

Roger Chennells and San representatives<sup>1</sup>

Project full title:	Creating and enhancing <b>TRUST</b> 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:	<a href="http://www.trust-project.eu/">www.trust-project.eu/</a>
GRANT AGREEMENT No:	664771
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<sup>1</sup> Thanks to input from Francesca Cavallaro, Julie Cook Lucas and Doris Schroeder

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# Workshop Programme

Date: 21-22 March 2016, Venue: Kimberley, Horseshoe Lodge

Participants: 28 people attended the workshop



## WORKSHOP AGENDA

### DAY ONE – March 21

<b>9:00</b>	<b>OPENING, WELCOME AND INTRODUCTIONS</b>	<i>Hennie Swart and Roger Chennells</i> Introduction to the TRUST project. The workshop objectives and organization.
<b>10:00</b>	<b>20 YEARS OF RESEARCH</b>	<i>Leana Snyders and Andries Steenkamp</i> The San Council: 20 years of protection, and problems.
<b>10.30 -11.00</b>	<b>Coffee break</b>	
<b>11:00</b>	<b>GENETIC RESEARCH</b>	<i>Dr Himla Soodyall</i> Why genetic research is important for the world and the San.
<b>12:00</b>	<b>SOCIAL RESEARCH</b>	<i>Kerry Jones</i> What are the risks and concerns
<b>12:30</b>	<b>SCIENCE RESEARCH</b>	<i>Marietjie Botes</i> Current perspectives, risks and concerns
<b>13:00-14:00</b>	<b>Lunch</b>	
<b>14:00</b>	<b>SCIENCE RESEARCH</b>	<i>Julie Grant</i> Respectful engagement
<b>15:00</b>	<b>COPYRIGHT LAW</b>	<i>Jodi Coxwell</i> IPR and the San

### DAY TWO – March 22

- Discussions On Priorities Identified On Day One
- Analysis Of Different Categories Of Risk For Different Research
- Identification Of Themes, Further Research, Tasks To Be Carried Out

## DAY ONE - 21 March

### Welcome Address

Hennie Swart, SASI Director

Hennie Swart opened the workshop, welcoming all 29 attendants (23 San, 6 others) and advising how the topic related to TRUST's examination of 'equitable research partnerships.' He provided a broad description of 'family' organisations as an introduction to the topic of how the San relate to the numerous institutions and bodies in their world. This would be examined further, later.

### 20 Years of Research

Andries Steenkamp, Chair San Council

Andries Steenkamp described how the San had attempted to protect their communities from researchers and media for the past 20 years. He described how the San had used the WIMSA contract, which had generally worked despite many frustrating failings. He confirmed that **San communities needed educating as to the dangers of research, and that an ethical code is required for the San to publish for researchers.** The purpose of responsible research was to respect, and benefit, the San community.

From the audience:

Collin Louw (San Council Secretary): the dangers of abuse were worse when researchers were allowed to approach San individuals directly.

### Genetic Research

Prof. Himla Soodyal, Division of Human Genetics, School of Pathology, Faculty of Health Sciences, University of the Witwatersrand and National Health Laboratory Service, SA

Prof. Soodyal presented on genetic research, firstly providing a broad overview of the field, using packets of different coloured sweets to denote the DNA of people in the world. The San are, according to her research, the oldest lineage living population on earth, and for that reason **genomic research would continue to benefit from San participation. At the same time the San should participate, not only to assist the world, but also to provide new health (and other) understandings that would benefit all humankind.** She described how she had attempted to apply ELSI (Ethics Legal and Social Implications) principles in her research, and believed in trustworthy, careful "community engagement" as a two way process. Finally she dispelled the myth that genetics could be used to determine a person's identity of a certain tribe. She recommended that the San should make their

*Trustworthy, careful  
"community engagement"  
is a two way process, and  
the San should make their  
own "rules of engagement".*

own clear “rules of engagement” so that researchers would in the future know exactly how to work with the San.

From the audience:

Discussions took place, largely around the issue of people who claimed heritage and identity based upon DNA testing. Prof. Soodyal confirmed again that this was based upon misunderstanding or misrepresentation. Petrus Vaalbooi called this “*lieg bedrieg en misleading*” (lies, fraud and misrepresentation).

## Social Research

Kerry Jones, San Linguist, and owner and director at African Tongue, SA

Kerry Jones presented on why the San languages were important to linguists. San languages form only 2% of African languages, and only 12 out of the 35 known San languages are still ‘alive’. Some are under threat of extinction. She described the different forms of ethical clearances and permissions required by universities, as well as the entirely different process of gaining overall permission (from communities, including leaders, gatekeepers, elders) and informed consent (from individuals). It was pointed out that **communities should be aware of what questions to ask of researchers, including what benefit the research will provide to the community**. Some of the difficulties were discussed, such as the fact that some universities offer ‘compensation’ money to informants, who then refuse to participate in research without being paid. Unrealistic expectations by communities or individuals, as well as unclear roles and responsibilities between community organisations, make it difficult for researchers. These can be cleared up if the community reaches agreement with all its leadership bodies on roles, legitimacy etc. The risks are that as a result of this confusion, researchers might get away with unethical research, or playing one body against another, with all sorts of negative consequences for San.

*Unrealistic expectations by communities or individuals, as well as unclear roles and responsibilities between community organisations, make it difficult for researchers.*

From the audience:

Collin Louw asked about ‘freelance’ researchers, and those who promise copyright to San but then fail to deliver. (A case study of the N/uu language school will be discussed later). Plus, where researchers avoid leaders and go straight to community individuals, confusion and conflict results. **San leaders should be better trained in IPR law, including copyright law, to prevent their being tricked or confused**. Risks thus include entering into agreements without knowing the consequences.

## Science Research

Marietjie Botes, lawyer, Phd candidate at University of South Africa

Marietjie Botes provided a detailed presentation on the topic of risks and concerns of social/genetic research. In an analytical presentation she described the physical, psychological and social/economic risks that can follow research, and added that the vulnerability of a research population generally increased these risks. Drawing on interviews with San, she listed a number of reasons given for mistrusting scientists, as well as conditions for allowing consent to use of samples for genetic research. Case studies referred to included the Hoodia case for Traditional Knowledge (TK), and the Schuster genomic research case of 2011.

Remark from the speaker:

**Lack of trust in and information received from researchers were the biggest causes of non-consent; gathering proper informed consent with San would always require and would be built on a combination of respect, and truthfulness.**

## Copyright Law

Jodi Coxwell, IPR lawyer, off-site consultant at ENSafrica, SA

Jodi Coxwell gave a short presentation on the different kinds of intellectual property law, with a focus on copyright law, which was very relevant to San. The author of all literary original artistic and musical works is protected by copyright law, with certain exceptions for researchers and those working for institutions. Discussions took place around a case study involving the !Khomani N/uu language school. The point was made that **copyright can be shared, but it has to be done by agreement, usually prior.**

## Respectful Engagement

Julie Grant, community worker, Zakheni Arts Therapy Foundation

Julie Grant explained that permission to engage and circumstances differed between:

1. Researchers
2. Journalists
3. Photographers
4. Artists
5. Authors and
6. Film-makers

Each category could vary from private to institutional. The design of a contract setting out consent needed to differ in respect of each category, and universities and other institutions each have their own usually rigid rules. In addition, each category presented different types of risks and benefits, and differed in their ability to provide benefits to the interviewees as

well as the community. The biggest problem in her view was the fact that community members sometimes did not want to receive protection from the San Council, (individualism vs community interests) and there was currently confusion as to

- a) Who should sign a research contract,
- b) Which body should administer the contract, and
- c) How the negotiations regarding payments should take place.

From the audience:

Mario Mahongo (San !Xun chairperson) made the point that the San need researchers. They are often very useful, such as the Dries Veldhuizen conflict studies group.

Dries Veldhuizen (UNISA, researcher) suggested that the San need a 'media and research plan' in order to deal with the multiple challenges.

Rina Mbamba (SASI administrator) suggested that the San should publish a list of their research objectives so that future researchers could see what was needed.

Collin Louw (San Council Secretary) stated that time is money. Most researchers can afford to pay. A 'win-win' situation is required to balance the interests of both.

**Agreed by all:**

**Clear guidelines are needed, with legitimate bodies given powers to negotiate and finalise research contracts.**

## DAY TWO - 22 March

### Social science research, Platfontein

Dr Dries Veldhuizen, Senior Researcher in the Institute for Dispute Resolution in Africa, College of Law, Unisa, SA

Dr Veldhuizen described how in his institute's long term project with the !Xun and Khwe, it started with discussions, confidence-building, training of San individuals to facilitate the interviews, followed by research in collaboration with trained San. In essence the project sought an 'equality' of status between the university and the San community, represented by their leaders. The project paid only for work done, the parties acquired knowledge jointly, and the shared outcomes were learning, change, and publications. Honorariums were paid to 'gatekeepers' for the work that they did on the program. His case resulted in many publications for the university, and a lot of different forms of benefit for the community.

Risks of harm: A different and less careful approach with this project would have resulted in poor information being gathered due to lack of communication between researchers and interviewees, unhappy community members at the end of the project, 'burnt bridges' for future research, perpetuation of a low self-image by interviewees, possible bad publications leading to damage, including perpetuated discrimination.

### San Research and Media contracts

Dr Roger Chennells, SASI lawyer

Roger Chennells informed the delegates that the TRUST project had its origins during the previous PROGRESS project, where San delegates had requested help to develop their ability to manage research. The TRUST project would thus hold both this and a future workshop (on 31 May, 2016) to examine this issue, and to develop better Research and Media contracts. A film would be made as part of the TRUST project which would document the San request and the progress of the research contract. The San Council would prepare a media contract for this film. All delegates were asked if they endorsed such a film. There was unanimous approval for the film, which would eventually be available for the San to use on their website.

### GROUP DISCUSSION

After Dr Veldhuizen's and Dr Chennells' presentations, the workshop participants were divided into three groups, to consider and report back on two main topics:

1. Good and bad case studies,
2. What are the solutions proposed in order to improve the outcomes of research on San people?



## EXAMPLES OF GOOD PRACTICE

- **The Unisa conflict studies at Platfontein, (Dr Dries Veldhuizen).**
  - Application leading to prior consent.
  - Respect and collaboration and good communication throughout. C
  - lear agreements with leadership.
  - Respect for individuals.
  - Delivery of promised outcomes.
  
- **The Genetic research cartoon by Marietjie Botes.**
  - Application leading to prior consent.
  - Research contract negotiated with San Council.
  - Clear exposition of methodology and outcomes.
  - Delivery of promised outcomes to community.
  
- **The Kalahari Desert Festival media coverage.**
  - Prior consent.
  - Ddelivery of publication of information as promised.
  
- **The CSIR and the Hoodia project.**
  - After initial problems, (not prior) consent was negotiated with the San Council.
  - Agreement was reached on use of scientific knowledge.
  - Clear benefits negotiated for San, as well as learning, capacity building, enhancement of knowledge.
  - Relationship of trust developed as a result, still continues.

## EXAMPLES OF BAD PRACTICE

- **The Schuster genomic studies case of 2011.** This case is now well known to the San, and is the epitome of damaging research. Key issues are:
  - Lack of respect for the community.
  - Researchers directly approaching vulnerable and illiterate San.
  - Refusing to engage with leadership.
  - Refusing to acknowledge role of leadership.
  - Failure of international Ethical oversight which failed to recommend community consultation.
  - Publication of pejorative, damaging, and insulting information.

This will be written up as one of the key San case studies of bad research processes.

- **Patricia Glyn and the N/uu language school,** both examples of private academics who made promises to the community prior to conducting research (history, and language issues), but who retained copyright and thus ownership of their books despite promising the books would belong to the community.

Damage consisted mainly in:

- Breaking of trust.
- Failure by community to enforce promises made verbally and not in a contract.
- No benefit to community as promised.
- Glyn used wine to encourage agreement.
- Ownership of book was researchers.
  
- **The CSIR Hoodia.**
  - The San were unable to prevent the Hoodia being appropriated by international opportunists who marketed illegal or fraudulent products, thus damaging the primary Hoodia success.
  - Lack of legal power to manage and control the information about the Hoodia.
  
- **The Kalahari Desert Festival.**

- A film company made promises to community without signing a media contract, resulting in them using key actors who were needed elsewhere (Isak and Lys).
  - Filming children without parents' permission.
  - Lack of a proper contract leading to multiple problems.
- 
- **The Klaas & Trooi Pienaar.** Although this case took place a century ago, it is mentioned as an example where 'scientific research' was inherently damaging to the San community.
    - Theft of two bodies by anthropologist in 1909 for research in Germany. Bodies were repatriated in 2012.
    - In the interests of 'science' the two San bodies were treated with disrespect.

No form of 'consent' took place.

## SOLUTIONS AND PROPOSALS TO IMPROVE RESEARCH ENGAGEMENT

The following, in no particular order, need to be in place to enhance better research practice, and to prevent the negative outcomes discussed above:

- A single central body needs to be created with clear external and internal authority, and capacity to manage research and media issues. (The San Council is the obvious suggestion). The body should have a 'review panel' to deal with more complex applications.
- Both a Code of Conduct and a Code of Ethics need to be established, whereby researchers are able to understand the 'Dos and Don'ts' of engaging with San. This information should be freely available, e.g. on San Council and SASI websites.
- Training needs to take place, both of the leaders/ gatekeepers of research, as well as amongst the communities and individuals who are required to participate. There needs to be increased awareness of the dangers and issues. The community needs to understand trust the role of the San Council.
- Research and media contracts need to be drawn up in such a way that research is not discouraged, but is managed to the benefit of the community. Research which is not felt to be useful should be refused. Non-commercial research or engagement should be managed with basic contracts. More intensive research should be managed with more complex contracts as appropriate.

- There should be consequences and penalties for failure to comply with the terms of such contracts. San Council members need training, the capacity to follow up and monitor research etc. Funds should be raised in order to establish a research monitoring/compliance body with SASC.

### CLOSE OF MEETING

Hennie Swart closed the workshop, reminding delegates that a follow-up workshop would be held on the 31 May and 1 June, in Kimberley. The proceedings of that workshop would be filmed, and some interviews conducted. During this second workshop both the media and research contracts and the Codes of Ethics proposed in this workshop will be finalised.

After a prayer by Reverend Mario Mahongo, the workshop closed at 5pm.