

THE SAN CODE OF RESEARCH ETHICS

Its Origins and History





Kimberley, 2014

THE SAN CODE OF RESEARCH ETHICS

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Roger Chennells and Doris Schroeder



This report is dedicated to the memory of Andries Steenkamp and Mario Mahongo.



"I don't want researchers to see us as museums who cannot speak for themselves and who don't expect something in return, as humans we need support."

Reverend Mario Mahongo (1952 – 2018)

[FOR A VIDEO, CLICK HERE](#) 



"Your house must have a door so that nobody needs to come in through the window. You must come in via the door, that is to say via the San Council."

Message to researchers from **Andries Steenkamp** (1960 – 2016)

[FOR A VIDEO, CLICK HERE](#) 



EXECUTIVE SUMMARY

The San peoples, widely known as ‘first’ or ‘indigenous’ peoples of Southern Africa, have been the object of much academic research over the past centuries. In recent years San leaders have, with increasing confidence, arrived at the conclusion that most academic research on their communities was neither requested, nor useful, nor protected in any meaningful way. In many cases dissatisfaction if not actual harm was the result.

In 2017, the South African San published the ***San Code of Research Ethics***, which requires all researchers intending to engage with San communities to commit to four central values, namely fairness, respect, care and honesty, as well as to comply with a simple process of community approval. The Code was launched as part of the EU-funded ***TRUST project***, which catalysed a global collaborative effort to stop ‘ethics dumping’, i.e. the application of double standards in research.

Above - San meeting with researchers, industry and policy makers, Kimberley 2014, ProGReSS project



San Code of Research Ethics launch March 2017, Cape Town.
From left, Joram /Useb, Leana Snyders, Roger Chennells, Mario Mahongo, Collin Louw

This report is compiled by a lawyer and an ethicist who have both worked with the San for many years, with significant input from San leaders and activists who were part of the journey. It describes the trajectory from early institution-building and collaboration with NGOs (1990s), to major land claim and benefit sharing successes (early 2000s), to the release of the San Code of Research Ethics (2017).

Key to the achievements of the San in South Africa have been: dedicated San leaders of integrity, supportive NGOs, legal support, and long-term relationships with key individuals who also assisted with fundraising.



The publication of this Code has been greeted with unprecedented interest from the international media.



South Africa's San people issue ethics code to scientists



San Council launches code of ethics for researchers



San people of Africa draft code of ethics for researchers



The ethics of research: How to end the exploitation of vulnerable communities



San Council launches code of ethics for researchers



San Council launches code of ethics for researchers



San Council launches code of ethics for researchers



Code for Research



Can Native research codes avoid culture clash



San people write ethical code for research



San people draft code of ethics for researchers



South Africa's San people issue ethics code to scientists



The world's oldest population of humans is pushing back against unethical researchers



San people become first African group with their own research ethics code



The ethics of research: How to end the exploitation of vulnerable communities



San people of South Africa issue code of ethics for researchers

The Code has been warmly welcomed by other groups who perceive themselves as being similarly vulnerable to exploitation through research. Other members and representatives of vulnerable groups have requested advice so that they can develop their own, tailor-made

research ethics codes. We hope that this storytelling of the San experience will inspire others and support their own developments.

Roger Chennells and Doris Schroeder, December 2018



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!Khwa ttu Graduation 2014; left to right Willemina Montzinger (Ouma Sensi), Katrina Esau (Ouma Geelmeid) and Mieta Harnoster





INTRODUCTION




This report aims to help others to develop protection against exploitation in research, but it is essential to take note of the following points:

- 1. The local context must drive efforts.** There is no “how to” list that can be produced by the San community and its supporters for easy transplanting to other communities. This report focuses on the trajectory to success of one community, which can hopefully be replicated elsewhere.
- 2.** This is not an academic publication. It therefore includes the authors’ personal views, and photos of the authors and (with permission) those who supported the writing of this report.
- 3.** Optimistically speaking, **it should be much easier to develop sister codes of the San Code by using the San example**, for at least two reasons. First, the four values framework used by the San has been applied successfully globally and is therefore ready for application outside of South Africa.¹ Second, discussions between the San and representatives of sex workers from Nairobi - another vulnerable population involved in research - showed significant overlaps of concerns. But it is not necessary to have 25 years experience! The reason 25 years are described here is to provide all background.

¹ See the launch of the Global Code of Conduct for Research in Resource-Poor Settings, now made a mandatory reference document by the European Commission for Framework research funding programs. <https://www.nature.com/articles/d41586-018-05616-w>

THE AUDIENCE FOR THE REPORT

This report is written for three main audiences:

<p>Members of the San community who would like to learn more about the history of the San Code of Research Ethics.</p> 	<p>Members of other communities, as well as their supporting NGOs, who believe their community would benefit from a locally driven code of research ethics.</p> 	<p>Researchers and others who are generally interested in research ethics codes and community engagement.</p> 
<p>Sections of most relevance</p>		
<p>CHAPTER 2 Institution-building</p> <p>CHAPTER 3 Challenges and Successes</p> <p>CHAPTER 6 Code drafting</p>	<p>CHAPTER 5 Success factors</p> <p>CHAPTER 6 Code drafting</p>	<p>CHAPTER 1 The San People</p> <p>CHAPTER 4 International research collaborations</p>

Photograph: David Hees



THE SAN CODE OF RESEARCH ETHICS



RESPECT



We require respect, not only for individuals but also for the community.

We require respect for our culture, which also includes our history. We have certain sensitivities that are not known by others. Respect is shown when we can input into all research endeavours at all stages so that we can explain these sensitivities.

Respect for our culture includes respect for our relationship with the environment.

Respect for individuals requires the protection of our privacy at all times.

Respect requires that our contribution to research is acknowledged at all times.

Respect requires that promises made by researchers need to be met.

Respectful researchers engage with us in advance of carrying out research. There should be no assumption that San will automatically approve of any research projects that are brought to us.

We have encountered lack of respect in many instances in the past. In Genomics research, our leaders were avoided, and respect was not shown to them. Researchers took photographs of individuals in their homes, of breastfeeding mothers, or of underage children, whilst ignoring our social customs and norms. Bribes or other advantages were offered.

Failure by researchers to meet their promises to provide feedback is an example of disrespect which is encountered frequently.

HONESTY

We require honesty from all those who come to us with research proposals.

We require an open and clear exchange between the researchers and our leaders. The language must be clear, not academic. Complex issues must be carefully and correctly described, not simply assuming the San cannot understand. There must be a totally honest sharing of information.

Open exchange should not patronise the San. Open exchanges implies that an assessment was made of possible harms or problems for the San resulting from the research and that these possible harms are honestly communicated.

Prior informed consent can only be based on honesty in the communications, which needs to be carefully documented. Honesty also means absolute transparency in all aspects of the engagement, including the funding situation, the purpose of the research, and any changes that might occur during the process.

Honesty requires an open and continuous mode of communication between the San and researchers.

We have encountered lack of honesty in many instances in the past.

Researchers have deviated from the stated purpose of research, failed to honour a promise to show the San the research prior to publication, and published a biased paper based upon leading questions given to young San trainees. This lack of honesty caused much damage among the public, and harmed the trust between the collaborating organisation and the San.

Another common lack of honesty is exaggerated claims of the researcher's lack of resources, and thus the researchers' inability to provide any benefits at all.

JUSTICE AND FAIRNESS

We require justice and fairness in research.



It is important that the San be meaningfully involved in the proposed studies, which includes learning about the benefits that the participants and the community might expect. These might be largely non-monetary but include co-research opportunities, sharing of skills and research capacity, and roles for translators and research assistants, to give some examples.

Any possible benefits should be discussed with the San, in order to ensure that these benefits do actually return to the community.

As part of justice and fairness the San will try to enforce compliance with any breach of the Code, including through the use of dispute resolution mechanisms.

In extreme cases the listing and publication of unethical researchers in a “black book” might be considered. An institution whose researchers fail to comply with the Code can be refused collaboration in future research. Hence, there will be “consequences” for researchers who fail to comply with the Code.

We have encountered lack of justice and fairness in many instances in the past. These include theft of San traditional knowledge by researchers. At the same time, many companies in South Africa and globally are benefitting from our traditional knowledge in sales of indigenous plant varieties without benefit sharing agreements, proving the need for further compliance measures to ensure fairness.

CARE

Research should be aligned to local needs and improve the lives of San. This means that the research process must be carried out with care for all involved, especially the San community.



The caring part of research must extend to the families of those involved, as well as to the social and physical environment.

Excellence in research is also required, in order for it to be positive and caring for the San. Research that is not up to a high standard might result in bad interactions, which will be lacking in care for the community.

Caring research needs to accept the San people as they are, and take note of the cultural and social requirements of this Code of Ethics.

We have encountered lack of care in many instances in the past. For instance, we were spoken down to, or confused with complicated scientific language, or treated as ignorant. Failing to ensure that something is left behind that improves the lives of the San also represents lack of care.

PROCESS

Researchers need to follow the processes that are set out in our research protocols carefully, in order for this Code of Ethics to work.

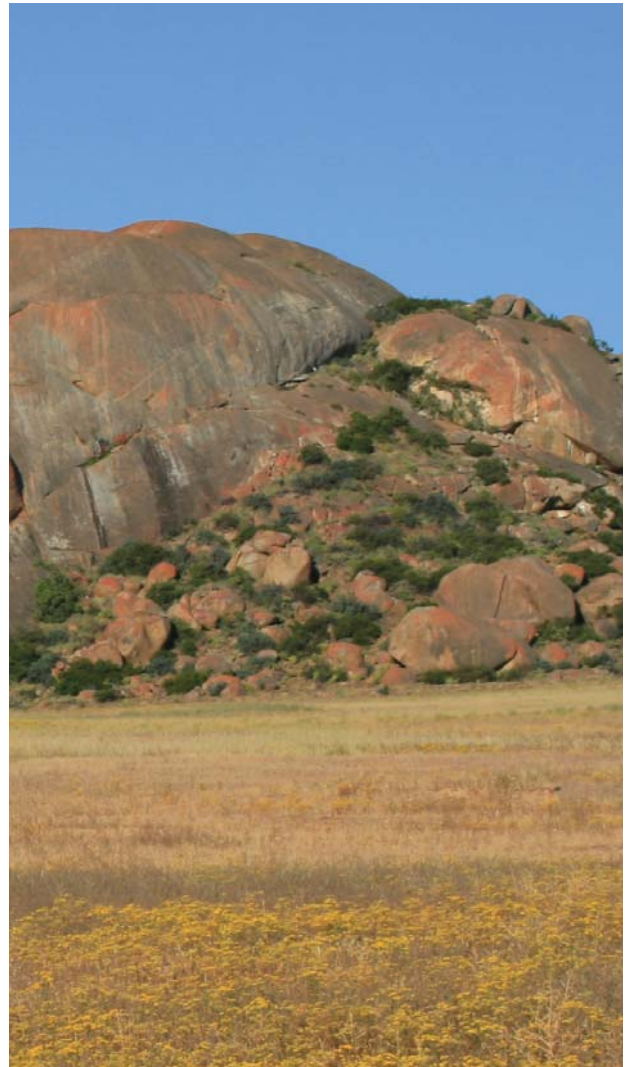
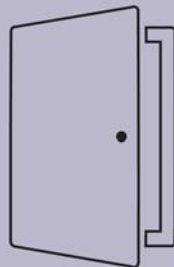
The San research protocol that the San Council will manage is an important process that we have decided on, which will set out specific requirements through every step of the research process.

This process starts with a research idea that is collectively designed, through to approval of the project, and subsequent publications.

The San commit to engaging fairly with researchers and manage effectively all stages of the research process, as their resources allow. They also commit to respecting the various local San structures (e.g. Communal Property Association, CPA leaders) in their communications between San leaders and San communities.

Andries Steenkamp, the respected San leader who contributed to this Code of Ethics until he passed away in 2016, asked researchers to come through the door, not the window.

The door stands for the San processes. When researchers respect the door, the San can have research that is positive for us.



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CHAPTER 1

THE SAN PEOPLE OF

SOUTHERN AFRICA

Above - San meeting with representatives from Namibia, Botswana, South Africa, Molopo Lodge 2006, PIC Project

The San peoples of Africa are iconic, and widely known as the quintessential hunter-gatherers of Africa, said to be the oldest genetic ancestors of modern humans.ⁱ

Once ranging over the whole of Southern Africa, their numbers have now dwindled to approximately 111,000 San living primarily in Botswana, Namibia and South Africa, with small remnant populations in Angola, Zimbabwe, Zambia and Mozambique². Although the San peoples speak at least seven distinct languages³ with numerous sub-dialects, they nevertheless recognise a common cultural identity which is readily identified as a hunter-gatherer heritage, with a shared ancestry also confirmed by genetic research.ⁱⁱ

Prior to 1990, the San peoples lived typically in extended families and small clans in the remote reaches of South Africa, Botswana and Namibia, as well as in smaller scattered populations in Mozambique, Zimbabwe, Zambia and Angola. The fact that the San generally live in small groups in remote locations has added to their isolation, and contributed towards their vulnerability to exploitation by others.

Generally impoverished, marginalised and cut off from the modern world, the San peoples received minimal support from their respective governments. **Almost no communication took place between the leaderships of these far-flung communities**, with the result that their ability to share information and empower their

peoples remained structurally constrained. This lack of internal as well as external communication capacity contributed towards the San being excluded from the vibrant Indigenous Peoples movement that became increasingly active during the 1980s and 1990s⁴.



Andriesvale 2011 (Photograph David Hees)

² Various estimates of San populations have been published, with marginal differences from one another. Populations of Namibia 35 000, Botswana 55 000, South Africa 11 000, Angola 3,000, Zimbabwe 3,000, Zambia 2,000 and Mozambique 2,000 have been estimated since 2000 by WIMSA as being appropriate. Working Group of Indigenous Minorities in Southern Africa (WIMSA) annual report 2008.

³ Without claiming linguistic exactitude, the following are the most common major San languages currently spoken in the region. Botswana hosts Nharo, Gwi, G/anna and Khwe; Namibia hosts Ju/’uasi, Hei/’om, Kung, !Xun and Khwe, South Africa hosts !Khomani, !Xun and Khwe. Zimbabwe hosts Tyua.

⁴ The United Nations held two successive “decades of Indigenous Peoples”, 1995 to 2004, and 2005 to 2015. In addition, after decades of negotiations by the United Nations Working Group of Indigenous Peoples, the United Nations Declaration on the Rights of Indigenous Peoples was adopted in 2007, and the United Nations Permanent Forum on Indigenous Issues was formed by the General Assembly in 2002.

Ouma /Una with Roger Chennells 2011 (Photograph David Hees)



The fate suffered by the San peoples in Africa is similar to that of many indigenous peoples in other parts of the world. Expansion and conquest firstly by assertive local pastoralist and agriculturalist communities, followed later and with similar devastation by colonial powers, has decimated their former existence. **The San history over the past centuries has been one of dispossession, enslavement, cultural extinction and recorded patterns of officially sanctioned genocide.**ⁱⁱⁱ

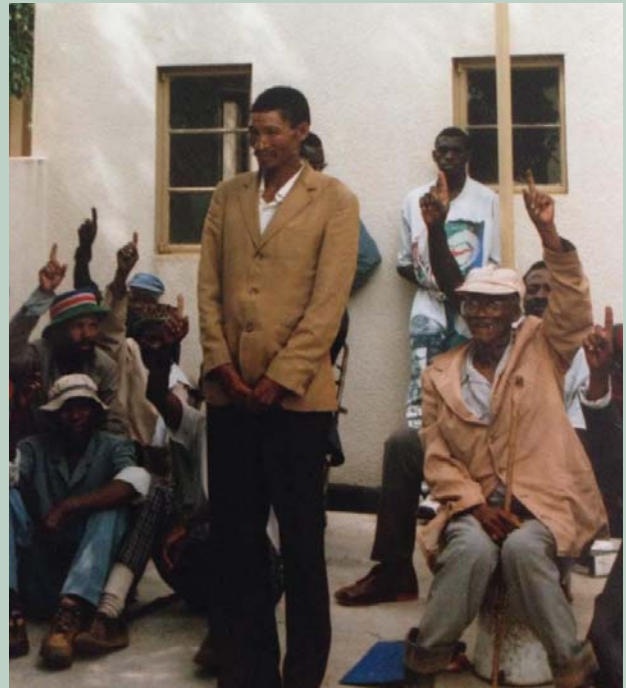
The apology famously given by the Australian government^{iv} to the indigenous Aborigine population in 2008, in which the admission is made of the collective harm perpetrated on them and their ancient cultures, has not yet been given in Africa.

For many reasons, including their existence until recent times as hunter-gatherer peoples, and their unique genetic properties as descendants of possibly the oldest form of humankind, **the San have found themselves in high demand as research populations.**

Modern San leaders faced with increasing societal challenges had no means of discussing their problems with other leaders, of learning about their human rights, or of deliberating ways in which they might legitimately challenge the unwanted interventions from researchers and other outsiders such as media.

In addition, the San world view is generally one of seeking harmony, and avoiding all forms of conflict. Several scholars of conflict resolution have based their principles of good practice on ancient San systems, in which prevention of disputes and reconciliation of interests are deeply ingrained.^v

The outside world regarded the San, arguably with much justification, as a classic example of a 'vulnerable population',^{vi} lacking the means to organising a collective response to their common interests and concerns.



Election of a traditional leader Frederick Langman, Namibia 1966

David Cruiper 2011 (Photograph David Hees)



Prior to 2000 virtually all research was externally conceived, and was perceived by the San as being disruptive and on occasions harmful for the research populations. Internet searches of the words San, Khoisan⁵ and Bushmen deliver thousands of papers, books, and research theses, supporting the statement that the San are among the most researched peoples worldwide. **But until they formed their own representative organisations as described below, they did not have a unified voice and thus remained powerless to resist unwanted attention from outsiders.**

THE SAN ON EXPLOITATION AND THE NEED FOR A CODE OF ETHICS



TO SEE A VIDEO, CLICK HERE



<https://www.youtube.com/watch?v=H0dW3mv7JSo>

Andries Steenkamp, Doris Schroeder,
Dawid Kruiper. Andriesvale 2006



Kxao Moses and Chief John Arnold from Namibia, 1996



⁵ Whilst the term "Khoisan" is often and increasingly used in the public domain as a unifying name for the two distinct groupings in Southern Africa, namely the Khoi, or KhoiKhoi and the San, or Bushmen, this umbrella term is of no relevance when discussing the San peoples. The Khoi or KhoiKhoi, previously known in South Africa as Hottentots, are regarded as pastoral, and of more recent descent. See: Barnard, Alan (1992) *Hunters and Herders of Southern Africa: A comparative Ethnography of the Khoisan Peoples*. New York: Cambridge: Cambridge University Press.





CHAPTER 2

THE DEVELOPMENT OF SAN REGIONAL INSTITUTIONS

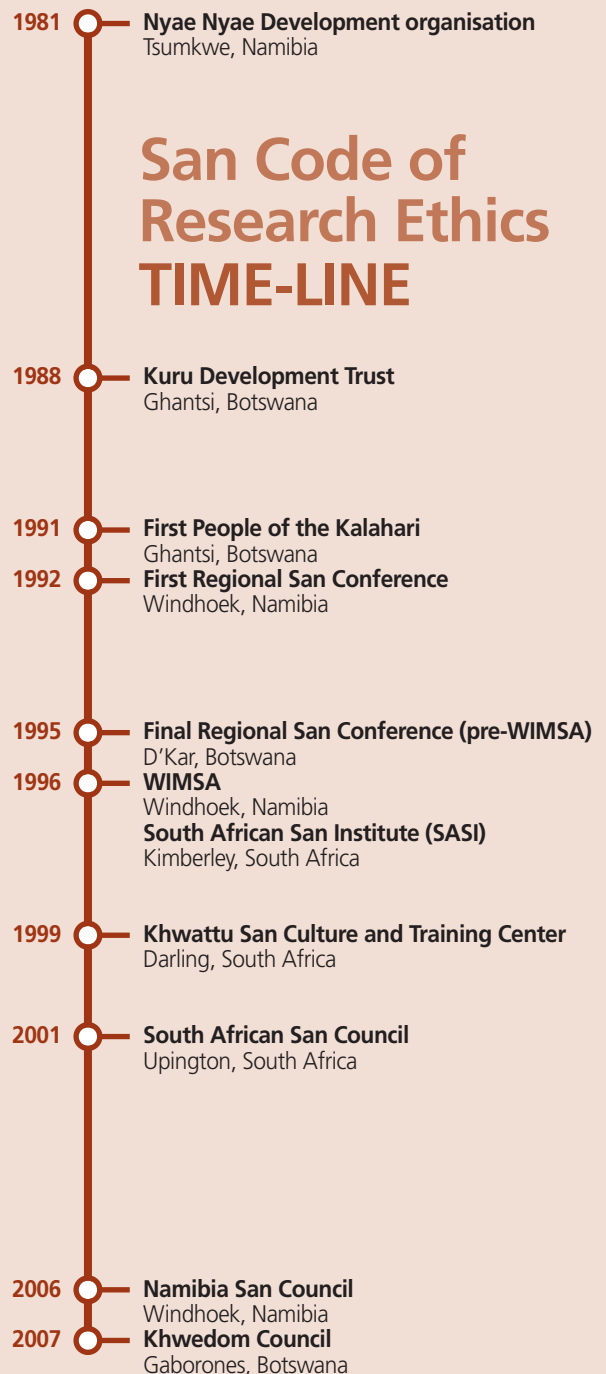
Above - Hoodia Benefit Sharing discussions in Uptington 2008, PIC project

The most important step towards the San Code of Research Ethics was local institution-building, a step which made all other successes possible.

Prior to the 1990s, the San communities had no institutions dedicated to coordinating efforts to advance their interests. The Kuru Development Foundation in Botswana, and the Nyae Nyae Development Foundation in Namibia were already in existence, but the formation of new key institutions provided the platform for San leaders to articulate concerns, advance their knowledge of the world, and begin to articulate their human rights. The following is an approximate timeline of when these key institutions were formed; some of them are singled out for discussion below.

Six of the above institutions have been central to the various successes the San of South Africa have experienced in their mission to protect themselves from exploitation:

- **WIMSA**
- **The South African San Institute (SASI)**
- **Three regional San Councils (South Africa, Namibia and Botswana),** and
- **!Khwa ttu**



WIMSA

During the early 1990s, following disparate and uncoordinated efforts by non-government organisations (NGOs) to assist San communities in the different countries, a sustained effort was made by community activists to bring together San leaders to discuss their common issues and problems. Axel Thoma and the late Braam le Roux⁶ responded to the significant challenge of bringing together community leaders from remote and far-flung communities, as well as across national boundaries.



Kippi George, First WIMSA Chairperson, Khwe 1996 (Photograph Axel Thoma)

In June 1992 the first regional conference, aimed at gathering San leaders of different languages and from different countries, was held in Windhoek for San leaders of Namibia and Botswana, followed by a second meeting in Gaborone in 1993^{vii}. At both meetings, San communities acknowledged the significance of sharing their common problems and life experiences, and also **expressed the joy of discovering that they were part of a larger San family or community.**



Kippi George in Skonheid 1996 (Photograph Axel Thoma)

In early 1995, the Netherlands Development Organisation SNV and the Swedish development organisation DIAKONIA funded a “needs assessment” to be carried out by Axel Thoma and Braam le Roux, in collaboration with San community leaders. These two funding agencies, later to be followed by others, supported the institutional empowerment of the San, and particularly promoted the intention to form a cross-border, regional organisation.

In May 1995 a final regional San development conference was held in Botswana in order to receive the recommendations of the needs assessment, and to determine the road ahead. For the first time, South African San leaders were invited. The conference on “Self-development and Resettlement” was held in D’kar, Botswana, and 54 San leaders from Namibia, Botswana and South Africa attended.

After debate, Thoma, le Roux and San leaders were mandated to take the recommended action towards building San unity with start-up funds from Swedish DIAKONIA. In the words of **Axel Thoma, “This was the start of the vision to coordinate the advocacy work of San leaders in the entire region under one organisation.”**^{viii} In January 1996, WIMSA (the

⁶Axel Thoma (a German development worker, then employed with his wife Magdalena Brogmann as field workers for the Nyae Nyae Development Foundation, which supported the Ju/hoansi San of East Bushmanland in Namibia), and the late Braam le Roux (then working with his wife Wilhemien as church leaders in D’kar, near Ghansi, primarily with the N’aro community, in Botswana), first consulted with San leaders such as the late Kxau Moses Toma (Ju/hoansi), Kippi George (Khwe) and John Arnold (!Kung).



Augustino Victorino speaking at WIMSA San Conference in Groß Barmen, 1996

Working Group for Indigenous Minorities in Southern Africa) was formed in Windhoek, Namibia. Windhoek was chosen due to its relatively central location, and good transport networks for all San populations.

At the time, the governments of Botswana and Namibia were not supportive of exclusive ethnic groupings, and the word "San" was not permitted in public discourse in either country. Hence the name WIMSA was chosen.^{ix}

WIMSA's primary objective, as stated in its first constitution, was the protection of the rights of all San peoples in Southern Africa. The first board of WIMSA initially consisted of equal numbers of representatives from San community organisations in Namibia, Botswana and South Africa, with one representative from Angola being nominated in 1998.

The first Chairperson of WIMSA was Kippi George, from the Khwe San. On his death he was followed in 1997 by Kxau Moses ƛoma of the Ju/hoansi. Axel Thoma became the first Coordinator of WIMSA and held the position for ten years.

The first board meeting of WIMSA was held on 30 January 1996 in South Africa, and a policy was adopted for rotating board meetings between the three member countries (where possible) to prevent perceptions of bias towards any country. In the words of the late Mario Mahongo, **"for the first time we were meeting San leaders from the whole region,** and we realised that this new organisation WIMSA could really help our people."



WIMSA AGM, 1997

WIMSA functioned effectively as a regional organisation from its inception in 1996 until approximately 2016. The early successes of this important San organisation in raising awareness and promoting advocacy amongst the San cannot be overstated, and are captured in its annual reports, which were provided to the institutional funders that supported WIMSA's objectives over two decades. WIMSA's Annual report on activities April 2003 to March 2004, listed no less than 25 institutional funders.

WIMSA offered consistently strong advocacy relating to the protection of San culture and heritage. International successes include sending of delegates to the annual United Nations Working Group of Indigenous Populations from 1998 to 2008, where the International Declaration on the Rights of Indigenous Populations was being negotiated

Importantly, WIMSA also drafted the San's first Media and Research Contract in 1998, which was aimed at managing the external incursions into San culture which up until that time had occurred with no San control at all. San leaders throughout the region were trained in implementation of the contract and it was used to deal with researchers, film-makers, authors and others who entered San territory with a desire to gather information.



Axel Thoma and Petrus Vaalbooi, WIMSA AGM, 1998

The WIMSA Media and Research Contract was still in use in 2015, when the TRUST project (the project, which launched the San Code of Research Ethics) obtained permission to work with the San. **This contract acted as a direct precursor for the development of the San Code of Research Ethics in 2017.**

In spite of these notable successes, running WIMSA was not without challenges. In 2005, Namibian San Leader Joram /Useb, a Hei//om, replaced Axel Thoma as coordinator of WIMSA. Joram /Useb has reflected on some of the challenges he experienced during his period of managing WIMSA:

In WIMSA the divisions were very deep. Democratic governance is crucial to organisations, for ensuring that they are run in the interests of their members rather than in the interests of a small elite. When I took over leadership of WIMSA in 2005, the Board came with their demands, that they needed to be paid N\$300 per meeting plus petrol allowance, each one coming to meetings with their private vehicles.^x

These words reflect one knowledgeable San person's view on the internal struggles for control of an important community organisation, which had no effective checks and balances for the governance of conflicting opinions. Subsequent WIMSA managers were not able to resolve the Board's divisions and funder confidence began to diminish. **Without the support from international funders, WIMSA began to experience difficulty raising funds which led rapidly to the sale of assets and its eventual closure in 2016.** At the time of writing this report, San leaders are in the process of exploring options for reviving WIMSA, or a similar organisation, to represent the San in the Southern African region.



WIMSA during a meeting with Hoodia growers, 2009

SOUTH AFRICAN SAN INSTITUTE

The South African San Institute (SASI) was formed in 1996 and initially took the form of a dedicated San service NGO. SASI's original mission was to assist the !Khomani San with their restitution land claim in the Kalahari. This was completed successfully in 1999, but SASI continued to be active.

SASI also supported the !Xun and Khwe San communities, who were relocated to South Africa from Namibia after termination of the "bush wars" in 1990, and settled in a temporary army camp near Kimberley, where SASI is based. The communities' first needs were for assistance in relation to housing and other social problems arising from their exceedingly disruptive and war-torn history, where they were caught in the cross-fire between the Apartheid government of South Africa and freedom fighters in Angola and Namibia.

SASI's Board is constituted equally of San leaders and other Trustees. Since its inception, the Board has guided the NGO through periods of successes as well as through subsequent lean periods where funding was limited and personnel had to be laid off. SASI employed a legal advisor (Roger Chennells) as well as anthropologists and other consultants who were instrumental in many of the South African successes listed below, including the !Khomani land claim, the !Xun and Khwe resettlements, and benefit sharing cases involving medicinal plants such as Hoodia, Sceletium, Buchu and Rooibos.

SASI played a key role in development of the San Code of Research Ethics, working with WIMSA on the first Media and Research Contracts, and latterly as part of the TRUST project, organising the workshops that brought the San communities together for this purpose.



Hennie Swart and Ouma Sensi in Kalahari Festival Innovation-tent, June 2015.
Co-sponsored by ProGRess



Salesti Jack (Khwe), Rita Munawgo (Khwe), Julia Dammann (SASI), !Khwatlu 2018



SOUTH AFRICA SAN COUNCIL

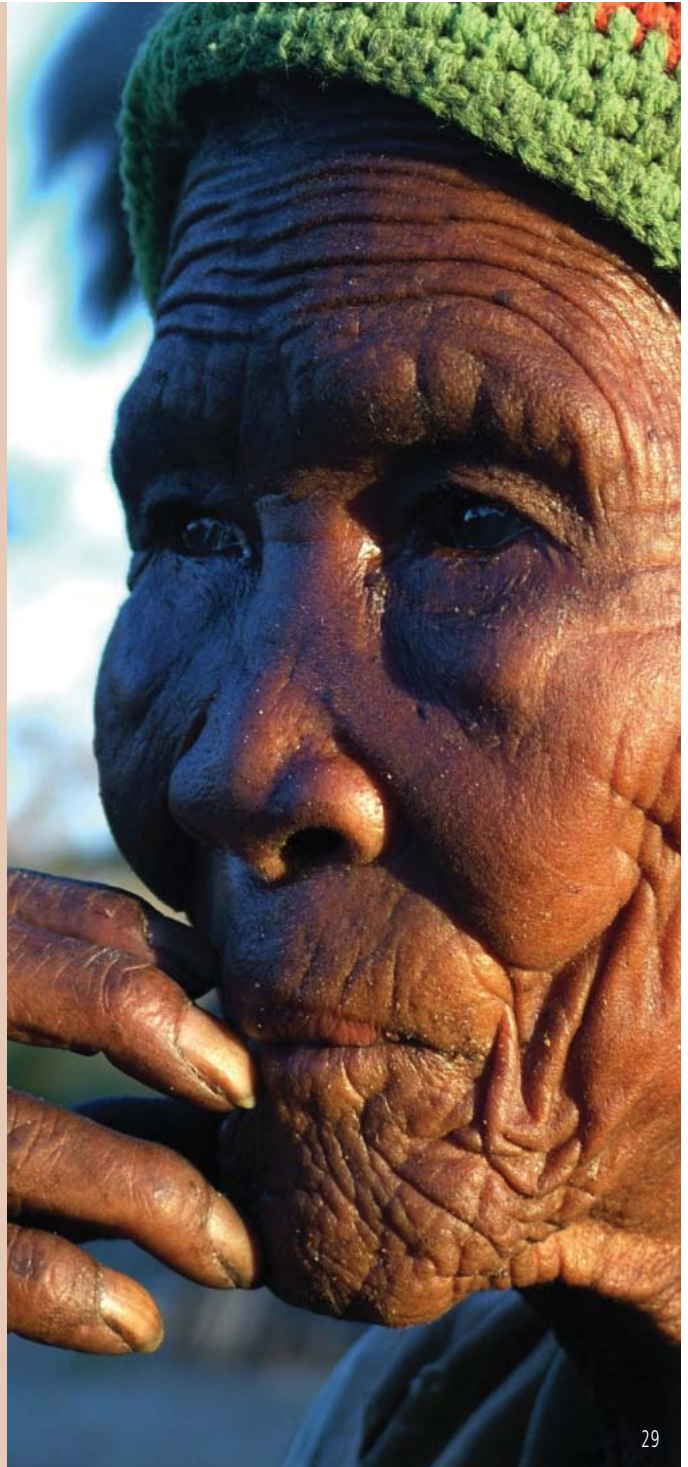
One of WIMSA's legacies was the proposal, on behalf of the first Norwegian funder, to form democratically elected San Councils in the three main countries (Namibia, Botswana, and South Africa). South Africa's San Council had existed informally since 1996 in the form of the elected leaders of the three South African San communities represented on the WIMSA board (!Khomani, Khwe, !Xun). In 2001, the Council was first constitutionally formed as a separate legal body because of the need to negotiate formally as an institution with the South African Council for Scientific and Industrial Research (CSIR) in relation to the San's traditional knowledge rights to the Hoodia plant (see below).

San institutional needs in South Africa were varied, but particularly pressing at the time were:

- Land claims following legislation brought in by the Mandela government.
- Benefit sharing agreements in relation to medicinal plants, following South Africa's adoption of the **Convention on Biological Diversity** with its protection mechanisms for traditional knowledge.
- Protection from exploitation in research and loss of cultural heritage.

With ongoing legal and administrative support from SASI, the South African San Council has grown from strength to strength, with one of its greatest successes being representation of the traditional knowledge (TK) rights of the San for various medicinal plant varieties.

Mama Xasae Kgao (Photograph Rein Dekker) 2006



In the words of Leana Snyders, the current Director of the San Council, “Our relationship with SASI has helped increase our capacity to understand the law, and also to represent our people. **With the legal knowledge gained from negotiating benefit sharing agreements resulting from our traditional knowledge, the San have become acknowledged leaders in this field**”.

The successes achieved by collaborations between the San Council and SASI are described later, and include the San Code of Research Ethics.



Hoodia Trust with two visitors (DS and SW), 2006.
Top from left: Zeka Shiwarra, Mathambo Ngakaeaja, Doris Schroeder.
Bottom from left: Anna Festus, Mario Mahongo, Collin Louw, Samantha Williams
(University of Cape Town), Andries Steenkamp, Roger Chennells

NAMIBIA SAN COUNCIL AND BOTSWANA SAN COUNCIL

Both Namibia and Botswana formed elected San Councils in the early 1990s and were represented regionally on the Board of WIMSA until the organisation ceased to operate in 2016.

A number of NGOs operated in Namibia and Botswana, forming institutional resources not only for the San but also for the San Councils. In Namibia there were two dedicated San NGOs, the Nyae Nyae Development Foundation and WIMSA.^{xi} In Botswana, no less than six dedicated San NGOs were registered and formed part of what was for many years known as the “Kuru family of organisations.” In a publication entitled “KFO twenty one years”^{xii}, the Kuru family of organisations celebrated over two decades of San development in Botswana. This included established NGOs such as Kuru, Letloa Trust, Ghantsi craft, Komku Trust, Trust for Okavango Cultural and Development Initiatives (TOCaDI) and Bokamoso Trust. **The Letloa Trust** is the lead organisation that coordinates and manages these San Trusts in Botswana.

Namibia and Botswana are amongst the most sparsely populated countries on earth; the logistical and financial challenges of coordinating and unifying widespread communities without strong collaborative support from existing organisations, were huge. In the words of Joram /Useb:

The South African San Council survived because leadership remained the same, and it only represents three communities. They had a budget and income from different sources. In the case of Namibia and Botswana with huge and diverse communities, it was difficult for them to organise themselves. They had no budget or income and were thus totally dependent on WIMSA.^{xiii}

Much of the funding available to the South African San Council arose from funding efforts by NGOs, in particular SASI. **It is therefore reasonable to suggest that the support of dedicated NGOs is a crucial component of success in mobilising widespread communities,** and has been a component of the success of the South African San Council since 1996. The allocation of certain tasks and administrative functions to a close-working NGO enables a committee, comprised of leaders drawn from remote communities and lacking administrative facilities such as Internet, computer and telephone access, to function more easily and efficiently.



!Khwatla graduation, Castro Maliti 2014



Trainees and guests watching a video documenting the year's activities. !Khwatla Graduation 2014

!KHWAA TTU: THE SAN CULTURE AND EDUCATION CENTRE

In the decades following the formation of WIMSA, certain topics emerged as clear priorities amongst San communities:

- Access to land
- Benefit sharing for traditional knowledge
- Protection of heritage and culture



Trainees, training staff and Board members in joyful celebration. !Khwaa ttu Graduation 2014

The love and indeed passion for culture emerged as a powerful theme that united and defined the disparate San peoples, and made them talk animatedly into the night at workshops. Despite their material disempowerment in the modern world, and despite the difficulties they experienced in engaging with the modern world, their culture remained to them a unique and precious commodity, in urgent need of protection.

During meetings about heritage, passionate stories were shared of how they had allowed their heritage rights to be abused. Of how researchers had taken medicinal knowledge, stories, songs and images under various pretexts, resulting in unacknowledged films, books, medicines and

research papers being published in faraway lands. Of how photographs had been taken of San hunters at the roadside, which ended up as glossy postcards or photos in Western magazines. And of how books of San stories and myths had been researched and published without acknowledgement of the original storytellers. Teas, medicines and natural remedies based on San plant knowledge became commercial successes, whilst the San languished in poverty.

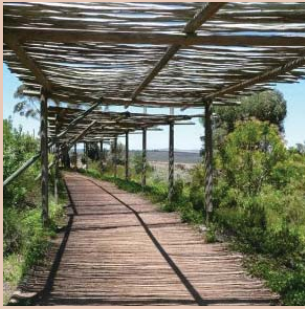


Trainees sporting their graduation T-shirts. !Khwaa ttu Graduation 2017

The need for protection of heritage and culture thus became more and more urgent for San communities, requiring a collective response.

When San delegates at a WIMSA annual general meeting in 1997^{xiv} decided that as part of their cultural revival, and in response to decades of disempowerment by others in the research and tourism industries, they should seek assistance for the creation of their own cultural and tourism training centre, a foundation stone of San heritage revival was laid.

A Swiss anthropologist and philanthropist, Irene Staehelin, had previously indicated an interest in assisting and working with the San if they ever decided to commit to a long-term culture and training



!Khwattu 2009

project. She was informed that the San were now serious about taking heritage and tourism into their own hands, and soon a joint venture partnership was formed between the San leaders representing WIMSA and the Swiss Trust, **Ubuntu Foundation**, founded by Irene Staehelin. **The aim was to start a heritage project that would train San youth and showcase the best of San culture.**

After a long search, on 1 April 1999 a farm on the South African west coast named Grootwater, 70 kilometers north of Cape Town, was purchased by the Ubuntu Foundation. Numerous community workshops helped to jointly establish the vision for the exciting new venture, which was named !Khw ttu, meaning 'waterhole' in the now extinct Xam San language.

!Khw ttu, managed by a board from both Ubuntu and WIMSA, was formally launched on 6 March 2006. Trainees are selected annually from Botswana, Namibia and South Africa, with **training consisting of practical topics such as tracking, guiding, computer skills and restaurant work, as well as subjects such as rock art, intellectual property, history and San culture.** The annual graduation of trainees takes place in October of each year, which is invariably an exuberant celebration of San graduates bursting with new-found confidence and enthusiasm for their lives ahead. At the time of writing (November 2018), !Khw ttu is staffed by around 40 people, most of whom are San, and has

successfully trained no less than 150 trainees. During the previous year, 12,000^{xv} visitors experienced the various cultural tours, exhibits, shopping and restaurant that are proudly offered at !Khw ttu.

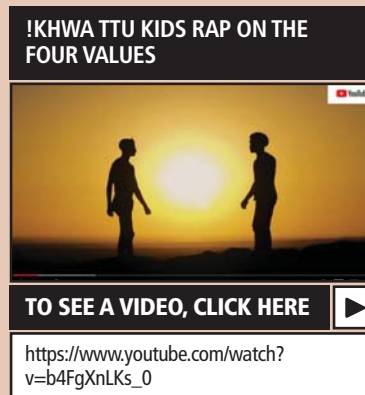


Trainees posing with an Ouma and Mother who joined the festivities. !Khw ttu Graduation 2014

On heritage day, 24 September 2018, and after a gestation period of five years, the long-planned San heritage museum was launched. **The museum exhibits San culture from a grounded San perspective, and honours Irene Staehelin for her dedication to the early vision.** The !Khw ttu museum displays are reflective of ongoing, in depth consultation with San advisors, drawn from communities across Southern Africa.

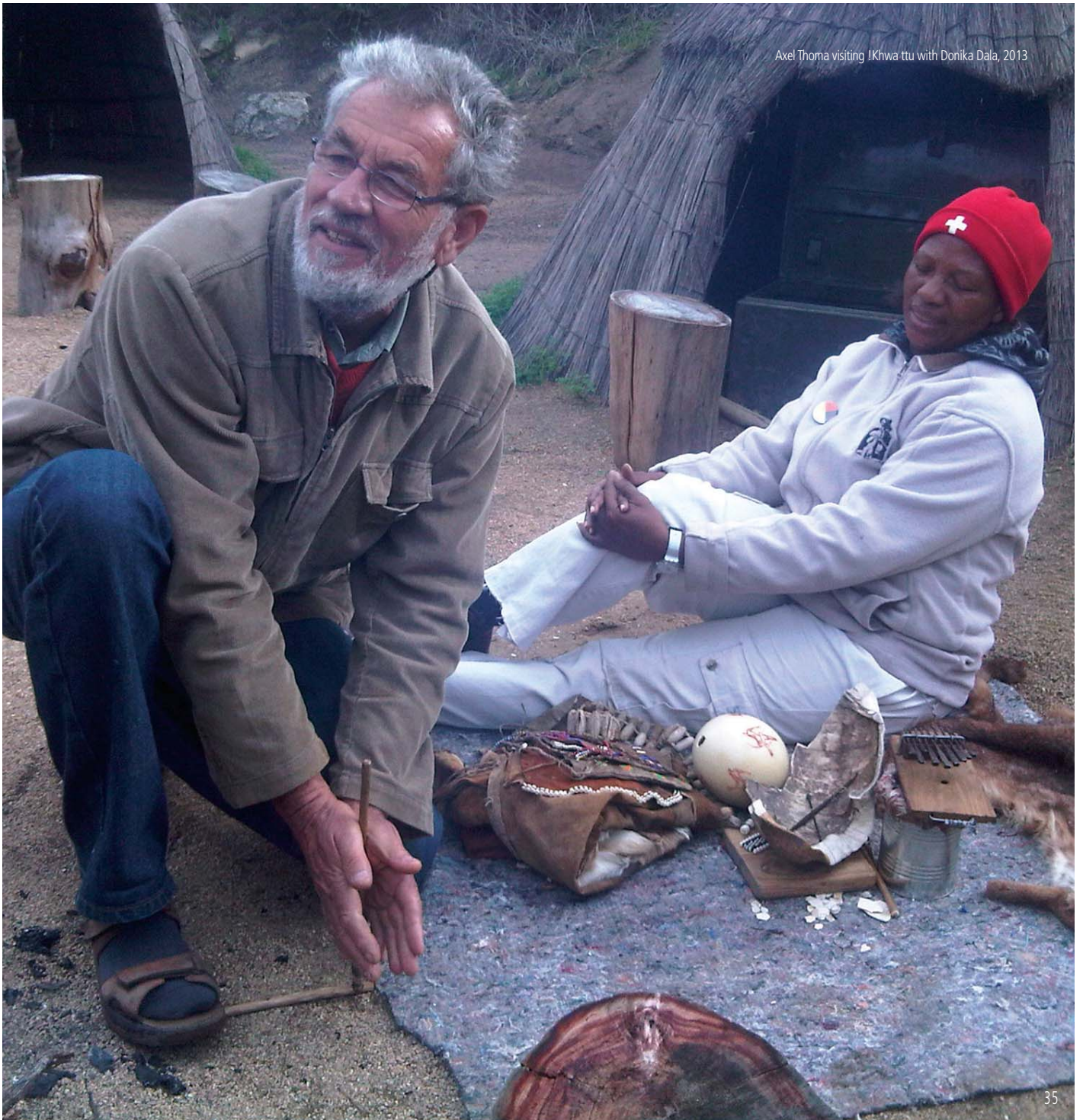
It promises to be a museum of world class standard, and another significant milestone in this long-term project. A sustained drive to maintain the involvement of past trainees/alumni, including regular outreach initiatives with the San communities, strives to preserve and improve a sense of pride and investment in this joint venture heritage project. In the words of Joram /Useb, who works for !Khwattu, “Khwattu has become a project where San trainees feel at home, whilst they learn how to engage with tourism and the modern world.”

A few months before the museum was opened, !Khwattu Kids won a rap competition to explain the four values of the San Code of Research Ethics (fairness, respect, care and honesty) in music.



Opening of museum, September 2018. Irene Staehelin bottom row left







CHAPTER 3

SUCCESSSES AND CHALLENGES FOR THE SAN REGIONAL INSTITUTIONS

Above - !Khwatlu workshop, 2014, with Zembrin colleagues and Ministry of Science and Technology involvement, ProGRESS project

The establishment of San regional institutions has transformed the ways in which the San from different communities are able to work together. Regional networks have enabled major successes and these in turn have strengthened the San leaders, and the willingness to tackle possible exploitation wherever it is encountered.

MAJOR SUCCESSES OF THE REGIONAL INSTITUTIONS

As is stated in many conventions and statutes^{xvi} relating to the rights of indigenous peoples, **heritage and culture are inextricably linked to, and dependent on, access to traditional land.** Culture, which includes the knowledge systems, language, songs and stories relating to their landscape that are passed down over centuries and even millennia, is deeply rooted in traditional lands. It was therefore a particular success when the South African San won a land claim.

Land claim in South Africa

Access to land and the longing for tenure security on traditional land was shared by all members of the regional WIMSA organisations as a powerful prerequisite for stability. Access to land is one of the rights regarded by international instruments⁷ as being central to indigenous peoples' empowerment.



Dawid Kruiper and Petrus Vaalbooi, Traditional leader and Chairman of the !Khomani San CPA, together with Thabo Mbeki (then Vice-President of South Africa), on the occasion of the announcement of the successful San land claim. March 1999

The words and names the San have for landmarks, medicinal plants and animals, all relate to specific traditional land, and wither away when their access to that land is compromised. **The removal of San from their traditional lands by more assertive external communities over the past centuries, combined with the challenges of modern society, are seen as the most powerful factors threatening San culture and livelihoods.** In South Africa, land claims were won between 1999 and 2002; in Namibia and Botswana, access to and ownership of land is more complex, and remains as a permanent aspiration.

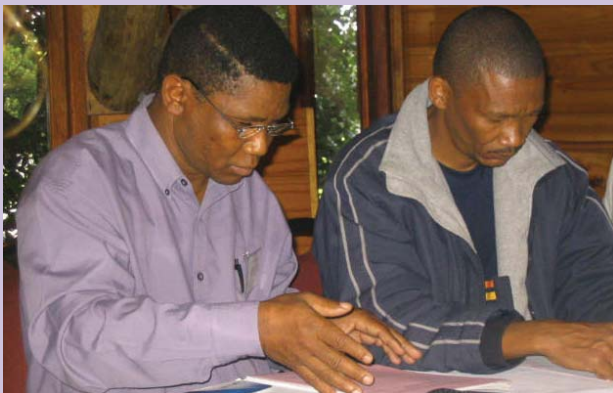
After the release of Nelson Mandela in 1990, legislation was drafted in South Africa aimed at undoing the Apartheid state that had reigned for close to half a century. The Restitution of Land Act of 1994 was designed to return land to claimants who had lost land as a result of one of Apartheid's race-based policies.

⁷ For example, clauses 10, 11, 25 and 26 of the United Nations Declaration on the Rights of Indigenous Peoples UNDRIP 2007 <https://www.un.org/development/desa/indigenouspeoples/declaration-on-the-rights-of-indigenous-peoples.html>

The San, the first inhabitants of South Africa for millennia prior to later invasions, had by then been reduced to a few scattered clans in the Northern Cape living on the outskirts of villages, in dire poverty. Roger Chennells spent four years from 1992 tracing San members of the !Khomani,/Auni and N/Amani language groups, under the charismatic leadership of clan head Dawid Kruiper. Many of Kruiper's clan had been forcibly removed from the (then) Kalahari Gemsbok National Park between 1931 and 1965, and had spent the past decades moving and living from hand to mouth.

By 1996 it was clear that these San people, the last surviving indigenous San of South Africa, had a powerful legal right to launch a land claim. The NGO SASI was formed in the same year to provide the newly re-forming San community with both legal and socio-linguistic support (under the leadership of Nigel Crawhall). The SASI legal program held a large number of meetings for educating San about their legal rights, and developing the legal structures necessary to pursue the land claim. The socio-linguistic program explored the language and cultural aspects of this San revival.

By 1997 no less than 20 fluent speakers of the N/uu language had been located in the Kalahari, a remarkable occurrence given that this language had previously been declared as officially "extinct".



Andries Steenkamp and Collin Louw, Monkey Valley Cape Town, 2004

During 1996 SASI also began to provide support to two further San communities, the !Xun and the Khwe, as noted earlier. The !Xun and the Khwe were originally from Namibia and Angola, and had been forced to join the South African forces during the "bush wars". They were evacuated rapidly to South Africa following Namibia's independence in 1992. These two immigrant San communities were settled in a tented camp outside Kimberley and were in need of a wide range of social and legal services as they adapted to changed circumstances.

A committee comprising both traditional and 'westernised' San represented the land claimants, and **in March 1999 South Africa's first and last San land claim was concluded at an emotional and joyful ceremony.** Former President Thabo Mbeki officiated over the land handover, which aroused great interest because most South Africans had, until then, believed the San peoples to be extinct. The San, now formally named the !Khomani (as the largest of the various language groups involved) were awarded 45,000 hectares of land outside the Kgalagadi Transfrontier Park (KTP), as well as "symbolic heritage rights" over a massive area within the KTP. At about the same time, the !Xun and Khwe San were moved from their tented camps to a farm named Platfontein, near Kimberley.



Mama Xasae Kgao
(Photograph Rein Dekker) 2006

Meeting of members of the Hoodia Trust
with Doris Schroeder, Kimberley 2009.
From left back, Tommy Busakwe,
Collin Louw, Helena Heystek
(Council of Scientific & Industrial
Research), Andries Steenkamp,
Mario Mahongo, Doris Schroeder;
from left front: Zeka Shiwarra,
Roger Chennells



After the three San communities had achieved access to their land, SASI continued to receive support from **fundors, who understood that vulnerable indigenous communities require a wide range of dedicated assistance in order to manage the transition to land ownership and stable community development.** Governance matters such as leases, management, livelihoods and land uses were amongst policies and decisions that affected these communities. The three South African-based San groups had together formed the San Council in 2001 in order to coordinate their advocacy for the Hoodia case (see below), and the Council's capacity continued to grow and develop as it expanded its work to advocacy in the fields of heritage, culture and traditional knowledge. The struggles for land and the demand for development in their communities, provided the San leadership with multiple challenges and an incentive to collaborate with SASI as a dedicated long-term San NGO.

Benefit Sharing Agreements

The global UN Convention for Biological Diversity (CBD) of 1992 first provided for the principle that commercial users of plants with active ingredients based upon Traditional Knowledge (TK) needed to negotiate 'benefit sharing' agreements with the TK holders, in order to ensure fairness.^{xvii} With this development, the San rediscovered the value of their culture and heritage in the form of their TK of a wide range of medicinal and other useful indigenous plants.

In 2003 the first benefit sharing agreement was negotiated with the South African Council for Scientific and Industrial Research in relation to appetite-suppressant qualities of the famous Hoodia plant.^{xviii} **The Hoodia benefit sharing case achieved iconic status in the CBD world, but sadly despite its initial promise,**

the anticipated commercial successes of the utilisation of Hoodia have failed to materialise.

Over the following years, further important benefit sharing agreements were signed in relation to plants, including Sceletium, Buchu, Honeybush and Rooibos. This provided crucial acknowledgement of the San (as well as the Khoi) for the tangible value of their heritage, and also the means to transform such acknowledgement into financial strength. Whilst other benefit sharing agreements have since been negotiated relating to plants including Devil's Claw, **the Sceletium benefit sharing agreement stands out as a milestone for a stable and mutually beneficial partnership between community and industry.**

The Sceletium case began with a scientist, Dr Nigel Gericke, registering a patent on the healing properties⁸ of an indigenous plant. Before entering the market with a product, the company, HG&H Pharmaceuticals (Pty) Ltd, chose to proactively enter into negotiations with the San Council. Dr Gericke's research indicated that the plant was referred to in the 17th century diary of Jan van Riebeeck, the first Governor of the Cape of Good Hope, as Kanna (or Canna) in the Nama language, kougoed (literally, "chewing stuff") in Afrikaans, and Ik"wai in the now extinct Xam San language. Van Riebeeck regarded it as highly valued by the indigenous peoples, stating that the power of a certain chief "flowed from the precious Canna that grew in the desert."^{xix} Another early account states:

"there is a root, gather'd in the Hottentot Countries, called Kanna: which is in such esteem among the Hottentots for its great virtues that they almost adore it. ... They look upon it as the greatest clearer of the spirits, and the noblest restorative in the world. They will run twenty miles, or perform a hard day's work, for a very small bit of it."^{xx}

⁸ The plant, used by San and Khoi as a mood enhancer, was found to have an influence on the central nervous system, and after tests, an active component was found to be a potent 5-HT uptake inhibitor. The patent, registered in 1996, was based upon this activity. Iatridis K and Schroeder D, (2016) The Basics of Responsible Research and Innovation. In "Responsible Research and Innovation in Industry". In SpringerBriefs in Research and Innovation Governance. DOI 10.1007/978-3-319-1693-5_2

In a decision that was to be later followed in other cases, **the San traditional knowledge holders elected to provide equal benefits to two Nama communities.**

Certain healers from the hamlets of Paulshoek and Nourivier had collaborated with Dr Gericke during his early research, and these two communities were jointly allocated half of the annual benefits resulting from the commercialization of Sceletium-based products. The benefit sharing agreement was signed in 2008, prior to the launch in 2010 of the final product aimed for the dietary supplement market, and known by the trade name of Zembrin. Further international patents were secured in overseas markets, and by 2015 no less than 26 branded dietary supplement products contained Zembrin.

Sales of Zembrin have continued to rise each year following the commercial launch, with the San and Khoi beneficiaries receiving annual financial reports of commercial performance, as well as the negotiated royalty on sales. The applicable legislation ensures that the money is paid into the Bioprospecting Trust fund administered by the South African government Department of Environmental Affairs, and that annual reports are provided by the San Council of South Africa

as well as the two village Trusts. **The Department of Environmental Affairs regularly praises the Sceletium agreement as representing a 'best practice' model of mutually beneficial partnership between commerce and indigenous knowledge holders.**



Sceletium benefit sharing agreement signed in 2008 (Dr Gericke, right top row)

San settlement, Platfontein, near Kimberley 2016



MAJOR CHALLENGES FOR THE REGIONAL INSTITUTIONS^{xxi}

Many tangible advantages have sprung from coordinated regional efforts but the establishment of cooperative relationships and institutions has not been without its challenges.

Following its inception, WIMSA proceeded over the next fifteen years to coordinate the collective efforts of the San in Namibia, Botswana and South Africa towards 'empowerment', a term used by the European-based funders who supported the process. The term 'empowerment' could be understood as an increasing capacity and power to survive or thrive in a fast changing world. However, this term also encompasses a subtler connotation of 'development' from a state of disempowerment to empowerment and in this instance, 'development' implies acceptance of a Western democratic model.

Western assumptions about development were incorporated as both overt and implied conditions of accepting funding support. European funders supported training programs and workshops based upon specific assumptions about relationships between men and women, as well as between the San people and modern development. As stated by Joram Useb:

It was difficult to communicate to funders from Europe the complexity of the world of San communities, who lived in conditions of deep poverty and isolation.

For example, as a condition and requirement of funding support, it was often assumed by funders:

- that the most pressing empowerment needs of the San were for money, jobs and access to the opportunities and amenities of the modern world. This assumed that they needed to be trained to fit into society, rather than to contribute to their own communities.

- **that modern democratic forms of representation should be instituted whereby leaders were formally elected, despite the fact that most communities had never experienced elections.** San persons who were elected representatives thus found themselves immediately catapulted into previously unimagined positions of power and status, based purely upon their elected positions. Such status elevation was problematic to egalitarian San societies.
- that San women should (within strict timeframes) form 50% of all leadership structures. They were expected to undertake leadership positions in order to show gender equity, despite strong and ancient San cultural prohibitions against women speaking out in public. A married woman elected to a committee might thus, despite strong cultural taboos, be expected to travel without her husband to attend far-away workshops, with resultant anxiety all round;
- that strict time lines and outputs were appropriate for San projects, notwithstanding the San need for consultative and unrushed decision-making processes.

San Councils, as members of WIMSA, were elected to represent the local San communities in Namibia, Botswana and South Africa. **They were required to follow the democratic processes prescribed by Western funders, which were new to San communities, as well as fraught with anomalies and cultural tensions.** Elections resulted in outcomes that were different from those that might have resulted from less Western-based processes. Elected leaders were in some cases those who were able to lobby for support rather than more traditional leaders. Leadership was new to them, as was the exposure to new forms of temptations provided by money, freedom and mobility. Elected leaders were immediately hoisted to a relatively higher position of wealth and status compared to their peers and this often resulted in jealousy, confusion, and a longing by some in the communities for earlier, simpler, more predictable times.



Kimberley 2014

Whilst the imposition of Western governance policies and democratic structures on the San by well-meaning European funders was simply regarded as being ‘best practice’ for development funding, there was scant cognisance of the difficulties the conditions attached to the funding might cause in communities that had for millennia embraced sheltered, egalitarian and loose governance systems.

At the same time, the International Indigenous Peoples’ movement was benefitting from the first United Nations Decade of Indigenous Peoples^{xxii}, and WIMSA was determined to become part of the international movement. Each year between 1998 and 2008 WIMSA coordinated the selection and training of leaders to attend the United Nations Working Group of Indigenous Peoples in Geneva, where they mingled with other similar indigenous and vulnerable peoples, and contributed towards the development of the Universal Declaration on the Rights of Indigenous Peoples (UNDRIP), which was finally adopted in 2007. **Leaders who became exposed to the debates and realms of the United Nations Institutions in Geneva returned home to impoverished communities, and to the vast challenges facing their peoples.**

A major benefit of the formation of San institutions was networking. Within a relatively short period of time, and with a radical learning curve being imposed on their leaders, San communities were benefitting from being connected with each other and the outside world by a functioning network of organisations. At the same time, alongside these benefits came challenges such as the newly awakened politicisation of their structures, the emergence of materialism, disputes over positions of power, jealousy, and envy of others. In many cases the sheer difficulty of engaging successfully with the outside world, or the pressure of jealousy by others, led to leaders resigning. Meanwhile, widespread poverty persisted, with feelings of helplessness, and the breakdown of social relationships within San communities.

During the first two decades of institution-building, San leaders were reminded repeatedly by their communities about the cultural disempowerment that was still happening in front of their eyes. In other words, despite many significant milestones and achievements, problems at the community level remained serious. **In the eyes of the world, the San had transformed from their initial state of relative disempowerment in 1996, to the assertive and organised indigenous community which in March 2017 published the San Code of Research Ethics.** This undoubted achievement was praised by many indigenous and other organisations, who requested guidance so that they might emulate the San’s progress towards developing their own research ethics codes. Some imagined that the process might be straightforward, and achievable by simply following some clear rules and suggestions. However, **the reality is far more complex. In the less than straight trajectory of San developments, significant mistakes were made, and the leaders continuously overcame setbacks in their struggle towards the relatively strong position that they occupy today.** We will return to essential elements in overcoming these setbacks later, after looking at the international research dimension.



CHAPTER 4

THE CONTRIBUTION OF INTERNATIONAL RESEARCH COLLABORATIONS

Above - Book launch, 2010, Cape Town.
Back from left: Mario Mahongo, Andries Steenkamp,
Dr Vinesh Maharaj, Mathambo Ngakaeaja, Dr T Abrahams.
Front from left: Roger Chennells, Rachel Wynberg, Doris Schroeder, PIC project

In 2003, a BBC documentary about the Hoodia benefit sharing agreement generated international attention for the San. As a result of watching the documentary, Prof. Doris Schroeder started to collaborate with Roger Chennells and other South African colleagues like Prof. Rachel Wynberg of the University of Cape Town. To date, this collaboration has yielded five international research projects (BeSha, PIC, GenBenefit, ProGRess and TRUST) and one PhD study, all of which contributed to the groundwork for the San Code of Research Ethics. The funding for these research projects was generated by Doris Schroeder as Lead Investigator together with her academic and activist networks. Each of these six projects is described briefly here, together with their primary benefits for the San.



Doris Schroeder with San children in Andriessvale, 2016 (Photograph Amy Azra Dean)

BESHA – GENOMICS AND BENEFIT SHARING 2004-2005

Funded by the European Commission, the aim of **BESHA** was to work towards a programme of 'benefit sharing capacity building' for low and middle income countries (LMICs). A specific focus was on providing an intercultural perspective on the concepts of 'community' and 'benefits'.



Cape Town workshop 2004

Doris Schroeder invited two San leaders, Andries Steenkamp and Collin Louw, to the main academic workshop in Cape Town. **The presentation by the San leaders on benefit sharing drew the audience's attention like no other.** Not normally part of academic workshops, what Andries Steenkamp and Collin Louw had to say was spellbinding. **The idea that vulnerable populations cannot speak for themselves, as Doris had been told by colleagues, died a quick death.**

It was clear that the San had achieved significant successes (like the land claim and Hoodia agreement) with legal and NGO support and that the community had traditional leaders of integrity.

Seeing development challenges through the perspective of 'ethics' rather than anthropology provided an interesting angle. Doris Schroeder and

her colleague Dr Miltos Ladikas found the funding for a short reconnaissance mission to the Kalahari, where traditional leaders Andries Steenkamp, Collin Louw and Petrus Vaalbooi, as well as Roger Chennells, explained further research needs. The idea for the next project was born: PIC.



Cape Town workshop, 2004. From left, Roger Chennells, Doris Schroeder, Collin Louw, Andries Steenkamp

PIC – PRIOR INFORMED CONSENT AND BENEFIT SHARING, 2006-2008

The Wellcome Trust funded **PIC project**, later renamed to San-!Khuba (San word for Hoodia), investigated the most famous benefit sharing case to date, the Hoodia case, which was also covered in the earlier BBC documentary.



Andriesvale, 2004.
Back from left, Andries Steenkamp, Petrus Vaalbooi, Doris Schroeder, Collin Louw, Miltos Ladikas.
Front, Roger Chennells

Three main achievements can be recorded from the project that are directly relevant to the San:

1. Extension of the network to include a renowned Australian indigenous colleague, who was named an 'unsung hero of the 20th century' by Kofi Annan: Jack Beetson. Jack fed his valuable views on benefit sharing into the San discussions.
2. A major workshop in the Kalahari bringing together San leaders and representatives from South Africa, Botswana and Namibia in an effort to develop principles for sharing Hoodia Trust funds. Importantly, **the principles of fairness and respect, two of the four pillars of the San Code of Research Ethics, were first emphasized at this event.**

WORKSHOP IN THE KALAHARI



TO SEE A VIDEO, CLICK HERE



<https://www.youtube.com/watch?v=bi0SF4jb-AU>

3. An academic book with high interest internationally and significant praise as in Box 1, linking the Hoodia case to international debates on the Nagoya Protocol to the Convention on Biological Diversity.
Indigenous Peoples, Consent and Benefit Sharing-Lessons from the San-Hoodia Case.
Royalties from the book go to WIMSA.

Box 1 – Praise for *Indigenous Peoples, Consent and Benefit Sharing*

“It is good to see philosophers engaging with the UN Convention on Biological Diversity, and doing so by looking in depth at a real situation in which it has been invoked.”

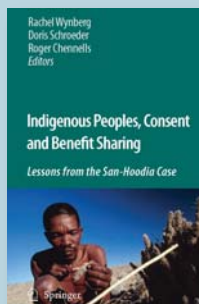
Peter Singer, Ira W. DeCamp Professor of Bioethics in the University Center for Human Values, Princeton University

“This book arrives at a critical juncture in the history of genetic resource use and policy making - not only in southern Africa, but across that continent and, indeed, around the world. ABS Regime negotiators would do well to study closely the pages of this insightful and provocative volume.”

Timothy J. Hodges, Co-Chair UN CBD Working Group on Access and Benefit Sharing of Genetic Resources (ABS)

“A timely study of the way in which the key elements of the CBD relating to access to genetic resources - prior informed consent, benefit sharing - may, or may not, work in the real world, especially as it relates to the knowledge and innovations of indigenous peoples and local communities. Analytical, in-depth and insightful. An excellent work of scholarship.”

Gurdial Nijar, Director of the Centre of Excellence for Biodiversity Law [CEBLAW], Professor of Law, University of Malaya; Lead negotiator for Malaysia and the Like-Minded Megadiverse countries (LMMC) for The International ABS Regime.



<https://www.springer.com/de/book/9789048131228>
Released 2009

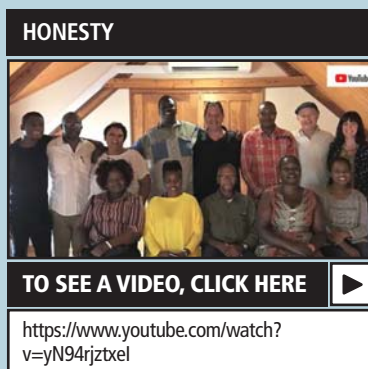
GENBENEFIT – GENOMICS AND BENEFIT SHARING WITH DEVELOPING COUNTRIES – FROM BIODIVERSITY TO HUMAN GENOMICS, 2006-2010

Interest in the benefit sharing experience of the San was considerable and hence it was possible to obtain further EU funding. **GenBenefit** expanded the work with the San to include another vulnerable research population, sex workers from informal settlements in Nairobi. This was possible thanks to co-operation with Prof. Pamela Andanda from the University of Witwatersrand in Johannesburg, and Dr Joshua Kimani, Clinical Director, Nairobi University.



COP9, Bonn 2009.
Back from left: Sachin Chaturvedi, Graham Duffield, Julie Cook, Saskia Vermeylen, Andries Steenkamp, Doris Schroeder, Victoria Haraseb.
Front from left: Rachel Wynberg, Mathambo Ngakaeaja, Roger Chennells, Kate Davies

In 2017, thanks to the TRUST project, the San and sex worker representatives finally met in person to exchange experiences. A short video records this meeting here:



The value of honesty as an essential element in an ethics code of conduct was discussed at length at the joint meeting, as recorded in the video.

The following main achievements can be recorded from the project, as relevant to the San:

1. Consultation and training meeting on Pre- and Post-Study Obligations in Biomedical Research at the invitation of the Kenyan Ministry of Medical Services. This deepened the collaboration with two vulnerable populations (San, sex workers), which later led to the TRUST project.
2. Input into ongoing benefit sharing negotiations between the San and Hoodia farmers.
3. Input into Nagoya Protocol discussions through close collaboration with Protocol Co-Chairs and a **UNEP publication**. One of the two Co-Chairs, Tim Hodges, joined a mission to !Khwatuu and a consultative meeting in India.
4. Input at CBD meetings to emphasize the importance of bottom-up approaches to involving traditional

knowledge holders. To represent interests from South Africa, Namibia and Botswana, three San colleagues travelled to a CBD meeting in Bonn to provide input: Andries Steenkamp, Victoria Haraseb and Mathambo Ngakaeaja.

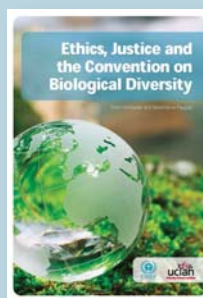
5. An **academic book** outlining the first comprehensive analysis of benefit sharing in relation to human biological resources was published. Royalties of the book go to the Fistula Foundation.



Consultative meeting with Kenyan Ministry of Medical Services, Nairobi 2009



Consultative meeting with Hoodia farmers at !Khwatuu, 2009, to include Tim Hodges, Co-Chair responsible for Nagoya Protocol



<http://www2.ecolex.org/server2.php/libcat/docs/LI/MON-088698.pdf>

Box 2 - Praise for the UNEP report:

"The report will make an excellent contribution towards enhancing our understanding of justice and the CBD. This issue is coming up repeatedly in discussions and it will be great to have a resource one can use for guidance. This report really does the job well!"

Prof. Rachel Wynberg, University of Cape Town, South Africa

"This is a new perspective for many CBD hands and I can't wait to hear their reactions. An excellent piece! I hope all those who read the report will react and hopefully think further."

Tim Hodges, Co-Chair, UN CBD Working Group on Access and Benefit Sharing



GenBenefit Conference hosted by **RIS** (Research and Information System for Developing Countries), New Delhi 2008.

From left: Veronique Fournier, Sanjay Kumar, Tim Hodges, Gurdial Nijar, Fatima Alvarez-Castillo



COP9, Bonn 2009. From GenBenefit, Dr Sachin Chaturvedi (far left) and Prof. Doris Schroeder (speaking)



<https://www.springer.com/gp/book/9789400762046>

EQUITABLE ACCESS TO HUMAN GENETIC RESOURCES – BALANCING BENEFIT SHARING AND UNDUE INDUCEMENT 2011-2014

Between two major EU-funded projects (GenBenefit and ProGRess), Roger Chennells undertook PhD research focussing on a major objection to benefit sharing, namely that **benefits provided to research stakeholders could form undue inducements** to participate. The funding was provided by the Wellcome Trust, Doris Schroeder was the PhD supervisor.

The choice of the topic was inspired directly by the difficulties experienced by San leaders following a highly publicised genomic research project carried out on San individuals in Namibia, where publication took place without recognition of or permission obtained from the San leadership.

The details of the case can be read by **clicking here**.
https://link.springer.com/chapter/10.1007/978-3-319-64731-9_3

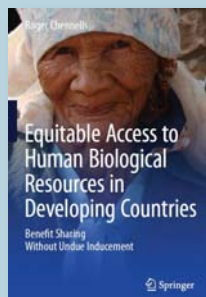


Andries Steenkamp, Roger Chennells, Petrus Vaalbooi, !Khwatla 2014

The PhD study focussed on research involving human biological resources, in view of the increasing demand for the unique and valuable DNA of indigenous peoples. In particular, focus was placed on the question whether and under what terms the notion of benefit sharing, adopted by the Convention for Biological Diversity, could and should be applicable for the use of human DNA.

Strongest and most strident of objections to benefit sharing with humans involved in genetic research was the fear of undue inducement, namely **the concern that individuals and groups from low and middle income countries might be tempted by benefits into taking part in harmful or inappropriate research**. The PhD study explored exploitation generally, as well as undue inducement and coercion in particular, in assessing whether this concern was justified. Notions of equity and fairness were explored, leading to the conclusion that **indigenous peoples should not be precluded by such concerns from receiving appropriate benefits**.

In order to achieve fair treatment, or a fair deal in research, **respectful engagement with the indigenous leadership is required for any research to be regarded as ethically responsible**. These conclusions supported the final development by the San leadership of the San Code of Research Ethics.



<https://www.springer.com/gp/book/9783319197241>

PROGRESS – PROMOTING GLOBAL RESPONSIBLE RESEARCH & SOCIAL AND SCIENTIFIC INNOVATION 2013-2016

In 2013, SASI was ready to receive EU-funding in its own right, and thanks to Meryl-Joy Schippers, SASI's then Director, they were able to join this major research project as an official partner. **ProGRess** was an EU-funded project on the topic of global responsible research and innovation.



Andries Steenkamp, representing San interests in Beijing, 2014

The following main achievements can be recorded from the project as relevant to the San:

1. The concept of inclusive innovation, prominent in India, China and South Africa, was **pushed into the European debate** on Responsible Innovation. Inclusive innovation is relevant to the San in two respects. First, they are contributors to innovation by sharing their traditional knowledge. Second, they are in need of innovation to improve their livelihoods.

2. Workshops with the San, academics and colleagues from the South African Ministry of Science and Technology led to three highly beneficial outcomes:

- a. A contract for San institutions to record San traditional knowledge for a South African database.
- b. The selection of ProGReSS as a *success story* of EU funding, with special emphasis on the role the San played.**
- c. A revision of the WIMSA Research and Media Contract, the early tool to stop exploitation, prior to the San Code of Research Ethics.

3. Bringing San interests to conferences abroad, in particular:

- a. Explaining the needs of the San at a high-profile event at the Chinese Academy of Social Sciences (IWEP) (Andries Steenkamp and Leana Snyders)
- b. The further promotion of San interests at a major final project event in Brussels (Mario Mahongo and Hennie Swart)

4. A contribution to the Kalahari Festival Innovation Tent.

Leana Snyders, representing San interests in Beijing, 2014



TRUST – CREATING AND ENHANCING TRUSTWORTHY, RESPONSIBLE AND EQUITABLE PARTNERSHIPS 2015-2018



Mario Mahongo (with Doris Schroeder and Vivienne Parry) introducing his native language to a high-profile audience in Brussels, 2016



Mario Mahongo and Hennie Swart at high-profile meeting in Brussels, 2016

The EU-funded project that has been most successful in promoting San interests to date is **TRUST**, the project which launched the **San Code of Research Ethics**. The main goal of the TRUST project is to catalyse a global collaborative effort to improve adherence to high ethical standards in research around the world, in other words, to stop double standards in research. What is not allowed in a high income setting should not generally take place in a resource-poor region.

What San leaders have felt about academic research in their communities, namely that it was **neither requested, nor useful, nor protected in any meaningful way, is not acceptable**. The San Code of Research Ethics makes this clear with reference to four values: fairness, respect, care and honesty. It also ensures that research involving the San has a process dimension, namely prior approval of research protocols by the South African San Council.



Dafna Feinholz, Dorian Karatzas, Doris Schroeder, Jeffrey Sachs, Stelios Koologlou, Klaus Leisinger, Leana Snyders, Joyce Adhiambo Odhiambo, Michael Makanga, European Parliament, June 2018



San and sex worker representatives' workshop in Kimberley, February 2017

The following main achievements can be recorded from the project as relevant to the San, in addition to the San Code, which will be described in more detail below:

1. San representatives have contributed to the **Global Code of Conduct for Research in Resource-Poor Settings**, which is now mandatory for EU and European & Developing Countries Clinical Trials Partnership (EDCTP) funding. Hence, **San interests and input were built into an ethics code used by one of the biggest funders of research globally**, see NATURE article [here](https://www.nature.com/articles/d41586-018-05616-w).

<https://www.nature.com/articles/d41586-018-05616-w>

2. San representatives have had the opportunity to discuss their concerns about research involvement with another vulnerable population, namely those representing the interests of sex workers in Nairobi. A TRUST workshop brought the two groups together in Kimberley, South Africa.

3. Opportunities for San representatives to raise their concerns at high-level venues, including the European Parliament, the UN Leadership Council of

the Sustainable Development Solutions Network, the European Commission and the University of Oxford.

4. TRUST was chosen as a **success** story on two occasions by the funder (European Commission). Both **success** stories mentioned the San Code of Research Ethics.
5. News coverage for the San Code of Research Ethics was extremely impressive and global, which was – in part – due to the efforts and connections of the TRUST team with high-profile media.



Kimberley group workshop February 24th & 25th 2017

Doris Schroeder, Leana Snyders, Klaus Leisinger.
Meeting UN Leadership Council of the Sustainable
Development Solutions Network, Stockholm, May 2018



In summary, five international research projects and one PhD have funded activities which have enabled San representatives to deal with the research or intellectual property issues of the day, whilst also feeding in directly to the research agenda. The broader issue of the San speaking for themselves, rather than having their views represented by others, was a strong point from the start of the collaboration with Doris Schroeder's research team. As Mario Mahongo said at a TRUST workshop in 2017:



Mario Mahongo

I don't want researchers to see us as museums who cannot speak for themselves and who don't expect something in return, as humans we need support.

TO SEE A VIDEO, CLICK HERE



<https://www.youtube.com/watch?v=jMhCUNw9eAo>

Each successive project enabled productive workshops to be held, at which the San's rights were further debated, and where the outcomes were not only used by the San in practical cases, but also by the project to publish and disseminate.

Finally, the TRUST project united the efforts of many years to tackle the challenge of how unwanted research could be controlled. This latter focus resulted in the San revising, improving and launching the San Code of Research Ethics in March 2017. **Without the collaborative support of international research partners, it is doubtful that the San Code of Research Ethics would have emerged.**



CHAPTER 5 ESSENTIAL INGREDIENTS FOR SUCCESS

Above - Buchu plant, Cedarberg Mountains (Photograph Amy Azra Dean)

The development of the San Code of Research Ethics rests upon the aforementioned activities at both regional and international level. Each of these undertakings helped to shape the landscape from which the Code emerged in 2017. Additionally, the vision of the Code may never have been realised without various essential ingredients for success.

These ingredients are:

- Icons of leadership
- Supportive NGOs
- Legal support
- Workshops
- Relationships of trust

ICONS OF LEADERSHIP

It is perhaps a truism that collective progress is impossible without leaders of vision and integrity. When the San began their process of institutional development in 1996, they were fortunate to have a group of pioneering leaders who drove and supported the vision to end the isolation of the past and to enter the organisational modern world.

Andries Steenkamp, Nairobi, May 2016



We are not going to attempt a detailed account of those leaders who distinguished themselves over the period, partially out of concern about leaving people out, but also out of acknowledgement that the leaders themselves were always reliant upon the support of dedicated allies and colleagues. It can nevertheless be stated that **the San were blessed during this period with strong leaders, some of whom are still active, who had the wisdom to support change, to engender consensus amongst sometimes differing opinions, and the ability to retain the confidence and trust of their people.**

One can be forgiven however for singling out the following leaders, who died prematurely whilst dedicated to the process of empowering their people: Kippi George (Khwe) /Xau Moses, (Ju//Huasi) Augustino Victorino (!Xun), Robert Derenge (Khwe), Dawid Kruiper (!Khomani), Andries Steenkamp (!Khomani), and Mario Mahongo (!Xun).

Modern San leaders have the precedent of the authentic and principled voices of the leaders who preceded them, providing them with a strongly perceived responsibility to continue the vision of San collective empowerment.

These leaders rose above their peers for many reasons. They were strong, and able to take difficult decisions, without losing an element of softness and humanity. Each were regarded as honest and dedicated to their people, rather than to their immediate families and clans. **They were respected both by their own communities as well as by outsiders for their intelligence, integrity, and wisdom.** These factors alone made them unique, and like Mandela, they are constantly referred to as icons of leadership.



Jack Beetsen, Doris Schroeder, Collin Louw, Andries Steenkamp, 2007



Mario Mahongo, Brussels, January 2016



Rachel Wynberg interviews Mario Mahongo for the Hoodia book, 2006

SUPPORTIVE NGOS

The San benefitted from of a number of dedicated NGOs (like WIMSA and SASI), who from the mid-1980s helped to mobilise the widespread communities. The relationship between NGOs and the community they aim to represent is not always without tension. However, **where NGO partnerships existed, San communities have thrived.**

SASI, which prides itself on supporting San peoples in South Africa since its inception in 1996, has regularly reviewed and renegotiated its relationship with the San Council, in order that the roles, tasks and purposes of each is made clear, and that no form of domination or other perceived unfairness persists.

What is often not publicly recorded is the fact **that activist NGOs are frequently blessed with dedicated individuals whose energy and commitment, albeit behind the scenes, are every bit as important as the San leaders that they support.** SASI is fortunate to have such a dedicated and selfless Director. Hennie Swart, Director of SASI, has worked with San peoples since 1990, and is a tireless, humble, dedicated, San support professional.

LEGAL SUPPORT

Many of the important steps undertaken along the path of community empowerment require legal support or intervention. Formation of constitutions, leases, basic legal documents underpinning salaried appointments, drafting of basic agreements with government, funders, and other external actors all require the services of a lawyer to protect the San's interests.

WIMSA and SASI have, from the outset, retained the services of an in-house lawyer (Roger Chennells), which has paved the way over tricky steps. In addition to basic institutional legal support, the most visible advocacy successes of the San were all based upon close collaboration with a legal advisor.



Doris Schroeder, Roger Chennells, Brussels 2016

San policy interventions at the United Nations, land claims, and successful San claims for intellectual property rights related to their traditional knowledge (for Hoodia, Buchu, Sceletium, Rooibos etc), which raised the international profile of the San as indigenous peoples, all required committed legal support. This was made available mostly via SASI.

The prohibitive cost of standard commercial lawyers is a well-known deterrent to obtaining legal advice. In addition, utilizing lawyers who do not have knowledge of the ethos and needs of the community can lead to expensive mistakes or misunderstandings. It is suggested that where possible, **a long-term relationship with one or more lawyers who are not only committed and competent, but also prepared to represent the community legally on a 'pro bono' or 'non-commercial' basis, is a significant advantage to an indigenous community.**



WORKSHOPS

Many academics and NGO members are accustomed to a proliferation of workshops.

One could say that invariably the same people attend a range of workshops led by consultants, appreciate a good meal, and leave without any tangible or lasting benefits at all.

This was not the case with the many San workshops we took part in. Workshop titles have included education, project management, small-stock farming, job creation, empowerment, life skills, leadership, and skills development, as well as topics such as traditional knowledge protection, heritage, benefit sharing intellectual property and the like. Were these a waste of funders' money? No.



In assessing the value of these workshops, a more positive view has been observed, namely that all participants were invariably exposed to new ways of thinking, and certainly did benefit. **There is much anecdotal evidence of individuals who later reported that their thinking, and indeed sometimes their lives, were forever altered by some or other insight gained at a workshop.** Such an outcome is surely an indicator of capacity that has been built.

The San development programmes conducted by WIMSA, SASI and the San Councils held such capacity building workshops on a range of topics. In addition, the research projects funded by the European Commission and the Wellcome Trust added more. **There is no doubt that significant numbers of attendees emerged from these workshops both inspired and enlightened,** later joining San organisations or proceeding in other ways to contribute towards San advancement. From being a disempowered and unorganised community over twenty years ago, the San now run their own meetings, manage their own negotiations, and own and manage their own organisations. Their capacity has been built both individually and collectively, by a process which included all of the struggles, challenges and workshops that they attended over the years.

Andries Steenkamp said that his favourite workshop of all time was the TRUST workshop in Nairobi in 2016, which established the four values of fairness, respect, care and honesty as the basis for further work. Andries did not know this was to be his last workshop, for he died shortly afterwards. The TRUST project remains indebted to his contributions to the four values framework.

Benefit Sharing workshops with Hoodia Farmers.
From left, Mario Mahongo, Collin Louw, Roger Chennells,
Andries Steenkamp. !Khwatla 2009, ProGRess project



Andries Steenkamp, Leana Snyders, and Doris Schroeder with colleagues at a workshop in Beijing, 2014, ProGRESs project



Hennie Swart (left), Doris Schroeder (middle) and Roger Chennells (2nd from right) with colleagues, Brussels 2016

RELATIONSHIPS OF TRUST

For trust to be formed, leaders need to engage with the outside world in a balanced manner which enables development of this priceless commodity. Leaders of poor communities facing the world of government, research academics (local and international) and other business entities might be tempted by circumstances to become overly ingratiating, aggressive, or pleading in order to secure some or other advantage. These approaches might succeed in the short term, but fail to lead to authentic human connections, which in turn are a pre-requisite for more enriching and beneficial long term relationships. For example the long-term WIMSA partnership with the Ubuntu Foundation, in developing the !Khwa ttu training and education centre, was built upon strong and personal trust relationships.

The San leadership, via the South African San Council, have acquired and maintained an approach which was open to forging authentic human relationships with potential partners and allies. Every project meeting or negotiation was regarded as an opportunity to meet a certain person, who might prove him or herself to be mutually open to a relationship of trust. **Even disputes were regarded as opportunities to get to know the individuals opposing them, and where possible, to convey the fact that San leaders were both accessible as humans, and also worthy of trust.**

Because it is easier to extol the virtues of deceased leaders, Andries Steenkamp of the !Khomani San and Mario Mahongo of the !Xun San, both former chairpersons of the South African San Council, can be singled out as such leaders. **Not only was the famous San humour seldom far from the surface, but they exuded an air of confidence and open curiosity, quick to understand and appreciate the persons across the table, and slow to take**



Khwa ttu Graduation, Ouma Geelmeid, Michael Daiber, Katrina Esau, 2014, (from left)

personal offence. Their personal integrity shone through, and the trust that they generated in others translated into untold benefits for the San.

Their approach ensured that the San Council was highly respected in South Africa, as well as supported by all parties that it came into contact with. In addition, the relationships of trust developed with international researchers contributed towards long-term relationships, and over a decade of mutually beneficial interaction with European Union and Wellcome Trust-funded research and policy projects.



CHAPTER 6

DRAFTING THE SAN CODE OF RESEARCH ETHICS

Top - Kimberley workshop, November 2016. TRUST project

Building on various efforts of the past, and with the support of the aforementioned essential ingredients, the San Code of Research Ethics was drafted over the course of three workshops and much work during the year prior to its launch in March 2017.

On 21-22 March 2016, SASI organised a preparatory workshop in which San representatives voiced their concerns and reported their past involvement in national and international research studies. **Examples of good and bad research case studies were identified**, in order to guide a revision of the San Research and Media Contract and the drafting of a San Code of Research Ethics. The aim was to help the South African San manage their involvement in research and heritage studies. Delegates included San Council members plus leaders from the !Xun, the Khwe and the !Khomani, together with selected invited experts from the fields of genetics, sociology, ethnology, research ethics and law. During this workshop the participants received background information on research in the different fields, delivered by the experts attending the workshop. Based on this input, initial ideas to improve research engagement were developed. The following ideas were voiced:

- I. A single central body needs to be created with clear external and internal authority, and the capacity to manage research and media issues. The body should have a 'review panel' to deal with more complex applications.
- II. **A code of ethics needs to be established, whereby researchers are able to understand the 'Dos and Don'ts' of engaging with the San.** This information should be freely available, e.g. on San Council and SASI websites.



Pre-workshop, Kimberley, March 2016, From left, Prof. Himla Soodyall, Reverend Mario Mahongo, Hennie Swart, Andries Steenkamp, Jafta Kapunda, Anita Harnoster, Dr Kerry Jones, Ouma Sensi. TRUST project

- III. 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 around research engagement. The community needs to understand/trust the role of the San Council.
- IV. **Research and media contracts need to be drawn up in such a way that research is not discouraged, but is managed for 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 in-depth research should be managed with more complex contracts as appropriate.
- V. There should be consequences and penalties for failure to comply with the terms of such contracts. San Council members need training, and the capacity to follow up and monitor research. Funds should be raised in order to establish a research monitoring/compliance body with the San Council of South Africa.

On 31 May/1 June 2016, SASI organised a full workshop with 22 San representatives and a further eight guests. On this occasion, work was undertaken to ensure that the San could protect themselves from exploitation in research through the redrafting of their original research contract, and by the development of what was to become the San Code of Research Ethics. In addition, a short documentary was filmed in which representatives of the San of South Africa express their opinions with regard to the protection of their rights and heritage in research.

THE SAN ON EXPLOITATION AND THE NEED FOR A CODE OF ETHICS



TO SEE A VIDEO, CLICK HERE



<https://www.youtube.com/watch?v=H0dw3mv7J5o>

During this important workshop, the San developed a range of general principles that applied to their own community, which had as their purpose to ensure that they would never again be subjected to the harm and disempowerment of unethical research interventions. These principles were as follows:

- I. **Respect.** To the environment, to San leaders and individuals, to cultural values.
- II. **Honesty, integrity, honour** between all partners.
- III. **Cultural and spiritual values** must be fully honoured and respected in all research and media projects.
- IV. The right formal **process**, application and approval, should be followed to protect communities in research.
- V. A **prioritization of processes** should be identified and followed (i.e. first apply, engage, debate, get approval, report back, etc.)
- VI. Informed consent is central to all research.
- VII. Genetics samples should only be used for the purpose stated in the application and research contract. For further research on the sample, further consent must be sought.
- VIII. Researchers should not enter a community without being guided and led by members of the community itself.
- IX. **Mutual benefits** should be ensured where possible. Both researcher and community should benefit from the interaction.

DURING THE ENTHUSIASTIC DISCUSSIONS ABOUT A SAN CODE OF RESEARCH ETHICS AND THE REVISIONS TO THE WIMSA RESEARCH AND MEDIA CONTRACT, VIEWS FROM THE DELEGATES AT THE WORKSHOP WERE FILMED:

ANDRIES STEENKAMP

The “entry by the front door, or by the window” analogy: the Code of Research Ethics describes how researchers may get access to the community and be welcomed as guests, through the front door, instead of acting like thieves passing through the window.



PETRUS VAALBOOI

“Respect for animals and birds”: in the San cosmology should rather be “Respect for the entire creation, seen and unseen, above and below”. The San grew up with ‘respect’ as being at the centre of how we should live; respect for all beings.



ZEKA SHIWARRA

The San have given away too much for too long, it is time to take control of our heritage. This Code of Research Ethics attached to a contract is a strong way to do this.



OSIA MAKUMBU

Some groups, like the elder members of the community, are even more vulnerable when it comes to be involved in a research study. We need this contract to protect them.



HIDEE MAASDORP

The hierarchy of the entire process must be efficiently followed in order for the contracts to achieve their purpose. Approach, submission of application, approval, feedback and follow-up must all take place. Whilst the San Council is the body to control the contracts, Prior Informed Consent must still be ensured from individuals in the community.



LUCE STEENKAMP

The research contract must have clear guidelines, the shoulds and shouldn'ts, so we can protect our communities.



DIRK PIENAAR

This Code will ensure that when people enter our community they know what to do.



JAFTA KAPUNDA

By following the contract the researcher is already showing 'respect' to the community.



REVEREND MARIO MAHONGO

We need to remember that research has helped us a lot. Without research, we would be in a far worse place. So we should not put research off, only manage it.



LEANA SNYDERS

The review panel is an important component of the research contract. We will need training and help to form such a panel of San, as well as some experts.



DORIS SCHROEDER

The WIMSA research contract had a very good preamble. We should consider reviving the preamble, which explains why the contract is necessary for vulnerable people.



On 15 and 16 November 2016, SASI organised a third workshop to finalise the content for the San Code of Research Ethics. The overall goal was to achieve fair research partnerships. The following threats and weaknesses were discussed.

- Vulnerable and far-flung populations
- Serious poverty
- Undue influence by researchers, due to poverty
- “Free riders” who do not support San community concerns when taking part in research for cash
- Exploitation possibilities due to illiteracy
- Social problems in communities
- Ignorance of research, what it means and what its risks are
- Lack of knowledge about San leadership approach to research
- Non-assistance by government
- Low self-esteem in engaging with externals
- Previous theft of traditional knowledge, therefore mistrust of researchers
- Lack of system to combat the problems
- Lack of institutional/financial support to the leadership who aim to improve the situation

Based on these challenges, the draft of the 2nd workshop was handed out to the participants at the 3rd for revision. The essential principles on which the first draft was based were now further refined, finding their ways into one of the four TRUST ethical values of Fairness, Respect, Care, and Honesty. These values had been agreed previously by the TRUST group, with San input. **A highly important decision made was that past exploitation examples would form part of the Code itself.**

The four core values were going to be supported by a fifth value, which the San delegates deemed essential, namely proper process. In small groups the key points of each value were written out in greater detail.

The results of the 3rd workshop were then given to colleagues who undertook further work. In December 2016, Roger Chennells worked on the Code from a legal perspective. In January 2017, Doris Schroeder worked on the Code from an ethical perspective.

The subsequent draft, which had been edited from both a legal and an ethical perspective, was then presented to the San leadership for adoption. Further minor changes were made until **the Code was unanimously adopted and declared ready to be launched by the San leadership.**

**THREE COLLEAGUES
WHO MADE IMPORTANT
CONTRIBUTIONS
TO THE CODE GIVE
THEIR VIEWS.**

COLLIN LOUW - SAN LEADER (!KHO MANI)
CHAIR OF SOUTH AFRICAN SAN COUNCIL

The San Code of Research Ethics is important for us and is a stepping stone to work hand-in-hand with researchers and to help each other to understand the issues of the San, and most importantly to guide people to what kind of research the San need.



ZEKA SHIWARRA - SAN LEADER (KHWE)
VICE-CHAIR SOUTH AFRICAN SAN COUNCIL

In my personal view, this Code is the most important thing ever for us. All people wanting to work with the San are now required to knock on our door. We give permission only after getting copies of what is proposed, and only if all are satisfied we then give the go-ahead.



LEANA SNYDERS - DIRECTOR SOUTH AFRICAN SAN COUNCIL

The San Code of Research Ethics is the voice of a community that have been exploited for so many years. This code also manages to bridge the gap between the research community and the San Community through dialogue. By taking ownership of the Code the San Community will ensure that this document will remain relevant for generations to come.





RECORDINGS WITH A STEENKAMP AND M MAHONGO

It is no exaggeration to say that Andries Steenkamp and Mario Mahongo were the two San leaders who contributed most to the San Code of Research Ethics.

Tragically, Andries could not see it launched, and the untimely death of Mario less than a year after the Code's launch has robbed the San of these two outstanding leaders. The loss is unimaginable for the community and the wider networks. The San Council, with Leana Snyders as the experienced Director, is aware of its responsibility to continue the work begun by these two visionary San leaders.

LAST CONVERSATION RECORDING WITH ANDRIES STEENKAMP

In June 2016, Doris Schroeder, Roger Chennells and Andries Steenkamp recorded audio messages, which were meant to start a conversation about more than 10 years of working together. The photo above was taken after the recordings. Two months later, Andries died of a preventable disease. His recording is transcribed below. Recorded in Afrikaans, and translated into English.

*My experience is that many people have come and gone with research in our community, and not all people engage with us in the same way. In order to explain this, for example when a person meets with me for the purpose of doing research, whether from overseas or local, I expect to be able to develop **a relationship of trust which enables a long term working relationship.***

When we trust one another, and we have a relationship of trust, then we are able to work better, and we can also bring others in to work with us, within that relationship of collaboration and trust.

RECORDED IN ENGLISH

*PhDs, from outside, from the North, but studying in Cape Town or another University in South Africa, he is coming to work with us on indigenous heritage of the San. And sometime, **he goes back and comes never again.** So sometimes, it is not easy to work with them, but **for us as San people, there is a need, a need to work with other peoples.***

*From my side in the San community, the best thing to come to the San to do research is that I must know what I can get from you and you can get from me. Not all the time the same thing. That is not money and only money, there are some things that one can do together to make the situation better for us and for the other people from the North. So, as you come to the San, the easiest thing to do is to meet at the same time the Leaders, to connect with the people. **As you connect with the leaders you can connect with the people.** So the best thing is you come and make sure you do the right thing and to ask the right questions. And the right questions will help you AND me to understand each other. And that is the way I will work with the North.*

LAST RECORDED TRUST CLIP OF REVEREND MARIO MAHONGO

In May 2018, Reverend Mario Mahongo was meant to travel to Stockholm to introduce the San Code of Research Ethics to a high-profile UN audience together with Doris Schroeder. Two days before flying to Europe, he tragically died in a fatal car accident. His last recorded clip can be seen here:

REVEREND MARIO MAHONGO
ON FAIRNESS



TO SEE A VIDEO, CLICK HERE

<https://www.youtube.com/watch?v=jMhCUNw9eAo>



TRUST team at the San Code of Research Ethics Launch in Cape Town, March 2017

OUTLOOK

Judging from the number of requests the San Council and the authors of this report receive to assist other communities to develop their own ethics codes, the San Code of Research Ethics is regarded as a success that warrants replication. Whilst this is true, there are still hurdles that need to be overcome and questions to be answered.

1. Why do some researchers still come into the San community through the window, like thieves? For instance, are they not aware of the community structures? Do they not trust the structures? Is there intent to avoid community approval?

2. How can awareness of the San Code of Research Ethics be spread throughout the far flung San communities in South Africa and potentially into Botswana and Namibia? How in a practical sense and how in a financial sense?

3. How can the on-line approval and Code adherence system that the San Council wishes to install be designed and funded, both in terms of development and in terms of maintenance?

4. Could the San effort be captured in a model ready to assist other communities who do not have a 25 year history of institution building around their rights?

5. As the San community wishes to assist others in developing their own codes, how can such efforts be funded?

VIDEO CLIPS FROM THE RESEARCH PROJECTS



All video clips below were filmed, edited and created by Amy Azra Dean with support from Doris Schroeder for TRUST.



Amy Azra Dean



Doris Schroeder

THE SAN CODE OF RESEARCH ETHICS LAUNCH



TO SEE A VIDEO, CLICK HERE



https://www.youtube.com/watch?v=Px-0l_-wjjY

THE SAN ON EXPLOITATION AND THE NEED FOR A CODE OF ETHICS:



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ANDRIES STEENKAMP AND PETRUS VAALBOI ON RESPECT

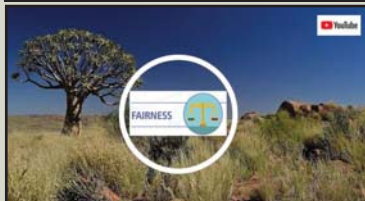


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REVEREND MARIO MAHONGO ON FAIRNESS



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SAN AND SEX WORKER REPRESENTATIVES ON HONESTY

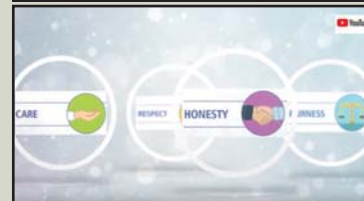


TO SEE A VIDEO, CLICK HERE



<https://www.youtube.com/watch?v=yN94rjztxel>

FAIRNESS, RESPECT, CARE AND HONESTY



TO SEE A VIDEO, CLICK HERE



<https://www.youtube.com/watch?v=wzPQSGk6pw4>

Filmed by Richard Wickstead for PIC.

MOLOPO WORKSHOP 2006



TO SEE A VIDEO, CLICK HERE



<https://www.youtube.com/watch?v=bi0SF4jb-AU>

Produced for the RAP competition, funded by the *Foundation Global Values Alliance* in Basel.

THE !KHWATU KIDS' RAP FOR THE SAN CODE



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BENEFIT SHARING AND BUCHU



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!XUN GIRLS RAP FOR THE SAN CODE



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/ÁUNI CHILDREN CLIP FOR THE SAN CODE



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GLOBAL VOICES PANEL WITH REVEREND MAHONGO AND HENNIE SWART



TO SEE A VIDEO, CLICK HERE



<https://www.youtube.com/watch?v=CDheO6980jw>

Video clips below filmed, edited and created by Amy Azra Dean with support from Doris Schroeder for ProGRess.



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Dr Roger Chennells is the Founding Partner of Chennells Albertyn Attorneys. As an attorney in private practice since 1980, Roger has practiced in a wide legal field ranging from labour, environmental, human rights to commercial and constitutional law. In the last 25 years, he dedicated much of his work to representing the interests of the San community.



ANDRIES STEENKAMP

Andries Steenkamp, who passed away in 2016, was the Chairman of the South African San Council and a leading figure amongst the Khomani San in Andriesvale.



MARIO MAHONGO

Reverend Mario Mahongo, who passed away in 2018, was the Chairman of the South African San Council and a revered leader of the !Xun people. Reverend Mahongo launched the San Code of Research Ethics in Cape Town in March 2017.



DORIS SCHROEDER

Prof. Doris Schroeder is the Director of the Centre for Professional Ethics at UCLan, UK. She is Europe's leading ethics specialist on benefit sharing and has co-ordinated large research projects on global justice. She started collaborating with the San in 2003 and she is the Leader of the TRUST project.



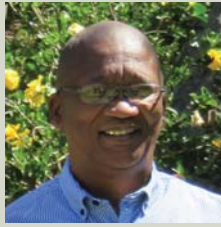
JOREM /USEB

Jorem /Useb was the Co-ordinator of WIMSA from 2006 to 2007. He now works at !Khwa ttu and supports the training of young San.



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Collin Louw is the Chairman of the South African San Council with specialist interest in cultural heritage and the protection of intellectual property.



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Leana Snyders is the Director of the South African San Council and also its specialist on the San Code of Research Ethics. She has promoted the Code widely, nationally and internationally.



HENNIE SWART

Hennie Swart is the Director of the South African San Institute and has worked in education and training roles with the San for the last 25 years.



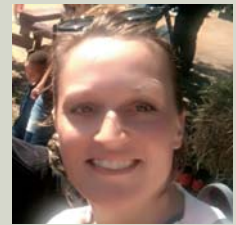
AXEL THOMA

Axel Thoma is a German development worker who successfully led efforts to create WIMSA, the first organisation, which brought San leaders from several countries into contact. He was also WIMSA's first Co-ordinator.



JULIA DAMMANN

Julia Dammann is an anthropologist who works for the South African San Institute and who led website and Twitter efforts for the TRUST project.



KATE CHATFIELD

Dr Kate Chatfield is the deputy Director of the Centre for Professional Ethics, UCLan UK. A philosopher and social scientist, she reported the San Code of Research Ethics launch for the Conversation, **see here**. <https://theconversation.com/the-ethics-of-research-how-to-end-the-exploitation-of-vulnerable-communities-74203>



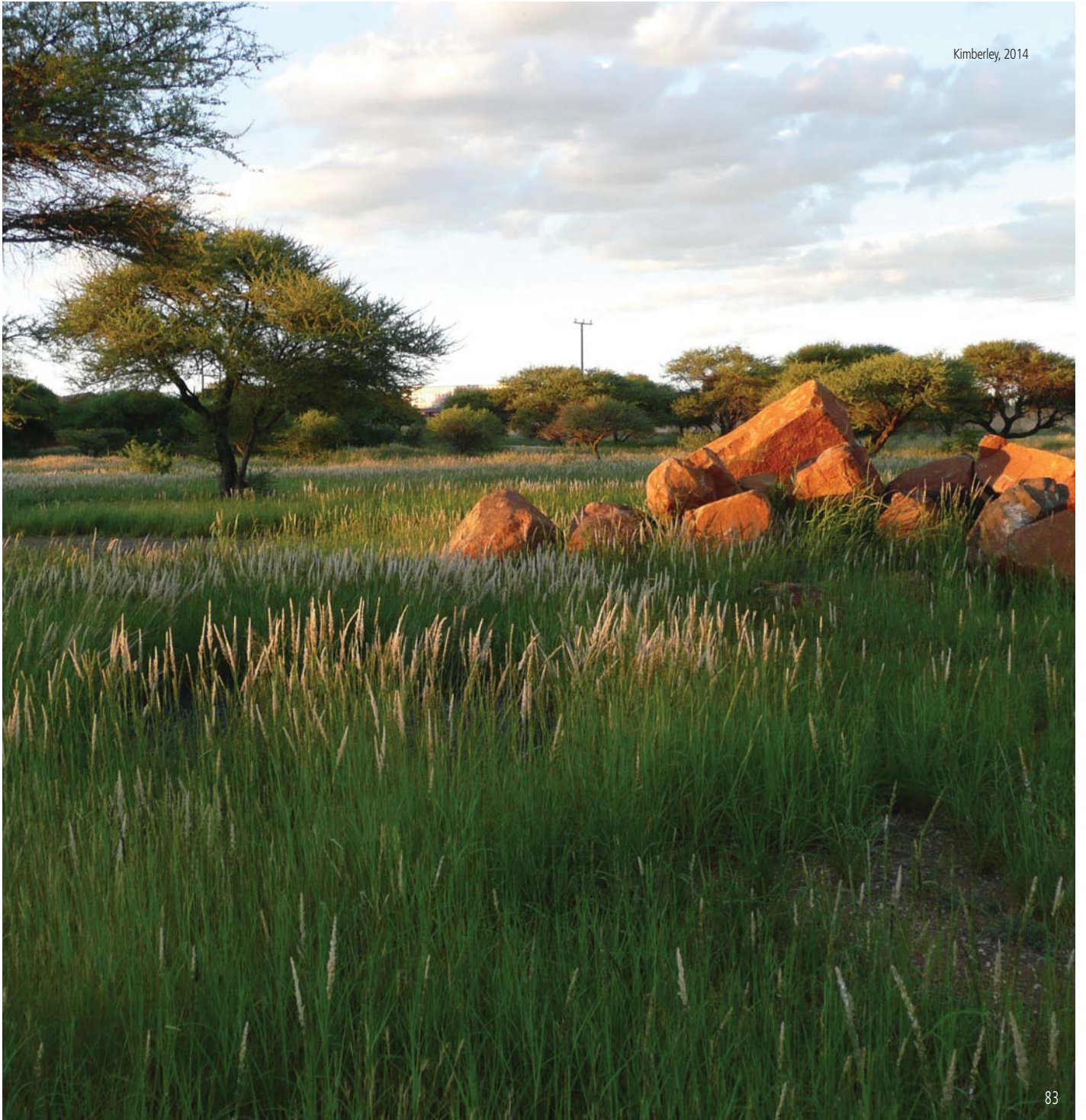
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Julie Cook is a professional editor and also a Research Fellow for the Centre for Professional Ethics, UCLan UK. She has been contributing to and editing work on San issues since 2005.



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- ^{xv} Michael Daiber personal communication with Roger Chennells 1 May 2018
- ^{xvi} *The United Nations Declaration on the Rights of Indigenous Peoples General Assembly 61st session agenda 68 Human Rights Council Report; International Labour Organisation Convention 169 on Indigenous and Tribal Peoples in Independent Countries 1989.*
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THE SAN CODE OF RESEARCH ETHICS

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