edited minutes

Workshop on
Benefit Sharing with Developing Countries
The Case of Human Genetic Resources

Monkey Valley, Cape Town, South Africa
5th - 6th May 2004

by Thofi Bishop and Doris Schroeder
pictures by Himla Soodyall

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This document summarises papers presented at the workshop on **BENEFIT SHARING WITH DEVELOPING COUNTRIES** in South-Africa in May 2004. Funding was provided by the Science & Society programme of the European Commission. The conclusion of the conference (pages 31-37) was fully transcribed.

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programme

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Closing Remarks • Prof. Udo Schuklenk	16.30-18.00 Day 2

speakers

in alphabetical order

Fatima Alvarez-Castillo	Professor of Politics, University of the Philippines, Manila, Partner 3 in project
Pamela Andanda	Advocate High Court of Kenya, Certified Public Secretary (Kenya), Director of Komati Foundation, Women Development Committee, Lecturer, Faculty of Law, Wits University, Johannesburg, South Africa
Roger Chennells	Principal Lawyer for the San Council in the Hoodia Plant Case, South Africa
Dafna Feinholz	Coordinator Mexican Commission for the Human Genome, Mexico, Subcontractor 1 in project
Jacquie Greenberg	Professor of Human Genetics, University of Cape Town, South Africa, Chair of Southern African Society of Human Genetics
Marthinus Horak	CSIR, Centre for Scientific and Industrial Research, Head of Bioprospecting Unit, Pretoria, South Africa
Anita Kleinschmidt	Lecturer, Attorney, Wits Bioethics Division, South Africa
Miltos Ladikas	International Development Officer, ESRC Centre for the Economic and Social Aspects of Genomics, Lancaster University, UK, partner 4 in project.
Colin Louw	Secretary Heritage Sub Committee San Council, South Africa
Eugenia Marinova	Operations Analyst, S. Africa / Namibia / Lesotho / Botswana / Swaziland, Country Unit, World Bank
Nosiphiwo Msitweni	Researcher at Earth Life Africa, Cape Town, South Africa
Vincent Nmehielle	Braam Fischer Chair of Human Rights, Faculty of Law, Wits University, Johannesburg, South Africa
Doris Schroeder	Reader in Philosophy, Centre for Professional Ethics, University of Central Lancashire UK, Project Co-ordinator
Udo Schuklenk	Head Division of Bioethics, Professor of Bioethics and Human Rights, Wits Faculty of Health Sciences, South Africa
Lorraine Silverman	Owner of *Training and Development Options*, Johannesburg (company involved in capacity building for underprivileged groups), South Africa
Himla Soodyall	Professor and Director: MRC/NHLS/Wits Human Genomic Diversity and Disease Research Unit (HGDDRU), Division of Human Genetics, National Health Laboratory Service (NHLS), UNESCO Bioethics Forum Representative for South Africa
Andries Steenkamp	Chair Heritage Sub Committee, San Council, Vice-Chair WIMSA (the Working Group of Indigenous Minorities in Southern Africa)
Rachel Wynberg	Biowatch South Africa

welcome

Participants	Chair: Doris Schroeder and Udo Schuklenk
Doris Schroeder  with Roger Chennells	**General Welcome and Short Introductions (speakers and participants)** **What is special about this workshop?** Each person invited individually- no difference between delegates and speakers, each with expertise in the area. Workshop is part of an ongoing one-year project involving people from four continents. Countries represented - South Africa, Germany, UK, Mexico and Philippines. Project work started earlier this year. Funded by the European Commission. Need to specifically look at benefit sharing for human genetic material research. Short presentations to provide room for in-depth discussion. Speakers to talk for 10-15 minutes. **Why discuss benefit sharing?** Tension between North and South is increasing, particularly in the area of traditional knowledge (invited two members of San Council, as their benefit sharing case is a good example in terms of traditional knowledge potentially leading to pharmaceutical products). Quoted example of misconduct (American research group conducting work in China without any benefit-sharing). **Main objectives of workshop:** To get feedback from all participants on our ideas, for instance for earmarking benefit sharing funds for certain priority areas (e.g. women's health and neglected disease research). Potentially write a statement on benefit- sharing based on the workshop. Clarify certain questions, e.g. are there qualitative differences between benefit sharing in developing as opposed to developed countries?
Udo Schuklenk 	**Conference pack** includes background reading material to cover a number of issues, namely: • Overview paper on Neglected Disease Research. • Philippines asked to include summary of major report on Advisory Committee on Health Research (WHO). • Useful paper by Wayne Hall – Office of Public Policy and Ethics at the University of Queensland: Question of patents on human DNA sequences, whether these are right or wrong. • Siegrud Sturks- coming out in the May issue of Developing World Bioethics: looks at patents and access to drugs in developing countries. Good background reading for those who are not well informed about access to drugs etc. • Paper on affordable access to essential medication in developing countries and ethical and economic imperatives. • Document included from the Secretary of the Convention on Biodiversity. Interesting how this convention translated into government policy/ regulation in parts of the world including the Philippines and India. **Worth pointing out** that content for this workshop was not dictated by EU but was a joint effort by people from different countries to ensure local input. The following might also **be of interest**. Neglected disease research funding from the EU to be administered by South Africa. Contracts been signed. One problem: who will own the results of the research when it takes place here? Not resolved. **Introductions by attending delegates and speakers followed.**

panel 1

Representation, Participation and Capacity Building

Participants	Chair: Doris Schroeder
Doris Schroeder Miltos Ladikas  with Eugenia Marinova	**Introductions for Panel 1** **Presentation: Participation and Representation of Lay Stakeholders in Decision-Making** Overview looking at stakeholder control and influence, moral imperatives, practical and effective approach as well as social sustainability. Tools for increasing stakeholder participation to utilise can be citizen's juries, consensus conferences, deliberative polls, public forums and perspective workshops. Guidelines to be considered in participation: Bonn Guidelines and Convention on Biodiversity. Bonn Guidelines include measures on public education, contract negotiation skills, legal training and co-ordination activities. Problems experienced during participation or that pertain to participation are: deficit model, one-way education that may be seen as patronising, levels of debate and the issue of trust. The issues that need to be considered for any benefit sharing agreement are: a bottom up approach, proper community representation, alignment to minimal universal standards and trust building
Eugenia Marinova 	**Participation in Development Policy Formulation, the World Bank Approach and Experience** (Presentation unfortunately inaudible on tape) Main presentation slide = Fundamentals of Participation • Stakeholder Identification • Country context assessment • Consider type and stage of reform • Scope, objectives and role (management expectations) • Building the process into a participation strategy • Build on existing structures • Disseminate information • Budget adequately • Document the process • Provide feedback
Lorraine Silverman 	**Capacity Building by the South African Department of Labour** Three levels of capacity building in South Africa: Government, NGO's and grassroot initiatives. Will talk about capacity building as far as DoL (Department of Labour) in South Africa is concerned. The initiative was started due to lack of skills and lack of jobs in SA. Joint initiative by DoE (Department of Education) and DoL in a really small nutshell: Consists of SAQA (South African Qualifications Authority), giving us the SAQA Act, and NQF (National Qualifications Framework), a framework on which all qualifications are based, simply to register qualifications. Other acts: Further Education and Training Act- purpose is to transform education and training. Making it more accessible to more people, making it more relevant.

panel 1 cont.

Representation, Participation and Capacity Building

Participants	Chair: Doris Schroeder
Lorraine Silverman 	**Capacity Building by the South African Department of Labour cont.** Objective is betterment of teachers and teaching EE Act (Employment Equity Act): aims to increase the number of women, black and disabled people in the workplace at all levels within an organisation. All organisations are required to pay a levy of 1% of their payroll into Skills Development Levy Fund. If they show that they have trained staff, they can claim 70% of the levy, the rest is retained by SETA's (Sectoral Education and Training Authority). Economy has been divided into 25 different seta's. If you are in banking, you will pay into the banking levy fund. Not a new phenomenon, several countries have utilised this model for skills development. Levy grant system is one way towards skills development. Every year organisations need to make a plan of how they are going to train staff. Learnerships and internships- arrangements being made whilst somebody is learning, theoretical training and practical training in a workplace. Vehicles for capacity building within the workplace. Also relevant skills programmes- if you add up the credits of the programmes over a number of years, you will ultimately end up with a qualification. National Skills Fund (NSF) If your programme looks like a national priority then the NSF contributes towards the funding of the teaching of the programme. DoL also offers employment services, which they outsource. Current priorities are life skills. Partnerships- capacity building needs to happen in partnerships between government, employer, workforce, education, training providers and community. The point of all this is to encourage growth for global competitiveness. Quality of work life – giving people an opportunity to gain access to jobs they would like to have. Aimed at people entering the workforce. And people having difficulty finding work. Other programmes : Extended Public Works Programme and the Social Development Programme. Public Works Programme is a labour intensive programme that looks at building infrastructure. The Social Development programme is still being developed. At the heart of all this is the Life Skills Programme, which involves HIV/AIDS education, self-knowledge, and making informed career decisions. Flaw with the programme: How do people, who have never been in dialogue about what their needs are, express them? Presentation should raise questions about capacity building, see the person, and not the theoretical construct, and assume what people cannot and can do etc. *Lorraine, who used a flip chart to write down all capacity building programmes of the DoL combined various points in the end to show a smiling face.*

panel 1 cont.

Representation, Participation and Capacity Building

Participants	Chair: Doris Schroeder
	Questions and Discussion[1]
Doris Schroeder	Panel looked at capacity building on a local and global level. Job creation in South Africa presents the local level. Miltos identified problems in Bonn Guidelines, whilst Eugenia introduced World Bank policies, both apply to global level.
Thofi Bishop	Has there been an emergence of life skills programmes with regard to civil society? Use participation tools Miltos talked about in terms of mobilising civil society organisations?
Fatima Castillo	Topic needs clear definition of stakeholders - who are they?
Doris Schroeder	Panel and audience need to think who should be responsible for capacity building – outsiders such as the EU?
Loraine Silverman	Use storylines- presentations can be very intimidating. Create the story and the picture and how it will affect people at the end of the day.
Udo Schuklenk	Who is the legitimate target for capacity building? How do we identify the targets? How can you empower people to negotiate the terms of the deal? Traditional knowledge- pinpoint of originator- how do we patent that knowledge?
Himla Soodyall	When Miltos talked about participation, who sets the agenda? Do the participants themselves set the agenda? Maybe they should outline the process?
Miltos Ladikas	Facilitators set the agenda.
Himla Soodyall	Didn't follow the idea of a bottom up approach. What is the purpose of the agenda if a bottom up approach is considered?
Tint Khin	Measurement of how we know we have been successful in participation? What measurements are considered?
Thofi Bishop	Would be ludicrous to think people all have will power, and yes there are those who will take advantage. Life skills is a way towards helping people to access willpower.
Tint Khin	Bottom up approach does not always work- there needs to be a merging between bottom up and top down. Liked Lorraine's presentation particularly seeing the person.
	 Panel 1

[1] Discussions are not summarised fully, as it was difficult to tape proceedings in a large room with one recorder. Hence, it may appear as though some questions were not answered or that the discussion jumped one from topic to the next unsatisfactorily.

panel 2

Legal Issues in Benefit Sharing

Participants	Chair: Udo Schuklenk
Udo Schuklenk Pamela Andanda 	**Introductions for Panel 2** **International Legal Frameworks for Benefit Sharing** Overview Litigation background-approach taken Oxford University and University of Nairobi dispute case Case still going on until September 2004. Oxford and Nairobi have been working together for four years. International Aids Institute decided to fund project run by Nairobi, carried out medical research on HIV in a slum area called Majengo… Subjects were the so-called “Twilight ladies” (prostitutes). Details of case- Legal Framework Under penal code in Kenya prostitution is a criminal offence. Will refer to participants as twilight ladies in presentation: Was discovered that the twilight ladies apparently had some cells that made them resistant to HIV. Nairobi decided to carry out a study and came up with a formula, and because they did not have infrastructure in terms of money and technology, they partnered with Oxford. Subject matter was a DNA based vaccine. Nairobi group was to carry out the clinical studies, easy for them to get approval from the Kenya Medical Research Institute. Memorandum of Understanding (MoU) between Oxford and Nairobi was signed and Oxford came up with interesting findings on immune issues and how their findings could be extrapolated to other countries in Africa experiencing problems with HIV/AIDS. Took genetic samples from twilight ladies in order to determine what made them resistant in order to develop a vaccine and use it elsewhere. Oxford group proceeded to file an application for patent without acknowledging the other participants, Nairobi and twilight ladies. Thanks to the media, people got to know about this. When speaker calls it a case, it is not actually a court case but through the media that she deems it a case. Emerging Issues Community- bear in mind prostitution is a criminal offence- would you tell would-be-criminals about benefit sharing and have them share the benefits with you? Also bear in mind that community is not only geographical, cultural, also determined by choice and sharing the same interests such as the twilight ladies, considering that because of poverty and economic hardships they were forced into such circumstances, and being branded criminals. Legally they are a community through a conventional description. What sort of benefits can they be given? After the dispute, Oxford and Nairobi came up with an MoU. What the MoU briefly entails: 1. Each party will disclose to the other what innovation and discoveries they have come across so that no-one benefits alone. 2. Will not disclose to the media what process is taking place.

panel 2 cont.

Legal Issues in Benefit Sharing

Participants	Chair: Udo Schuklenk
Pamela Andanda  with Udo Schuklenk and Anita Kleinsmidt	**International Legal Frameworks for Benefit Sharing cont.** 3. MoU is valid until September 2004, but media is now barred from extracting information. 4. Kenya will benefit from technology transfer Regulatory framework can be identified as: Human Rights Instruments, Conventions and, Intellectual Property Rights Law These are not strictly speaking international frameworks with genetic resources in mind. Could learn from this case; extract what is relevant and work on an international benefit-sharing framework. In terms of international human rights instruments, the only document that is relevant is a document, which is not operative automatically. All parities of this covenant; International Covenant on Economic, Social and Cultural Rights, if you are not a party, you are not bound in terms of what it provides for. Oxford smart in terms of going to a jurisdiction that allows them to patent because Kenya would not allow them. Novelty- a difficult issue to consider. Natural status of the genetic material. Has to be determined when applying for a patent. Trial is still continuing, no clarity yet on whether DNA based vaccine could actually work. First of all looking at three frameworks, do they deal with issues at hand? In terms of community, does it recognise other forms of community as outlined? If you look at larger community, people will not approve of their activities, lack of bargaining power here. When MoU was signed, did not specify how twilight ladies were going to benefit. And we know that if it was not for the genetic material the research would not have taken place. They are not parties to the research and can therefore not be considered as a community. If we look at benefits in MoU, technology transfer is one. Is technology transfer going to eradicate the poverty that has driven twilight ladies into such activity? Capacity building- nothing is mentioned about capacity building in the MoU. Was not stated at all in the initial memorandum. Just out of interest, this particular case does not feature anywhere in scientific journals but only in the media, three publications in Kenya- Financial Times, Daily Nation and News in Nature. One more major limitation put on public disclosure by the MoU. Not going to facilitate work amongst interdisciplinary groups since they do not have the background.

panel 2 cont.

Legal Issues in Benefit Sharing

Participants	Chair: Udo Schuklenk
	Questions and Discussion[2]
Udo Schuklenk	Are you saying discoveries do not count in terms of patent application?
Pamela Andanda	You cannot patent discoveries. An invention is vital - if it is not present the patent office will not grant the patent. That is a very crucial legal step before one can be granted a patent. Reviewers will look at whether the item is still in its natural state or you have introduced something to make it novel or original.
	There is only one relevant international convention, the Convention on Biodiversity.
	Previous speaker mentioned this convention, I will not go into much detail but how it can be utilised in terms of genetic resources. Not a human genetic resource instrument; deals with agriculture and does not acknowledge human genetic resources. Has many shortfalls. States that human genetic resources are covered by other international documents, whilst these actually do not exist.
	Maybe they had in mind first human rights instrument referred to but it is not specific at all. Can only learn how this tool is applied to non-human genetic resources and utilise the same approach in human genetic resources.
Udo Schuklenk	What is your answer to the statement?
Pamela Andanda	Using the non- human genetic convention- the Convention on Biodiversity, which is quite specific in its particular application. It will help a lot towards a draft for human genetic resources.
	When we use collaborative arrangements at a practical level have to hope that goodwill prevails and not have a situation where one does something behind the other's back.
Thofi Bishop	Where can one access the MoU?
Pamela Andanda	It is not accessible. Information is not being disclosed. In Kenya, no access to information act as in South Africa.
Fatima Castillo	Were the twilight ladies mentioned in the second phase of negotiations?
Pamela Andanda	Not at all. Were not considered in any phase of negotiations. Did not agree on how much and how they were going to identify them. Criminal law may have agent provocateur utilised and have them arrested. Genetic material has been extracted but they have no benefits.
Anita Kleinsmidt	Under the National Human Tissue Act of Kenya, you are not supposed to be paid. Had they been paid it would have been a criminal offence.
Pamela Andanda	When you have a natural substance that has been extracted, and in order for you to patent it you have to look at the way the substance has been extracted and the final product. Has there been a change in the natural product? That is how they assess.

[2] Questions for Pamela were taken straight after her presentation, as she had to leave.

panel 2 cont.

Legal Issues in Benefit Sharing

Participants	Chair: Udo Schuklenk
Anita Kleinsmidt 	**Legal Issues in Benefit Sharing for International Research** Overview: Pamela has given us the framework. Look at examples of benefit sharing in society and what the lessons are that can be learned from these arrangements. In preparing for the presentation there were more questions than answers. Two main types of benefit sharing, 1st, bioprospecting and patenting of traditional knowledge- around plants and what we will hear about the hoodia plant; where another company or corporation comes in and patents the traditional knowledge. Question that arises is whether these knowledge systems should be patented and are they patentable? 2nd category, patenting of genes. Genetic material donated by a community. And should they be paid for something they have donated? How do you define the benefiting community? Do you define community by language or by geography or by particular activity as with the Kenyan women. No clear legal answer to these questions. Called the CSIR to find out how they went about with their case on the hoodia plant. Hope we can discuss these issues and find out whether there should be legal arrangements and legislation around these issues. Next question is should there be an international legally binding instrument that all countries have to adhere to, or should we have regional arrangements e.g. in the SADC region etc. And then the pros and cons of international versus regional arrangements. International arrangements tend to be dominated by the developed community, which has well educated lawyers to lobby governments. International agreements tend to have more standing than local arrangements. Pro for local arrangement is that they do what is suitable for them. Corporations and researchers look for countries that have weak arrangements and then do the research there. When you look at who negotiates international agreements, we need developing countries and people at equal numbers to pull their weight just as effectively as the more powerful international representatives. As Pamela mentioned research institutes should be made aware of benefit sharing arrangements. Benefit sharing not mentioned in Kenyan arrangement. Benefit sharing to be incorporated into international arrangements like the Helsinki instrument. Indigenous knowledge and patent law. Huge difference in the ethos of how indigenous knowledge should be seen. Contribution is often done by women who are not about to run off to the patent office. Concept of ubuntu – sharing your knowledge and using it for the good of the entire community, which is different from the patenting issue. The way in which indigenous knowledge is used puts people at a disadvantage internationally in the patent arena. Quite eurocentric. Interesting example of community protection of knowledge. In US there is an organisation that documents indigenous knowledge and remedies and they have a link to the US patent office, and those remedies listedmay not be patented. Raises the question: if someone wants to commercially apply for patenting of an indigenous remedy, how do you work out the benefits? Also found examples of benefit sharing arrangements: none of them were human genetic but will provide us with some lessons.

panel 2 cont.

Legal Issues in Benefit Sharing

Participants	Chair: Udo Schuklenk
Anita Kleinsmidt	**Legal Issues in Benefit Sharing for International Research cont.** There was one over a plant and the Kerala province in Indian. Plant was found to be energising and they entered into an arrangement with the Indian government for it to be developed. Pitfall only patented in India, and people in other countries took it and developed it in their countries and there is no benefit for the community there. University of Illinois has an example of a complex arrangement- people who live in a national plant harvesting area. There is a licensing arrangement where people identified what they needed and infrastructure had been upgraded, each family is given a certain amount of money and they can use this to their own benefit. Doing quite well under this arrangement. Very problematic: Bella people in Mali- resistance to a type of bacteria. University of California will provide PhD fellowships and finance to the Bella people. Unfortunately none of the people are in a position where they can do PhD's etc. Even if they did there is no requirement that they should go back to Mali and share that knowledge. Regulation Framework International instruments are voluntary. Hopefully there is an embarrassment factor. Lessons from past arrangements are that they have been financial and non financial- what are the immediate needs of the community? Should we be setting up government watchdogs and develop policy around this and establish acceptable norms?
Vincent Nmehielle  with Anita Kleinsmidt	**Pharmaceutical Company Law-Suit – Ethical and Legal Issues** Overview Sensitive issue for me and other people, would not fit into a Powerpoint presentation. Not here to bash any company but will talk about what happened. Background is in international law and ethical issues particularly bioethical issues. I get particularly affected when it comes to issues pertaining to developing countries and how standards are lowered when it comes to developing countries. Will do an introduction, give the facts and background and ask a question and then conclude. A lot has been written about pharmaceutical ethics and the activities of pharmaceutical companies. There is a growing concern that ethical considerations are discounted by pharmaceutical companies. Disguised medical intervention in developing countries preys upon desperate, uninformed and vulnerable people. Pfizer case can be beneficial for this meeting in terms of it being a benefit-sharing meeting, and the case looks at whether the interest of communities is given any consideration. Mission is to share the Pfizer case and juxtapose ethical issues by asking where did Pfizer go wrong. A case being litigated in the district court of the US in New York. Even if Pfizer wins the case ethical questions will remain. Facts Summary In the interest of full disclosure, speaker is personally involved in litigation.

panel 2 cont.

Legal Issues in Benefit Sharing

Participants	Chair: Udo Schuklenk
Vincent Nmehielle	**Pharmaceutical Company Law-Suit – Ethical and Legal Issues cont.** Prominent new media etc has investigated facts. In the mid 1990's Pfizer developed an antibiotic called Trovin, projected sales meant to exceed $1bn a year. Pfizer desired approval from FDA (Food and Drug Administration) to market the drug to lucrative drug market in the US. Animal testing showed when drug administered to young animals abnormal joint cartilage – a condition called osteo-condiosis. Also caused liver damage regardless of age of animal. Clinical trials showed drug had the same effect on humans, but the company desperately needed convincing data to show that the drug was safe for children. But by 1996 Pfizer had no such data, not tested Trovin on children. By 1996 Dr. Hopkins, Director at Pfizer Central Research Division, learnt about bacterial meningitis in Northern Nigeria, a disease for which a number of medications already exists. Opportunity came for Pfizer to travel to Nigeria in order to test the efficacy of their drug and administer it orally so they could submit records to the FDA and have marketing approved for the drug. Even though testing protocols could take over a year to develop, Pfizer put together its protocol in six weeks. In order to have the drug tested in Nigeria in March 1996, Pfizer obtained a letter of consent from the Nigerian government, it being under autocratic rule at the time. Pfizer got into a government owned infectious disease hospital. Research team consisted of three US doctors including the director and his wife and four Nigerian doctors. Nigerian government gave Pfizer two large hospital wards to conduct its tests. Pfizer was not the only foreign medical team in Nigeria at the time. Pfizer established a treatment centre on the grounds of the hospital. Despite a very effective and inexpensive drug, chlorophenicone, recommended by the WHO (World Health Organisation) for treatment of meningitis, Pfizer went ahead and conducted its Trovin tests. Employed protocols that were not reasonable to yield reliable results. Pfizer's protocol stated that Trovin had to be taken orally whereas oral medication was only considered for critically ill patients, thus making the results less reliable and putting children's lives in danger. Conducted no test prior to administering Trovin to determine whether the strain of meningitis was responsive to the drug, nor did they test the children to find out whether they in fact suffered from meningitis even though measles and other diseases were also prevalent. They did not evaluate the children for side effects such as joint problems and liver damage. Children with pre-existing liver damage and joint problems were not excluded from the study. In violation of basic clinical practice, children who were not responsive to Trovin were not switched to conventional treatment, as it would have been in the US. Most tragically, they purposely and secretly lower-dosed the drug to conventional meningitis treatment to show efficacy was better than conventional treatment. Pfizer selected the children from those who were in the hospital and took children to special rooms inside the hospital so that the parents could not witness what was going on. Nor were the parents and children informed that the treatment was experimental and that conventional treatment was available. Pfizer did not obtain parents' signatures on the consent forms that were brought to Nigeria. Pfizer's research team spent only one month in Nigeria and offered no further care to the test participants. Pfizer's findings were submitted to FDA in September 1996, and in fact Pfizer's research team used seriously ill, uninformed and non-consenting children for highly unreliable medical experimentation.

panel 2 cont.

Legal Issues in Benefit Sharing

Participants	Chair: Udo Schuklenk
Vincent Nmehielle  Panel 2	**Pharmaceutical Company Law-Suit – Ethical and Legal Issues cont.** MSF who observed the procedures were highly critical. Out of 200 patients 5 who received Trovin died. Others suffered paralysis, blindness. In 1997 the FDA discovered a non-consistency in Pfizer's submission. Pfizer submitted ethics approval from another hospital in March 1996, a hospital in Canada when in actual fact no such ethics committee, existed in 1996. The director of Pfizer allegedly forged the letter. In 1998 FDA approved Trovin for use in adults only, Nonetheless Pfizer used the data they received from Nigeria to continue testing children in the US. A number of private law suits prevailed vis-à-vis the administering of Trovin. In 1999 the EU banned the use of Trovin and the FDA informed physicians that because of the liver damage associated with Trovin it could only be used for emergency care. As already indicated the parents who decided to sue in the US had an effect, and parents in Nigeria also sued. They alleged that they were never informed about the nature of the tests, that it was experimental and that there was alternative conventional treatment. Apart from those who died, others suffered brain damage, paralysis and blindness and the case was filed in the US, alleging the use of non-consenting human subjects, for these kinds of medical experiments, which constituted a violation of international common law and ethical standards. I ask the question: where did Pfizer go wrong? The Pfizer case is an example of domination of private interest in developing countries in terms of promises made to patients and consumers. Patients are sometimes tested without understanding that they are guinea pigs. Pfizer overlooked industry guidelines. Do you experiment in an epidemic? Pfizer developed its protocol in six weeks. Whereas meningitis treatment is given intravenously in the US, Pfizer administered it orally to children in Nigeria. They did not obtain consent from the patients. Pfizer as a private company is not absolved from this in any way. They failed to inform patients of alternative conventional treatment. Pfizer failed to avail itself of an expert in Bioethics and Health Law. Conclude - Pfizer case shows how ethical standards can be disregarded. It is no less than multinational organisations ship hazardous materials to Africa. While many medical experiments have proven successful in the treatment of diseases it has become necessary to question corporate ethics. Point must be made that lives in developing countries are not worth less than lives in the developed world. Not against multinationals but against their underhand activities. Profit must be made within the confines of the law and ethical guidelines. Personally not against any company but you find that these companies want to jeopardise your reputation. Because of my involvement in this case I have been personally investigated by the company to ensure that I possess the legal qualifications that I claim to possess. I thought I should share this because it affects beneficiaries even in genetic material. The conference we did in Stellenbosch implicated some of these issues mentioned. I am not a socialist but believe in the free market. But I believe ethical considerations need to be developed in a capitalist society.

panel 2 cont.

Legal Issues in Benefit Sharing

Participants	Chair: Udo Schuklenk
	Questions and Discussion
Doris Schroeder	I have a question with regard to benefit sharing in fauna and flora and benefit sharing in genomics research with regard to Bonn Guidelines. What are the exact cases where there should be benefit sharing?
Vincent Nmehielle	Will depend on what is meant by benefit sharing in certain cases. In terms of traditional knowledge, easier in a plant. In terms of human genetics, what could have been given to patients in this case. Perhaps medical treatment. How do we measure? Not necessarily everyone but ensuring that procedures are adhered to; sometimes it is difficult to quantify benefits. In the case of the twilight ladies the government, if it was progressive, could negotiate on their behalf rather than just getting 100 shillings. There needs to be a benefit for them whether it is undue or not will depend on the framework endorsed and produced by a particular government.
Udo Schuklenk	Ethical rationale is that they contributed some material to actually generate a product. It is fair for them to ask what is in it for me.
Dafna Feinholz	What about those who are not sick?
Udo Schuklenk	Those who get HIV in South Africa benefit from trials on antiretroviral treatment.
Doris Schroeder	What about a clinical trial of malaria where the person benefits from the treatment? Is that sufficient benefit or not? If it is not, then we need to make a qualitative case of difference between developed and developing countries.
Udo Schuklenk	In South Africa there are binding regulations in that regard. Regulation states that once that a is completed participants must be provided with a substantially sound product. Government basically says you are the sponsor, and you must guarantee access to that medication. In terms of vaccine trials obviously for person who turns positive the vaccine would not work but they must be provided with the AIDS drugs. Ethics committees in this country have to keep to that decision all the time because they are bound by legislation. Not true for many other countries. SA regulations are tremendously progressive but the worry is that this will become very expensive and these companies will go to the cheapest place.
Vincent Nmehielle	Strong-state- weak- state syndrome. Takes a government with authority to agree with what benefits are okay for its citizens. Further case that older people hold some traditional secrets. In a case that someone wants to develop that, there needs to be longer sustainable benefits. Circumstances should dictate the benefits.
	 Audience

panel 3

Gender Issues in Benefit Sharing

Participants	Chair: Miltos Ladikas
	Opening – Day 2
Doris Schroeder	Doris went through the programme for the day. Additions to Programme: Jackie Greenberg and Nosiphiwo Msitweni.
Miltos Ladikas	**Introductions**
Dafna Feinholz	**Gender Issues in Benefit Sharing**
	Overview - We need a clear framework of what we are going to talk about. Sometimes women or gender issues are over-simplified. The presentation is not about women and benefit but about gender and benefit sharing. Will talk about what gender means, particularly how society influences women and men and how inequalities influence gender in society. Why a gendered approach to benefit sharing? First of all because we are thinking about the power forces in South Africa, because these powers decide on the allocation of these benefits and gender plays an important role in this allocation. Because women are regarded as a vulnerable group. Women tend to suffer from poverty, affected by disease and lack of education. Inequalities are intertwined. Being a woman is a vulnerability in itself, and together with poverty and lack of education inequalities can be accumulated. Poverty is concentrated in developing countries. Of all poor people 75% are women. Inequalities in proportion of research, 10% allocated to women. Who will be setting the priorities when it comes to who will be researched and how do we define benefits for women? Several international instruments can serve as a framework to discuss benefit sharing. HUGO Ethics Statement does not mention women at all and has no gender framework. Other statements mention gender to be considered in populations. For instance, the US National Bioethics Commission refers to women but very general and vague. If we think about benefit sharing in genomics there are two considerations; genetic research has a different impact on women. Science and technology is not neutral to women. Let us look at the concept of gender first. The concept began to be used in the 1960's with various definitions. Until 1995 it was only an academic issue. After the conference in Beijing it became an international commitment. So now countries are committed and have to submit reports on what they are doing about it. In Mexico it has only been in this year that women and health have become a priority. How do we understand gender here? There is a difference in the anatomy of men and women. Every society builds symbols around femininity. What should be considered feminine given cultural symbols? A complicated issue but in many cases you have the goddess of earth represented as a woman. Cultures build these images of feminine and masculine. They build these as separate universes. We have to go a step forward. These universes have separate value judgements. Translated into social disadvantages for women.

panel 3 cont.

Gender Issues in Benefit Sharing

Participants	Chair: Miltos Ladikas
Dafna Feinholz	**Gender Issues in Benefit Sharing cont.** So, as said gender is a new dimension to take into account. Gender can also help to determine how access to power is organised and how women and men relate to each other. Lack of power that women have because of what we decide what is feminine and who should have access to what. Example: study in the UK in the 1980's. Selected a very representative sample of babies. They changed the blankets, girls covered with blue blankets and boys with pink blankets. Recorded all the comments and reactions. All reactions to pink blankets were "she's so sweet so quiet and gentle". And reactions to blue blankets were "he's going to have a strong character".
Tint Khin 	**Negotiation Levels** At an individual level, three factors; • Professions - obligation of professionals especially with regard to consent. • Respect - for the less dominant, in this case, women, • Space The role of women: three points • Access to information • Negotiation • Entitlement Entitlement Rights alone not enough. Entitlement for women means primary decision maker over her own body and reproductive capacity. In order to translate her needs and legimitise her claims. Strategies for developing countries Women tend to go along with traditional expectations, in order to gain other advantages under existing power relationships. Example is an African woman who goes to village and kneels in front of chief but she knows she is more qualified but she also knows the expectation is that she acts like this in order to get other advantages. Policy approach: Survivor position in benefit sharing is not enough. Policy of benefit sharing ignores gender norms. Do we hope to make women's lives easier without changing the existing inequalities? We recognise everything and hope to make changes and choose to promote gender equality. Strategies that women use are quite different from strategies that men use. Men have access to information and they have more power. Women tend to make more decisions more flexibly. They have different skills, particularly communication skills. And for that reason women need to be included in benefit sharing negotiations from the start.

panel 3 cont.

Gender Issues in Benefit Sharing

Participants	**Chair: Miltos Ladikas**
Fatima Alvarez-Castillo 	**Women and Benefit Sharing – The Asian Perspective** Will try to be more practical after two more formal presentations. Purpose of presentation is to show the importance of representation in relation to negotiations and decision making about how benefits should be shared. In many years of university and community teaching, I always found case studies to be very effective especially if the elements encourage some self-reflection. Encourage each person to do some reflection especially about the concepts of community, participation and representation. Intend to use the case studies to draw out some points regarding women's participation, representation and decision- making and draw out implications of this concerning approaches for capacity building. Dafna mentioned that gender is an analytic category that should be used to examine current understandings of representation and participation. A few case studies with questions: • Is it important for the community to participate in making decisions around benefit sharing? • What do we mean by community and community participation? • What do we understand by community representation? Case Study is completely factual, the only fiction is the mixture from several cases, put together for the purpose of the presentation. In a typical rural community in South Asia lives a 33-year-old wife and mother of five. She got married at age 18 and had 7 pregnancies. Her husband is a worker at the coconut oil refinery with a net wage of US$80 a month. Sometimes on Sundays to augment the income he goes into town to drive a rickshaw for his friend, a rickshaw driver who will take a day off from the streets. He is sick with tuberculosis and has taken medication on and off. With the new Department of Health strategy, an adult gets the medicine from the local clinic and submits a report there with regard to his compliance with the medication, having been assigned by the local clinic with his medical supervisor. She has to do this for him in order to get the drug replenishment. Lately she suspects that she has the disease too. She has been planning to stay longer in the clinic next time every time for a medical check-up, but has always postponed it. Two of the older boys are in school. The two girls have stopped schooling to help their mother. The younger sells vegetables at the local market Monday to Friday. The other one aged 8, stays at home to care for the infant boy and take care of the household work. When the mother returns from the market she takes care of the baby to let her daughter rest. When the baby is sleeping she prepares food for her husband. When everything else is done she does the laundry and makes sure the boys and her husband have clothes to wear the following day, since they only have a pair each. Having had no schooling, the dowry, which her parents gave to her husband during the wedding, is in her husband's name. She cannot own property by law; she cannot enter into property arrangements without her husband's consent. Once she gently asked her husband that they sell the jewellery from the dowry to send the older daughter to school. She had experienced how difficult it was to be illiterate.

panel 3 cont.

Gender Issues in Benefit Sharing

Participants	Chair: Miltos Ladikas
Fatima Alvarez-Castillo	**Women and Benefit Sharing – The Asian Perspective cont.** For example last month she had to pay a fine of US$20 for failing to pay a new fee in the market but did not know what the fee was for. What she remembered was she got a one-page notice and had asked another to explain what it said. When she complained to the market people about the fine she was told to go to the local government. It is the husband who must file a complaint and sign a promissory note that says he will pay on time in the future. Her husband decided it was better to keep the jewellery for emergency cases, and told her not to worry about her daughter because he will get her a good provider for her future. On Saturday, when she is not in the market she visits her ailing father-in-law to attend to his needs. In the afternoon she visits her parents. This is also the day to do other things, to mend clothes and to make entries into her report for the clinic. But despite all this she is pleased she is fulfilling her roles as a mother, daughter etc. Now would you like to know what happened to the market fine? She went back to the market people and explained that her husband could not absent himself from work because loss of wages would create difficulties for the family. So eventually after visits to the market people they agreed to allow her to bring the paper so her husband can sign the promissory note, and she could take it to the local government.
	Questions and Discussion of Case
Fatima Castillo	What does this tell us about women's situation and the implications for education for women?
Thofi Bishop	Almost non-existent, no capacity to protect her interest.
Lorraine Silverman	The woman was able to negotiate but it took her longer.
Fatima Castillo	Please remember the point.
Dafna Feinholz	Multiple burden of women.
Vincent Nmehielle	She was illiterate. How could she enter the entries into the report?
Fatima Castillo	The midwife in the local clinic trained her and she just enters checks.
Anita Kleinsmidt	Her husband decides which of her children gets educated.
Fatima Castillo	Use of time shows she has no time for herself. Implication of this is her inability to participate in issues outside her domain. About ownership of property. Applies in many developing countries. By law women cannot own property. If there are benefits accrued for the community in the form of money etc., or land what are the implications for women's capacity to be economically independent? Answers look linear and neat but they are not. What about her legal personality? Why is it that she has to bring her husband to the market people and have him sign the promissory note? Maybe because she does not know how to sign? According to a philosopher in order for you to participate you have to have the legal recognition. What do we understand by community?
Dafna Feinholz	Defined by common interest. Neighbourhood. Some elements like culture etc. all these community elements have a gender dimension. That is what I am saying; our usual understanding of community may be ungendered.

panel 3 cont.

Gender Issues in Benefit Sharing

Participants	Chair: Miltos Ladikas
	Questions and Discussion of Case cont.
Fatima Castillo	What do we mean by participation? In political science literature it means a presence. But there is the process of thinking, the process of speaking, acting. You cannot participate if you do not have the capability and the autonomy. You must have certain foundational requirements.
 Tint Khin with Udo Schuklenk	Representation? Being there. Familiar mechanism is election. Mandate to some people. When somebody is representing somebody, somebody is taking the place of that somebody. Levels of representation from anthropological data. You can have sacred representation like priests and symbolic representation and secular like an election. Class in the case study is an active analytic category. Some women have better lives. Gender should not be looped up and used as an analytic category. Last questions: Nobody talked about the layers of marginalisation and we need to take it up. Should there be indicators for meaningful participation? And if the answer is "yes" should indicators be different for women and for men and for the rich? Should processes of participation or representation be different for men and women? Is this approach of differentiating processes and strategies to be used for decision-making? Would it be fair to put poor women alone to negotiate with pharmaceutical corporations? If the answer is 'yes' what capabilities should women have? Poor women have been used to living a life of disempowerment. Should we expect them to immediately one day go and attend a negotiation meeting? What paradigm shift should they play in our capacity building? Is it just a matter of building skills? In terms of our capacity building approaches and strategies, in relation to what has been written in feminist literature, do women have different styles solving problems or solving conflict? Women naturally in their daily lives negotiate the difficulties of their daily lives. They are skilful in negotiation. Let us not be simplistic of what we need to achieve here. Question to Tint regarding Department of Health research ethics guidelines. Should the guidelines make provision for women at a principal investigator research level considering the obligations and duties as per the guidelines? Should it say that if the research subjects are women that the principal investigator should be a woman etc?
Tint Khin	Point is about representation, not saying that principal investigator should be a woman .
Roger Chennells	Such legislation should probably endorse it more tangibly rather than leaving it to other forms of legislation that may not specifically deal with the issue.
Dafna Feinholz	Need to consider the risk males have to violence.
Tint Khin	Question is whether benefit sharing can take place in a very unfair society.
Doris Schroeder	One needs to look at existing structures and review them and put in place protective measures so that much of the inequity can be dealt with. If there were a universal framework it could help towards making local and regional benefit sharing frameworks more tangible.
Tint Khin	Not saying 50% men and 50% women but that there must be equity.
Lorraine Silverman	What if we interfere with relationships with men and women, bad or good they may be? How sensitive are we to these issues?

panel 3 cont.

Gender Issues in Benefit Sharing

Participants	Chair: Miltos Ladikas
	Questions and Discussion of Case cont.
Udo Schuklenk	Should we be concerned about the outcome of representation?
Tint Khin	Outcome is dependent on the representation. There are issues of representation that are essentially historical.
Dafna Feinholz	Same debate in political arena.
Colin Louw	In the Northern Cape there are women who want to be beaten by men, domestic violence is also culture. What do you do in a case where women beat their men?
Tint Khin	A strategy of women to keep men since it is seen as done out of love. Comes down to inequality because women beating men is seen as wrong.
Fatima Castillo	Men need to be included in discussions of these issues.
Vincent Nmehielle	Who conceived the idea of being beaten out of love. is it women or men? What is the origin?

Panel 3

Evening music

case study

The San People and the Hoodia Plant

Participants	Chair: Anita Kleinsmidt
Anita Kleinsmidt	**Opening remarks and Introductions** Setting the Scene - San people in South Africa have traditionally been oppressed from both sides [Black and White], in the past you could be paid for hunting down the San. Were also oppressed by other indigenous groups, land was taken away. Were forbidden to hunt and forbidden to own land. The reason why they are here today is because of a plant they have been using for thousands of years, which allows them to stay in the desert without food. The plant has been the subject of commercialisation between the CSIR, a company called Phytopharm and an arrangement with Pfizer [Pfizer has meanwhile dropped out]. Speakers will talk about the benefit-sharing arrangement and given our discussion this morning, we will see if there is a gender input: if women are involved, if not why not. The pros and cons and the lessons we can learn in terms of what went wrong and right and extracting what we can learn in terms of developing a benefit-sharing framework. At the end we will try to draw together all the different strands of the discussion.
Roger Chennells 	**Legal Issues of the Hoodia Case** Short time to cover something so huge. Disadvantage of being a lawyer. When lawyers discuss ethics it is usually a straight line, how much did you charge, and did you do the right thing? Ethical question faced, as a lawyer for this case was linked up to the previous statement made. When speaker sat as arbitrator for a sexual harassment case, a male arbitrator, I was meant to be fair. On the one hand very angry women, on the other very defensive men. Men were very reassured that I was male. Women said you cannot judge this case fairly, and no matter how ethical you think you are, you are not a woman. With regard to the case study: outline the case study as it happened. In 1995, San people started organising themselves across the boundaries. A community relatively unchanged in 40 000 years. Very rapidly over the colonial period the dividing lines were drawn according to language, culture and families in the most crazy manner. In 1995 they started the creation of WIMSA the overarching organisation. What makes this case study successful to a certain extent is that the San people organised themselves before the issue, the Hoodia patent. We have reached a level of so-called community acknowledgement. What they understood was that we are building on democracy and have brothers and sisters who are San people. Another important thing is that no individual person or clan or tribe owns heritage. Heritage is something we must put on the table and share. The most critical decision was taken by this organisation and that applies to rock art and traditional knowledge etc. In 2001 the San people first realised that a patent had been taken out on the properties of the hoodia plant. The news was spred over the world and the San people scrambled to organise themselves. In a very short time a meeting was arranged with the CSIR, and the first issue was how could they have gone so far without prior consent. There was not even knowledge let alone consent. How we dealt with this is an entirely different matter and we could go into it if we had the time. What actually happened was the San people chose to engage and at this stage a framework for negotiations was laid out. In a nutshell the San people realised they had more to gain by negotiating than trying to object to the lack of consent.

case study cont.

The San People and the Hoodia Plant

Participants	Chair: Anita Kleinsmidt
Roger Chennells	**Legal Issues of the Hoodia Case cont.** The agreement was struck and the very private negotiations attempted complete transparency between the San group and Pfizer. They were negotiating with scientists and the inequities of knowledge were very apparent. The attempt on our side was to try and rectify this. An agreement was reached and everybody asks: Did you reach a good agreement, did you win? I am sure that we all have different views on this one. As a lawyer it is very tempting to defend what you have done and say it is really good. I would rather say that we did the best we could. The agreement was signed and struck in 2003, which meant that the San people are now partners of CSIR. If our overseas partners are successful, income streams will come towards the CSIR, of that income stream 6% will go to the San people, and that amount will go into a trust. Andries and Colin will talk about various issues of the trust. It is work in progress. We have participated in something called late informed consent because that is what happened. We are criticised hugely overseas for - in effect - approving a system that goes against all the conventions for biological diversity's ethical and principled requirements, as pharmaceutical companies must always get consent in advance. What we have done is in effect approve in the wrong way and that is something we have to live with. One of the obvious aspects I am really interested in is benefit sharing, what it means in a community that used to be hunter-gatherers for 40 000 years with a very flat social system, based upon small groups and human resources that are small by nature. They have a different social system where the gender dynamics are quite different. The entire structure of WIMSA is such that communities vote for representatives to sit on the trust. Flagging up points: • Patent on life- a whole series of debates internationally, on the notion of pharma companies acquiring patents on life, also based on traditional knowledge • The benefit sharing process itself was an enormous benefit in itself. • Getting ourselves up to date and in a position to negotiate we had to educate ourselves on the council and the leadership had to become educated. This will carry on and this will probably lead to a joint venture with the CSIR. We are currently negotiating for a database capture and research project with them. In the end we will try to draw together all the different strands of the discussion.
Andries Steenkamp  with Colin Louw	**The San Perspective on the Hoodia Case** (translated from Afrikaans by Thofi Bishop) It is quite a privilege for me to be here amongst all these learned people. And I am just an ordinary person from the Kalahari. I am only a grade seven learned person but am not afraid to speak for what I want. The first thing I want to talk about I will talk about now, but you will have to ask me questions at the end. Before we started communicating with the CSIR, a fault slipped that the San people were extinct. This angered us tremendously and we felt that people could not do with us as they pleased and dismiss us. As leaders we had to look at the best alternative. We had to take the anger and establish trust out of the anger. And after we started trusting one another, it became easier for us to talk to one another. The road to negotiation is not that difficult anymore.

case study cont.

The San People and the Hoodia Plant

Participants	Chair: Anita Kleinsmidt
Andries Steenkamp	**The San Perspective on the Hoodia Case cont.** There were many problems that obviously emerged from the anger And we had thought about going to court to sort out the issues. As a leader one needs to look at things realistically so we decided not to go to court. Indeed the San did not have money to go to court. It made us come to an appropriate arrangement for all San people. I believe that it is possible that if you have a good lawyer, that you can come to certain agreements. In 2002, 19th March, we decided to undergo a MoU with the CSIR. We were therefore forced to speak to one another. The longer you negotiate with people the more you come to understand each other as you share your problems. The purpose of the negotiations was such that we both could benefit from the agreement. We did not only talk about money but also about capacity building in our community. And most importantly do not forget that if something is yours that you need to stand up and talk about it. The San women are very reserved, and I had to negotiate at the agreement level, as we have only two women on the San Trust and only a few on the San Council. We had to look at issues of financial management, what we needed to do with regard to the money coming into the trust. The trust is made up of San people, one person from the CSIR and one from the Department of Arts and Culture. And we believe that it may not work in other countries but it was the best path we could walk, as we are not educated people, and to reach an agreement we had to. If you take decisions, you need not take decisions for yourself but that you do take them for the broader community. If you go into that direction, you take decisions that are of benefit to the community. Word “haalbaar” in Afrikaans nuance is that it also means achievable.
Marthinus Horak 	**The CSIR Perpective** Thank you for the opportunity to present here today. CSIR owned by government but fairly autonomous. Purpose is to use science and technology to create economic and social benefit for the country. Mandate is not to act in favour of certain scientific disciplines but to create economic benefit. Have particular interest in organic chemistry. In 1990 undertook to investigate biodiversity of South Africa with the aim of whether it holds potential for economic and social development. Two years later conference was opened in Rio de Janeiro and South Africa was also a signatory. Recurring interest by pharmaceuticals in natural products. Our task was to try and find out whether taxpayer’s money in SA should be paid on research that was hugely expensive in pursuit of new products, new industries and new community benefits. We said at that stage it would probably take ten years and by the year 2000 we should begin to see the benefits of the programme. So we launched the programme and felt we could come up with a drug lead in ten years, with commercial potential. There were few guidelines. It had to be derived from our biodiversity and had to involve indigenous knowledge in some manner. Had to create new industries in South Africa like the pharmaceutical industry, which needed to be uplifted. So the creation of intellectual property became the main pursuit as the only way in which countries like South Africa could be competitive globally.

case study cont.

The San People and the Hoodia Plant

Participants	Chair: Anita Kleinsmidt
Marthinus Horak  with Andries Steenkamp	**The CSIR Perspective cont.** Global competitiveness is important as South Africa has but 1% of the pharmaceutical market. South Africa has significant mineral resources like gold and diamonds, and if biodiversity was to make any difference it was to be a global scale product. This was to be a very expensive project therefore the life cycle was ten years. Around 1997 we realised we were succeeding with products around asthma control, and malaria control, and this was all based on relationships with traditional healers. Will not talk much about that now. 200 000 traditional healers in South Africa use plants as medicine for people. Compare this to 25 000 medical doctors. In October 1998 we had a meeting where all scientific university people met with the CSIR and said we are now confident that we are satisfied with findings on South African biodiversity and we published a bio prospecting policy. The government did not have a bio prospecting policy other than limited legislation around conservation. No legislation passed even today on biodiversity protection, still in draft phase. In 1999 signed a benefit sharing agreement with traditional healers and went into cultivation of plants at community level and started a world- manufacturing facility at the CSIR, and increased our investment in the research laboratories and brought in technology from abroad. That time too the asthma depressant became attractive enough to take out an international world-wide patent and in 1998 signed an agreement with Phytopharm, because it became clear that SA would not have the capacity to take it into the global world. The question about involving a UK based company has to do with particular technology. For the CSIR it would be a technology transfer but in many cases SA companies, producing the final product for export, would wholly own some of the products. The major benefit of South Africa's biodiversity is to work closely with the owners of traditional knowledge like traditional healers, the San people which is an identifiable community. To take this mix of resources and make scientific discovery and patent and give license to world's biggest pharmaceutical companies. South Africa has 10% of world's biodiversity, highly adapted and highly rich diversity. But South Africa does not have 10% of the world's scientific or industrial capacity or pharmaceutical development capacity to take it to the market. So we have to always be in partnership but we want to be partners from a very strong point of view. In the absence of biodiversity legislation from our government or indigenous knowledge legislation, the most powerful approach to this is to take out international patents. Gives you a strong hand in negotiations. The fact that we could license technology to a huge company shows you the power of an international patent. I am not saying it is the only way. In parallel to help us learn we also pursued a mosquito repellent, which is also a patent but no multinational company, was involved. We had a direct link with communities in the Limpopo province where they were cultivated. Slowly but surely the government started catching up. CSIR now need to show government that indeed there was enough rationale to go into biodiversity legislation, worthwhile use of their time. Legislation is still hanging, but has been fast tracked.

case study cont.

The San People and the Hoodia Plant

Participants	Chair: Anita Kleinsmidt
Colin Louw  with Andries Steenkamp	**Structure of the South African San Council** The trust was formed in 2003, Hoodia P57. We decided on how the trust would work and how broad its operations would be. At the moment it is the South African San Council that has been most important in the negotiations. In the process we decided that we needed to include everyone in the sharing of the cake. So we sat down and identified San people in Namibia, Botswana in South African as well as Angola. We sat down again last year and decided how we were going to split the benefits. As you can see there is South Africa, Botswana and Namibia WIMSA is the regional entity. *Unfortunately, inaudible from here*
Rachel Wynberg	**A Critical Look at the Case from Biowatch South Africa** *Unfortunately, inaudible* For details of Rachel's position, please see Rachel Wynberg. Sharing the Crumbs with the San. At: http://www.biowatch.org.za/csir-san.htm, accessed: 17 January 2005.
Miltos Ladikas Udo Schuklenk Marthinus Horak  Rachel Wynberg with Andries Steenkamp and Colin Louw Thofi Bishop Roger Chennells	**Questions and Discussion** Circumstances under which this happened are far from ideal and perhaps Roger could give more information for further discussion. Roger was at the Global Forum on Bioethics a few weeks ago and talked about it and we would really appreciate more information around this case. Need to make sure the next cases do not go down the same path as this one. What does the CSIR get from Phytopharm because I am not too comfortable with the 6% from Phytopharm. Seeing that there is a patent for the hoodia, how come it can be licensed internationally anyway? My understanding is that a patent gives you a monopoly to own it and sell it as you wish. 6% was established at negotiation. This was an international benchmark of the pharmaceutical industry. Traditional knowledge of the San was mirrored to what a university's split would be in the industry, used that to determine for the San. Some comments about unfair negotiation, please note that the negotiations were done in an open forum in the public and were transparent. With regard to piracy there are false claims for the Hoodia and the FDA has not approved these claims. Companies were closed down. The MCC (Medicines Control Council) would take such products off the market in South Africa. What is patented is not the indigenous knowledge of the San but the actual invention. This is the only thing that is patented. Ownership of patent is a total red herring. The sharing of the benefit is more important. Was the benchmark model the only thing that could be utilised? It would be patronising to tear up an agreement that has resulted after three years of negotiations. From the outside it really looks wrong. One needs to go into it really to get a good debate. Why do the San not open up their own laboratories? The way the benefit sharing is structured made us think around all these things and some of them have gone into different arrangements.

case study cont.

The San People and the Hoodia Plant

Participants	Chair: Anita Kleinsmidt
	Questions and Discussion cont.
Roger Chennells	Community themselves have said we see a possibility of backing this course based on the figures we got and every decision was made on the basis of the best knowledge at the time. The agreement is binding. Why 6% from the CSIR? Must say that this is substantially different from what Pfizer wanted to offer. CSIR is the only patent owner. If Phytopharm was taken on internationally, we could have lost international patent and would have started from scratch, basically.
Tint Khin	How did you change from anger to trust?
Andries Steenkamp	We spoke about the mistakes that were made and we demanded an apology from the CSIR. We also asked that that they acknowledge and respect us and that is what they did.
	We spoke directly with one another, and if we had problems we would sort them out. If you have any other solutions in terms of how we can further deal with this issue, your suggestions would be appreciated.
Colin Louw	We did not only seek money but we also sought education benefits for our children. What NGO's are not observing is that we have been spiritually oppressed, and what happened in the past is still with us, and it is difficult to trust. Many of the San people left school, and perhaps we could do research on intelligence quotient testing, and the recognition of prior learning, or that type of diagnostic tool testing because of the oppression that has occurred.
Rachel Wynberg	The South African agreement has been set but that does not mean that other legal issues have been ironed out. The San in Namibia may not benefit under the South African agreement and these issues must be looked into.
	 Roger Chennells, Colin Louw and Andries Steenkamp with Doris Schroeder

panel 4

Statements on Benefit Sharing

Participants	Chair: Himla Soodyall
Himla Soodyall	**Introductions** Two additional speakers were asked for short statements, one on behalf of Earthlife, and one from the Chair of the South African Society of Human Genetics. After Udo Schuklenk's paper, Doris will summarise our progress over the two days.
Nosiphiwo Msitweni 	From a CBO (community based organisation) called Earth Life. Work for the health project in Earth Life. We would like to work together with organisations that are working in benefit sharing. Would like to engage with organisations that are here too. Earthlife Africa an organisation of environmental and social justice activists. Main activities are campaign related. While best known for highlighting problems, we also work to promote ecologically sound alternatives, like renewable energy and organic farming. We have also put considerable effort into participation in government policy development processes.
Jacquie Greenberg  with Claire Penn (left)	Did not do any preparation, but am happy to talk about the SASHG's in benefit sharing. I wear many different hats. One which is now the Chairperson of the SASHG. When I took the chair at the end of last year three issues were important from the last annual meeting. The first one is about legislation, how genetic research is taken back to the people for whom this research is being done. In other words the service development and the implementation of service. A process should be put in place and many people have tried this but there is still none. Then there is, second, the use of biobanks, which is something that has been developed in South Africa almost overnight. They exist all over the US and Europe and have just come to South Africa. Biobanks are really a buzzword where people are scrambling to get DNA together to work on. For genetic tracing and also for individuals where there is a high prevalence of disease. Really concerned about the genetic research ethics issues and how these genes are extracted, and how confidentiality can be protected. Also concerned about the power of DNA, what they are not being told, your DNA put into a public domain where everybody can have access to it. If it is anonymous then I am still concerned. DNA and the people in Africa should be for Africa, in Africa and by Africa. I do not see the necessity for it to be shipped off and sold off. Should be developed in Africa and not just in South Africa, and should work together for the betterment of humankind. Have a subcommittee driven by Professor Jenkins to look into how we are actually going to stop it. So we need input into how it is going to operate. Third, been invited to join a task group from the DoH to put together regulations that go with the act on cloning. Stem cell cloning would be good, as it would benefit humankind. Whilst at the meeting asked the question about DNA. There is the Tissue Act and DNA falls under the Tissue Act. So we have been developing legislation on DNA, and RNA. Also asked the question about DNA shipped out of the country in collaboration with a laboratory in the US. And what is not said on the consent form is that DNA cannot be used for anything else. And so that is also a third document we're working on.

panel 4 cont.

Statements on Benefit Sharing

Participants	Chair: Himla Soodyall
Udo Schuklenk 	**Benefit Sharing and Neglected Disease Research** Patenting research results is detrimental to creating access to research in developing countries. To jump onto the bandwagon of putting patents on anything imaginable is the crux of the very system that leads to the creation of problems. I want to suggest to you that while we all happily talk about benefit sharing the truth of the matter is that there is nothing much to be shared. The reason for this is that commercial operators do not undertake the type of research required to address health needs in developing countries. So what I am trying to say is that there will not be many benefits to share in the first place if we continue down that road. These are the problems in my mind. I want to suggest that there is intrinsic conflict between low price and high price goods from an access perspective and the maintenance of trade regimes that seek to finance research and development for such medication. We need new mechanisms to finance research and development particularly in developing countries. Every year US$70bn is spent on health research and development by the private sector. Only 10% is used for research of 90% of the world's problems. Diseases like cancer occur in the developed world hence there are people who are happy to buy those type of products hence pharmaceutical companies focus their research into that. The same goes for HIV/AIDS, though in this case it is slightly different as it is a popular disease. The Global Fund will focus on HIV/Aids rather than malaria because it is not that important at this time. This is really how these sorts of allocation of resources take place. There is no treatment for SARS despite the prediction that there will be a major break out. No one has considered significant investment in research to find a treatment for SARS or emerging infectious diseases. Will not go through all slides but wanted to say that patents do not stimulate research and development into infectious diseases because the people who have these diseases do not have enough purchasing power. What this means to me is that we need to create other forms of research and development expenditure. At this moment we have to get this off the ground. Research in genomics has exclusively focused on diseases in North America, etc. because this is where the cash is. Developed world economies account for 80% of global pharmacy sales. There is also a concern whether research and development in developed world countries is really public health focused. Why do we engage in biomedical research? To improve the understanding of human biology and to improve life and well-being of all human beings. Continued genomics research provides opportunities for new diagnostic tools. Intellectual property such as patents are effective in somehow attracting investment into development and research but only where there is a market. Public private partnerships have also come into being but not a single one has distributed large numbers of AIDS drugs to people for instance.

panel 4 cont.

Statements on Benefit Sharing

Participants	**Chair: Himla Soodyall**
Doris Schroeder 	**A Cape Town Statement on Benefit Sharing?** **The conclusion of the event is fully transcribed. Thanks to Kath Carruthers for the transcription.** What I would like to do is to have an interactive session with you, which summarises what we talked about and also makes it relevant to our one year project. We have to contextualise it again. We are not even half way through the one year project and you have now met everyone who is directly involved with it, Miltos, Tim, Dafna, Udo and me and we have Himla as our external advisor. Our brief is to work on benefit sharing with developing countries in the area of human genetics but it also includes working with people in the area of non-human genetics and that is why Andries, Colin, Roger, Rachel and Marthinus were invited because obviously they have been working on this for much longer and there will be opportunities for learning. I told you yesterday that if all goes well we would like to come out with a statement that we might ask people to sign, or organisations to sign. So for this statement it is best to sum up our ideas here. You gave us some feedback and I am going to try and bring all of this together and introduce it point by point and then get feedback from you or comments after every single one. So if we want to write this statement, the very first question one needs to ask is what are the potential "benefits"? Usually I would have thought that people immediately think of "technology transfer", or one to three percent of profits for public health measures etc. That is the typical benefit sharing thought but we have to start at a earlier point and we have to ask: what are the benefits traditionally and who gets them? I found four and the most obvious benefit from medical and pharmaceutical research seems to be new drugs, new medical services, new diagnostics. That is the reason why we have this type of research. But in addition, economists would always say "you have economic opportunities as well". These are also benefits which need to be taken into account. And then lastly there are various types of, what I would call, additional benefits that can be negotiated on a case by case basis. For instance, six per cent royalties, eight percent milestone payments to be spent on education, public health measures, etc. Now the interesting question for us is: are there major differences between developing countries and developed countries? Can we make a case for different arrangements or different demands for benefit sharing in developing countries? And I think we can. Because if you look at these potential benefits [*essentials of presentation were written on a flip chart*], and ask yourself whether they are available in the North or available in the South you will see that new drugs and diagnostics will always be available in the North after the research has been completed. There is no question of this. It would not make any sense for a company to develop a product and not make it available. It will always be available in Europe and America etc. – the countries Udo mentioned. Jobs, economic opportunities, pharmaceutical companies, they are still mostly based in the North so all of this will be available in the North. Now additional benefits…, and I am glad that Jackie mentioned this… Additional benefits are mostly available to Europeans in the area of genomic data bases in Europe. But in the South is it clear that new drugs and services and diagnostics are available once the research is completed? No. That is why there is the discussion in research ethics about reasonable availability. Jobs, economic opportunities – are they available? Not necessarily because as I said before the pharmaceutical industry is mostly based outside developing countries.

panel 4 cont.

Statements on Benefit Sharing

Participants	Chair: Himla Soodyall
Doris Schroeder	**A Cape Town Statement on Benefit Sharing cont.?**
	We can see this from the experience that the CSIR did not develop the Hoodia Plant product themselves but it will be developed where the capability is to develop it.
 Chair: Himla Soodyall	Additional benefits? There is hardly anything in terms of human genetic banking.
	Out of this list, what are the benefits? Europeans do not talk so much about benefit sharing because they already have all these. These are massive benefits so people do not ask for anything more. But it is different in developing countries and I will your point Roger in a moment, because these first two are not available I think we can make the argument that benefit sharing for developing countries has to be different. It has to be more demanding and we might be able to demand it for any research, including clinical trials for instance, which would not make sense in Europe because we already have all of these benefits.
Roger Chennells	Availability is not the issue, but the products cost too much.
Doris Schroeder	Right. So call it 'access' rather than 'availability'. I will just write it down so I do not forget it. Because there is no reasonable – That is why there is the word reasonable – no reasonable access to it different benefit regimes might be appropriate. That was one of the ideas with which we came here in the first place. But I think it has crystallised even more, for me at least, during the sessions here and it would be good to hear whether you have any objections to this, and whether you agree that one can make a case for benefit sharing with developing countries which is much, much more demanding than anything one could possibly justify in developed countries. Anybody who would not be happy with this?
Jacquie Greenberg	Jacquie (inaudible in parts, hence summarised):
	Let us look at work in genetics…. If we do not do it, no one else is going to do it for us. I need to distinguish gene based therapy and gene therapy. Gene therapy for me is quite a long way off. But gene based therapy is happening and can happen today and gene based therapy works on the premise that you know the mutation of any individual. We all do carry genetic mutations and tomorrow we can actually start seeing what they are…. And the point being that gene based therapy is going to have to be personalised, is going to have to be developed for that individual. Only we can do it because no one else is going to come and test the mutations in all South Africans so the opportunity is there for the application.
Doris Schroeder	Thanks. Jacquie. There are two sides to this. Benefit sharing arises if there are two parties and one party gets access to something, for instance, the pharmaceutical industry in the North and has to deliver something in return. That is easy within Europe because the benefits are there without any additional payments. Now who would do the research you are talking about? It would be a South African company doing research in South Africa on local health needs. So you have got the European situation which is ideal. You do not need complicated benefit sharing agreements if the research is focused on local health needs and the outcome is affordable. Do you see what I mean? Benefit sharing can only be a solution for the short term, in my view and it is a very flawed tool for coping with inequities in the long term. What you are describing is already the ideal outcome and then you would have what we take for granted in Europe.
	Do you want to add something to that?
Jacquie Greenberg	But there are so many missed opportunities here.
Doris Schroeder	Do you think benefit sharing could be problematic because it could lead away from own exploration?

panel 4 cont.

Statements on Benefit Sharing

Participants	Chair: Himla Soodyall
	A Cape Town Statement on Benefit Sharing cont.?
Marthinus Horak	Would it make any difference who does the research, whether it is a company in South-Africa or a company in the West?
Jacquie Greenberg	The point is they then have no reason to do this research. There is no point. *(Jacquie gives an example about Egypt, which is hardly audible on the tape)*.
Doris Schroeder	When you have arrived at this point, you are only dealing with A and B and nobody needs to go into complicated negotiations about benefit sharing. It is only because there is unfairness that the need for benefit sharing has arisen in the first place. We are putting too much into benefit sharing. That is important I think.
Himla Soodyall	I think a lot of this research is still of benefit to the companies rather than the patients. I do not think in my life time we will get there with the type of work we are doing.
Thofi Bishop	What was really useful for me from the presentation of the World Bank yesterday was that they categorise countries according to, for instance, the infrastructure they have, you have the least developed countries and you have the more advanced developed countries. I was wondering whether one could potentially build some sort of thinking around that in terms of benefit sharing. I see this list that you have here and I imagine that for instance in Uganda there would be more needs with regard to benefit sharing *inter alia* the research that could be undertaken in Uganda. May be that is something we need to think about too but it is not just about speaking of developing countries as one entity.
Doris Schroeder	That is an excellent point. We are currently just talking about these two blocks, developed countries and developing countries and obviously Eugenia knows which countries are in which sub-sectors, for instance, middle income countries etc.
	An inaudible audience contribution for about two minutes
 Thofi Bishop and Udo Schuklenk	But let us move on and ask who should benefit? It is a different question when we come to non-human genetics because there we mostly talk about communities and traditional knowledge but in human genetics there are other potential beneficiaries. Now the three possibilities at the individual level would be: (1) research participants; everyone who has taken part in the research, for instance who has given a blood sample. (2) If this is a malaria study, perhaps everybody who suffers from it, and (3) the hospitals or other facilities that are conducting the research. There is something when we look at the human genetics field something I find worrying with this potential distribution of beneficiaries and that is the possibility for undue inducement. If you draft somebody into a study with a promise of financial benefit on an individual level or even on a patient group level or even for a hospital this – from a research ethics perspective – could be regarded as undue inducement. You can force somebody into something simply because of extreme poverty. Force them to take risks upon their physical health that are not justifiable. In order to avoid this you say this is not allowed due to undue inducement. The alternative would be to go to the country level because I cannot see anything in between here. There are no communities, as such, or, and this is something Anita raised, it could all be paid into an international global fund and then be spent on the most pressing areas. Now we do not have undue inducement here and there might be opportunities if it is going to the country level or if it is going to the global fund level. If it goes to country or global fund level there is the possibility to earmark, that means to focus funds into a particular area and the two areas we mentioned [women's health and neglected disease research]. Can you see any other potential beneficiaries that I might have forgotten in the area of human genetics and what do you think about the possibilities?.

panel 4 cont.

Statements on Benefit Sharing

Participants	Chair: Himla Soodyall
	A Cape Town Statement on Benefit Sharing cont.?
Himla Soodyall	I do not quite see why you separate human and non-human genetics and say that there are no communities in the former.
Doris Schroeder	I separated the two in terms of undue inducement. You do not have undue inducement if you talk about plants. But I forgot communities in human genetics research rather than participants from disease groups, because I forgot research on local gene pools, the type of research you carry out, Himla. For instance the population of Tonga as a community group on whom genomic research might be possible and so this is definitely an omission. The point then, however is, is there undue inducement for community groups or not? Should they be the prime beneficiaries or not? This I think is difficult. Research participants are not individually paid because this is such a clear case of undue inducement and would be unethical. The same with hospitals; they could just draft people in. This is the point where we should ask: should benefits go to the country or to the community or to disease groups? If for instance out of 10,000 people 1,000 have their blood samples taken and the whole community benefits from the research. There is still an element of undue inducement even though there is no clear profit to be made for individuals but who then do you think should benefit from a benefit sharing agreement in the area of human genetics? (*End of tape, missed one answer*).
	
 UNESCO Woman of Science 2004 for South Africa, Professor Jennifer Thomson	There are clearly two possibilities. Universal formats or case by case approaches. Universal format could be considered patronising or euro-centric but there would be minimal standards. If there were agreement on minimal standards that would also avoid forum shopping etc. A case by case approach would not have the problem of being potentially patronising but there is more room for exploitation particularly if the people who join in the negotiations do not have the same starting point. One way out is to go on a case by case approach but in combination with data bases. Whereby a global organisation collects every single case study of benefit sharing and then opens it to everybody who wants to enter the negotiations. That sounds like a very long term bureaucratic approach. The other possibility, and that is one of the ideas with which we came here, would be to allow a case by case approach but say potentially in a patronising way that there should be earmarking. Earmarking for pressing issues. These are the two issues that we think are pressing. The one, which Udo just talked about, neglected disease research. It could be one per cent of all the funds out of benefit sharing have to be spent here and the other one is on women's health. We had a long session on women's issues I do not want to go into this again but this is a pressing issue as you heard this morning. So what are your thoughts on the approach? Should it always be a case by case approach .and if so, how do you avoid exploitation if the people who are at the negotiation table are not equal?
Vincent Nmehielle	On the issue of universal frameworks of course you know how international frameworks come about. There is a likelihood that there is going to be one because of the interests that are at stake, also commercial interests. From that point of view I was thinking that a national framework would be better. Mind you international frameworks are good as a minimum standard. But it must be clear that one does not have to stick to the minimum standards. It is just a level nobody can go below. Then at a national level you encourage to go above this. And hopefully all states would do this.
Doris Schroeder	Can I just say something briefly and then Jennifer. I think that one advantage of the Convention on Biodiversity and the Bonn Guidelines is that they got the ball rolling in individual nations. I am not sure whether something that is going to happen in individual nations if there is no global initiative.

panel 4 cont.

Statements on Benefit Sharing

Participants	Chair: Himla Soodyall
	A Cape Town Statement on Benefit Sharing cont.?
Jennifer Thomson	Coming as a complete outsider, I would say it is so important to do it on a case by case basis as everything is different in the environment in different nations.
Doris Schroeder	In your view then, somebody on the national level sets minimal standards to be followed by a case by case approach.
Marthinus Horak	The process normally works in that the country at a national level adopts some level of best practice and if it notices that there are exceptional cases where people are exploited then they decide upon measures to prevent that. The natural process therefore would be a case by case approach unless someone complains about exploitation and then minimal standards are given but people are still allowed to operate on a case by case but it would be illegal if they were outside the boundaries of a national framework.
Udo Schuklenk	Look, first of all. I agree with you. Starting from a case by case basis and then developing polices. International research ethics guidelines started exactly like that historically. They started off in Nazi Germany – that far back. You had the Nuremberg trials, we learned in the process and got the Declaration of Helsinki, but it was unworkable. You could not always get consent, you could not get psychiatric patients in. Now the Declaration of Helsinki is being subverted by people who do not like the standards, so they create their own documents. It does not matter which one you pick. But what is important from that is that individual countries, including South Africa started using the Declaration as a minimal standard. So we certainly do not do it in this country on a case by case basis as we have binding government regulations
Eugenia Marinova	I would rather see minimal standards and hope that countries would go above it.
Doris Schroeder	If by now we had answered all the questions we would know in which cases there should be benefit sharing, who should be the beneficiaries and what should the negotiations be guided by. But then the next question is obviously who takes part in the negotiations? The problem with representation is that not everybody who is affected can take part, so there has to be some sort of selection. What springs to the western mind immediately is democracy and informed affirmative action to make sure that democracy is guided by ideas about gender, equality, inclusion, marginalised people etc. This again comes from the western mind and could be imposed and run counter to ideas of representation that exist in other countries where the tradition might be to send a chief who is not elected to represent the groups that are negotiating benefits. Well, I think this is one of the most difficult questions. Who should go and sit at the table of negotiations and by whom should this be decided? Should there be the question of minimal standards as well? Should we have an alibi woman in there or not? This is such a massive question that we are probably not going to find an answer here.
Vincent Nmehielle	Just a comment. I do not believe that democracy is a western concept. Depending on what you mean by democracy and I do not believe that the chiefs are not elected depending on where you are coming from – what African culture. It may well be that the next oldest person in the village becomes the chief after the other person dies. That could be the generally accepted rule. But that is the person who comes on to represent the people so democracy has been very well thought about. It depends on how each society or each community works to be able to get representation. For instance there is a need for us to get engaged with say the researcher. The chief calls the counsel which supposedly will have a representative taken from each house. If they were going to form a delegation of our community to represent us it is normal that each person comes out of his house to join in to negotiate. I feel that is very democratic because each and every house is represented

panel 4 cont.

Statements on Benefit Sharing

Participants	Chair: Himla Soodyall
	A Cape Town Statement on Benefit Sharing cont.?
Vincent Nmehielle	I think it depends on how the society or the community in question functions to be able to decide whether it is democratic or not.
Doris Schroeder	Definitely. It is the interpretation of democracy that is the major issue. What probably came out from the session this morning is what we understand in Europe by democracy when it comes to participation. Everybody has the same say. So in a country with 50-50 men and women, there should at least be 30-40% of women representatives. That is not the case in benefit sharing negotiations. So something might have gone wrong with the democracy concept we have in the West but that is a question we definitely cannot answer here – the interpretation of democracy – unless Roger wants to.
Roger Chennells	*Unfortunately, Roger's contribution on democracy was inaudible mostly because of the sounds of agreement and disagreements from others.*
Doris Schroeder	If we had more time I would ask you [Andries, Colin, Roger], how you decided who should represent the San in your case but we do not have time for that.
Roger Chennells	Thank God! (*Enormous laughter from all*).
Doris Schroeder	The representation issue is one of the unresolved ones. But we have to go to the last one now.
	If there are inequalities at the stage of the negotiation process there could be or ought to be capacity building measures. But that is probably even more of a wasps nest than representation. Which capacities ought to be built by whom? The question I have is more about the real world. For instance, the European Commission has some funds to do something on capacity building in South Africa. But would this not run counter, well, to the whole idea of capacity building? Would it not just be a sort of teaching from one side to the other where teaching is completely the wrong word because the cultures could be so different that what they want to be taught is not the same as that which outsiders come in for? But how do you solve the problem that the funding for capacity building is in a different place from where it is needed?
Udo Schuklenk	I think one could learn something very useful here, those of us who are in human bioethics. We are flooded with money in research ethics basically. But it comes with strings attached. For instance, you have to be trained half the time in the United States which translates into really an ideology transfer. We saw the products of this training in Paris [at the Global Forum Meeting on Benefit Sharing]. They even used the same way of making bulleted lists in their power point presentations. So my suggestion would be that you still have a peer review and that could be in Europe, that would not bother me at all. You simply look at the quality of the proposals and you give it to somebody local with capacity, who can build more capacity. To fly to Boston for this is ridiculous. We have better research ethics than many European countries [in South Africa]. But this does not mean that you [Europeans] actually have to do the training. There are enough people here, provided they have the resources to do it.

panel 4 cont.

Statements on Benefit Sharing

Participants	Chair: Himla Soodyall
	A Cape Town Statement on Benefit Sharing cont.?
Fatima Alvarez-Castillo	You can even destroy capacity if you do not work with local NGOs and even undermine their work.
Clare Penn	External funds can provide local jobs and employment.
Doris Schroeder	But who sets the agenda?
Clare Penn	*Clare's response unfortunately inaudible.*
Lorraine Silverman	If you send people to the United States for training or if American trainers come to South-Africa, this is not really capacity-building. It is a strategy for finding jobs for foreigners. In the National Skills Programme, we have resisted this for quite a while. Usually, top managers are sent. They talk very nicely about skills transfer. But skills transfer never happens from the top. There is a glass ceiling for locals, because of this perception that skills have to be transferred from the top. Because these are the elite! In this country, we find these aspects of capacity-building quite onerous. But if foreign money comes with no strings attached, nobody will say, keep it away.
Doris Schroeder	But there are always strings attached. For instance, European Commission money requires the involvement of European researchers.
Lorraine Silverman	If it is transparent that there are benefits of this capacity-building for the funders that is fine. But it comes couched in charity. "What we are doing is such a favour". And it is not actually. From this point of view, it is a scary area. But if you are serious about capacity-building, link with government agencies, link with government organisations. See what is there, rather than imposing a new structure from outside.
Clare Penn	We must learn from each other.
Doris Schroeder	That is a very good point to end on, because this definitely applies to me. I have learned a lot here.
Himla Soodyall	Since I have the final say, I would like to congratulate Doris and Udo and the others involved here to bring us into the picture and to make us all think more seriously about benefit sharing. We can now see a bigger picture and hope that we can strive to contribute to beneficial outcomes. We wish you all in the pursuit of resolving the issues on benefit sharing particularly in developing countries the very best. So I now hand over to Udo.
Udo Schuklenk	Do not worry, it won't take long and it won't be painful. I will not add anything more of substance because our discussions have been extremely useful. I would also like to thank Doris who did a lot. I was worried at some point that the sessions would be too separate, but all came together well in the end. I am very grateful that you all took time out to spend two days with us. I hope that you all have something to take back. I would like to thank one person in particular, the guy with the green folders in the back. Saul Garcia. (*Loud applause*). He has worked frantically to bring everything together. Thank you very much again to all of you for coming and I hope you have a safe trip home.