

Chapter 3

International Genomics Research Involving the San People

Roger Chennells and Andries Steenkamp

Abstract In 2010 an international genomic research project entitled “Complete Khoisan and Bantu genomes from southern Africa” was published in *Nature* amidst wide publicity (Schuster et al 2010). The research aimed to examine the genetic structure of “indigenous hunter-gatherer peoples” selected from Namibia, and to compare the results with “Bantu from southern Africa”, including Nobel peace prize winner Archbishop Desmond Tutu. Four San individuals, the eldest in their respective communities, were chosen for genome sequencing, and the published article analysed many aspects of the correlations, differences and relationships found in the single-nucleotide polymorphisms (SNPs) (A single-nucleotide polymorphism is a variation in a single nucleotide that occurs at a specific position in a genome, where each variation is present to some appreciable degree within a population) within the sequenced genomes. A supplementary document published with the paper contained numerous conclusions and details that the San regarded as private, pejorative, discriminatory and inappropriate. The San leadership met with the authors in Namibia soon after publication, asking why they as leaders had not been approached for permission in advance, and enquiring about the informed consent process. The authors refused to provide details about the informed consent process, apart from stating that they had received video-recorded consents in each case (Hayes 2011). They defended their denial of the right of the San leadership to further information on the grounds that the research project had been fully approved by ethics committees/institutional review boards in three countries, (names of committees given to editors of this book) and that they had complied with all the relevant requirements. The San leadership wrote to *Nature*, expressing their anger at the inherent insult and lack of respect displayed by the process (Ngakaeaja 2011b). This case study details the most serious aspects of the perceived exploitative nature of the research, and the San response.

R. Chennells (✉) · A. Steenkamp
44 Alexander Street, Stellenbosch 7600, South Africa
e-mail: scarlin@iafrica.com

© The Author(s) 2018
D. Schroeder et al. (eds.), *Ethics Dumping*, SpringerBriefs in Research
and Innovation Governance, https://doi.org/10.1007/978-3-319-64731-9_3

Keywords Genomics · San · Southern Africa · Indigenous peoples
Informed consent · Vulnerable population · Ethics committee
Institutional review board

Area of Risk of Exploitation

This case study is about the conducting of genomic research on a vulnerable population, and it focuses on the enhanced need for respectful and authentic prior informed consent. While the research itself is undoubtedly of potential benefit to humankind as well as the participant population, the particular risk of exploitation lies in the fact that certain types of information gleaned from genomic research are essentially of a sensitive and private nature, and their publication can result in potential embarrassment, discrimination and collective psychological damage. The informed consent allegedly gained for this complex research project from the illiterate San participants was never disclosed to the San leadership, and, as is made clear below, the nature and content of the research publication was indeed damaging to the community on various levels.

Specific Case and Analysis

The general population of San peoples of southern Africa is known to carry the oldest human DNA on earth, and is consequently much sought after for population-wide genomic research aimed at understanding aspects of human evolution. The San peoples, known to be the earliest “hunter-gatherer” populations of southern Africa, number an estimated 100,000 individuals spread across at least five countries, with the largest populations in Namibia, Botswana and South Africa. Since 1986 the seven dominant linguistic groups have formed elected organizations in each country aimed at representing and protecting the rights of their illiterate rural populations. One of the most important roles of the San councils of Namibia, Botswana and South Africa is to protect their people from unwanted, inappropriate or exploitative research.

The stated purpose of the genomic research project under discussion was to sequence the genomes of four selected San individuals, and to “characterise the extent of whole-genome and exome diversity amongst them” – that is, the four San and a man of Bantu extraction. In addition it set out to “compare the described variants to known data-bases” in order to pinpoint genetic variations in genome-wide data, and to “facilitate inclusion of southern Africans in medical research efforts” (Schuster et al 2010).

In about 2009 researchers associated with the three universities began the process of obtaining informed consent and taking DNA samples from four selected San elders from three linguistic groupings, described as Tuu,!Kung and Ju/'hoansi. How

the researchers communicated the methodology, aims and objectives of the complex research project via translators to the four illiterate elders will perhaps never be known: the San leadership later formally requested access to this information, but were refused. According to the published research, “all participants consented ... via video-recorded verbal consent (Bushmen)”. In February 2010 the research was published – to wide publicity in the popular media – in an academic paper entitled, “Complete Khoisan and Bantu genomes from southern Africa”, which was accompanied by a document containing supplementary information (Schuster et al 2010).

The acting regional coordinator of the Working Group of Indigenous Minorities in Southern Africa (WIMSA), Ben Begbie-Clench, approached the paper’s authors requesting details of the informed consent process, as set out below. Mathambo Ngakaeaja, deputy director of WIMSA, subsequently wrote to *Nature* on 18 February 2011 objecting to the publication by Schuster et al., and describing how central the concept of prior informed consent was to all research affecting indigenous peoples. After commenting critically on the persistent refusal of the researchers to approach the official San leadership structures or engage meaningfully with them, Ngakaeaja stated that the purpose of his letter was “to draw attention to the absolute arrogance, ignorance and cultural myopia that is present here” (Ngakaeaja 2011a). He continued, “these researchers have basked in the glory of their publication whilst claiming smugly that they complied fully with the ethical requirements”.

From the perspective of the San leadership, many aspects of this research study were deeply problematic, and would have been objected to if one of their organizations (e.g. WIMSA, the South African San Council or the South African San Institute) had been given an opportunity to consider the research before it began or to approve the final form of the document prior to publication.

The San leaders engaged respectfully with the researchers following publication, requesting details of the informed consent process. Despite much correspondence,¹ the authors persistently refused to acknowledge the need to consult with San leadership or to provide details of the informed consent documentation or process.

We set out below some of the San leadership’s reasons for regarding the research project as exploitative.

Terminology

The use of words such as “Khoisan” and “Bushmen” and “hunter-gatherers” shows a lack of consultation with San leaders. All of these terms were freely used in the publication, but all are considered sensitive and problematic for different

¹The emails concerned are in the possession of the principal author of this case study, who is a lawyer, but are not reproduced here in order to protect the privacy of personal data.

reasons. For example, the San object to being referred to collectively as “Khoisan”, a descriptive term coined by anthropologist Leonard Shutze in 1928 as a way of referring to Khoi pastoralist and San hunter-gatherer groups collectively (Schlebusch 2010). The word “Bushman”, meaning “uncivilized people”, is widely regarded as pejorative in certain contexts. The anthropologically loaded term “hunter-gatherer”, frequently used in the paper and the supplementary information, implies a generally acknowledged low social status (Wynberg et al 2009). Consultation would have resulted in more acceptable uses of these and other terms.

Published Conclusions Far Removed from Genomic Research

Much of the discussion in the supplementary information document related to terms and concepts such as “hunter-gatherer”, the low status of “hunter-gatherers”, the payment of lobola and dowry, and marriage practices, for example:

A feeling of inferiority associated with the “Bushmen” or “San” ethnic classification meant that many Bushmen women tried to uplift their status via marriage to Bantu men (Schuster et al 2010: suppl 3).

These conclusions could not have been drawn from the results of the genomic research, nor could they have been permitted by a process of informed consent to the collection of genomic data. The publication thus draws on and publishes conclusions drawn from other sources and disciplines, which would *not* have been permitted in a normal research consent process. The bad practice and injustice of publishing information that could not have been envisaged by the participants at the time of their giving consent would have been lessened had the authors returned to the communities before publication and tried to explain the far-reaching and sensitive nature of their findings. The San leadership, however, are unaware of any attempt by the researchers to return to the communities and explain the complex nature of the published conclusions.

Individual Versus Collective Consent

It is well known that indigenous, rural and illiterate people do not understand individuality and individual rights in the manner of the West, their identity being deeply collective and associated with their communities. This research project only obtained informed consent from the indigenous individuals who participated, while it is known and accepted that genomic research by its very nature speaks to collective issues. There is no shortage of published research ethics guidelines (e.g. NHMRC 2003, CIHR et al 2014) that set out absolute requirements for research on indigenous peoples, one of which is that collective “permission” should be obtained

from the leadership, in addition to normal informed consent obtained from individuals. Not to do so is perceived as an expression of lack of respect for the community. However, one of the authors wrote to WIMSA saying, “As we are dealing with individuals in a personal manner (via their DNA) the individual has a right to participate or not as the information contained is of direct impact to that person” (Hayes 2011). This response does not take into account that genetic information also has a direct impact on family members of the participant.

Lack of Respect for or Reference to Indigenous Research Protocols

The need for “respect” to be shown to the particular community is perhaps the most important fundamental element in the indigenous research ethics guidelines referred to above. The requirement takes many forms, but can be summarized as authentic communication with the community leadership from the inception to the conclusion of the research project. None of the established suggested methods for showing respect to communities were employed in this case. The authors refused to consult with the leadership afterwards, relying upon the fact that allegedly none of the elderly and illiterate San participants had demanded to be represented by the San leadership. For that reason, they concluded that the San leadership had no say in the matter (Hayes 2011). This reliance on individual consent by an illiterate person who could have no idea of how the implications of genomic research related to the collective was and is regarded by the San (an abuse of power).

Failure of Research Ethics Committees/Institutional Review Boards

The researchers defended their methodology regarding consent and other aspects of the process by repeating that the project had been approved by no fewer than four separate research ethics committees. Yet not one of these committees referred to the published research guidelines on indigenous populations, which were readily available and with which they ought to have been familiar, despite the fact that the very purpose of the research was to examine the most famous of indigenous “hunter-gatherer” communities. In the words of Prof. Vanessa Hayes, geneticist and co-author of the *Nature* paper, these committees were formally designed to “approve, monitor and review biomedical and behavioural research involving humans with the aim to protect the rights and welfare of the research subjects” (Hayes 2011). In addition she stated that it was their duty to respect the “culture, dignity and wishes of subjects”. It is the San view that they failed dismally in this duty.

Breaches of Privacy in the Findings

The paper and its supplementary information included a number of discussions and conclusions that contained intimate, personal or pejorative information. The following are some examples discussed in the context of “Bushmen-specific phenotypes” (Schuster et al 2010: suppl 8): namely, how different genetic and environmental influences come together to create an organism’s physical appearance and behaviour.

1. *“Hunter-gatherer” associated with low social status*: Commentary in the paper on “traditional life-style” included the following, which contains far-reaching and unsupported assumptions:

A feeling of inferiority associated with the “Bushmen” or “San” ethnic classification meant that many Bushmen women tried to uplift their status via marriage to Bantu men (Schuster et al 2010: suppl. 3).

2. *Lactase persistence*: The following conclusion was drawn:

As expected for a foraging society, we found the Bushmen in our study all to be homozygous for the C-allele, suggesting an inability to tolerate milk consumption as adults (Schuster et al 2010: suppl 4).

3. *Human pigmentation*: Conclusions were drawn about levels of San melanin pigmentation, their susceptibility as a group to skin cancer, and their consequent selective advantage for survival in the Kalahari desert (Schuster et al 2010: suppl 5).
4. *Lipid metabolism and bitter taste alleles*: Complex conclusions were drawn relating to Bushmen digestive tracts, and also the ability to sense a bitter taste, a trait which would potentially assist human survival in the wilds. The “taste receptor gene” was also discussed in the context of human evolution from Neanderthal to the present (Schuster et al 2010: suppl 7).
5. *Genes related to hearing*: Drawing on the findings, the paper indulged in speculation that “Bushmen have better hearing than Europeans” (Schuster et al 2010: suppl 8).

Lessons Learned

The San leaders see the Schuster case as a telling example of the harm and disrespect that research can bring about, notwithstanding approval by ethics committees/institutional review bodies. It also highlights the need for San themselves to create their own protection mechanisms.

With this in mind, the San held a consultative workshop in September 2014 comprising San leaders from Botswana, Namibia and South Africa, as well as genomic researchers, ethicists and lawyers. The purpose of the workshop was to discuss the San’s perception of the exploitation inherent in the approach followed by the Schuster research, and to propose a San response to ensure that such research could never take place again.

In 2016 the San held two further workshops under the auspices of the TRUST project² designed to take the earlier discussions further and to consolidate proposals aimed at ensuring that the San could in future manage and control research being done on their communities. These proposals are set out below.

Recommendations

The following recommendations emerged from the San workshop aimed at preventing exploitation in research.

- Collective permission must be obtained for all research to be carried out on San individuals or communities.
- The San Council is the elected organization in South Africa mandated to engage in this process with researchers.
- The San have since developed a San Code of Research Ethics (San Council 2017) that has to be completed by all prospective researchers. This code contains a number of requirements relating to the need for research to be both respectful and useful to the San peoples, including:
 - early identification of research useful to the San
 - joint development, where appropriate, of design, content and methodology of all aspects of the research
 - full details provided in advance of all aspects of the research, including (potential) benefits to the San
 - commitment to pre-publication consultation, where appropriate, and post-publication feedback to the community

References

- CIHR, NSERCC, SSHRCC (2014) Chapter 9: Research involving the First Nations, Inuit and Métis peoples of Canada. In: Tri-council policy statement: ethical conduct for research involving humans. Secretariat on Responsible Conduct of Research, Ottawa ON. On behalf of Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada. http://www.pre.ethics.gc.ca/pdf/eng/tcps2-2014/TCPS_2_FINAL_Web.pdf
- Hayes V (2011) Personal email communication to B Begbie-Clench, WIMSA, 11 May
- Ngakaeaja M (2011a) Letter to editor of Nature, 18 February
- Ngakaeaja M (2011b): Personal email communication to B Begbie-Clench, WIMSA, 11 May

²TRUST is a European Union project with the main goal of catalysing a global collaborative effort to improve adherence to high ethical standards in research around the world. <http://trust-project.eu/>

- NHMRC (2003) Values and ethics: guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research. National Health and Medical Research Council, Australia. https://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/e52.pdf
- San Council (2017) San Code of Research Ethics. <http://trust-project.eu/san-council-launches-san-code-of-ethics/>
- Schlebusch C (2010). Issues raised by use of ethnic-group names in genome study. *Nature* 464:487. <http://dx.doi.org/10.1038/464487a>
- Schuster SC, Miller W, Ratan A, Tomsho LP, Giardine B, Kasson LR, Harris RS, Petersen DC, Zhao F, Qi J, Alkan C, Kidd JM, Sun Y, Drautz DI, Bouffard P, Muzny DM, Reid JG, Nazareth LV, Wang Q, Burhans R, Riemer C, Wittekindt NE, Moorjani P, Tindall EA, Danko CG, Teo WS, Buboltz AM, Zhang Z, Ma Q, Oosthuysen A, Steenkamp AW, Oostuisen H, Venter P, Gajewski J, Zhang Y, Pugh BF, Makova KD, Nekrutenko A, Mardis ER, Patterson N, Pringle TH, Chiaromonte F, Mullikin JC, Eichler EE, Hardison RC, Gibbs RA, Harkins TT, Hayes VM (2010) Complete Khoisan and Bantu genomes from southern Africa. *Nature* 463:943 – 947. <http://dx.doi.org/10.1038/nature08795>
- Wynberg R, Schroeder D, Chennells R (2009) *Indigenous Peoples, Consent and Benefit Sharing*. Springer, Dordrecht

Author Biographies

Roger Chennells works as legal adviser to the South African San Institute (SASI) and has been senior partner in the human rights law practice Chennells Albertyn, Stellenbosch, since 1980. Specializing in labour, land, environmental and human rights law, he has also worked for Aboriginal people in Australia.

Andries Steenkamp who died in 2016, was a South African community leader and the long-standing chairperson of the South African San Council. As a representative of the San peoples he was involved in many research projects, where his primary task was to understand the mutual needs in the research relationship, and to ensure that his community both provided and received benefits.

Open Access This chapter is licensed under the terms of the Creative Commons Attribution 4.0 International License (<http://creativecommons.org/licenses/by/4.0/>), which permits use, sharing, adaptation, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons license and indicate if changes were made.

The images or other third party material in this chapter are included in the chapter's Creative Commons license, unless indicated otherwise in a credit line to the material. If material is not included in the chapter's Creative Commons license and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder.

