

notably in Soweto ('South Western Townships') which is about the same size as Johannesburg, Cape Town or Durban. Fassin adopts an emotional tone, focusing on the tragedy for South Africa's blacks who, having just won political emancipation from the apartheid system, are now faced with the appalling consequences of this epidemic. He combines detailed life histories with an investigation of the politics of AIDS which combines the perspective of medical science with a defence of President Mbeki's 'political logics'. The book is aimed at a North Atlantic audience and its reception by South Africans has been rather critical, not least for what is sometimes taken as a relativist apologia for Mbeki's denialism.

Robert Thornton is an American who moved to Uganda when he was young and has since settled in South Africa. He has carried out extensive ethnographic research there, but the method of *Unimagined community* is strikingly different. Uganda was once in the forefront of the epidemic, but the infection rate fell dramatically in the 1990s. HIV/AIDS took off later in South Africa and has since continued to grow unchecked. Thornton's model is Durkheim's *Suicide* (1895), a virtuoso demonstration of isolating the influence of social structure on the most intimate decisions. HIV infection is a property of invisible sexual networks and a sustained attack on the epidemic must be directed at these, not just at treating individual cases. He argues that, for all its racial ideology, South Africa's sexual networks are unusually open, less segregated in practice than his original Chicago home. Uganda's corporate kinship system, on the other hand, was mobilized to create barriers against the spread of infection. Thornton is seathing of the Mbeki government's anti-scientism, preferring to emphasize social prevention rather than antiretroviral treatment. He makes interesting use of mathematical arguments in what is certainly a heterodox approach for an anthropologist.

Ida Susser started out in South Africa as the child of activist doctors who soon left the country, first for Britain and then the United States. She has carried out ethnographic research in Durban and Namibia, but her dominant method in *AIDS, sex, and culture* is historical. This extends from a full account of her own life history to global politics, ranging from apartheid, through gender to neo-liberalism. This focus on historical narrative is matched by her self-identification as an activist, concerned above all with how social movements advance the interests of people on the ground. She contrasts the ideological focus of religious and traditional groups on issues such as 'abstinence' and 'virginity' with the practical rationality of infected women, aided in their strug-

gles by 'organic intellectuals'. The result is wide-ranging and informative, as well as partisan.

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Anthropologists still have a lot to learn about writing for the general public and none of these books can match the style and impact of the South African writer Jonny Steinberg's *Three letter plague*. The relative emphasis on local ethnography, national politics and world history varies considerably between these books. Thornton's is the most self-consciously scientific approach, with less apparent moral and political commitment. Much writing about South Africa abstracts from the wider world, which cannot be said of these books. Yet none of them gives a convincing account of South Africa's changing social structure after apartheid, and the questions concerning entrenched inequality there and more generally should be pushing anthropologists to take an even broader historical perspective than is in evidence here. The question of South Africa's relationship to the rest of Africa needs to be addressed urgently. It is a question that Thabo Mbeki cannot be said to have neglected. Yet the tradition of regarding South Africa as a rather introverted outpost of metropolitan civilization detached from the surrounding region remains strong.

For all the ravages of AIDS, Africa still has by far the highest population growth rate of any major region. The latest projections forecast an African population in 2050 of 1.8 billion, or a quarter of humanity. The Asian manufacturers have already woken up to the implications of this development, but in Europe and America, Africa still features largely as the playground of the four horsemen of the apocalypse, not as a significant player in the world market. South Africa, as the only African country to have made the transition to national capitalism, in however flawed and partial a form, is bound to play a strategic role in the continent's future development, along with other countries like China, India, the United States and France.

It is hard to imagine a more hectic and contradictory social history than South Africa's last two decades. The overall picture there can be heartbreaking, but there is still a lot to play for too, and the outcome will have serious consequences for the world as a whole. South Africa has long been a major crucible of innovation in anthropology, reflecting its pivotal role in world history. Some of its seions, such as the Comaroffs and Adam Kuper, sustain that tradition today, but this living symbol of our divided humanity poses challenges to anthropologists that remain to be overcome. ●

The author wishes to acknowledge his debt to a long-term collaboration with Vishnu Padayachee. Their joint publications include: Indian businessmen in South Africa after apartheid: New and old trajectories, *Comparative Studies in Society and History* 42(4): 683-712 (2000) and South Africa in Africa: From national capitalism to regional integration, in Padayachee, V. (ed.), *The political economy of Africa*, pp. 410-427 (London: Routledge, 2010).

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I suspect that I was one of rather few people who watched the movie *Avatar* and thought, 'How did they acquire those DNA samples from the Na'vi that allowed them to make that synthetic body?'

Standard operating procedures for the procurement and disposition of blood samples from indigenous peoples have been coming under increased scrutiny since the public debates about the Human Genome Diversity Project (HGDP) in the 1990s.<sup>1</sup> Conceived by population geneticists in the wake of the success of the biomedically-oriented Human Genome Project, the HGDP invoked hoary tropes of salvage anthropology and 'purity' to drum up support in the scientific community for the large-scale collection of the blood of Native peoples. Unfortunately, it was proposed at the beginning of a new era for US anthropologists, of heightened sensibilities on relevant issues such as indigenous property rights, enacted in the Native American Graves Protection

and Repatriation Act (NAGPRA) of 1990. While the HGDP managed to control the scientific discourse for several years, and dismiss any challenges to it as coming from the dark realm of anti-science, it was ultimately deemed unworkable because of its failure to grapple with the bioethical questions it raised – about consent, disclosure, coercion, identity, economics and race. (The Genographic Project, begun in 2005, simply circumvented those issues by having private funding in place at the outset.<sup>2</sup>)

The HGDP has already been analysed from several directions by cultural historians. The last couple of years have also seen the publication of important full-length works on related, and highly pertinent, subjects. Warwick Anderson's *The collectors of lost souls: Turning scientists into whitemen* (2008) documents not just the life and career of the charismatic, tragic Nobel laureate Carleton Gajdusek but also the circulation of New Guinean blood samples as commodi-

## Science, samples and people

Guest editorial by Jonathan Marks

ties around scientific laboratories, not unlike *kula* shells. Rebecca Skloot's *The immortal life of Henrietta Lacks* (2010) has received a good deal of attention for its meticulous and sensitive discussion of the family and the woman (poor, uneducated, black) whose body produced the HeLa cells from which 99 per cent of our knowledge of human micro-biology is derived. Both of these books have helped to fuel a growing popular consciousness that interrogates, in the era of free-market genomics and biotechnology, whether the science of human cells and genes is really there to fulfil the Baconian promise of a better life for all, or whether it is principally just serving the ends of scientists and shareholders.

In spite of the biomedical knowledge that the study of Indian bones has helped to produce, the passage of NAGPRA served notice that the activity of scientists incurs responsibilities to the other people who help it to progress. Indeed, it could be argued that the major biomedical advance of the 20th century was neither antibiotics nor genomics, but rather the recognition that progress in science is great, but when it comes into conflict with human rights, human rights wins, hands down. The nature of those rights and what constitutes a violation of them are necessarily evolving subjects, but if science is to flourish, it must do so in the context of public ideas about what is fair, decent and appropriate. The scholar who seeks or uses science for self-aggrandizement or baser purposes – the amoral actor – has been a resonant target of suspicion from Christopher Marlowe's Doctor Faustus, through Mary Shelley's Dr Frankenstein, and up to *Jurassic Park*'s John Hammond (who isn't himself a scientist, but who, even more insidiously, knows that he can buy the science he wants).

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On 21 April of this year, a resolution was announced in a legal case that touches on all of these issues. In the early 1990s the Havasupai, an impoverished Indian tribe who live in northern Arizona at the base of the Grand Canyon, were approached by geneticists from Arizona State University (ASU) to give blood samples. They understood that the samples were to be used to help find a cure for diabetes, which afflicts them (and many other Native American groups) terribly. The consent form that some of them signed mentioned that it was to 'study the causes of behavioral/medical disorders'. Most gave oral consent, however, understanding unambiguously that they were participating in diabetes research.

In 2003 a member of the Havasupai tribe was enrolled at Arizona State, and serendipitously learned that the samples that had been given for diabetes research were also being used in schizophrenia, inbreeding, and population history studies, without the knowledge or conscious consent of the participants. Not only were the blood samples (obviously a highly sacred substance) being used in ways the participants had not been apprised of, but far from helping to cure diabetes, they were being used to cast the tribe in what seemed to them to be a very unflattering light – that is to say, as inbred schizophrenics. Moreover, the population history research contradicted the tribe's idea of their own autochthonous origin. Had they known all this, they would not have consented to have the blood taken, and in 2004 they filed a \$50-million lawsuit against Arizona State University.<sup>3</sup>

The case followed a tortuous path over the ensuing years. The university spent \$1.7 million on fighting it, and initially managed to get it dismissed. The tribe persisted, however, and in 2008 the Arizona Court of Appeals overturned the lower court's dismissal. The university soon decided to settle out of court, and eventually negotiated a settlement with the Havasupai and their lawyers (and the team of bioethicists and legal scholars assisting the tribe *pro bono*). The settlement includes a cash payment of \$700,000 and return of

the samples. More significantly, perhaps are the provisions for collaborations between the Arizona Board of Regents (ABOR) and the Havasupai people in areas such as health, education, economic development, and engineering planning. For example, the Havasupai will collaborate with ASU, the largest public research university in the United States, to seek third party funding to build a new health clinic and a high school. Havasupai Tribal Members will also be eligible for scholarships at ASU, the University of Arizona and Northern Arizona University.

The principal investigator in the original research, Therese Markow, has long since left Arizona State. But she was simply following a standing tradition in the collection of blood as a scientific object from Native bodies. The rules have always been: say whatever it takes to get the sample, and once it is out of the Native's circulatory system, it is yours – that is, er, science's.

This is, in large measure, what sank the Diversity Project. Granted, there have always been many scientists – especially human biologists – who have developed sound, honest relationships with the people they work with. But the obligations on the part of the researcher to the people have rarely, if ever, been made explicit; the transaction has traditionally been governed by 'gentleman's agreement' – with the scientist as gentleman, and a reliance on his or her good will. But this is precisely the unidirectional relationship that the HGDP inadvertently began to call into question a decade and a half ago, and its weakness has been magnified by the increasingly commodified value of exotic DNA samples for biotechnology and genomics.

Since the Havasupai case was settled out of court, it does not constitute a formal legal precedent. However, it does provide an informal bioethical guideline for future cases to consult. This particular case afforded (1) sympathetic victims, (2) indisputable evidence that they were misled about the studies they were participating in, and (3) a university anxious about its image vis-à-vis Native Americans. Other blood repatriation scenarios are unlikely to have quite that convergence of features. Consequently, we are probably no more likely to see a mass raid on population genetics laboratories any time soon than we are to see the Elgin Marbles in Athens.

Nevertheless, Yanomamo genetic samples collected by James Neel about half a century ago remain in University Park, Pennsylvania, controlled by the geneticists, not by the Yanomamo – a situation whose propriety is indeed being contested. Introductory anthropology classes these days sometimes even incorporate a class project, to draft a letter requesting their repatriation.<sup>4</sup>

There has also been a backlash to the Havasupai case, with some predictably paranoid accusations of mass 'anti-science' attitudes among the Indians and their sympathizers. What links these various examples together, however, is the question of just how the progress of science could actually be held back by scientists being honest, generous and respectful towards participants. It's the behaviour we would expect of any social actor. Why should scientists be exempt?<sup>5</sup> ●

The Editor has contacted the Arizona Board of Regents (ABOR), who requested inclusion of the following statement: 'ABOR and ASU have formally apologized to the Havasupai people, and the Tribe has acknowledged that great efforts have been made to improve the oversight and conduct of human subject and biomedical research at ASU as a result of the lawsuit. Ernest Calderón, President of the Arizona Board of Regents, said that "The Board of Regents has long wanted to remedy the wrong that was done. This solution is not simply the end of a dispute but is also the beginning of a partnership between the universities, principally ASU, and the Tribe."'

The Editor has contacted Mr Robert A. Rosette, the Attorney representing the Havasupai in this legal case, who requested inclusion of the following statement: 'This is much more than a settlement. It is a victory for the Tribe. This is an opportunity to partner with the largest research institution in the United States to create programs which will help the Tribe build a stronger sovereign nation.'

Professor Therese Markow has been offered a right of reply.

1. See Schroeder et al. (2006), Marks and Harry (2006).
  2. On the Genographic Project, see Wald (2008) and Hollowell and Nicholas (2009).
  3. The details of the Havasupai case are taken from Dalton (2004), Beard (2006), Collom (2007), Capriccioso (2009, 2010) and Harmon (2010).
  4. Glenn (2006); see also <http://www.publicanthropology.org/Yanomami/09-Spring/background.htm>
  5. Thanks to Pilar Ossorio and Kimberly TallBear for their comments.
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