

# Human subjects in Chinese ethnic biobanks

China's ethnic minorities – *minzu* people – are intensively marketed as torchbearers of the country's human diversity. Yunnan has been designated as the exemplary province of biodiversity and human diversity alike. Tourist images of 'pure' and 'unspoiled' indigenous peoples are iconised in the state category of 55 nationality groupings. The imagery of colourful ethnic minorities in traditional dress, perceived as different from the rest of the society, has been adapted in the medical institutes of Yunnan to research activities regarding human variation.

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in the Mosuo language; the possible communication problems 'should not cause a problem'. The process of collection, according to Dr. Li, is less important than the eventual use to which these genetic samples are put.

## Research results 'not for common people'

Yunnan Laboratories (the *Laboratory*) has a significant collection of ethnic DNA, representing a major part of the ethnic diversity of the Chinese population. A person in charge of sampling work at the institute explained that there are no logistical problems during the sampling, because all the arrangements are made before the group enters the field site, leaving the *Laboratory's* researchers free to collect the samples. The lower-level hospitals are required to assist the lab researchers with the arrangements and establishing local contacts. Although the common language used during the sampling is standard Chinese, *Putonghua*, on the whole it is the minority representatives who deal with further communications with the locals.

At another meeting, I asked about the sampling protocols. When I pushed for answers, I received a better idea about the research circumstances in rural China. In the researchers' words, there is a contradiction between 'our' scientific worldview and 'their' (that of the ethnic minorities) traditional worldview, which has resulted in an overall difference in thinking. Nevertheless, these young researchers seemed to be genuinely concerned about how to build mutual understanding over the sampling, the research results, and communication between the academic community and communities being investigated.

health professionals, but there were no geneticists among them. When local hospital representatives were asked to explain the intentions of the genetic sampling implemented by their staff, they could only state that it was for 'scientific purposes'. And, because the biocollectors did not know the reason why DNA samples were collected, they were unable to inform research subjects about the purposes of the project.

## Discussing genetic issues

In the selected medical institutions in Southwest China chosen as part of this study it was not common practice to discuss genetic issues with sample populations. In addition, geneticists were not eager to educate the public about socio-biological issues. It emerged that it was important to carry out the sampling quickly and to waste no time in the field after the samples had been collected, as there is a rush to deliver the live samples to institutional facilities in Kunming. Due to this arrangement, it was explained, there was no time available to educate the research subjects or the local-level health professionals about the aims and objectives of the research project. There have been studies with different arguments about the reasons for not returning research results to the sampled populations. One view holds that it is never necessary to return results to subjects, as this is not the investigators' first priority. Another view holds that it would be too time-consuming and expensive to contact research subjects, and that this cost may even inhibit important research. This argument considers the research as more important than new genetic knowledge for individuals (Eriksson 2004:47–48). However, sound language and comprehension issues are cornerstones in taking informed consent, a standard international requirement in population sampling. Every time human variation intervention is conducted with a complicated research agenda, it is important to clearly communicate the plans and objectives to the community members in question. Individuals looking for additional clarification then have an opportunity to ask questions (Rotimi et al. 2007). 'Misunderstandings' in human variation research may occur because of the inappropriate appearance of people's participation in research (Dixon-Woods et al. 2007). The question, of course, is how to discuss genetic issues with the public. The increase in the public's involvement and the development of 'genetic literacy' (Collins & McKusick 2001) are some of the prerequisites for a sound understanding of genetic technologies and their applications.

IN EARLY 2006, the Chinese Ministry of Health announced that a database consisting of all Chinese ethnic groups had been established in Yunnan (People's Daily 2006). The headlines boasted of the 'world's largest ethnic biobank'. A biobank is a general term for a repository of biological material. Biobanks can be classified by a range of characteristics, including: objective, ownership (e.g. a university, a company), sample group, and size of the collection. Large-scale national and regional population biobanks collect data from the population of a given region or nation. Participants in the biobanks represent the population as a whole. But because beliefs about the uses of blood and tissue vary among ethnic cultures, the utilisation and storing of biological material in large population biobanks is highly sensitive and a great responsibility for the accountable institution.

## Constraints, communication and sampling

I was familiar with Southwest University (*Southwest*)<sup>1</sup> prior to my field research. I found it easiest to form contacts through official channels. The foreign affairs office of the institute introduced me to geneticists and laboratory personnel working in the field. I met two people at the Biology Faculty working on the biobanking of ethnic minorities. They focused on genetic susceptibility studies of certain genetic illnesses prevalent in the region among ethnic groups in Southern Yunnan.

Dr. Li disclosed that, together with his students, he has undertaken sampling in three villages in Southern Yunnan. The base for these operations is a prefectural centre. Considering the transportation of the samples to laboratories in Kunming, the prefecture is a convenient place: direct air routes link the city with Kunming allowing blood samples to be transported within a few hours from the sampled village to the repository at *Southwest*. Dr. Li explained that county hospitals assist with the practical matters of the sampling. However, *Southwest* has neither the capacity nor the resources to carry through the entire sampling process. After collecting the samples, 'electronic' versions are sent to genomics companies in coastal China. After analysis, the processed data are sent back to Kunming.

As there are always time constraints involved in the sampling activities, I was told that so far there had been no time to carry out a survey on the socio-cultural aspects of their projects. Apparently, Yunnan's Mosuo *minzu* represents an ideal minority population for ethnic sampling: it is seen as a homogenous community, has a compact size, and has identifiable records of ancestry. 'Mosuos are 'very special' (*feichang tebie*),' said Dr. Li, who is fairly certain that he could understand the Mosuo people when they spoke in *Putonghua*, standard Chinese, rather than

ABOVE: Mosuo woman near Lugu Lake, Yunnan.  
BELOW: cheek cells DNA

When I asked how their research and its results could eventually reach local populations, the researchers were sceptical about whether anything they publish would interest their sample population. One researcher said:

*"The results will be for small audiences, not for the common people. It would be very unlikely that results end up in public forums, such as local newspapers, educational material, or in another type of media. What researchers do has scientific relevance and is not interesting to the masses of the people".* (Interview at Yunnan Laboratories, March 2007)

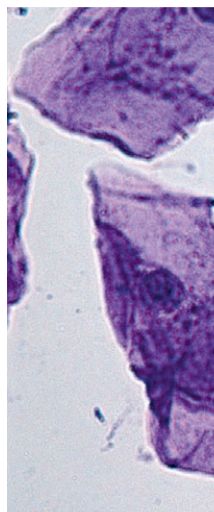
It was not regarded as necessary to educate the population being researched about genetic issues or the research results and the implications for their lives.

## 'Some ethnic groups are easy to handle'

Xishuangbanna, populated predominantly by Dai ethnic minorities in the southernmost part of Yunnan Province, is regarded as an ideal site to study Chinese minority populations because of its ethnic diversity. Mountainous topography, isolation, and its distant position have reinforced the belief about its genetically 'unique' populations. I was given permission to conduct interviews in the Banna Hospital (*Banna*) and in the Jiuoshan Clinic (*the Clinic*), both of which have participated in a regional human variation programme. In *Banna* it was suggested to me that I plan my own genetic research operation, even though it was not my intention to be personally involved in DNA data-gathering. It was stressed by the hospital staff that, as long as the permission from a minority cadre was granted, it was possible to carry forward any type of genetic research, notwithstanding the views of the community in question. It was explained that some ethnic groups are easier to 'handle' than others, and that this had an influence on the success of the genetic interventions. Possible difficulties in research subjects' cooperation with human variation researchers were associated with a 'low level of education among the ethnic and rural research subjects'. Apparently, they do not correctly understand the aims and intentions of the biobankers.

I was also granted a visit to the *Clinic*. In this medical facility, it was unclear what the various ethnic biobanking programmes being implemented in their district were about. Furthermore, the programmes were planned and administered outside their district, from the prefectural hospital. The *Clinic* was not aware of the objectives or plans of the various genetic interventions. The duty of *Clinic* personnel was simply to implement the sampling. The staff at *Banna* consisted of medical doctors and

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This study shows the closed nature of genetic information in the chosen medical institutes of Yunnan province, and that research subjects and the general public have little or no access to genetic and medical knowledge. Biological samples as well as genetic knowledge are kept behind closed doors in the medical institutions of the provincial capital, and research results are published in scientific journals which are out of the reach of ordinary people. My research showed that the reason why the human variation projects studied have not been under local discussion at any stage is that this type of research is simply not accessible to non-specialists. Furthermore, there appears to be no shared understanding of what the programmes are about and who is benefiting from them - be it the human variation researchers, on the one hand, or the officials executing sampling programmes, on the other. Medical doctors in regional hospitals have a first say in decisions about possible sampling interventions. Ethnic cadres come second in the hierarchy but they often have no alternative but to comply with the decisions made higher above. The extent to which health conditions of the sampling population are taken into account remains unclear.

The article is based on the author's ten months of ethnographic research in Yunnan, PRC, during 2006–2007.

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## Notes

1. Names of persons and institutions have been changed to protect the informants.

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