

Public Perceptions of Biobanks in China: A Focus Group Study

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During the past decade, biobanks have been the focus of broad attention due to their potential value for scientific research and public health. China has recently made a significant investment in biobank research. Public attitudes towards biobank issues such as consent and privacy are key factors in their development. A number of studies about the public perception of biobanks in Western countries have been conducted, but little is known about the public perception of biobanks in China. This study shows that the public perception of medical research (e.g., with biobanks) is undergoing fundamental transformation in China that is yet to be acknowledged by the public authorities.

Introduction

RECENT YEARS HAVE WITNESSED a boom in biobanking in China.^{1–4} Biobanks are repositories of human biological samples and the data associated with them. Since the nineteenth century, researchers, pathologists, clinicians, and law enforcement officers, among others, have been collecting various kinds of biological samples (e.g., blood, tissue, and cells) to be used in different domains (e.g., judiciary, clinical settings, scientific laboratories, and commercial markets). However, it was only when large population-based studies were initiated two decades ago that biobanks began to gain significant attention and interest all over the world.⁵

The creation and operation of biobanks depends on addressing a series of technical, ethical, and societal issues including privacy concerns, informed consent, benefit sharing, and commercialization.⁶ There is agreement in the literature that overall the positive public perception of biobanks in Western countries is a key factor in their development. Public perception and expectations are essential because biobank research requires the recruitment of a large number of participants who also consent to the utilization of their personal information, such as lifestyle data and health records, for research purposes. This is a challenge for biobank research in Western countries as well as in China. Numerous studies about the public perceptions of biobanks in Western countries have been conducted.^{7–9} However, except for one study on the attitudes of Chinese patients and the general public regarding consent for storage and use of leftover bio-samples,¹⁰ nothing is known about what Chinese people think about biobanks. Our goal was to explore the Chinese

public's perceptions of biobanks, drawing on empirical material from focus groups.

Methods

A key challenge for our research was to study the public perception of biobanks in a country with more than 1.3 billion inhabitants and dozens of ethnic groups. In our research we assumed that “public” is not the sum of all the individuals within a certain geographical or political area. We considered “public” not as something given or pre-existing but as something emerging around issues and thus to be studied in the context of these issues and concerns.^{11,12}

Based on this theoretical point of departure, in May, 2010, we conducted six focus groups in Hangzhou and Wenling, two cities of Zhejiang Province, Southeast China. Focus groups offer a qualitative method of data collection that concentrates on group interaction on topics posed by a moderator.¹³ Such groups can be seen as a forum for generating public discourse rather than uncovering the “real views” of participants.¹⁴ Instead of aiming at representative evidence about opinions, we provided knowledge about typical ways of addressing certain issues in the realm of biobanking and how they are put into context in discourse.

We also assumed that education plays a key role in the public perception of biobanks.¹⁵ Considering that many citizens in China lack scientific literacy and education,^{16,17} our study differentiated between people with high and low education. We categorized those who had not finished high school as low-educated public; the higher-educated public consisted of those who had at least completed high school. In

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China, the average education level of the public in urban areas and large cities is considerably higher than that in rural areas and small cities, so the differentiation between low- and higher-educated Chinese public could also help explain rural and urban distinctions in the public perception of biobanks.

Each focus group consisted of ten participants (five males and five females) with a range of backgrounds. The 60 total participants ranged in age from 18 to 73 years old with an average of 39 years of age. The participants of focus group 1 (FG 1) were university students in Hangzhou including undergraduate, graduate, and postgraduate students with various majors. The participants of focus group 3 (FG 3, in Hangzhou) and focus group 5 (FG 5, in Wenling) were members of the public with low education. The participants of focus groups 2 and 4 (FG 2 and FG 4, both in Hangzhou), and focus group 6 (FG 6, in Wenling) were a mixed general public with both low and higher education. The participants in Hangzhou were from different cities around China, but all currently lived in Hangzhou, while those in Wenling were both born, and still live, in that city.

We did not have the expectation that the Chinese would be especially knowledgeable about biobanks, which constituted another methodological challenge. As we know, even in Western countries, most people have little knowledge of biobanks.¹⁷ Therefore, we gradually introduced participants to the topic and led them to narrate their issues out of their own life experiences. Our aim was to provide information in such a way that people could form their own opinions about biobanks. However, for comparability reasons, the focus groups were semi-structured by use of a standardized script, which contained open-ended questions on the following eight topics: 1) The definition of biobanks; 2) Reasons for and against participation; 3) Privacy and data linkage; 4) Informed consent; 5) Benefit sharing; 6) Commercialization; 7) Internationalization; and 8) Governance and appropriate legal-political structures. These topics cover key ethical-societal issues in the field of biobanking.^{19,20}

In a short questionnaire distributed at the beginning of the focus group discussion, participants used a five-point Likert scale ("not at all," "hardly," "50-50," "most of it," "all") to indicate the extent to which they were familiar with biobank research. Each focus group discussion lasted approximately 150 minutes and was audiotaped. All of the discussions were transcribed in Chinese and then translated into English. A structured content analysis was applied.²¹ A comparable and in-depth interpretive analysis was performed.²² All analysis steps were conducted using the computer software Atlas.ti. A coding structure was created both deductively and inductively and was continuously adapted.

Results

Results of the questionnaire show that all participants had very little knowledge of biobanks. For the biobank familiarity question, the majority responded with "not at all" (33 out of 60 participants) and "hardly" (19 out of 60 participants).

Results of the focus group discussion were divided into four main themes: (1) privacy, (2) informed consent, (3) benefit-sharing and commercialization, and (4) internationalization, and are described below using quotations from the transcripts.

Privacy

Concerns about privacy violations differed considerably between the higher and lower education groups. After participants had finished reading the standardized script and acquired a baseline knowledge about biobanks, we asked them to write down their first impression of one positive and one negative aspect of biobanks. For the university students (FG 1), the first association of negative aspects of biobank research was related to leaks in privacy. For the three mixed focus groups (FGs 2, 4, and 6), 11 of 30 participants thought critically of privacy issues right away, but no one in the two low-education groups (FGs 3 and 5) mentioned privacy issues as a problem. Later, in the discussion of privacy, when the moderator asked participants whether they were concerned that their biological material would be connected with their personal information, the majority of the participants of FGs 1–4 and FG 6 became concerned; but none of the FG 5 participants were concerned. As one participant said:

Take me as an example. If my information was announced on the Internet, I wouldn't be scared. Why should I be scared? It doesn't matter. If someone reveals my name and my ID number online, I won't be scared. We are all decent people. There's nothing to be worried about. (FG 5)

The people who expressed concerns about privacy mainly cited personal examples in which their personal information had been leaked, and also cited the media and science fiction films, in which digital data were assaulted by hackers. Several individuals expressed a fear about being re-contacted for commercial or other interests:

We often receive these harassing calls. We don't know who releases the information. Maybe one day while you have high blood pressure, you will receive calls to sell health medicine, that sort of thing. (FG 2)

Informed consent

People from Western countries are typically very reluctant to provide broad consent for biobank research.²³ In contrast, most of the Chinese study participants expressed hypothetical agreement to future research usage of their samples. In our study, we explained to participants the meaning of different types of informed consent, such as blanket consent (samples can be used for all purposes including commercial and research uses), broad consent (consent is given for medical research on all diseases), specific consent one (research can only be done for one particular disease, such as cancer or diabetes), and specific consent two (research can only be done for a particular study, e.g., a cancer study). Participants were then asked which type of informed consent they would choose. Our data reveal that the participants tended to be relatively positive about consenting to biobank research. Nine out of 60 participants chose blanket consent, and 39 of 60 participants chose broad consent. Ten of 60 participants chose specific consent one (disease-specific), and only two participants chose specific consent two (study-specific). Their preferences of broad consent were mainly to support the development of scientific research. The following views represent the majority of participants.

What we provide is only a sample. We think it is not very easy [to gain samples]. If one sample could have many uses, if I provide one sample [for all sorts of biobanking research], it could have more uses. I choose broad consent for the sake of scientific research. (FG 2)

Although they were willing to contribute samples as much as they could, if they knew it was to be used for other purposes, or if it could lead to some results that they didn't expect, all participants stated they would withdraw from the biobank projects. For those who chose specific consent, or those who preferred consent for each new research project, their main concern was that something could change in the process, and they wanted to be in control and to be well-informed about how their samples would be used in the future.

Benefit-sharing and commercialization

We found that the majority of participants did not expect financial compensation except for basic travel expenses if the biobank was far from where they lived, but almost all wanted to have feedback from their physical examination results, regardless of whether such results were positive or negative.

In China, economic growth and healthcare reform have not yet resulted in equitable healthcare protection, and individual Chinese citizens still have to pay for their own healthcare. Inflation in the cost of medical services has made healthcare difficult to afford even for the educated Chinese from urban coastal regions.²⁴ Focus group participants in both the lower- and higher- education categories therefore hoped to find out their health status, such as blood pressure and heart rate, and whether they had any diseases, through participation in biobank studies, and regarded it as part of a fair collaboration.

For us, the most ordinary citizens, actually we mainly want to reach this aim. We provide blood for biobanks, for the benefit of human beings. On the other hand, since I provide you with my information [for biobank research], you also need to give me some help, some benefits, is[n't] that right? (FG 6)

The participants also expected to receive individual results from analysis of their biobank specimens, and they hoped those results would guide their decisions about what they should not do and what they should not eat in their daily lives. If they learned that there was a problem with their blood pressure and heart rate, or if the physical examination revealed that they had a disease, they could then pay attention to their lifestyles and nutrition in the future, and seek timely treatment.

In terms of commercialization, the majority of participants perceived commercial cooperation for drug development as a positive outcome, but commercial profit, namely, making profit out of biosamples, as a negative outcome. Some participants realized that it is impossible to separate commercialization from commercial profits. The reasons against commercialization were typically rooted in concerns about uneven distribution and the exploitation of donors. As one participant expressed:

There surely will be cooperation between scientific research and commerce. The results must be industrialized, and applied research must be industrialized. Actually, the current key issue is still whether we trust it or not, whether there are some illegal activities in the process, whether some people do it for their own interest, whether it is very normative. If, as he [R2] said, we make contributions to your scientific research selflessly, but you use it to make big profits in the end, we will be badly affected. (FG 4)

Hence, some participants rejected the idea of cooperation with the private sector per se, as they understood that their

research results might then become uncontrollable. They expressed fears in this context, without pointing out concrete scenarios:

I feel it difficult to control stuff like commercialization. Once it is related to commercialization, everybody will go for profits. For example, drug development is of course good, but it's difficult for me to think of commercialization in a good way. (FG 1)

Internationalization

The internationalization of biobank research was welcomed by a majority of participants. They felt positive towards international cooperation with nations or regions like the United States and the European Union. At the same time, however, there was a strong desire for equal cooperation and clear regulations, rooted in fear about potential assaults and exploitation.

Internationalization is a trend. For scientific research, it also needs cooperation with one another, for example, some problems could only be solved by cooperation, but it needs some regulations. For example, what respondent 2 said makes sense: the extraction of genes may have protections in different nations. For example, [regarding] species, there should be some legislation in each country to protect species and something else similar. Some national protection is necessary. But there are premises for cooperation. If there are standards, cooperation can be healthier. (FG 4)

Drawing from historical experience with genetically modified food, biological warfare, and researchers from abroad buying and collecting blood samples from China, participants expressed their fears of being exploited and their skepticism of fairness in international cooperation.

We can do research together, but I don't agree that foreigners [should be allowed to] come to China to collect blood samples. I completely disagree with this.... Equal cooperation is fine. (FG 3)

Concerns associated with international research were often discussed in relation to the exchange of biological samples. Participants perceived these samples as very sensitive and having the potential to do harm to the Chinese people as a group via bio-piracy or bio-weapons; the Chinese therefore preferred that biological samples be kept within national borders.

After all, genes of every nation are different, for example, our DNA is different. After foreigners grasp it, if by any chance there are national conflicts or competitions, if biological weapons are used, you will be killed invisibly. (FG 6)

Linking Knowledge, Consent, and Trust

We found that the participants in the different focus groups had very little knowledge about biobanks. However, overall, 42 of the 60 participants showed willingness to participate and donate samples for research. Participants from the two groups with lower education (FGs 3 and 5) expressed more willingness to participate (18 of 20) than did the university students (FG 1) (only one in ten). Moreover, our study shows that even after gaining some basic knowledge about biobanks, half of the low-education groups didn't identify any negative aspects of biobanks. Our data suggest that younger people with higher education are least likely to participate, which is consistent with findings of other studies conducted in Sweden.^{25,26} Again, the Chinese groups with higher education were also much more critical of privacy issues in biobanking.

We found that more people preferred broad consent (39 of 60) and blanket consent (9 of 60) than preferred specific consent (12 of 60), and they also didn't want to be re-contacted repeatedly. However, when discussion turned to topics such as benefit sharing, commercialization, and internationalization, all participants, including those with lower education levels, were critical of common motives, commercial interests, and international cooperation. In fact, they stipulated that their participation in biobanks would not be unconditional, and they would expect some personal gains.

In her study of the Chinese public's attitudes towards biotechnology, Lü found that the Chinese public perceives that the national development of advanced biotechnology will improve their quality of life. It is the benefit of biotechnology applications that might prompt their increasing support.²⁷ Lü's research finding resonates with ours. The participants in our study expressed the view that the point of their participation was not only to support the national advancement of medicine, but also to have the opportunity for a thorough physical examination and follow-up consultation. Their motivation for participation was not only altruistic, but also linked to personal health needs. In contrast to the European welfare states in which people have better access to a healthcare system, China doesn't have a robust healthcare system that can meet the needs of every citizen. In particular, those from rural areas of China have poor healthcare access and do not undergo regular physical check-ups or basic medical treatment. In this sense, the public expects that participation in biobanks will give them access to healthcare.

The importance of trust in biobanks has been discussed in many studies.²⁸⁻³⁰ For the Chinese participants, trust in "authoritative institutions" is the basic precondition for their participation. As our respondents pointed out in the focus group discussions, they didn't trust advertisements, and some of them doubted the motives of insurance companies. Obviously, they had their own judgments about authoritative institutions. In fact, the phrase "authoritative institutions" arose repeatedly in each focus group. Here we also found a main difference between the younger educated group and the mixed lay public groups. Although the latter groups couldn't specify what these authoritative institutions were, they presumed these were institutions such as university research institutes and national hospitals. They expected authorities to guarantee that biobanks would be properly operated and regulated, and that the type of research would not go in the wrong direction of commercial involvement. This kind of expectation is similar to that in studies from Western countries.²⁰ In contrast to the mixed lay public groups, university students were more critical. They questioned state authorities and didn't trust university researchers, doctors, the government, or the police.

All 60 participants expressed concerns about commercialization and internationalization and a lack of trust in some researchers and institutions. In their narratives, the shadow of historical experiences, such as from the Chinese-Japanese War, when Japanese troops invaded China and conducted experiments with humans, as well as experiences with foreign researchers collecting Chinese blood samples and taking them outside of the country for research, remains an issue in China.³¹ They fear that samples could be used for private profit at the expense of the public good. These oft-repeated examples show how public perceptions are rooted in shared (national) experiences.

Conclusions

In this article we present findings about the public perceptions of biobanks in China. This study has its limitations, as it is a small-scale, exploratory study. However, our research provides a glimpse into a largely unknown and unexplored topic: the public perception of new medical technologies in China. Overall, the Chinese public we studied is supportive of scientific research with biobanks. Most interestingly, the data from the focus group discussions indicate that the public perceptions of biobanks in China are in many respects comparable to those in Western countries, which can be attributed to the rapid globalization and modernization taking place in China. In particular, the educated public appears to have preferences in the area of privacy protection that are very similar to their counterparts in Western countries. Thus, patients, or potential partners in research, are changing from displaying passive attitudes towards research to a more active pattern of having clear expectations about their involvement in medical research. With respect to the internationalization of biobank research, participants tended to be more concerned with exploitation by foreign researchers due to historical experiences. They expected that the biobank projects could be led by reliable authoritative institutions with a sound system of governance.

To follow the international trend of developing biobanks and to promote scientific research and public health, the local and central governments in China have recently put more effort into this field.³² However, less attention seems to have been paid to the transformation of the Chinese public from having a passive interest in biobank research to a more active interest. Although current biobanks in China have been successful in recruiting volunteers,¹⁻⁴ it is difficult to predict whether young and more educated Chinese would be as willing as older ones to participate in these projects in the future. Our study shows that the participation of the Chinese public in biobank research is not unconditional and that younger and more educated participants in these studies increasingly express clear expectations towards research.

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