



Public Perspectives on Genetic
Information:
Is there an essential difference
between China and the UK?

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- ↪ Rethinking on the differences between China and UK
- ↪ What differences make them essential
- ↪ Targeting the mechanism on promote public population's trust on donating genetic information



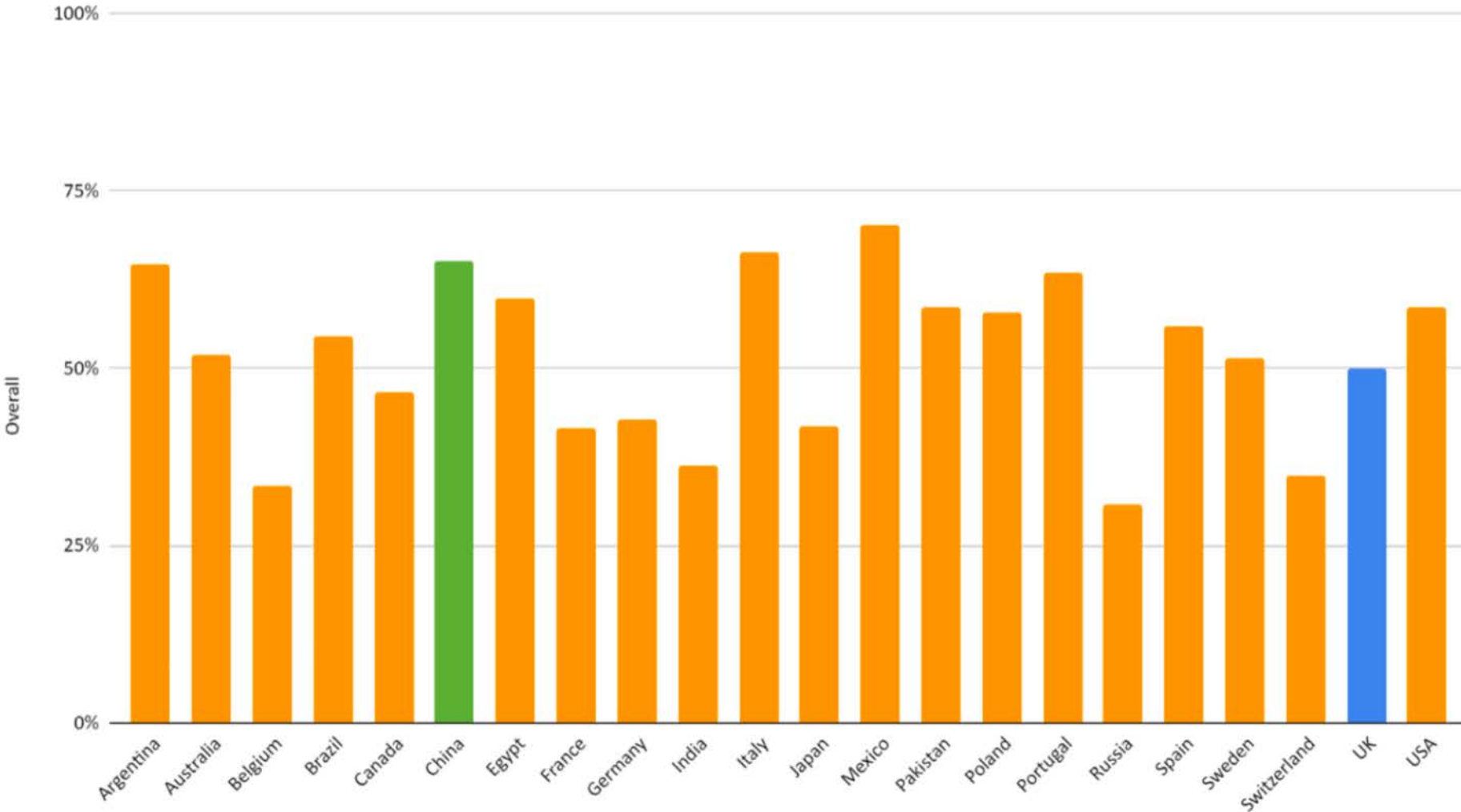
Based on joining the project+literatures

- ❧ Wong M L , Chia K S , Yam W M , et al. Willingness to donate blood samples for genetic research: a survey from a community in Singapore[J]. Clinical Genetics, 2004, 65(1).
- ❧ Kaufman D , Murphy J , Scott J , et al. Subjects matter: a survey of public opinions about a large genetic cohort study.[J]. Genetics in Medicine Official Journal of the American College of Medical Genetics, 2008, 10(11):831.
- ❧ Kettis-Lindblad A . Genetic research and donation of tissue samples to biobanks. What do potential sample donors in the Swedish general public think?. 2005.
- ❧ Yi M , Dai H L , Wang L M , et al. Consent for Use of Clinical Leftover Biosample: A Survey among Chinese Patients and the General Public[J]. PLoS ONE, 2012, 7(4):e36050-.
- ❧ E. Lownik,E. Riley,T. Konstenius,W. Riley,J. McCullough. Knowledge, attitudes and practices surveys of blood donation in developing countries[J]. Vox Sanguinis,2012,103(1):
- ❧ David E Lanfear,Philip G Jones,Sharon Cresci,Fengming Tang,Saif S Rathore,John A Spertus. Factors influencing patient willingness to participate in genetic research after a myocardial infarction[J]. Genome Medicine,2011,3(6):
- ❧ Domaradzki Jan,Pawlikowski Jakub. Public Attitudes toward Biobanking of Human Biological Material for Research Purposes: A Literature Review.[J]. International journal of environmental research and public health,2019,16(12):

- ❧ Middleton A, Niemiec E, Prainsack B, et al. 'Your DNA, Your Say': global survey gathering attitudes toward genomics: design, delivery and methods.[J]. Per Med, 2018, 15:pme-2018-0032-.
- ❧ S.-J. L S , Cho M K , Kraft S A , et al. "I don't want to be Henrietta Lacks": diverse patient perspectives on donating biospecimens for precision medicine research[J]. Genetics in Medicine, 2018, 21.
- ❧ 王娜, 王倩倩, 赵丹慧,等. 不同人群对生物样本库的认知状况及捐赠意愿调查[J]. 中华医院管理杂志, 2018, 34(011):947-952. (Wang N, Wang Q, Zhao D. Research on Cognition of Biobanks and Donation Willingness of Various Population.[J]. Chinese Journal of Hospital Administration, 2018, 34(011))
- ❧ Domaradzki J , Pawlikowski J . Public Attitudes toward Biobanking of Human Biological Material for Research Purposes: A Literature Review[J]. International Journal of Environmental Research and Public Health, 2019, 16(12):2209-.
- ❧ 蒋聪. 生物样本库相关知信行情况的公众调查[D]. 上海交通大学, 2015. (Jiang C. A Public Survey on Biobank-related Knowledge, Attitude/Belief and Practice (KAP). [D]. Shanghai Jiao Tong University, 2015)

More people in China (65%) than UK (50%) think DNA is different to other types of medical information – but both in top half of countries

"For Me DNA Information is Different to Other Medical Information"



Transparency, does matter

What would help trust?

Results (with India, Russia and USA for comparison)

| Measure | Overall | China | India | Russia | UK | USA |
|--|---------|-------|-------|--------|----|-----|
| Transparent information about WHO will benefit from the data access | 61 | 32 | 61 | 47 | 67 | 62 |
| The option to withdraw your information in the future | 54 | 39 | 46 | 49 | 61 | 51 |
| Knowing exactly who is using your information, and for what purpose | 53 | 46 | 40 | 62 | 53 | 45 |
| Transparent information about HOW others will benefit personally, professionally and commercially from the data access | 49 | 38 | 56 | 36 | 55 | 53 |
| The option to opt out of having your information accessed by other researchers | 45 | 51 | 42 | 37 | 54 | 44 |

Notice the characteristics among those willingness to donate to sepcific groups

Percentage of people who would generally be trusted with DNA and health information

| Country | Own doctor | Any doctor in country | Non-profit researcher in my country | Company researcher in my country | My government |
|----------------|------------|-----------------------|-------------------------------------|----------------------------------|---------------|
| China | 70.80 | 43.40 | 46.20 | 33.50 | 66.60 |
| United Kingdom | 77.40 | 46.90 | 33.00 | 9.70 | 16.40 |

Most trust in own doctor in both, and more trust in doctors and university researchers – but much more trust in company researchers and government in China than the UK



Reminds us: who will take key responsibility to keep trust

**Levels of willingness to donate DNA and health data higher in China,
particularly for for-profit research**

| | Donate for use by Dr | Donate for use by non-profit researcher | Donate for use by for-profit researcher |
|----------------|----------------------|---|---|
| China | 66% | 62% | 50% |
| United Kingdom | 49% | 42% | 23% |

Genetic research and donation of tissue samples to biobanks. What do potential sample donors in the Swedish general public think?
Asa Kettis-Lindblad, Lena Ring, Eva Viberth, Mats G. Hansson

✎ The public's willingness to contribute to genetic research is relatively high according to some American and Asian studies. **Characteristics of those in favour of donation include:**

- high age, higher education
- a positive family history of a genetic disorder,
- a belief that genetic research will benefit people,
- a willingness to participate in governmental research on health,
- a belief in genetic determinism,
- having no fear of blood, injections or needles,
- and non-concern about the loss of confidentiality



The willingness to donate tissue samples

When presented the linked scenario, a majority of the respondents (86.0%) would donate an extra blood sample for research purposes (figure 1). Some (18.7%) said that their decision would be influenced by whether the funding was public/independent or provided by private companies. However, the majority (68.2%) was indifferent to the financial source and would delegate this judgment to the research ethics committee, or was undecided (13.1%).

Of those who said no, or were undecided about donating in the linked scenario, about one-fourth would consent if the sample would be unlinked, i.e. anonymous (figure 1). This means that a total of 89.0% ($n = 2520/2830$) would provide a sample (linked/unlinked). As seen in figure 1, a vast majority of these potential donors also approved of their sample being stored for future research. Therefore, 78.4% (2220/2830) of the donors would agree to both donation and storage. Of the potential donors, 13.2% reported that there were types of samples that they would not donate. The most common examples were brain tissue, heart tissue, and germ cells.

The most common motives for donating a sample was for the benefit of future patients (89%) and for the benefit of 'myself or my family' (61%) (table 3). A sense of duty motivated one-third



Review

Public Attitudes toward Biobanking of Human Biological Material for Research Purposes: A Literature Review

Jan Domaradzki ^{1,*}  and Jakub Pawlikowski ^{2,3} 

3.3. Willingness to Donate

Better knowledge and positive opinions on biobanks correlate positively with respondents' willingness to donate. In a Pan-European study, only 10% of respondents who had never heard about biobanks would not donate [61]. For instance, in Scandinavian countries, where the knowledge about biobanks is highest, 83% of Finns and 86% of Swedes declared such willingness [26,35], while only 4% of Greeks did [8]. On the other hand, out of 67% of American respondents who lacked knowledge about biobanks, 69% would donate [43], and among Saudi students surveyed 89% would donate [47]. In other studies, this percentage oscillated between 41% and 81%, although sometimes 25% of respondents would decline [29,33,45]. In the UK, almost 75% of respondents agreed with donation while 18% did not [10]. In China, it was 65% and 29%, respectively [7], in Saudi Arabia 81% and 47% [36], and in Jordan 64% and 33% [40]. It should be emphasized once more that, due to significant cultural differences between various research groups, such comparisons are of limited relevance.



Consent for Use of Clinical Leftover Biosample: A Survey among Chinese Patients and the General Public

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Abstract

Background: Storage of leftover biosamples generates rich biobanks for future studies, saving time and money and limiting physical impact to sample donors.

Objective: To investigate the attitudes of Chinese patients and the general public on providing consent for storage and use of leftover biosamples.

Design, Setting and Participants: Cross-sectional surveys were conducted among randomly selected patients admitted to a Shanghai city hospital (n = 648) and members of the general public (n = 492) from May 2010 to July 2010.

Main Outcome Measures: Face-to-face interviews collected respondents-report of their willingness to donate residual biosample, trust in medical institutions, motivation for donation, concerns of donated sample use, expectations for research results return, and so on.

Results: The response rate was 83.0%. Of the respondents, 89.1% stated that they completely understood or understood most of questions. Willingness to donate residual sample was stated by 64.7%, of which 16.7% desired the option to withdraw their donations anytime afterwards. Only 42.3% of respondents stated they "trust" or "strongly trust" medical institutions, the attitude of trusting or strongly trusting medical institutions were significantly associated with willingness to donate in the general public group ($p < 0.05$) The overall assent rate for future research without specific consents was also low (12.1%). Hepatitis B virus carriers were significantly less willing than non-carriers to donate biosamples (32.1% vs. 64.7%, $p < 0.001$).

Conclusions: Low levels of public trust in medical institutions become serious obstacle for biosample donation and biobanking in China. Efforts to increase public understanding of human medical research and biosample usage and trust in the ethical purposes of biobanking are urgently needed. These efforts will be greatly advanced by the impending legislation on biobanking procedures and intent, and our results may help guide the structure of such law.

Two groups: hospital patients with diverse medical conditions and the general public. time: **May 2010 and June 2010** at the Shanghai Renji hospital

Trust in medical institutions

Only 42.3% of total respondents stated that they “trust” or “strongly trust” medical institutions to manage their donations properly (Figure 1a), while 43.9% of respondents stated “neutral” and 13.8% stated either “mistrust” or “strongly mistrust”. Respondents who chose “trust” or “strongly trust” were significantly more likely to have no concern about the biosample donation, as compared to those who chose “mistrust” or “strongly mistrust” (21.5% *vs.* 0.8%, $p < 0.001$). Only one respondent didn't trust medical institutions and chose the option “I have no concern about donation”. Given the choice of which type of institutions were most trustworthy to manage biosamples, the majority of respondents chose hospital research institutions (37.7%), followed closely by Chinese medical association (34.6%), and government institutions (30.3%). Only 4.7% of the total respondents chose management by ethics committee or IRB, and even fewer (2.0%) chose the for-profit company research institutions (Figure 1c). Patients were more likely to trust hospital research institutions ($p < 0.05$), while general people were more likely to trust government institutions ($p < 0.05$) (Figure 1c).

After adjusting for potentially confounding factors, the attitude of trusting medical institutions were significantly associated with willingness to donate in the general public group ($p < 0.05$) (Table 1).



Short Report

Willingness to donate blood samples for genetic research: a survey from a community in Singapore

Willingness to donate blood by sociodemographic and other variables

About 49.3% (95% CI, 45.1–53.5%) of the respondents were willing to donate blood specimens for genetic research, and 39.2% (95% CI, 35.1–43.3%) among them were willing to have their blood stored for future research. Among willing donors only, the majority (80.4%) were willing to have their blood stored for research.



Progress of medical treatment, benefits to society, future generation. need incentives.

Reasons for and against donating blood

The most common reasons reported for willingness to give blood were for medical advancement (81.9%), to benefit future generations (81.1%), and to create employment in life science research (40.4%). Reasons given by those who were unwilling to donate blood specimens were fear of pain, needles, injections, and blood (38.1%); no self-benefits (24.8%); fear of finding out that they have a disease (22.3%); and fear of discrimination by employers and insurance companies (18.7%). A small but significant proportion of respondents were concerned about adverse effects on their health such as becoming weak (15.1%) or gaining weight (9.4%) from giving blood specimens. As only half have heard about genetic testing before this survey, the reasons were analyzed after stratifying by their prior awareness of genetic testing to assess whether

it has an effect on their reported reasons. The two groups did not differ in their reasons except for the reason on discrimination. About 26.5% of those who had prior knowledge of genetic testing did not want to give blood because of the fear of discrimination compared to 13.3% ($p < 0.05$) of those without prior knowledge of genetic testing.

Incentives and preferences

About half (40.9%) of the unwilling donors reported their intention to give blood, if incentives were provided. Health-care-related incentives, such as free medical check-ups, and treatment as well as priority in receiving health care, were most preferred. Money was least preferred with less than 20% opting for this incentive. Significantly, more people would donate blood, if the research was conducted by the government (64.5%) compared to the university (47.4%) or a private organization (14.7%).

Discussion

About half of adult Singaporeans in the sample were willing to donate blood samples for genetic research. Willingness to give blood showed a significant independent association with those who **believed that genetic research would benefit people; who had intention to participate in government organized studies;** who were not afraid of pain, needles, injections, and blood; and who were not concerned about the loss of confidentiality. **The level of willingness in our study was much lower than that in the USA (7–9) and Europe (10), which reported levels from 60 to more than 90%.** It was also lower than that reported in a study among ethnic

Donate: no self-benefit. if need suffer?

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Factors influencing patient willingness to participate in genetic research after a myocardial infarction

David E Lanfear^{1*}, Philip G Jones², Sharon Cresci³, Fengming Tang², Saif S Rathore⁴ and John A Spertus²

Discussion

We sought to define characteristics associated with participation in a genetic sub-study of a large acute MI registry. We found that the vast majority of patients chose to participate in genetic testing (around 80%), with few differences between those who did and did not agree to donate DNA. Although we found race to be mildly associated with patients' willingness to participate in genetic studies, other factors such as gender and education level were not. Most importantly, the strongest predictor of participation in the genetic sub-study was hospital site, with wide variability seen in rates across sites.

Reduced genetic participation among racial minorities is a particularly critical issue since racial disparities in health outcomes are high-priority research topics, and the genetic versus non-genetic components of health disparities need to be better elucidated. Higher rates of participation in genetic studies among white patients, as compared with African Americans, have been previously described [4,7,8]. A lower likelihood of African

ance in the researchers being one important factor [17]. Similarly, trust is one of the most often cited mediating factors for participation in genetic studies [2], and this is also the case in studies specifically focusing upon racial differences in genetic research; patient concerns about confidentiality were a consistent reason for choosing not to participate [12,18]. In our study, African Americans were 7% less likely to participate than whites, a modest difference in participation rates. While further qualitative studies may help illuminate the mechanism, awareness of this potential selection bias is important during study enrollment so that under-representation of racial minorities can be minimized. Making every effort to establish trust and rapport with subjects, as well as confidence in the research team and their confidentiality protections, may help reduce refusal rates.

To our knowledge, the association of genetic consent with BMI has not been previously reported, and the magnitude of the association is of questionable clinical significance. Given the number of possible predictors included in this study, this association may be spurious.



Published in final edition
Genet Med. 2019.

"I Don't Want to be Henrietta Lacks": Diverse Patient Perspectives on Donating Biospecimens for Precision Medicine Research

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adult, men, white



some survey on genetic testing, about the disclosure the information to family members, and other stakeholders

Two other surveys
conducted in sole Chinese
context (in Chinese):

Shanghai:2014-2015
Beijing: 2017

Dissertation Submitted to Shanghai Jiao Tong University
for the Degree of Master

**Public Survey of Cognition, Attitude and Behavior towards
Biobanks**

| | |
|---------------------------------------|-------------------------------|
| Candidate: | Cong Jiang |
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| Cultivation Unit: | XinHua Hospital |

willingness less than 50 percent

significantly higher than the two populations ($p < 0.05$). The general public showed the lowest willingness on donation of samples; intentions to participate were significantly associated with the education level and experience of studies, other factors included religion, marital status and gender.

Cross-sectional survey. A total sample of 478 Chinese was surveyed via questionnaires between December 2014 and March 2015.

Results:

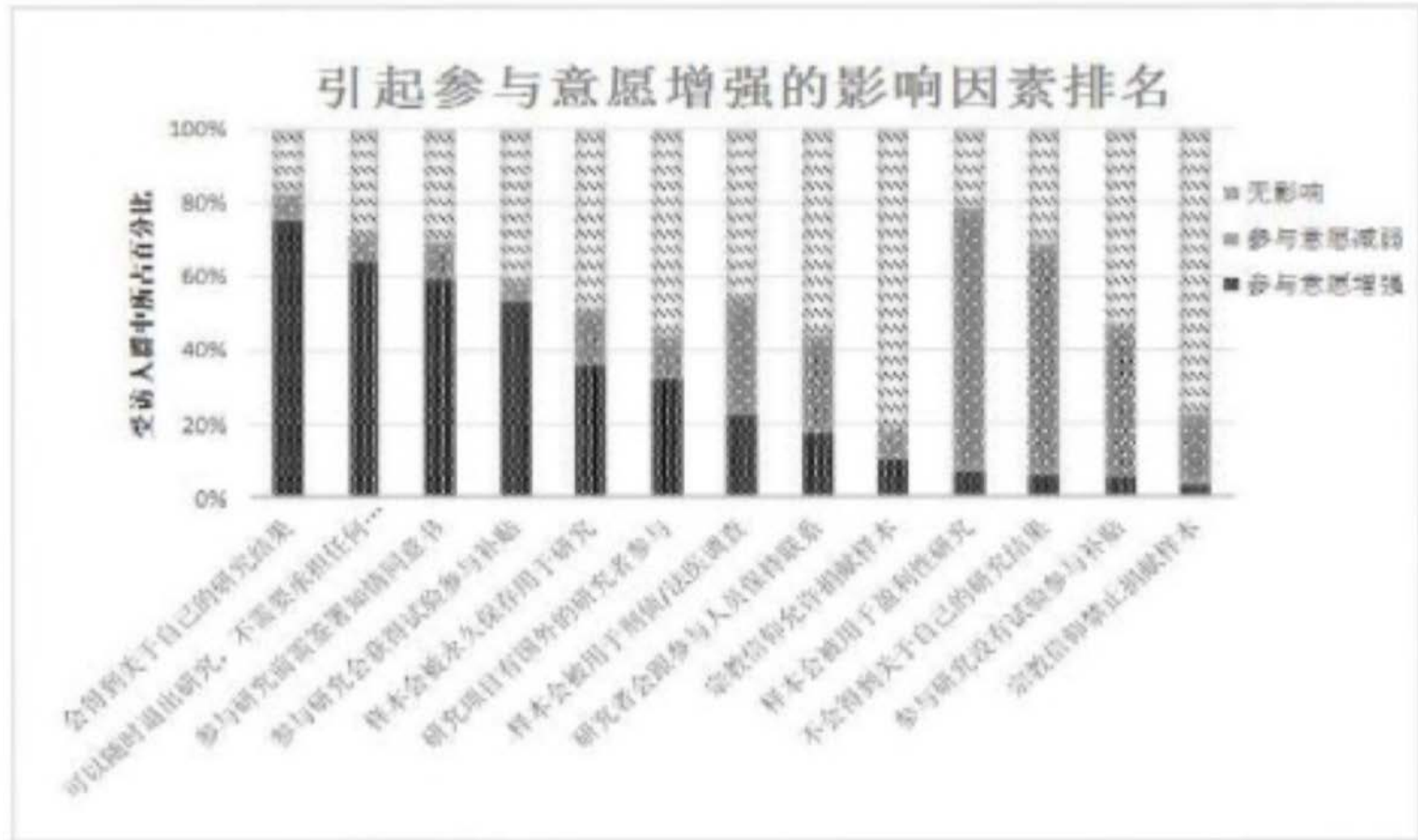
In the general public ($n=292$), only 51.0% had ever heard of the biobank; the willingness of participation was 46.2%, 55.7% and 75.6% in the three population, respectively; the willingness of administrators in medical institutions was significantly higher than the general public ($p < 0.05$); 66.8% of the general public agreed that the donation of samples was of high risk,

edge of biobank, educations regarding
rove the willingness to participate in

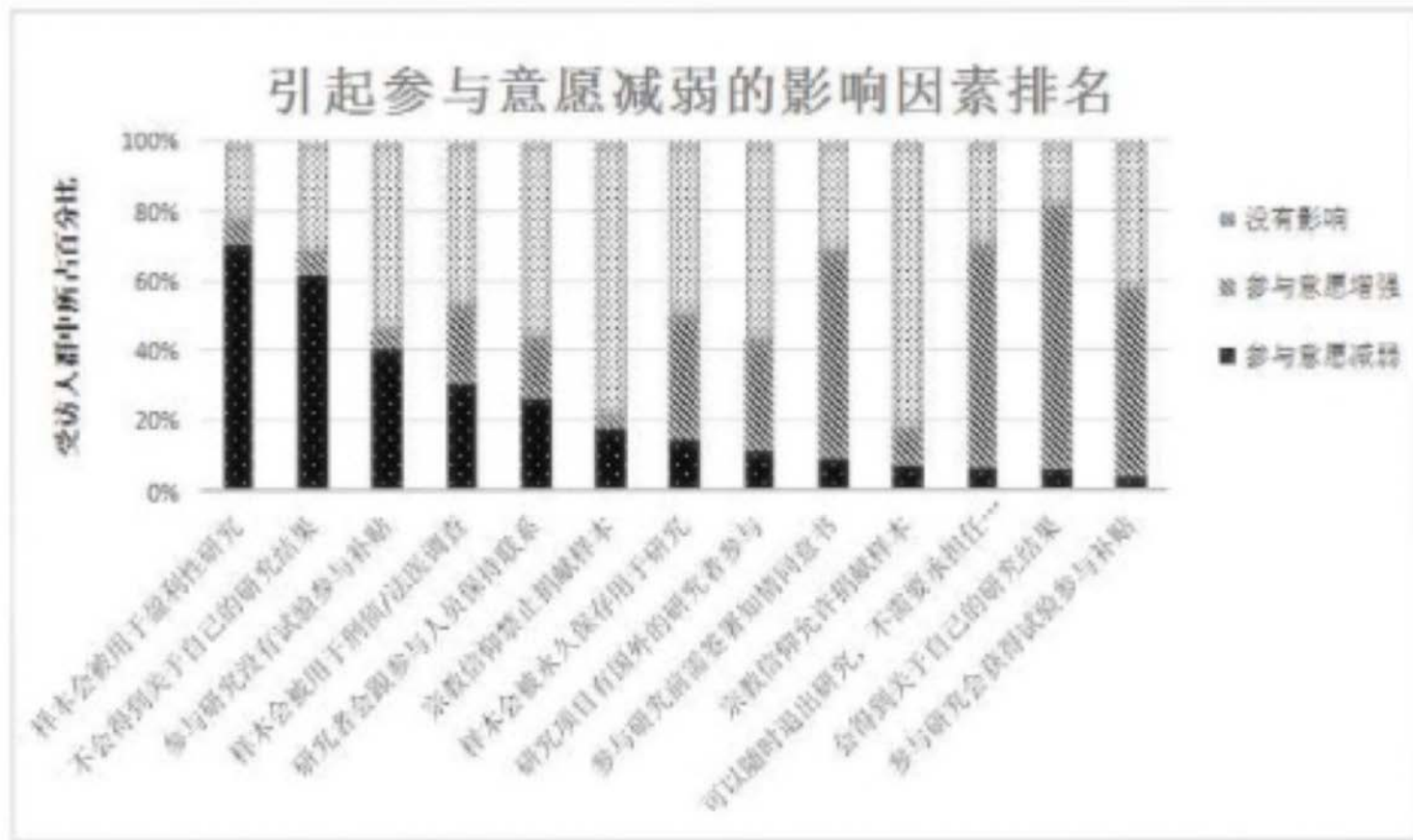
public, questionnaire survey, perception

lowest:
the public

Strength: get the result back, can withdraw, good informed consent, etc.



Weaken: sample be used for profit, can't get result back, no stipend/money for joining



不同人群对生物样本库的认知状况及捐赠意愿调查

王娜 王倩倩 赵丹慧 吴成爱

【Abstract】 Objective To understand the cognition and attitude of patients, medical staff and medical examination people on biobanks and their willingness to donation. **Methods** A cross-sectional study was conducted among 452 individuals, including patients, medical staff and people receiving health checkup at a hospital in Beijing from July to September, 2017. The questionnaire assessed the respondents' demographic data, general knowledge about biobanking and the factors influencing their willingness to donate specimens to biobanks. Pearson's Chi-square test, student *t* test or ANOVA were used for univariate analysis. Additionally, the linear regression analysis and logistic regression analysis were used for multivariate analyses. **Results** A total of 452 questionnaires were delivered, and the effective questionnaires amounted to 440, including 196 medical staff, 123 patients and 121 health checkup individuals. The awareness score of biobanks was significantly different among the medical staff, patients and health checkup individuals ($P < 0.05$). After adjustment for potential risk factors, we found that the population characteristics and the experience of participation in a medical research were the independent beneficial factors of the awareness score. The percentage of the willingness of donation in medical staff, health checkup individuals and patients were 83.7%, 76.9% and 70.7%, respectively. The results of univariate analyses suggested that the population characteristics, education level, health conditions, the history of blood donation, and the experience of participation in a medical research were significantly associated with the willingness to donate (all $P < 0.05$). Population characteristics and health conditions were independently relevant to the willingness of donation, after multivariate analyses of logistic regression. **Conclusions** Despite the strong willingness to donate biospecimens, patients and health checkup individuals lack knowledge of biobanking. It is apparent that we need to strengthen promotions and to encourage the ethics and humanities to improve the knowledge of biosample donation, for healthy development of hospital-based biobanks.

reason to donate: benefit medical development, can feel contribution to society, including own family, possibly help myself to reduce medical cost..

表3 愿意捐赠的原因分布($n = 344$)

| 原因 | 人数 | 百分比(%) |
|--------------------------------|-----|--------|
| 生物样本库将促进医学科学的发展,造福社会和未来一代 | 308 | 89.5 |
| 我和我的家庭可能受益 | 178 | 51.7 |
| 参与使我感觉对社会做出贡献 | 223 | 64.8 |
| 希望被告知异常结果 | 143 | 41.6 |
| 生物样本库已经成为发达国家生物医学研究的重要机构 | 195 | 56.7 |
| 参与生物样本研究有可能帮助我,给我提供更有效和更少花费的医疗 | 143 | 41.6 |
| 生物医学研究可能会提供新的工作机会 | 88 | 25.6 |
| 我的宗教信仰支持我参与 | 9 | 2.6 |

unwilling: individual information, misuse, lost control to own sample, be used for profit, physical harm

表 4 不愿意捐赠的原因分布($n = 96$)

| 原因 | 人数 | 百分比(%) |
|---------------------------|----|--------|
| 丧失了自己对样本的知情权和决定权 | 31 | 32.3 |
| 我认为医学研究对我没有益处 | 10 | 10.4 |
| 担心在医学研究中个人样品被误用 | 34 | 35.4 |
| 对发现某些疾病遗传倾向的担忧 | 12 | 12.5 |
| 担心疾病基因信息泄露可能遭受歧视 | 10 | 10.4 |
| 担心捐献生物样本会对人身有伤害 | 25 | 26.0 |
| 担心个人信息泄露 | 46 | 47.9 |
| 不信任医学研究 | 3 | 3.1 |
| 我担心研究者会经常联系我 | 11 | 11.5 |
| 担心医学研究违反伦理原则 | 17 | 17.7 |
| 恐惧(不想)署名/签字 | 9 | 9.4 |
| 个人健康原因 | 12 | 12.5 |
| 我不愿意让我的数据/样本被研究机构保存不确定的时间 | 20 | 20.8 |
| 担心个人样本可能被用于商业 | 26 | 27.1 |
| 害怕抽血等可能带来的身体疼痛 | 8 | 8.3 |
| 为研究而捐献样本与我的宗教信仰相悖 | 2 | 2.1 |

back to the comparison

Percentage of people who would generally be trusted with DNA and health information

| Country | Own doctor | Any doctor in country | Non-profit researcher in my country | Company researcher in my country | My government |
|----------------|------------|-----------------------|-------------------------------------|----------------------------------|---------------|
| China | 70.80 | 43.40 | 46.20 | 33.50 | 66.60 |
| United Kingdom | 77.40 | 46.90 | 33.00 | 9.70 | 16.40 |

Most trust in own doctor in both, and more trust in doctors and university researchers – but much more trust in company researchers and government in China than the UK

Levels of willingness to donate DNA and health data higher in China, particularly for for-profit research

| | Donate for use by Dr | Donate for use by non-profit researcher | Donate for use by for-profit researcher |
|----------------|----------------------|---|---|
| China | 66% | 62% | 50% |
| United Kingdom | 49% | 42% | 23% |

Essential: donation itself; transparent; Lack of trust; how to view genetic research

- ✧ generally support--for the people understand this
- ✧ how to view the genetic research and its impact? whether hold genetic determinaiton?
- ✧ related to whether genetic service is mature, whether family genetic be diagnosed and be treated.
- ✧ the donation rate is relatively low, related to the “donation” itself.
- ✧ donation, Vs. treat back directly
- ✧ fear of suffer, pain, is need pointed out.
- ✧ worry information confidentiality, related to legal regulation, and insurance system



common: in the future

- ✧ misuse, concern. governance is key, as always.
- ✧ who can encourage/access to the public, need separately addressed
- ✧ tradition of public engagement, ethnic factor, vary.
- ✧ research finding is key to the public
- ✧ suggest to take consideration of cohort, ongoing, Precision medicine.
- ✧ before 2000; around PM (2010) , and around 2020 after big data era





Big thanks for Richard's help