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A National Survey of Public Attitudes toward Biobanks and Human Bioresource Donation

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Abstract

The increasing use of human biospecimens and health data in research raises ethical and legal concerns regarding privacy, consent, and ownership. This study examined public awareness, attitudes, and concerns related to biospecimen and health data in South Korea. A nationwide online survey was conducted with 500 adults, stratified by region, age, and gender. The questionnaire assessed awareness levels, donation experience, motivations, and concerns related to biospecimen and health data donation. Statistical analyses using SPSS (version 29) included chi-square tests across demographic variables such as gender, age, education, and occupation. Awareness of biospecimen donation was moderate for biomedical research (55.2%) but lower for industrial research (42.2%). Awareness of biobanks was low (21.4%). Willingness to donate was higher for biomedical research (biospecimens 54.0%, health data 50.6%) than for industrial purposes (48.2%, 43.8%). The main motivations included humanitarian concerns and public benefit, while major concerns focused on privacy and physical discomfort. Most participants (72.2%) preferred detailed consent. Men were more willing to donate and expressed more favorable attitudes toward biospecimen and health data donation than women. The findings indicate moderate public awareness and willingness to donate biospecimens and health data, alongside persistent concerns about privacy, ownership, and compensation. Enhancing ethical governance and public engagement is essential to building trust in biobank-based research.

Keywords: biobank; human bioresources; health information; informed consent

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No potential conflict of interest relevant to this article was reported.

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Data availability
Upon reasonable request, the datasets of this study can be available from the corresponding author.

I. Introduction

With advancements in medicine, biotechnology, big data processing, and information and communication technologies (ICT), research utilizing human biospecimens and associated health data has significantly increased in the field of biomedical research and development (R&D). To promote the feasibility and efficiency of such research, institutional and systemic efforts have been implemented

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Ethics approval
This study protocol was reviewed by the Institutional Review Board of Ewha Womans University College of Medicine (approval No. N/A; exempt determination issued on April 19, 2023).
Informed consent was obtained from all participants prior to the survey.

both domestically and internationally to collect, manage, and distribute research resources derived from human biospecimens [1]. In South Korea, the Korea Biobank Project, initiated in 2008, has been working to establish a standardized and comprehensive national system for the collection, management, and utilization of biospecimens to support biomedical research and industry [2].

The use of human biospecimens in Korea is governed by the Bioethics and Safety Act (hereinafter referred to as the "Bioethics Act"), which sets forth measures and principles to protect research participants, including both individuals and human-derived materials. In this legislation, biospecimens are defined as materials collected or obtained from the human body – such as tissues, cells, blood, bodily fluids – and derivatives including serum, plasma, chromosomes, DNA, RNA, and proteins. Under this Act, biobanks that collect and store biospecimens, genetic information, epidemiological data, and clinical information must obtain consent from donors before directly using or providing these materials to third parties. The Act emphasizes informed, written, and specific consent, ensuring that donors are fully aware of the purpose and nature of the research involving their biospecimens and data [3].

However, the primary role of biobanks is to serve as research infrastructure by collecting and preserving biospecimens and associated data for future use by researchers. At the time consent is obtained, it is often impossible to specify the exact research projects or investigators who will later utilize the donated materials. Consequently, except when conducting specific research, biobanks are permitted to obtain broad consent, allowing donors to agree to the future use of their biospecimens and data without detailed knowledge of particular studies or researchers [4].

Although biobanks strive to collect comprehensive clinical, epidemiological, and genetic data with donor consent, health-related information remains particularly sensitive, raising ethical and legal concerns such as potential violations of autonomy and breaches of privacy [5,6]. Therefore, to ensure the stable and efficient collection and utilization of biospecimens and associated data for future biomedical R&D, including precision medicine, it is essential to establish robust legal, social, and ethical frameworks, along with complementary measures [7–9]. Establishing such ethical and governance frameworks requires not only legal mechanisms but also social legitimacy grounded in public acceptance. Public perceptions directly influence willingness to donate, acceptance of long-term storage and secondary use of biospecimens and data. Therefore, understanding public attitudes is essential for developing a governance system that reflects social expectations and ensures continued participation in biobank-based research.

In this context, the present study gathered public opinions regarding the donation and use of biospecimens and related data, recognizing the public as both potential donors and beneficiaries of biomedical research.

II. Methods

An online survey was using an online panel operated by Hyundai Research. Panel respondents are pre-registered individuals, and stratified quota sampling was applied based on gender, age (19 to 69 years), education, and region of residence (n=500).

The questionnaire included 14 core items, with additional branching questions depending on participants' responses. Topics covered included awareness, prior donation experiences, willingness to donate biospecimens and healthcare data, preferred types of information disclosure, perceptions of ownership and commercialization, expectations for compensation, and opinions on the use of anonymized healthcare data without consent. Awareness of biobanks and willingness to donate to biobanks were also assessed, along with motivations and reasons for or against donation.

The survey was administered through an online panel platform. Participants provided electronic informed consent prior to beginning the survey.

All statistical analyses were performed using SPSS version 29.0 (SPSS, IBM, Chicago, IL, USA) for Windows. Chi-square tests were applied to examine associations between key demographic variables (gender, age, region, education level, and occupation) and survey responses.

Ethics Statement: This study protocol was reviewed by the Institutional Review Board of Ewha Womans University College of Medicine (approval No. N/A; exempt determination issued on April 19, 2023).

III. Results

1. Demographic Features of the Respondents

A total of 500 respondents participated in the survey, comprising 253 males and 247 females. The age distribution was 18.0% in their 20s, 17.6% in their 30s, 21.4% in their 40s, 23.2% in their 50s, and 19.8% in their 60s. Respondents' residences were proportionally distributed according to regional population rates in Korea. Educationally, 81.2% held a university degree or higher, while 18.8% were high school graduates or below. White-collar workers represented the largest occupational group, accounting for 39.8% of respondents (Table 1).

2. Level of Awareness about Donation of Biospecimens and Healthcare Data

Overall, 55.2% (n=276) of respondents reported awareness of biospecimen donation (e.g., blood, urine, tissue) for biomedical research, while 44.8% had not

Table 1. Demographic characteristics

Categories	Numbers	%
Gender		
Male	253	50.6
Female	247	49.4
Age		
19–29	90	18.0
30–39	88	17.6
40–49	107	21.4
50–59	116	23.2
60–69	99	19.8
Regions of residence		
Capital region (Seoul, Incheon, Gyeonggi)	257	51.4
Chungcheong region (Daejeon, Chungbuk, Chungnam, Sejong, Gangwon)	64	12.8
Gwangju and Jeolla region (Gwangju, Jeonnam, Jeonbuk, Jeju)	57	11.4
Daegu and Gyeongsang region (Gyeongbuk, Gyeongnam, Daegu)	78	15.6
Busan and Ulsan region (Busan, Ulsan)	44	8.8
Education level		
≤Middle school	3	0.6
High school	91	18.2
University	349	69.8
≥Graduate school	57	11.4
Occupation		
Professionals/academics (teachers)	57	11.4
White-collar workers	199	39.8
Blue-collar workers	33	6.6
Sales/service workers	24	4.8
Self-employed	38	7.6
Students	23	4.5
Full-time homemaker	72	14.4
Unemployed/others	54	10.8

heard of it. In contrast, only 42.2% (n=211) were aware of biospecimen donation for bio/medical industry purposes, with 57.8% reporting no prior knowledge. Among those aware, 21.0% had previously donated biospecimens for biomedical research, and 16.6% had donated for bio/medical industry-related research.

Regarding healthcare data donation, 53.0% (n=265) indicated awareness of donating healthcare data for biomedical research, whereas 47.0% were unaware. Awareness of healthcare data donation for bio/medical industry purposes was lower, with only 36.6% (n=183) reporting familiarity and 63.4% indicating no prior knowledge. Among those aware, 11.3% had experience donating healthcare data for biomedical research, while 15.3% had donated for bio/medical industry research.

Awareness of biobanks—institutions that store donors' biospecimens and healthcare data for research purposes—was relatively low, with only 21.4% of respondents indicating awareness, compared to 78.6% who were unaware (Figure 1).

3. Willing to Donate Biospecimens and Healthcare Data, and Reasons

Overall, 54.0% of respondents indicated willingness to donate biospecimens for future biomedical research, whereas 15.6% were unwilling and 30.4% were uncertain. For biospecimen donation aimed at advancing the bio/medical industry, willingness slightly declined to 48.2%, with 17.4% unwilling and 34.4% uncertain. Willingness to donate healthcare data for biomedical research was reported by 50.6% of respondents, while 19.2% were unwilling and 30.2% were uncertain. In contrast, willingness to donate healthcare data for industrial purposes decreased to 43.8%, with 20.6% unwilling and 35.6% uncertain.

Regarding donation to biobanks, 53.4% of respondents expressed willingness to donate biospecimens, and 55.0% expressed willingness to donate healthcare data (Figure 2).

The most commonly reported motivations for donation were humanitarian reasons, such as helping patients (52.1% for biospecimens and 48.4% for healthcare data), followed by contributing to the advancement of medicine and society (42.7% for biospecimens and 47.3% for healthcare data). A smaller proportion indicated the absence of specific reasons to refuse donation (5.2% for biospecimens and 4.4% for healthcare data) (Figure 3).

Among respondents unwilling to donate, the leading reasons were general reluctance without specific cause (33.9% for biospecimens and 30.2% for healthcare data) and concerns regarding personal data breaches (32.6% for biospecimens and 43.1% for healthcare data). Other concerns included pain during

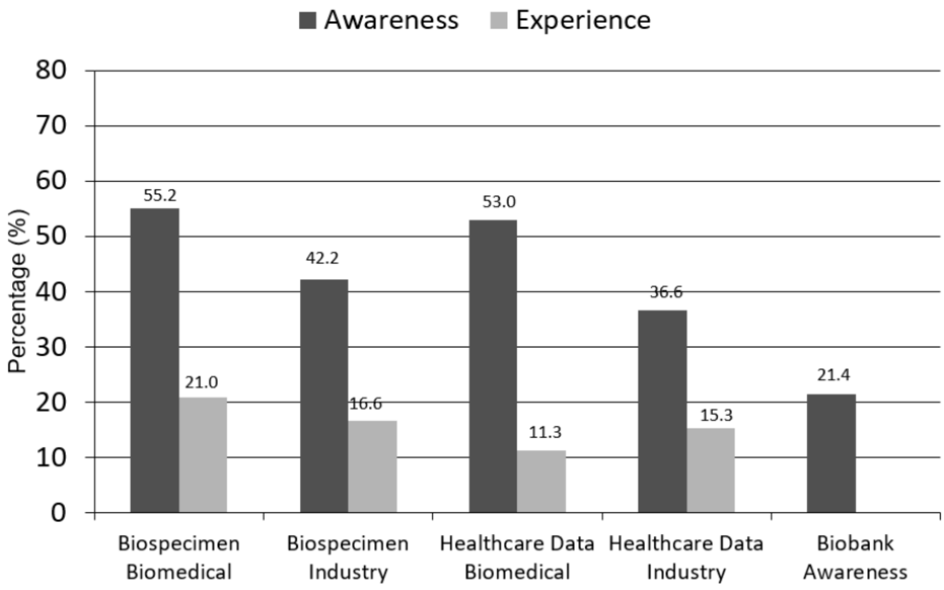

Figure 1. Awareness and experience of donating biospecimens and healthcare data.

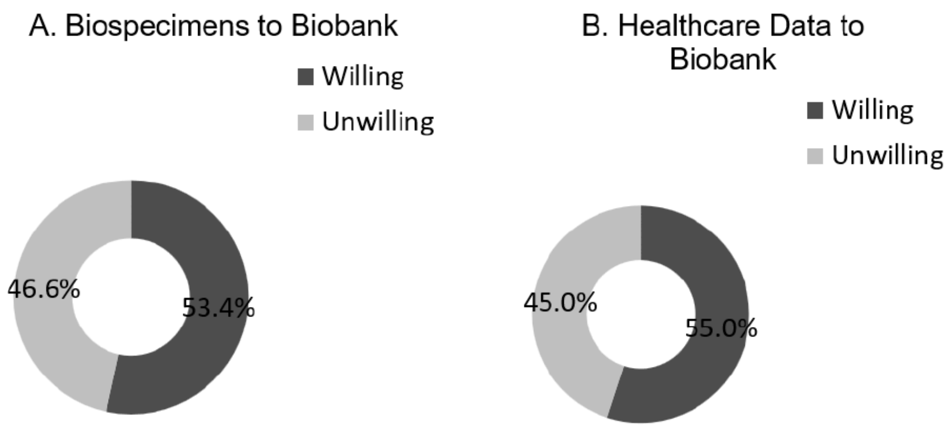

Figure 2. Willingness to donate biospecimens and healthcare data to biobank.

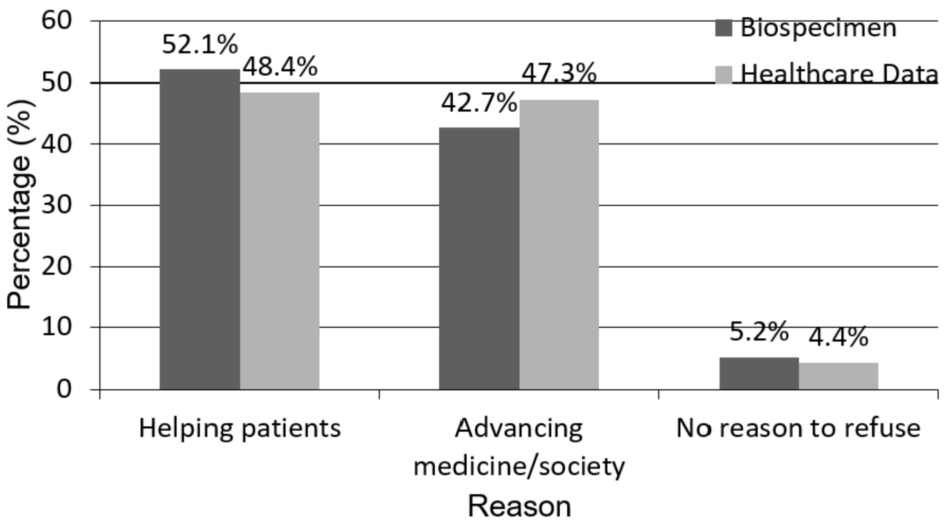

Figure 3. Positive reasons for donating biospecimens and healthcare data to biobank.

collection (13.3% for biospecimens and 8.0% for healthcare data; possibly due to misunderstanding of the data collection process), perceptions of unfair benefit distribution (12.4% for both), and distrust in researchers (5.2% for biospecimens and 4.0% for healthcare data) (Figure 4).

4. Preferred Types of Information When Donating Biospecimens or Healthcare Data

Most respondents (72.2%) preferred receiving detailed prior explanations and consent specifying the exact research purposes when donating biospecimens or healthcare data. In comparison, 17.0% indicated that a general explanation would suffice, and 10.8% considered a broad notification after the research as adequate (Figure 5).

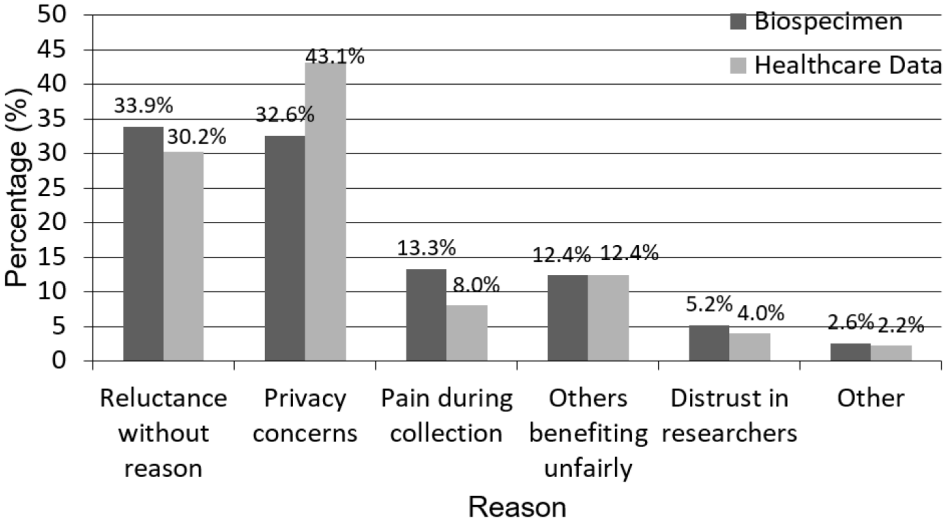

Figure 4. Negative reasons for donating biospecimens and healthcare data to biobank.

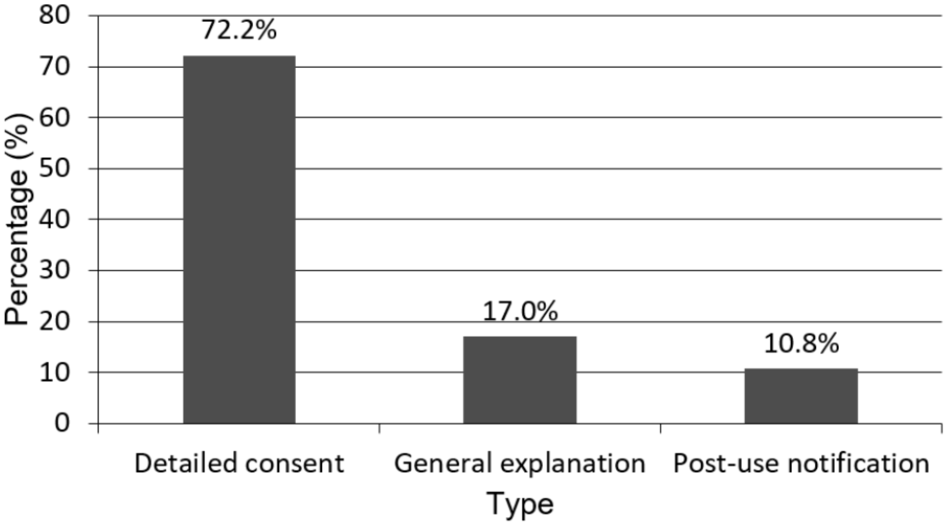

Figure 5. Preferred types of information when donating biospecimens or healthcare data.

5. Ownership and Compensation for Collected Biospecimens and Healthcare Data

Regarding ownership, 44.6% believed that collected biospecimens or healthcare data should belong to the donor, 39.8% attributed ownership to medical institutions, and 15.6% were uncertain. Concerning the use of anonymized health information for research, 33.8% opposed its use without prior consent. Meanwhile, 26.2% agreed with its use if managed by the state, 26.0% agreed if reviewed by an independent body such as an institutional review board, and 14.0% agreed without any additional conditions.

With respect to commercialization, 58.8% of respondents opposed the idea of selling their biospecimens or healthcare data, while 19.0% expressed support.

In terms of preferred compensation for donation, the most common response was modest monetary reimbursement to cover related expenses (38.0%). This was followed by compensation in an amount determined appropriated by the donor (21.4%), symbolic recognition such as volunteer service credits (13.8%), and no compensation (12.2%). Additionally, 14.6% of respondents were uncertain about compensation preferences (Figure 6).

Regarding willingness to donate in exchange for appropriate compensation, 49.4% indicated willingness, 22.4% were unwilling, and 28.2% were uncertain.

6. Variables Influencing Attitudes toward Biospecimen and Healthcare Data Donation

Significant differences were observed by gender. Male respondents were more likely to report having experience donating biospecimens for the advancement of the bio/medical industry (p=0.009). Additionally, males demonstrated higher willingness to donate healthcare data and biospecimens to biobanks for the advancement of the bio/medical industry (p=0.022, p=0.021, p=0.033, respectively). Males were also significantly more likely to believe they could sell their own biospecimens or healthcare data commercially (p=0.006) and to agree that anonymized healthcare data could be used for research without consent (p=0.029). Overall, male exhibited more favorable attitudes toward biospecimen and healthcare data donation.

Regarding age, respondents aged 50 and older were significantly more likely to believe that they should not sell their own biospecimens or healthcare data

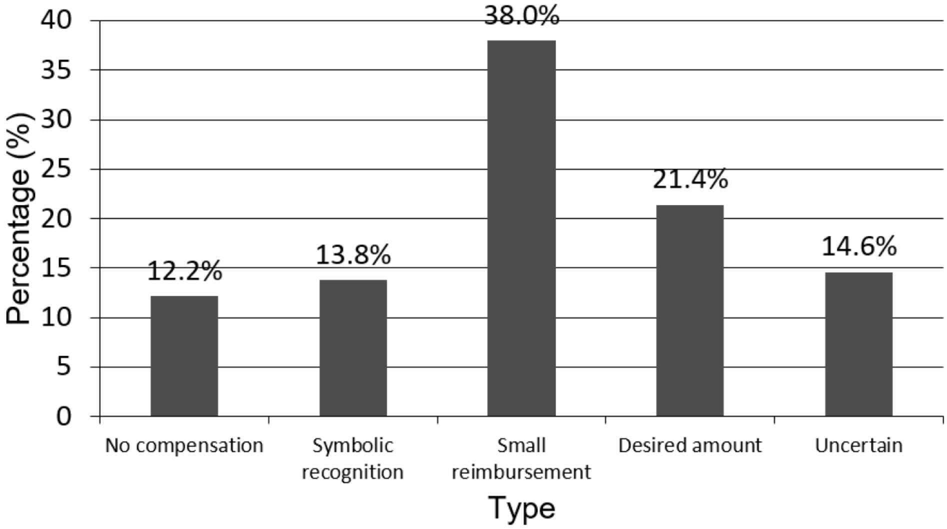

Figure 6. Preferred compensation for donation of biospecimens or healthcare data.

commercially (p=0.006). Furthermore, those who preferred detailed explanations when donating biospecimens or healthcare data were less likely to express willingness to donate. In contrast, respondents who considered a general explanation, such as stating that the donation would be used for biomedical research, to be sufficient were significantly more likely to express willingness to donate (p〈0.001 for both biospecimens and healthcare data).

Younger respondents were significantly more likely to believe that ownership of donated biospecimens or healthcare data rested with the donor (p=0.030). Additionally, white-collar workers were more likely than those in other occupations to consider the donor as the rightful owner (p=0.006).

No statistically significant differences were observed according to education level or occupation, apart from the noted finding regarding perceptions of ownership among white-collar workers.

Ⅳ. Discussion

The findings from the survey provide meaningful insights into how people in South Korea perceive biobanks, research participation, and the ethical implications of donating biological materials and data.

The relatively low awareness (21.4%) regarding biobanks is apparent compared with the European countries (65%–80% in Scandinavian countries), but similar with the USA (23%) and Jordan (25%) [10]. A majority (55.2%) of respondents were willing to donate biospecimens and healthcare data. Although this level is not low in absolute terms, it is but it is relatively lower than other countries (86% of Sweden, 67% of America, 75% of the UK and even 65% of China) [10]. It is sharply contrast with a survey result in Korea showing 81.3% of respondents wanted to donate their organ after death [11]. Therefore, the relative reluctance to donate biospecimens and healthcare data of Korean may due to unawareness regarding biobanks and their role. It is suggested by the fact that the major reason of unwillingness is “reluctance without reason (33.9% for biospecimens, 30.2% for healthcare data). This lack of awareness and low willingness to donate could impact public trust and participation in biobank-related activities.

Humanitarian reasons (e.g., helping patients) and public interest (e.g., advancing medicine and society) were the primary motivations for donating biospecimens and healthcare data. However, the most common reasons for not donating were concerns over data breaches and general discomfort. The Korean government established “Personal Information Protection Act” to make sure the confidentiality of the data provider [12]. “Bioethics and Safety Act” also strongly regulates the activities of biobanks and healthcare institutes regarding to the data protection of the doner [3]. But many Korean people are hardly aware of the laws and regulations and thus might conceive an ambiguous anxiety feeling against the research activities regarding biobanks although the current regulations are very strict and most activities of the biobanks are controlled by the governmental authority by direct acts and accreditation system [3]. It is also true for the “informed consent” process for the biobanks. A significant majority (72.2%) of respondents expressed the desire for detailed explanations and informed consent specifying the exact research purposes when donating biospecimens or healthcare data, which is strongly required by the law [3]. So, it is not the matter of any regulatory system or legal apparatus, but the matter of public trust. The findings highlight the importance of clear communication regarding the storage, handling, and potential future uses of the biospecimens and data to minimize ethical concerns.

There was a divide in respondents’ perceptions of ownership of biospecimens and healthcare data. While nearly half (44.6%) of respondents believed that donors should retain ownership, a large proportion (39.8%) felt that medical institutions should own the materials. Ownership of biospecimen (health data, too) is important but unsolved topic yet [13]. In current Korean legal system, the ownership may be attributed to the doner himself, but the purchasing of human biospecimen is prohibited by the law [3]. In spite of this prohibition, 19.0% of the respondents believed they could commercially sell their biospecimens or healthcare data, suggesting that more societal discussion should be necessary for the issue. Besides, many respondents expressed a preference for small monetary compensation (38.0%) for their donation, which aligns with the idea that compensation should cover expenses related to donation.

The analysis revealed notable gender and age differences in attitudes toward donation. Males were generally more willing to donate biospecimens and healthcare data, more likely to believe they could sell their biospecimens, and more favorable toward the use of anonymized healthcare data without consent. This result is interesting for there is little or no gender discrepancy in other similar surveys in the USA, China, and Italia [14–16]. It may be suggested that males tend to be more “bold”, “aggressive” or “heedless” than females [17,18] in participating for biomedical researches through biobanks, but it needs further investigation why such phenomena happen in Korea.

In contrast, unlike findings from studies in Western countries where variables such as occupation and education level often show significant associations with donation attitudes [5,14,16], such patterns were not clearly observed in the present dataset. This may partly reflect the uneven distribution of education levels, as most respondents were university graduates, which limits interpretation of sociodemographic effects. Beyond this methodological consideration, this divergence highlights the importance of considering local cultural, social, and institutional contexts when interpreting public perceptions of biobanking.

Age also played a role; older respondents are more likely to resist the commercialization of biospecimens, which indicates that older persons are more prudent in attitudes toward data privacy and commercialization. But there was no such difference in willingness to donate.

The findings emphasize the need for a more comprehensive legal, ethical, and social framework to govern biospecimen and healthcare data donation. Public concerns about privacy, data security, and the commercialization of human materials must be addressed to ensure public trust and encourage participation. Policies should prioritize transparency, informed consent, and clear guidelines on ownership, use, and compensation for donated materials. Researchers and institutions must also work to establish strong data protection measures and transparent practices to build public confidence. Additionally, educational campaigns are needed to increase awareness about biobanks and the research opportunities they enable.

This discrepancy highlights a gap in public knowledge about the biobank and suggests the necessity of active campaign and civil education about biobank.

Ⅴ. Limitation

This study has several limitations. First, the sample included a disproportionately high proportion of university graduates, which limits the generalizability of education-associated findings. In addition, the survey did not include detailed information on academic major or disciplinary background, limiting the ability to explore whether respondents' educational specialization might be associated with donation attitudes. Moreover, although international comparative statements were made in interpreting results, the survey instrument was not identical to those used in previous studies from other countries, which constrains direct comparison. These limitations should be addressed in future research to ensure more solid interpretation of public attitudes toward biobanking and biospecimen/data donation.

Ⅵ. Conclusion

The survey results provide an essential understanding of public attitudes toward biospecimen and healthcare data donation in South Korea. While there is a general willingness to donate, concerns over privacy, ownership, and compensation highlight the need for comprehensive ethical frameworks and public education and campaign. Addressing these concerns will be crucial in fostering trust and ensuring the success of biobank-based research initiatives that contribute to advancing biomedical science.

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