



What do people think about brain banks?

A survey of public awareness and attitudes toward brain research resource donation

Ji Hyun YANG(LLB, PhD), Ilhak LEE (MD, PhD). Division of Medical Law and Ethics, Department of Medical Humanities and Social Sciences, Yonsei University College of Medicine, South Korea

BACKGROUND

- The Korea Brain Bank was established in 2014. However, as of January 2023, only 232 individuals have been registered as post-mortem brain donors.
- Brain research resources are critical for comprehending the unique characteristics of brain diseases in Koreans. However, current resources are insufficient to meet researchers' needs. Donations of brain research resources are lower than brain-dead organ donations.
- As such, it is necessary to identify factors that may affect brain donation.

OBJECTIVES

- To understand public awareness and attitudes toward brain banks and brain research donation.
- To identify levels of potential willingness to donate, and factors that may influence decisions regarding donation.
- To examine how cultural characteristics that are strongly influenced by family in medical decision-making, including organ donation, are reflected in brain donation, and what is valued as a donor recognition program for donors and their families.
- To identify the demand for information related to the post-donation process, such as autopsy reports and research outcomes.

METHODS

- Online survey comprising structured questionnaires were administered over 7-days (2021. 10. 21. - 2021. 10. 27.)
- Sampling: A simple proportional allocation method considering age, gender, and region, based on the statistics of the resident registration of the Ministry of the Interior and Safety at Aug 2021 was conducted.
- Respondents: Men and women aged 20-59 (N=1000)

RESULTS

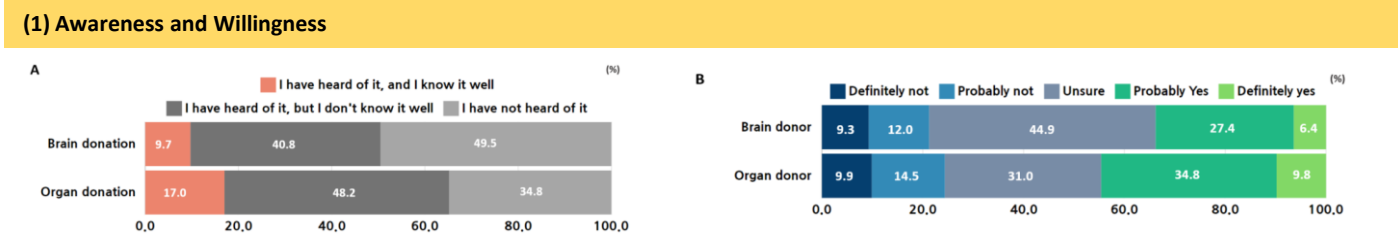


Fig 1. (A) Awareness of post-mortem brain donation and a brain-dead organ donation. (B) Willingness to register as a donor

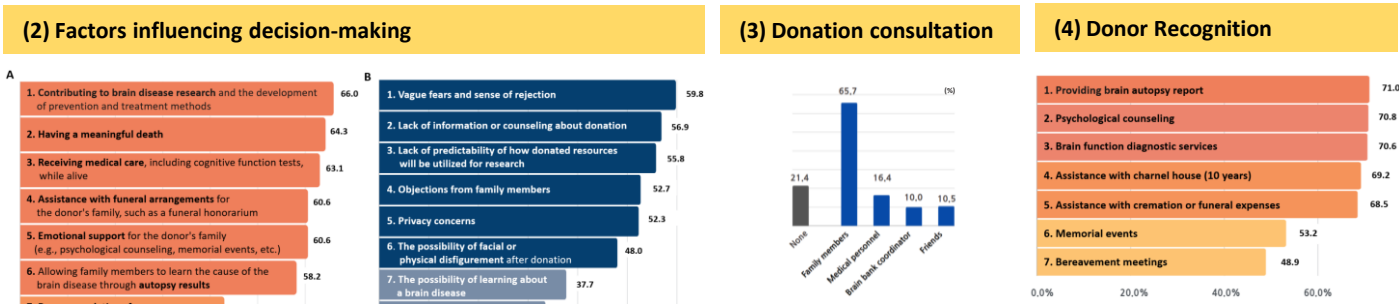


Fig 2. Positive factors (A) and Negative Factors (B) influencing the decision to be a brain donor.

Fig 3. Persons with whom respondents want to consult regarding their post-mortem brain donation.

Fig 4. Importance of donor recognition program.

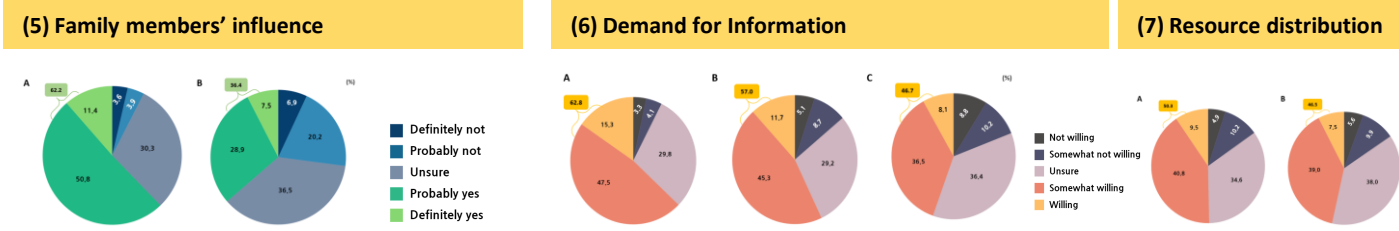


Fig 5. (A) Whether to respect and follow a family member's wish to donate their brain. (B) Whether to proceed with a brain donation after registered donor's death if the bereaved family objects.

Fig 6. (A) Willingness to receive a brain autopsy report. (B) Willingness to receive updates on the outcomes of brain research that have utilized resources donated by a donor or their family. (C) Willingness to receive updates on the status of brain bank resources.

Fig 7. (A) Willingness to share brain research resources with overseas researchers. (B) Willingness to share brain research resources with industry-affiliated researchers.

DISCUSSION

- Only about 30% of people are willing to register as brain resource donors, which is lower than the percentage of individuals who are willing to donate their organs after brain death (44.8%).
- There was a significant difference in the intention to register as a brain donor between those who were aware of brain donation and those who were not (46.5% vs. 20.8%).
- Of the factors that might influence donation, public good intentions, such as **contributing to research**, was the main positive factor, while **vague fears** were the most common negative factor.
- A majority of respondents (65.7%) valued consulting with their family members when deciding to donate. Further, over 60% of the respondents showed their willingness to respect the decision of other family members. However, only 36.4% stated they would proceed with the donation if they encountered **opposition from family members**.
- In addition to assistance with funeral arrangements, a high proportion of respondents emphasized the importance of **autopsy reports, psychological counseling, and brain function testing** as crucial components of a bereavement program.
- There is a high level of interest in informational aspects such as the results of the donor's **brain autopsy** and the **outcomes of research** utilizing the donated resources

CONCLUSIONS

- To encourage brain donation, it is important to **raise public awareness** about the significance of brain banks.
- **Emotional support** for bereaved families should be strengthened to ensure that family objections do not undermine the advance wishes of the donor.
- It is further crucial to develop strategies that respect the donor's desire to contribute to research and to have a meaningful death by **actively sharing information on the use of donated resources**. In addition, **transparency** in brain bank operations should be promoted to help establish trust with the public.



What do people think about brain banks?

A survey of public awareness and attitudes toward brain research resource donation

Ji Hyun YANG(LLB, PhD), Ilhak LEE (MD, PhD)

yjih@yonsei.ac.kr

❖ Please do not cite or distribute this data without permission. It has not been published yet. ❖

DISCLOSURE

- All authors have no conflict of interest to report in relation to this study.
- This study was part of a research program of the Korean Brain Central Bank Promotion Project (2021M3H9A103804712) by the Korea Brain Research Institute with support from the Ministry of Science and ICT.

BACKGROUND

- The Korea Brain Bank was established in 2014. However, as of January 2023, only 232 individuals have been registered as post-mortem brain donors.
- Brain research resources are critical for comprehending the unique characteristics of brain diseases in Koreans. However, current resources are insufficient to meet researchers' needs.
- Donations of brain research resources are even lower than brain-dead organ donations.
- As such, it is necessary to identify factors that may affect brain donation.

OBJECTIVES

- To understand public awareness and attitudes toward brain banks and brain research donation.
- To identify levels of potential willingness to donate, and factors that may influence decisions regarding donation.
- To examine how cultural characteristics that are strongly influenced by family in medical decision-making, including organ donation, are reflected in brain donation, and what is valued as donor recognition program for donors and their families.
- To identify the demand for information about the post-donation process, such as autopsy reports and research outcomes.

METHODS

- Online survey comprising structured questionnaires were administered over 7-days (2021. 10. 21. - 2021. 10. 27.).
- Sampling: A simple proportional allocation method considering age, gender, and region, based on the statistics of the resident registration of the Ministry of the Interior and Safety at Aug 2021 was conducted.
- Respondents: Men and women aged 20-59 (N=1000)

RESULTS (1) Awareness and Willingness

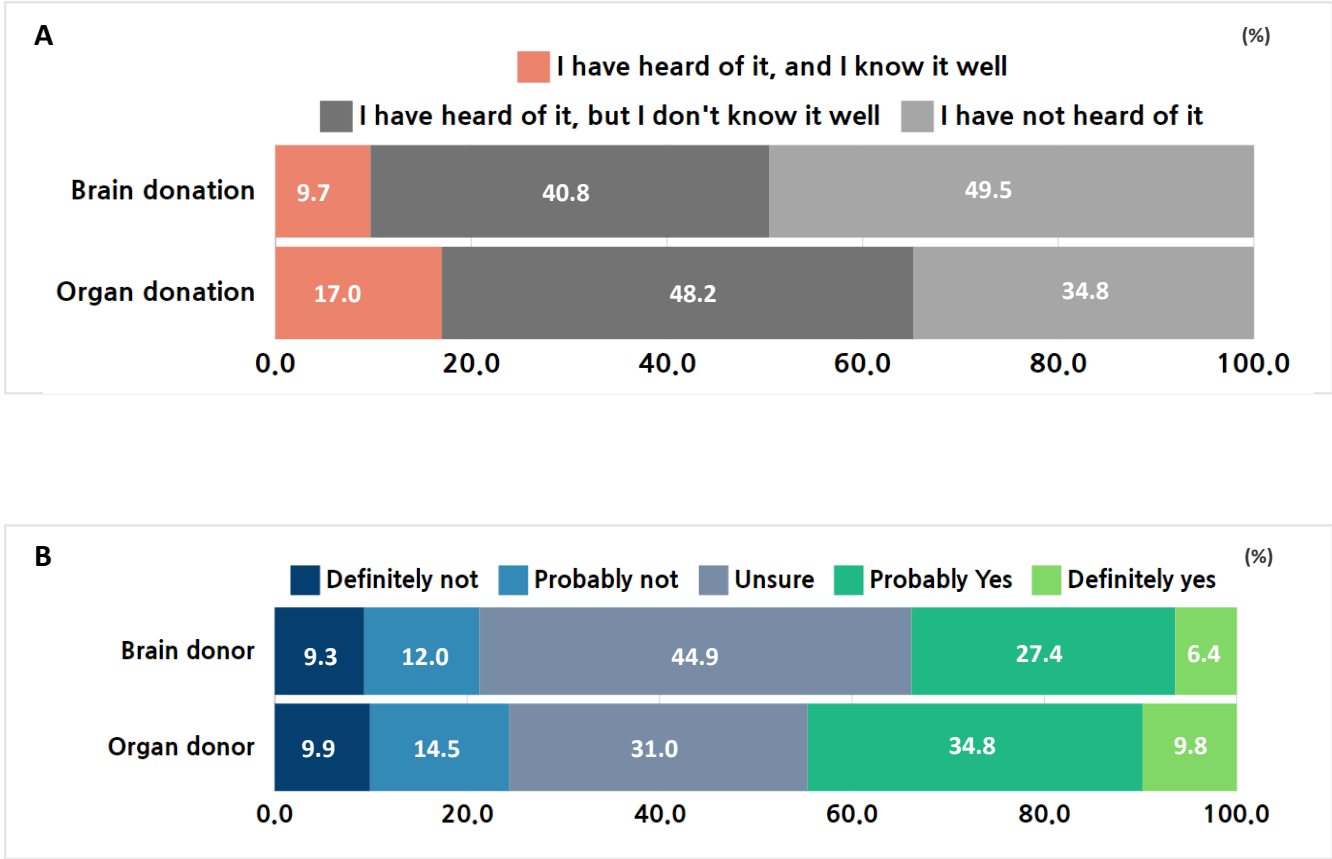


Fig 1. (A) Awareness of post-mortem brain donation and a brain-dead organ donation. **(B)** Willingness to register as a donor

RESULTS (2) Factors influencing decision-making

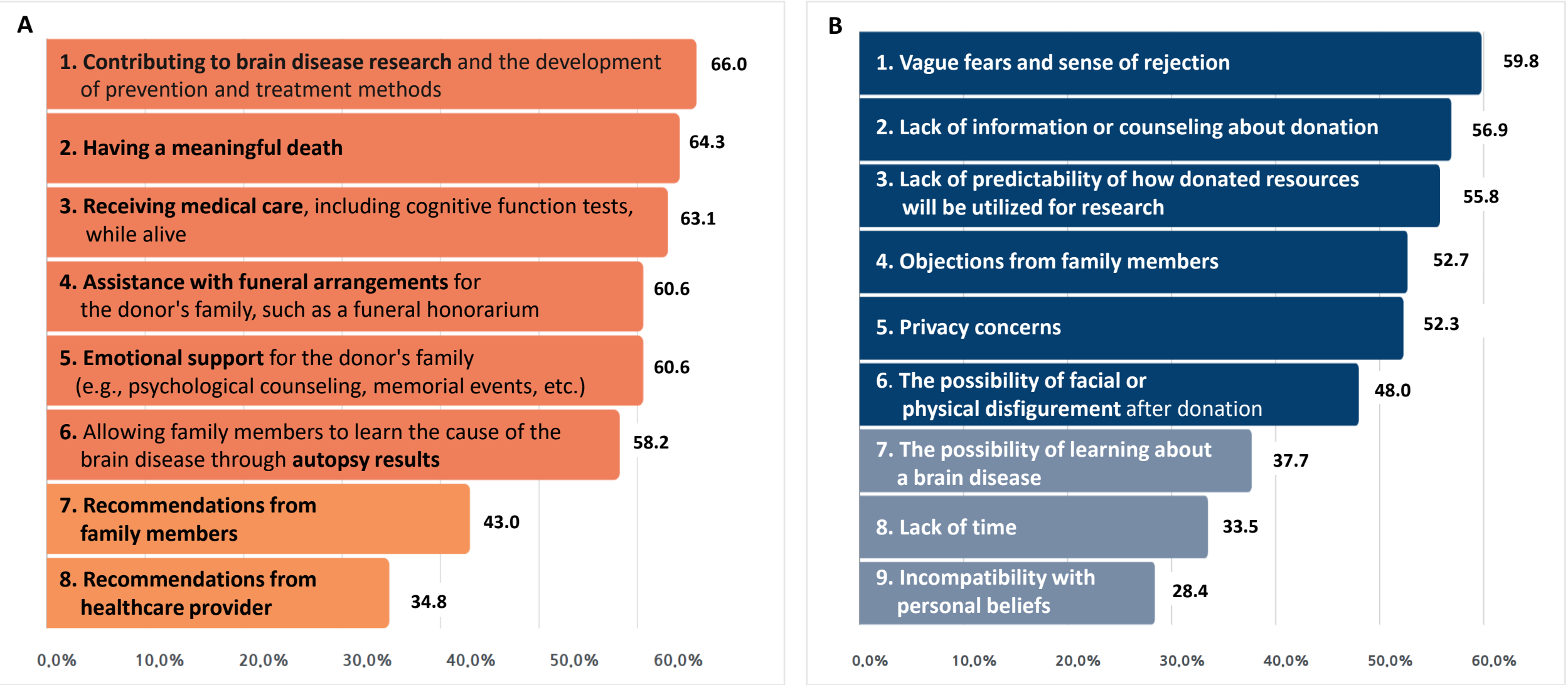


Fig 2. Positive factors (A) and Negative Factors (B) influencing the decision to be a brain donor.

RESULTS (3) Donation consultation

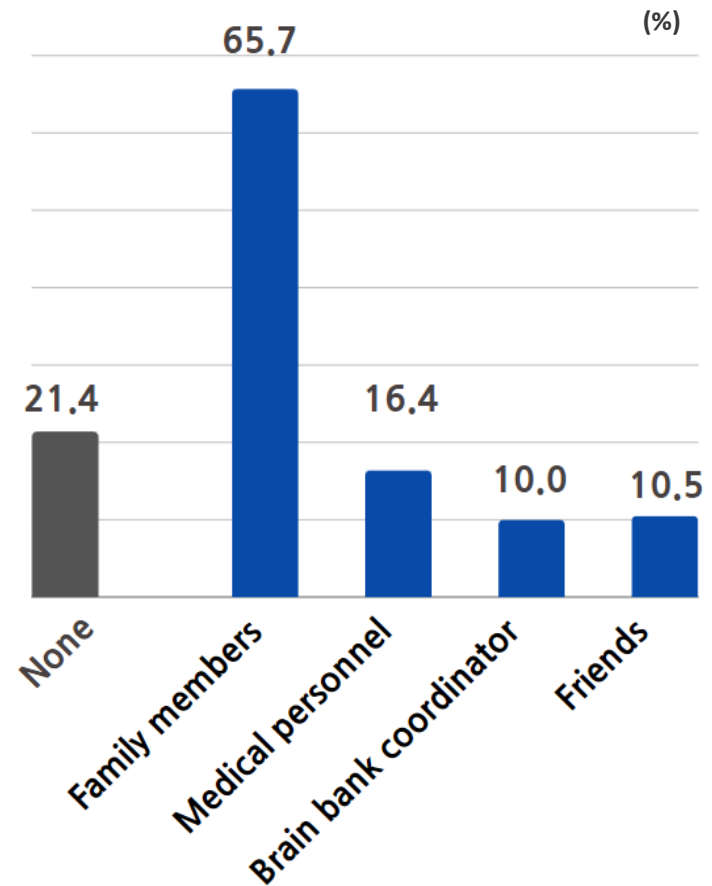


Fig 3. Persons with whom respondents want to consult regarding their post-mortem brain donation.

RESULTS (4) Family members' influence

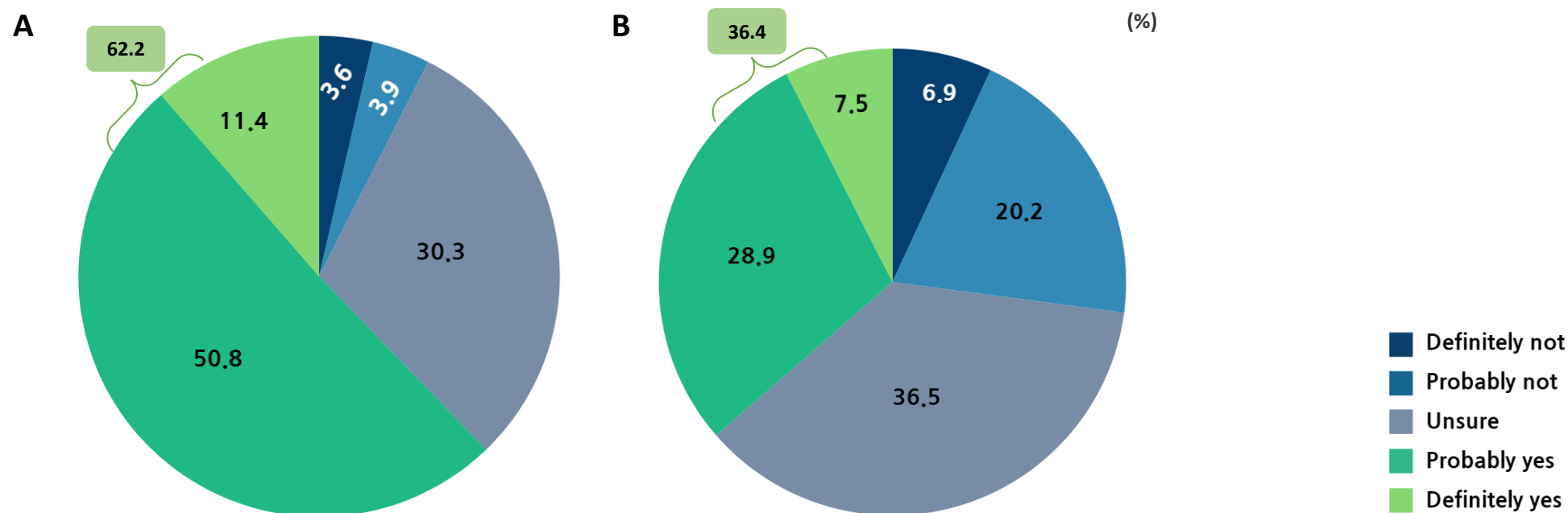


Fig 4.
(A) Whether to respect and follow a family member's wish to donate their brain.
(B) Whether to proceed with a brain donation after the registered donor's death if the bereaved family objects.

RESULTS (5) Donor Recognition

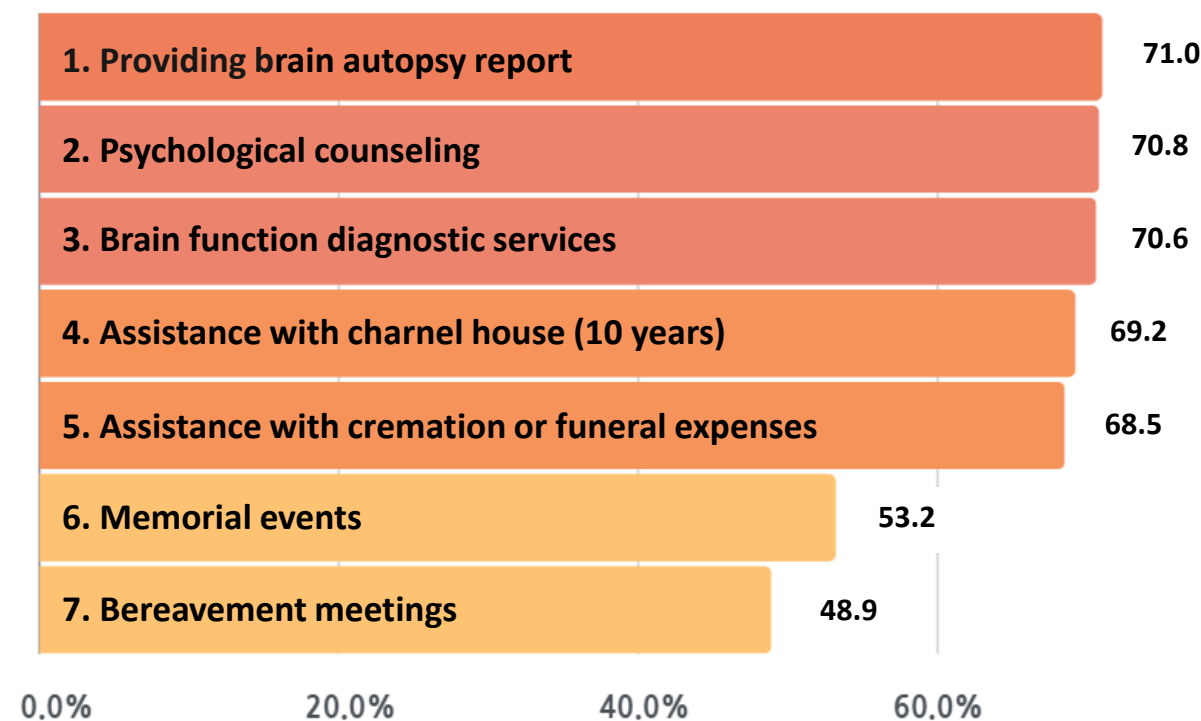


Fig 5. Importance of donor recognition programs.

RESULTS (6) Demand for Information

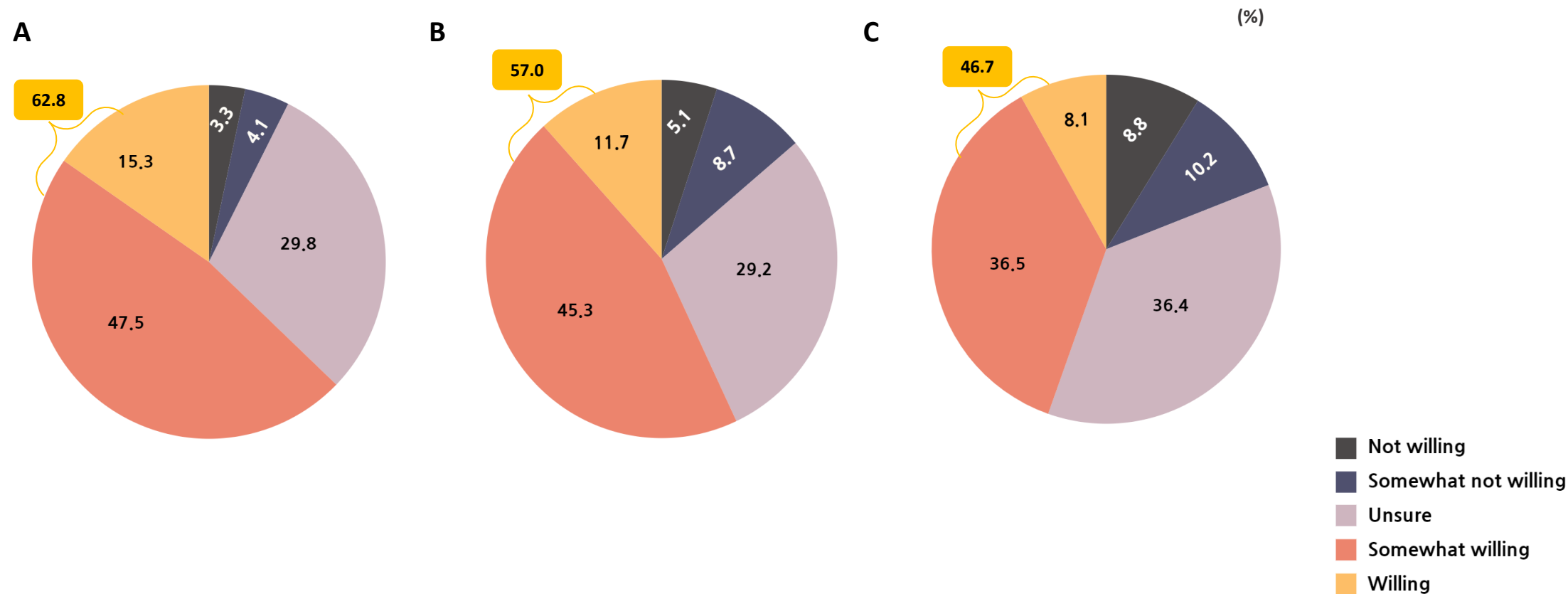


Fig 6.
(A) Willingness to receive a brain autopsy report. **(B)** Willingness to receive updates on the outcomes of brain research that have utilized resources donated by a donor or their family. **(C)** Willingness to receive updates on the status of brain bank resources.

RESULTS (7) Resource distribution

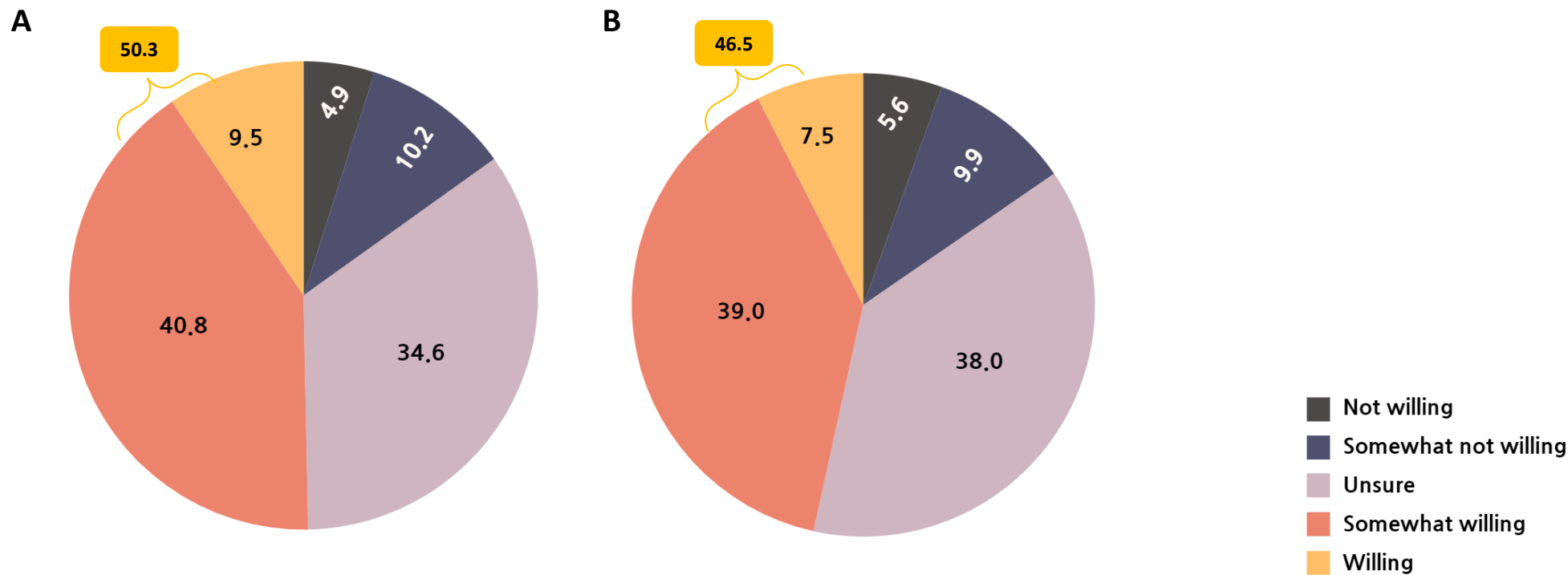


Fig 7.
(A) Willingness to share brain research resources with foreign research organizations or international consortiums,
(B) with industry-affiliated researchers.

DISCUSSION

- Only about 30% of people are willing to register as brain resource donors, which is lower than the percentage of individuals who are willing to donate their organs after brain death (44.8%).
- There was a significant difference in the intention to register as a brain donor between those who were aware of brain donation and those who were not (46.5% vs. 20.8%).
- Of the factors that might influence donation, public good intentions, such as contributing to research, was the main positive factor, while vague fears were the most common negative factor.
- A majority of respondents (65.7%) valued consulting with their family members when deciding to donate. Further, over 60% of the respondents showed their willingness to respect the decision of other family members. However, only 36.4% stated they would proceed with the donation if they encountered opposition from family members.
- In addition to assistance with funeral arrangements, a high proportion of respondents emphasized the importance of autopsy reports, psychological counseling, and brain function testing as crucial components of a bereavement program.
- There is a high level of interest in informational aspects such as the results of the donor's brain autopsy and the outcomes of research utilizing the donated resources.

CONCLUSIONS

- To encourage brain donation, it is important to raise public awareness about the significance of brain banks.
- Emotional support for bereaved families should be strengthened to ensure that family objections do not undermine the advance wishes of the donor.
- It is further crucial to develop strategies that respect the donor's desire to contribute to research and to have a meaningful death by actively sharing information on the use of donated resources. In addition, transparency in brain bank operations should be promoted to help establish trust with the public.