



Investigating the status of whole-body donation across the United States of America

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Abstract

Dissection of human body donors is a valuable part of anatomical education, research, and clinical training. In the United States, deceased human bodies are predominantly sourced through whole-body donation programs (BDPs) housed by academic institutions. Due to the lack of information regarding BDPs, the aim of this study was to gather information from US BDPs through a survey to better understand the donation process and standard operating procedures of these programs. In 2021, a Qualtrics survey was distributed to 125 BDPs and yielded responses from 72 program leaders. Collectively, these programs received more than 26,000 whole-body donations annually. Findings show that 70% typically receive enough donations to fit the needs of their institutions, 17% receive a surplus of donations, and 13% receive too few donations. Sixty-eight percent of programs permit next of kin body donation regularly or in times of need, and 44% allow next of kin to make changes to a donor's donation form after death. On average, over 85% of the registered donor population is composed of white individuals, and only 6 institutions have methods in place to promote diversity among their donor population. Overall, there is considerable variability in the operation of BDPs across the United States. These findings can be used to make recommendations about donor enrollment and program operations to ultimately improve the donation process. Future research needs to investigate the opinions and preferences of body donors along with their next of kin on the body donation process and associated policies.

KEYWORDS

anatomy, body donation, clinical training, ethics, medical education, oversight

INTRODUCTION

Dissections of deceased human bodies have been conducted for centuries in order to learn about human anatomy, conduct

research, and improve clinical practice. Anatomists, clinicians, and students all tout the importance of performing human dissection as a hands-on learning experience that provides a deeper understanding of the three-dimensional relationships between

Previous presentations: The information gathered from this study was shared in part as a poster presentation at the American Association for Anatomy conference in Philadelphia, PA in March of 2022.

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anatomical structures.¹⁻⁵ Further, dissection can impart additional knowledge and skills for students beyond the anatomical content, such as teamwork, respect for the human body, and helping students prepare emotionally for their future clinical work.⁶ This work could not be conducted without anatomical gifts from human body donors, and universities across the United States are reliant on the successful operations of their body donation programs (BDPs) to source the donations that make their educational and research endeavors possible.

Procurement of human bodies for educational and research purposes has a checkered history. In the 18th and 19th centuries, grave robbing and the use of unclaimed bodies became commonplace in order to supply deceased individuals for anatomical study.⁷ In the United States, bodies are now primarily received through willful donation by individuals or their families.⁸⁻¹⁰ These donations may be made to BDPs housed by universities across the country or to state anatomical boards which oversee state-wide donations.¹¹ Alternatively, there are also private, for-profit companies that specialize in procuring anatomical materials. These companies typically follow a for-profit business model to sell donated anatomical materials for a fee to institutions in need, and are sometimes referred to as "body brokers." Like many BDPs associated with universities and state anatomical boards, for-profit companies cover many costs for the donor and their family, take care of paperwork, and return cremated remains to loved ones.¹² However, unlike nonprofit organizations, the fee charged to those who buy the donated bodies is greater than the cost to the organization, resulting in a profit. Additionally, many for-profit donation companies have surgical training facilities associated with their programs as another means of producing profits.¹³ With minimal regulatory or ethical guidance, these companies have fallen under scrutiny. Citing concerns about unsafe shipping of body parts, illegal storage and selling of human bodies, and undignified disposal of remains, for-profit donation companies have been criticized by journalists and anatomists as well as by anatomical societies.^{8,11,12,14,15} The focus of this study is on not-for-profit BDPs.

Previous studies involving BDPs around the world have examined donor demographics to better understand the characteristics of those that commonly enroll as body donors.¹⁶⁻²⁴ These findings have commonly shown that donors are predominately white, educated, women over the age of 60.^{19,21,23-25} Within individual programs in the United States, researchers have described a lack of racial diversity in the donor population, with a disproportionately high number of white donors comprising registries of BDPs in Massachusetts,¹⁸ Mississippi,²⁴ Ohio,²³ and Rhode Island.²² While these studies have examined characteristics of body donors within specific BDPs, the racial composition of the United States donor pool as a whole has yet to be explored, and provides a potential avenue for outreach to increase donations nationally.

While many donors learn about donation through word of mouth,^{24,26} the use of direct advertisement of BDPs to donors and their families to solicit donations has been described as problematic in certain settings such as hospice¹² and the general public has been found to have poor awareness of the body donation enrollment

process.²⁷ In many countries around the world, the availability of human body donors has been reportedly low.^{9,28-31} As a result of these shortages, universities have either had to forgo the dissection experience, rely on unclaimed bodies for dissection, or import bodies from other countries to satisfy educational needs.^{9,31} Decades ago, researchers estimated that at least 12,000-15,000 body donors were required in the United States for medical education and research purposes each year,³² but current needs and the availability of donations to meet these needs is unclear. Not only do the needs of various universities vary, but evidence has shown that their approach to donation varies as well. A previous study that requested information about policies and procedures from 13 BDPs associated with US medical schools revealed great variability in donation criteria among institutions as well as considerable differences in preparation guidelines and disposition methods.³²

Many variations among programs may occur as a result of the lack of national legislation to regulate body donation in the United States, requiring BDPs to self-regulate and provide their own institutional oversight. Currently, American BDPs are required to adhere to donation guidelines set forth in the Uniform Anatomical Gift Act (UAGA), as well as any state legislation specific to the location of the institution. The UAGA was passed in the United States in 1968 (and later revised in 1987 and 2006) to regulate the donation of human tissues to science, medicine, and education.³³ However, the UAGA was initially devised to resolve inconsistencies in regard to organ procurement, and does not provide extensive detail regarding standard operating procedures (SOPs) for BDPs in the United States.^{8,34,35} Although some BDPs have robust internal oversight committees,³⁶ reportedly only 60% of BDPs have an ethical approval process to evaluate research projects involving human body donors.³⁷ Further, there is no established national regulatory body to oversee US BDPs to ensure that they are adhering to the UAGA and upholding ethical standards, resulting in a legislative vacuum that allows programs to operate largely unsupervised.^{8,34,38} Recommendations about ethical practices for BDPs have been proposed by the American Association of Clinical Anatomists (AACA), the International Federation of Associations of Anatomists (IFAA), and the American Association for Anatomy (AAA), but overall, these best practices are not legally mandated in the United States.³⁹⁻⁴¹ The recommendations made by these anatomical societies tend to follow an ethical framework to support the dignity of the donor and honor their anatomical gift. However, questions remain about how ethical guidelines can be effectively implemented, and further, how they may be nationally enforced. Prior research has shed light on some of the differences between BDPs across the United States and shown that there is little uniformity and compliance among American BDPs regarding the recommendations set forth by anatomical societies regarding consent and oversight.^{37,42,43} For example, despite recommendations to describe all possible uses of donated bodies to achieve fully informed consent,^{39,44} a review of US BDP consent forms revealed that these documents rarely provided specific language about use beyond education and research, and only 28% of these forms indicated that body parts may be permanently retained

by the institution.⁴³ This work highlights informational gaps found in many body donation consent forms, raising questions about just how informed donors and next of kin truly are when enrolling in these programs, and whether these programs are supporting donor autonomy to the best of their ability.^{42,43}

Additionally, the way in which BDPs handle donor anonymity varies among programs. A survey of BDPs showed that there is great variability in the amount of information provided to students about their donors, ranging from no information at all to universities disclosing the full names and complete health history of the donors to their students.⁴⁵ Although there is no national standard for sharing donor information, a study conducted at the University of Michigan showed that both anatomy students and donors were generally in support of providing detailed information about the donor's life in order to facilitate a closer relationship in the anatomy laboratory.⁴⁶ It is also important to consider donor consent and anonymity regarding photographs taken of human body donors. Prior research has shown that although only 11 BDPs disclosed that photos may be taken of donors on their consent forms, 53 institutions reportedly allow photography of donors, displaying inconsistencies in what registrants are told versus what programs permit.^{37,43} One of the few commonalities that has been found to be shared by BDPs across the United States is the desire to host a memorial ceremony to express gratitude.⁴⁷ The prevalence of these ceremonies highlights the growing emphasis on honoring the gift of whole-body donors across the country, in recognition of the important role that donors play in anatomical education.

To our knowledge, based on a PubMed search in February 2021 for studies involving US BDPs, this is the first published study of its kind to distribute a comprehensive survey to all BDPs in the United States. The purpose of this study was to survey program directors of BDPs associated with US institutions and state anatomical boards in order to gather information about the landscape of body donation in the United States, including the number of donations received and need for donations, as well as the racial composition of the donor pool. Additionally, given the lack of detailed national legislature and oversight in the United States, we sought to better understand differences between the SOPs of American BDPs, such as their criteria for donation, covered costs, donor anonymity policies, and methods of disposition. The survey questions were divided into general categories to gain a deeper understanding of the similarities and differences between American BDPs in an effort to elucidate the current national status of body donation.

MATERIALS AND METHODS

Survey design

A survey was administered to BDP directors and coordinators that run the whole-BDPs associated with universities across the United States. The survey consisted of a minimum of 39 questions with a mixed methods approach to gather information about SOPs.

Depending upon respondent answers, follow-up survey questions were revealed to gather **additional information** for a maximum of 58 total questions. Some questions required numerical answers, while others invited participants to explain procedures through open-answer text descriptions. For the purpose of this study, "donor applications" referred to completed enrollment forms submitted by individuals to register with a BDP with the intent to donate at the time of death, while "admitted donors" referred to individuals that have passed and whose bodies have been accepted into the care and supervision of the BDP. The questions addressed the process of donor recruitment, registration and admittance, annual numbers of donations over time, institutional policies for working with whole-body donors, and family or next of kin involvement in the donation process. The combination of question types allowed participants to not only answer multiple-choice questions about their institution's BDP, but also provided the opportunity to expand upon things like institutional policies, restrictions, and consent form options through written descriptions to allow researchers to gain a more detailed explanation of how these programs operate. The study was piloted by distributing the survey via email to the eight universities in the state of Ohio that have their own BDP. The pilot survey received six responses and the participants' feedback was used to revise and improve the questionnaire.

Participants

The survey was distributed by email to 125 BDPs affiliated with universities in the United States. The list of programs was obtained from the University of Florida's list of US BDPs compiled by the Anatomical Board of the State of Florida, which is available online at <https://anatbd.acb.med.ufl.edu/usprograms/>, and updates were made as needed. The contact information for the BDP directors and/or coordinators was verified through each individual institution's BDP website. Participants were informed of the purpose of the research project via email. They were notified that participation in the survey was voluntary and that any data collected would remain anonymous. This study was determined as exempt from review by the Ohio State University Institutional Review Board.

Data collection

The survey was created using Qualtrics XM (Qualtrics, Provo, UT) and distributed via email in October 2021. Participants were given 2 weeks to respond, and follow-up emails were sent at the end of this 2-week period. Microsoft Excel Version 16.57 (Microsoft Corp., Redmond, WA) was used to compile the data gathered from this survey for statistical analyses. Similarities and differences between programs were analyzed using descriptive statistics such as mean (*M*), standard deviation (*SD*), median, range, and percentage. The data from this project have been previously published as an abstract and presented as a poster.⁴⁸

RESULTS

Body donation programs

Results were gathered from 72 institutions, representing 38 states and Washington, DC. Surveys were predominantly completed by BDP leaders such as directors and coordinators, while some were completed by anatomy professors or department chairs. Some personnel did not answer all survey questions. These BDPs had been operating for varying lengths of time ranging from 5 to 120 years, with an average length of 55 years.

Donation numbers

At the time of survey completion, all respondents ($n=72$) were accepting body donation applications as well as admitting donated bodies into their BDP. The most commonly used strategy for raising awareness about the program was word of mouth ($n=68$, 94%), with additional strategies including healthcare providers ($n=43$, 60%), outreach efforts ($n=30$, 42%), marketing ($n=24$, 33%), other ($n=18$, 25%), and advertisements ($n=5$, 7%), as illustrated in Figure 1. Some strategies in the “other” category were described as networking with hospice services, BDP websites, donor memorial services, or donor monuments.

The size and scope of these programs varied greatly, illustrated by the wide range in the number of applications and donations

received by institutions across the country. The total number of body donation applications received annually by all BDPs combined was 26,524 (range=5–5000, $M=408$, median=200, $SD=319.5$). The total number of bodies admitted annually into the care of these BDPs was 11,710 (range=5–1500, $M=172$, median=100, $SD=227.3$).

The percentage of registered donors that belong to each racial group was as follows: white (86.5%), black or African American (6.5%), Asian (3%), Hispanic (2.5%), American Indian or Alaskan Native (0.2%), Native Hawaiian or Pacific Islander (0.5%), and other (0.9%). These percentages were weighted based on the number of applications received by each institution, and illustrated in Figure 2 in comparison to the racial demographics of the US population.⁴⁹ Nine percent of respondents ($n=6$) reported that they have methods in place to promote diversity among their donor population. Some of these methods include targeted outreach through community groups and faith organizations, providing consent forms in multiple languages, and offering translation services.

Regarding trends in annual donations in the 5 years preceding the COVID-19 pandemic, 43% ($n=30$) stated there was increase in donations, 43% ($n=30$) stated there was no change in the number of annual donations, and 13% ($n=9$) experienced a decrease in donations. When asked how the annual number of body donors admitted into each BDP suit institutional needs, 17% ($n=11$) said donations exceed their needs, 70% ($n=44$) said donations meet their needs, and 13% ($n=8$) said donations are below the needs of their institution.

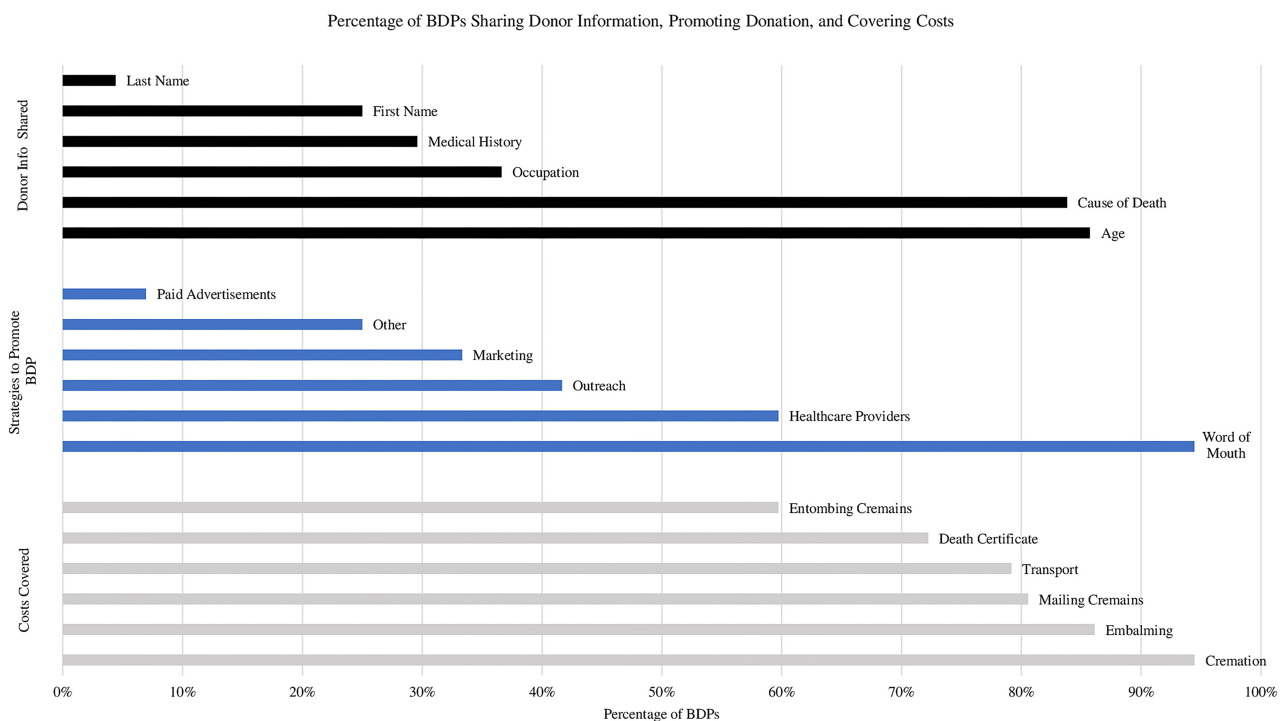


FIGURE 1 The percentage of BDPs that share specific donor information with students and researchers, employ various strategies to spread awareness about their program, and cover costs associated with donation.

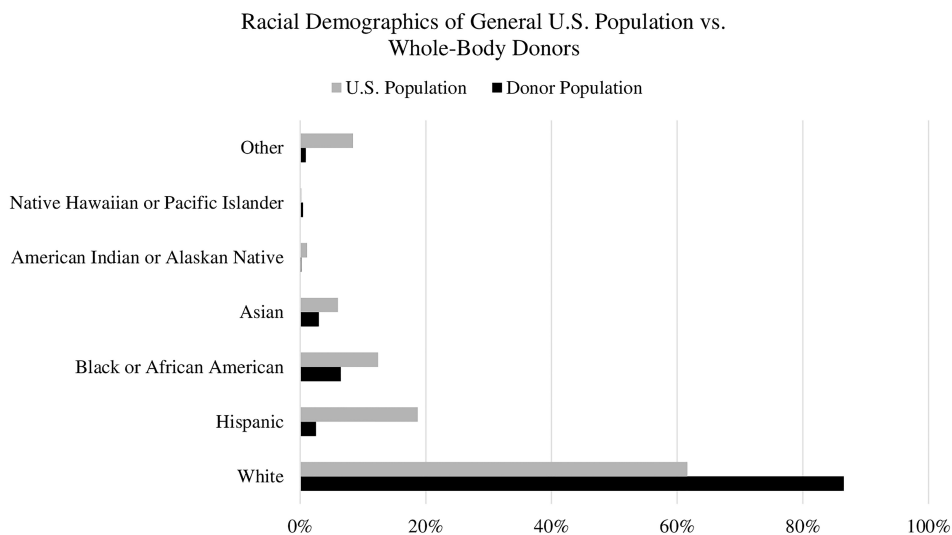


FIGURE 2 The racial demographics of the US population⁴⁹ compared to the proportion of whole-body donors from each racial group.

TABLE 1 Donation requirements as specified by BDPs.

Requirement	Number of BDPs (%)	Range	M	SD
Min. age (years)	51 (86)	16–25	18.4	1.5
Max. age (years)	2 (3)	100–110	105	7.1
Min. weight (lbs/BMI)	25 (36)	70–100/12–20	91.5/16.9	11.1/2.3
Max. weight (lbs/BMI)	67 (94)	175–350/29–30	237.2/31.4	33.3/1.9
Location (miles)	44 (72)	30–275	124.6	68.0

Note: This table demonstrates the number of BDPs that list each of the specified qualities as a requirement for admittance into their program. Location describes the distance between the donor and the receiving institution.

Abbreviations: BMI, body mass index; lbs, pounds; M, mean; SD, standard deviation.

Donation requirements

Donation requirements varied by institution, and are described in Table 1. A minimum age was required by 86% ($n = 51$) of institutions, while a maximum age was required by only 3% ($n = 2$) of institutions. A majority (88%, $n = 44$) of those requiring a minimum age specified the age as 18. For maximum ages, one institution stated the maximum age was 100 and for the other it was 110 years old. Donations of fetal materials were accepted by 10% ($n = 7$) of institutions.

Weight is another requirement specified by many BDPs. Some institutions request this information in pounds, while others calculate body mass index (BMI). A minimum weight for donation was required by 36% ($n = 25$) of BDPs, while a maximum weight was required by 94% ($n = 67$). A geographic requirement for admittance into the BDP was specified by 72% ($n = 44$) of programs. Of those that have this requirement, 17 institutions (38%) noted that the donor must pass away in the same state as the BDP in order to be accepted. Some admit donations from neighboring states, while others stated that donations would only be admitted within a certain radius of the institution, as shown in Table 1. A few respondents noted that if the donor was outside of the geographic requirement specified by the

university, the donation would still be admitted if the donor's family incurred the transportation costs.

Many diseases or conditions may disqualify a donor from being admitted into a BDP. The percentage of programs that deny donations in the event of these conditions can be found in Figure 3. Conditions in the "other" category specified by BDPs that may preclude a donation from being accepted include gangrene, necrotizing fasciitis, decubitus ulcers, sepsis, severe dehydration, herpes, jaundice, or amputations.

Costs

The results showed that just two universities (3%) charge an upfront fee to enroll in their program. One program stated this fee as \$100, while the other declined to specify. Many BDPs cover the costs associated with donation. The percentage of programs that cover each cost (Figure 1) is as follows: cremation (94%, $n = 68$), embalming (86%, $n = 62$), mailing cremated remains (81%, $n = 58$), transportation of the body (79%, $n = 57$), preparation of death certificate (72%, $n = 52$), and entombing cremated remains (60%, $n = 43$).

Conditions or Diseases Preventing Admittance

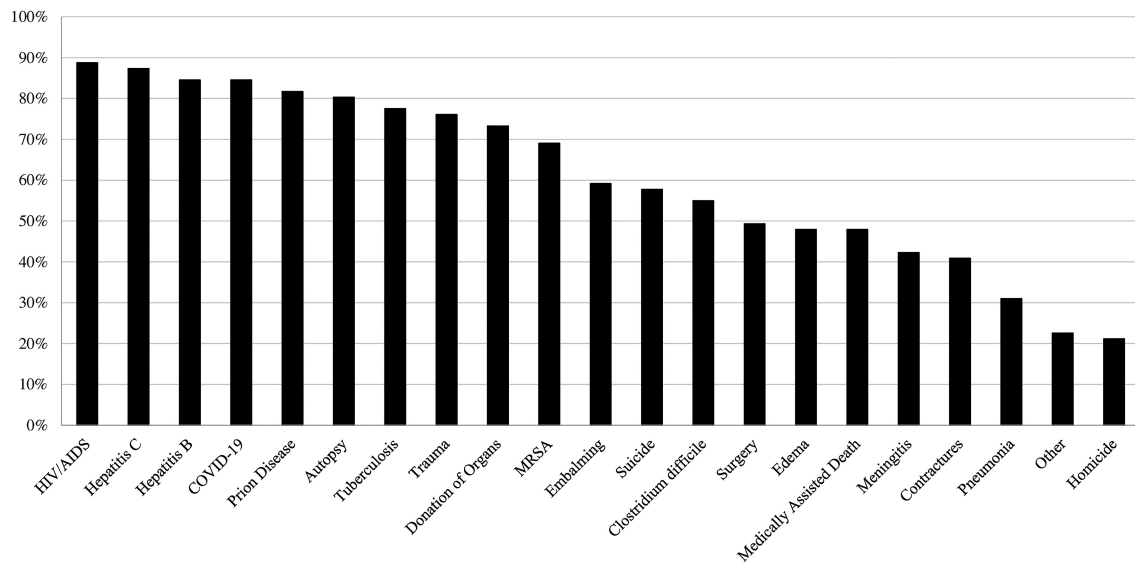


FIGURE 3 The percentage of BDPs that will not admit a donor into the program at the time of death based on the presence of these diseases or conditions.

External sources

Of those that responded to the survey, 29% ($n=17$) responded that they receive bodies from sources outside of their institutional donation program. Two specified that they do this for fresh tissues only. Another commented that they did not need to use external sources for donations previously, but now need to do so in order to accommodate their institutional needs because their donation numbers were impacted by the COVID-19 pandemic. Of those that elected to name their source, four purchased bodies from a for-profit body donation company, while others sourced bodies from nearby institutions that have their own BDP. The number of whole bodies sourced externally by these institutions each year ranged from 10 to 40, with an average of 22 whole bodies per annum.

Survey results showed that 43% ($n=30$) of respondents were aware of other departments at their institution that receive cadaveric materials from sources outside of their BDP. Sixteen BDP leaders (24%) stated that they are involved with monitoring these externally sourced anatomical materials.

Next of kin donation

One quarter of respondents ($n=17$, 25%) do not permit next of kin to make a body donation on the donor's behalf. Nearly half (48%) of the BDPs surveyed do allow this, and 20% only allow next of kin donation in certain circumstances. Of the programs that allow next of kin donation, 27% ($n=12$) require proof of the donor's wishes, such as a living will. The results also showed that 44% ($n=29$) of programs allow next of kin to make changes to the donor's donation enrollment consent form after the donor has passed. These changes predominantly involve disposition of the donor's remains, such as

changing the designated recipient of the remains or changing the method of disposition.

Retention and work with donors

Six institutions allow donors to dictate the maximum length that their body is retained by the university after death. The options provided to donors ranged from 1 year to indefinite retention. Eight respondents (11%) allow donors to opt out of types of education or research involving their donated remains.

BDPs varied in the amount of donor information that is provided to those that conduct work with the donors (Figure 1). The most commonly provided piece of information was age (86%, $n=62$), followed by cause of death (83%, $n=60$). Three institutions provided the last name of the donor to students or researchers. Other types of information shared with end users included self-reported gender identity, education, and smoking history. During dissection, 44 BDPs (77%) require that those working with the donor keep dissected remains in individual tissue containers without commingling.

Photo policies

Nearly three quarters of BDPs (73%, $n=44$) do not allow students to take photos or videos, while 22% ($n=13$) allow this only with prior approval. However, only 10% ($n=6$) of institutions do not allow faculty to take photos of body donors. Sixteen institutions (27%) allow faculty to do so, and 62% ($n=37$) allow faculty or staff to take photos and videos if they have prior approval. The approval process varies by institution, but generally requires a written request to the director of the BDP and a signed agreement about usage of the photos.

Disposition of donor's remains

Of the programs surveyed, 93% ($n=65$) were willing and able to return a donor's cremated remains to loved ones when the work with the donor has concluded. Nearly half (51%, $n=37$) of the BDP personnel that responded also provide an option to inter the cremains at a communal cemetery. Other options include scattering cremains at sea or burial at a veteran's cemetery, if eligible. Nearly all respondents (98%, $n=55$) host a memorial service to commemorate donors.

DISCUSSION

The findings of our study show that overall most BDPs across the United States are receiving a sufficient number of donations to satisfy the educational and research endeavors of each institution. Demographic analyses showed a disproportionately high percentage of white donors (86%) relative to the general US population, which leads to questions about equal access to and awareness of donation. Results showed great variability in the SOPs of these programs and how they function. One of the main differences is the criteria for admittance into a BDP. Age, weight, and geographic criteria varied widely across programs, and as seen in [Figure 3](#), there was not a single disease that would universally prevent a registered donor from being admitted into all programs. Registrants are given differing options during the enrollment consent process and are rarely able to customize the experience to suit their values. Only six institutions allow donors to dictate the length that their body is retained by the university, and eight programs allow donors to opt out of specific projects involving their donation. While next of kin donation is commonly permitted, most BDPs do not require proof of a donor's wishes before accepting this type of donation. Survey results showed that the level of oversight varies among institutions, with some programs allowing students and faculty to take photos of donors without approval. This lack of oversight may pose challenges to ensuring the ethical treatment of human body donors.

Supply and demand

One stark difference between American BDPs is the size of the programs. For example, one program admits just five donors per year, while another receives upwards of 5000 donations annually and distributes these donations to universities throughout the state. Collectively, the 72 participating programs admit nearly 12,000 human body donors into their care each year. Results showed that 70% of programs reportedly receive a sufficient number of donations to meet their institutional needs, with 17% even reporting a surplus of donations. BDPs experiencing donations that exceed their needs may temporarily stop accepting donation applications, turn away registered donors at the time of death, store donations for future use in the event of a shortage, or share donations with other institutions.

Additionally, 13% of institutions do not receive a sufficient number of whole-body donations to suit their institutional needs. This may explain why over a quarter of BDPs receive bodies from outside of their programs, and supplement their donations with additional bodies from neighboring institutional BDPs or for-profit companies. Purchasing bodies is problematic given the growing concerns about body brokers' unethical conduct.^{8,11,12,15} Increased communication between BDPs across the country could allow for programs with a surplus of donors to share donations with those that do not have enough, thereby reducing the need to engage with for-profit companies. While transporting donors to a university in the same city is likely achievable, transporting donors across state lines may be more challenging due to differing state laws and high transport costs. Beyond feasibility, it is important that donors are aware that their donation may be shared with other institutions, and this should be explicitly stated as part of the consent process so that potential donors can choose if they are comfortable with this option, or if they would like their donation to only be utilized by the institution to which the donation was originally made.

Results from this study showed that over 26,000 Americans are electing to register as whole-body donors each year and making the choice to bequeath their bodies after death. While each program receives a median of 200 donation applications annually, just half of that number are admitted into their care each year. There are a few possible explanations for why application numbers do not exactly mirror donation numbers. First, years often pass between the time of registration and death.⁵⁰ Research has shown that on average, people elect to enroll in a donation program in their 60s.^{19,21,24} This is consistent with research that has shown that this is the time when many individuals start contemplating their own mortality and reflecting on their societal contributions.⁵¹ Given that the average life expectancy for US adults is 76 years old,⁵² it is likely that years or even multiple decades pass between enrollment and death. Forty-three percent of programs reported an increase in donation applications in the 5 years preceding COVID-19, and thus these programs will likely see an increase in the number of donations admitted in the coming decade as those registrants age and pass away.

Another possible explanation for the discrepancy between application and admittance numbers is that not all registrants end up donating at the time of death. In order for a donation to be completed, BDPs are often reliant upon notification from a registrant's relatives that a donor has passed away. At the time of death, family members may donate their loved one's body to another program if the registrant has moved or died out of state, or decline to fulfill the wish to donate at all. It is likely that BDP registries across the nation are full of individuals who have already passed, and the institution was never notified of their deaths.

The "acceptable" donation

Even if BDP personnel are notified at the time of a registrant's passing, a donation may be declined admittance into a program based on

a set of strict acceptance criteria relating to age, weight, location, cause of death, and the presence of certain diseases or conditions. Results showed wide variability in the acceptance criteria required by these BDPs, suggesting that these parameters are not universally defined and may differ based on institutional resources or statewide regulations. For example, the maximum admissible weight ranged from 175 to 300 pounds. These restrictions may be prohibitive to a large percentage of the American public, given that the mean weight for Americans is 200 pounds for men and 170 pounds for women, and two thirds of the population has a BMI that classifies them as overweight or obese.⁵³ Such restrictions may be in place to ensure that donors can fit on the dissection table or to avoid risk of injury to students or researchers that must manipulate these bodies during their work.⁵⁴ Other criteria, such as the location of death, are likely related to logistical difficulties and increased costs that may be incurred by the program.

Furthermore, diseases that a donor may have contracted during life and his or her manner of death may also preclude a donation from admittance into a BDP. Findings showed that some causes of death that result in denial from many BDPs include death during surgery, traumatic deaths, or homicide. The reason for denial for some of these reasons is likely because causes of death that interrupt the intact nature of the body (such as a car accident or gunshot wound) make it difficult to perform dissection and study the organs.⁵⁵ Additionally, it can be emotionally disturbing for those working with donors to be faced with a donor that has endured a violent death.⁵⁶ Individuals that have donated organs, undergone autopsy, or been embalmed outside of the BDP are frequently denied. Thus, it is important that these qualifications are clearly communicated to family members so that they are aware that performing such actions after a registrant's death may prevent their donation from being admitted.

In the literature, suggested disease exclusion criteria include human immunodeficiency virus (HIV), hepatitis (B, C), tuberculosis, methicillin-resistant *Staphylococcus aureus* (MRSA), and Creutzfeldt-Jakob disease.⁵⁷ However, results from this study showed some programs in the United States still admit donors that have contracted these diseases—such as the eight programs that reportedly do not deny admittance even if a donor has tested positive for HIV. Most diseases that prevented donors from participating are contagious, even after death. For example, infectious HIV has been reportedly found in the blood, pericardial fluid, and pleural fluid of patients up to 16 days postmortem.⁵⁸ Thus, it is understandable that programs would screen for such diseases and prevent any donors that are found positive from being utilized in order to prevent the spread of disease to those that will work with these bodies. It is puzzling that given that the transmissibility of such diseases is consistent across the country, there is inconsistency in whether donors with these diseases are admitted or not depending on the institution. In fact, there is not a single disease or cause of death that universally prevents a donor from being admitted into all BDPs. It is unclear whether programs that admit donors with diseases like hepatitis and HIV have safety measures in place for those working with these donors (such as personal protective equipment), if they are utilizing these

donors for specific research projects to study these conditions, or if these institutions are being negligent about the safety risk to those working with these donors. Further research is needed to better understand how such donations are handled. It would be valuable to create a national, standardized list of exclusionary criteria for whole-body donations that is rooted in research on postmortem contagion. The health and safety of those working with whole-body donors must be prioritized.

Donor diversity

One interesting finding from this study was that the proportion of donors from each specific racial group did not closely match the racial diversity present in the American population, though it is of value to note that reports on the racial identity of donors from participating institutions are likely estimates. According to the US Census, approximately 62% of the American population is white,⁴⁹ while our survey found that over 86% of registered donors identify as white. Conversely, there are fewer black, Asian, and Hispanic donors than would be expected if the donor population was a representative sample of the American population. This can potentially be explained by minority groups' general distrust of healthcare and biomedical research due to these groups being exploited in the past.^{59–61} Cultural and religious factors may also partially explain the hesitancy from certain groups to participate in donation.^{26,62–65} Also, since the predominant way that these BDPs spread awareness of their programs is through word of mouth, it is possible that there may be a lack of awareness of this option in certain communities. Only five respondents reported efforts to promote diversity among their donor populations. BDP directors may attempt to diversify their donor pool by imitating the methods of the Minority Organ Tissue Transplant Education Program (MOTTEP). In the 1990s, MOTTEP used strategies such as community outreach programming, partnerships with voter registration, and collaboration with faith-based organizations to increase minority enrollment in organ donation.⁶⁶ As a result of this program, organ donations by minorities increased from 8 to 10 organ donors per million in 1982 to 35 organ donors per million in 2002. If other BDPs wish to increase diversity among their donor populations and provide equal opportunity for people from all racial backgrounds to participate in whole-body donation, they may employ such strategies in order to raise awareness about body donation and build trust within these communities.

Consent in life and death

The BDP enrollment process allows an individual to exercise autonomy by consenting to donation of their body after death. The difficulty posed by body donation compared to other forms of medical bodily autonomy is that once a donor has passed, they are no longer able to express consent or make their wishes known. As analyses of the disclosures in donor enrollment consent forms have shown, there is significant variation in

the consent process for body donation, and this has drawn into question whether some of the donation forms were truly gathering *informed* consent from prospective donors and providing appropriate disclosures.^{42,43} Similar findings were brought to light in this study when analyzing the options provided to donors during the consent process.⁴³ A majority of BDPs do not allow donors to dictate the length that their body is retained by the university after death, or to opt out of certain types of education or research involving their donated remains. Some programs noted that they may accommodate special requests by donors, but these options are not readily available during the consent process, limiting a donor's ability to express their wishes for what will be done with their donation after death. Donors in the United States are generally asked to provide blanket consent to institutions as part of the enrollment process, rather than dictate with more specificity how their donation will be used and how long it will be kept. Although it can be difficult to provide donors with many options and may put strain on the BDP to accommodate individual requests, it is important to ensure informed consent and make sure that detailed information regarding the utilization and care of the donation is explicitly stated during the consent process. Future work may gather insight from whole-body donors to understand which options are most important to them during donor enrollment.

After a donor has passed, often their next of kin may act as a steward to ensure that the donor's wishes are fulfilled. This can pose an ethical challenge at times when there is a perceived discrepancy between what a donor wanted and what their loved one wants. It is then important to consider prioritization of consent. Based on the survey results, American BDPs face these challenges in different ways. Some institutions accept next of kin donations at all times, while others only allow this type of donation under certain circumstances, such as when donations are in short supply. In many European countries, next of kin donation is not legally permitted without written consent from the decedent during their life, such as in the last will or testament⁵⁰—however, this is not the case in the United States. Of those that allow next of kin donation, less than a third require proof of a donor's wishes. There is no agreed-upon ethical standard among programs about whether it is permissible for someone to make a whole-body donation on another's behalf, especially if there is no evidence that the decedent expressed desire to be a donor. Similarly, 44% of programs allow next of kin to make changes to the donation enrollment form after the donor's death, which could pose a potential violation of the donor's wishes that they initially stated upon enrollment. Further research is needed in order to understand if such changes are acceptable to the donors themselves, or if they feel this is a violation of their initial consent. BDP leaders must consider if their ethical obligations lie with the decedent or with the donor's family.

The cost of a gift

When someone elects to donate their body to a BDP, the associated costs may either be covered by the institution or paid by the donor's family. Although the costs covered by many BDPs may be a potential

motivator for donation,²⁴ additional costs may serve as a barrier to some individuals interested in donation. The IFAA recommends that possible costs that may be incurred by the donor's family and the costs that are to be paid by the institution are clearly communicated during the enrollment process.⁴¹ Two programs stated that they charge a fee to enroll as a body donor, which may pose a challenge to individuals that wish to register as a donor but are not in a financial position to do so. A majority of BDPs reported that they cover many of the costs associated with donation, including transport, embalming, and cremation. However, none of the costs associated with donation were universally covered by all respondents. BDPs may encourage donations from individuals from multiple socioeconomic classes by covering as many donation-associated costs as possible in order to alleviate the financial burden on the donor's family. Regardless of which costs BDPs are able to cover for their donors, transparency is key. Even if programs are not able to list the specific fee amounts due to fluctuating costs over time, it is important for BDP personnel to explicitly state estimated costs that are to be incurred by the donor and their family, as well as clearly communicate what costs will need to be paid by the family in the event that a donation is not admitted into the program at the time of death.

Oversight

While a donated body is in the care of a BDP, it is that the program's responsibility to ensure that the donor is being treated with respect and that the work is conducted in an ethical manner. The revised UAGA and state laws mainly specify how donations are to be collected and disposed of, but scarcely comment on ethical conduct for working with body donors.³⁸ Research conducted on human body donors is not required to be reviewed by Institutional Review Boards because studies involving the deceased are not classified as human subjects research.³⁴ Thus, oversight and regulation have traditionally fallen upon the BDP personnel themselves to ensure ethical practice. The AAA and IFAA recommend that each institution create an oversight committee to oversee daily operations of the BDP and promote the ethical treatment of human body donors,^{67,68} and some institutions have effectively implemented such regulatory policies.³⁶ However, survey results revealed inconsistencies regarding oversight.

A majority of programs have channels in place to oversee the use of bodies that were acquired through their BDP, but the protocol varied among institutions. The IFAA guidelines regarding human tissue image acquisition state that information regarding images of a donor's body should be disclosed during the informed consent process and that programs should have an oversight committee in place to provide approval for processes regarding image acquisition, use, storage and destruction.⁶⁸ Results of this study showed that some BDPs allowed students and faculty to take photos or videos of human body donors without any prior approval, while others never allow any photographic documentation of donors or may require an extensive approval process to do so. While some programs had a robust review process for research projects involving donors that required an application and evaluation from an oversight

committee or approval from personnel at multiple levels, many respondents stated that their program requires approval from only one individual to conduct research on a human body donor. The person solely in charge of granting or denying approval for these projects was most commonly listed as the BDP director, but sometimes the responsibility fell to a laboratory manager or department chair. These results show that many BDPs do not adhere to the anatomical society guidelines which suggest that projects are evaluated by a multidisciplinary committee that convenes for the purpose of oversight.³⁹ While decision making by committee may be a more time-consuming and arduous process, it also allows for input from multiple voices with various backgrounds and perspectives, and distributes responsibility among multiple parties rather than placing the onus of ethical evaluation solely on one individual.⁶⁹ Given the lack of national oversight, institutional oversight is particularly important to guarantee ethical treatment of human body donors and ensure that donors are protected while under the care of the BDP. Additionally, 30 respondents reported that they are aware of other departments within the institution that source tissues of the deceased from outside of their BDP, but only 16 are involved with monitoring these materials. While the source of such materials is unclear, it is possible that these departments are utilizing unclaimed bodies or purchasing human tissues from for-profit companies, both of which are problematic.^{8,10,12,14,70,71} We encourage BDPs to act as the sole source and regulatory authority for all human tissues utilized within their institution in order to reduce the need for unethical procurement of these materials and ensure proper conduct. More stringent management and standardization of oversight protocols across institutions can ensure that body donors are being uniformly treated with dignity and respect, regardless of who receives their donation.

Concluding work with donors

One way that BDPs may honor their donors is by respectful disposition of remains, and practices to celebrate the memory of donors that have participated in the program. When the work with the donor has concluded, a majority of the BDPs surveyed were willing and able to return cremated remains to donor's loved ones, but a few do not offer this option. Given that so many programs provide this service, it seems that the BDPs that do not offer to do so are unwilling to offer this option to donors' families, potentially based on increased costs or challenging logistics. If the programs that do not currently offer this option started to do so, it may incentivize more donors to enroll, knowing that their cremated remains will be returned. Annual memorial services were held by all institutions except one. Despite the vast differences in the SOPs seen among these BDPs in the United States, memorial services are a nearly universal way that students, researchers, and donors' loved ones can come together to honor the gift of whole-body donation and express gratitude for this experience.

The future of BDPs

In the future, it is important that BDPs create guidelines, protocols, and procedures that align with institutional resources while upholding

the recommendations made by anatomical societies and acting to best support human body donors and their next of kin. When making decisions about which donations will be admitted into the program, universities should not only consider their institutional resources and ability to accept donors of varying size or from different locations, but also weigh the benefits and potential risks posed to those working with the body donors. Open communication between neighboring BDPs is recommended so that those with more resources or a surplus of donations may share with institutions that do not receive enough donations to fit their needs. If university-affiliated BDPs work together to share donations, there may be a reduced need to purchase bodies from for-profit companies because shortages can be readily addressed.

Despite varying legal requirements across jurisdictions, it is important that BDPs center ethical conduct when making choices about operational protocols or working with human body donors. When creating donation consent forms, donor autonomy should be prioritized. More work is needed to better understand the donor perspective and which options they feel are important to have during the consent process. Regardless of the options given to donors, enrollment forms should be as explicit as possible when describing the donation process in order to ensure informed consent.

As recommended by the various anatomical societies,^{39–41} it is important for BDPs to have an oversight committee to account for the lack of oversight on the national, state, and university levels, yet results showed that many BDPs do not have such regulatory protocols in place. The oversight committee should be responsible for reviewing proposed research projects involving human body donors to ensure ethical conduct and nonmaleficence, however, self-supervision at the university level may not go far enough to establish accountability for these programs. Thus, the creation of a state or federal governing body to provide comprehensive, standardized oversight throughout the United States is recommended.

Many programs were found to cover costs associated with death and donation, such as the cost of embalming and cremation. In order to encourage donations, it would be helpful for BDPs to continue to cover as many costs associated with donation as is financially feasible for the institution. Charging a fee to enroll as a body donor may limit the ability for certain populations to participate in the program.

Further, results revealed a lack of racial diversity among American body donors, with donation registries primarily composed of white donors across the country. It is imperative that institutions work to grow their programs and promote the option of body donation across diverse communities so that those from all backgrounds have the opportunity to participate. Researchers, students, and clinicians can all benefit from increased diversity in the donor population so that it more closely mirrors that of the communities surrounding these institutions.

Finally, BDPs should continue to find ways to honor their donors as an expression of gratitude for their gift. This can be accomplished by maximizing the gift of donation so that multiple parties may benefit, handling remains with respect, and memorializing the donors. BDPs can provide the option to return cremated remains to a donor's family members as well as invite loved ones to an annual memorial ceremony to share thanks for the gift of donation, and the few

programs that do not currently return remains or host a ceremony are encouraged to do so.

The information provided by the 72 participating BDP leaders illustrates the current status of donation in the United States, but it is important to note that 53 BDPs are not represented in these data. Self-regulation and the absence of national oversight has contributed to a lack of transparency among American BDPs. Due to the sensitive nature of the topic, some invited participants stated they were advised by leaders at their institution to not participate so as not to disclose institutional information. Additionally, even many that chose to participate elected to skip some survey questions. Although data gathered was anonymous and respondents were not required to state the name of their institution, some BDP leaders that were invited to take the survey may have felt uncomfortable sharing information about their programs, perhaps due to concerns about whether their SOPs will be scrutinized and compared to others in the country. It is our hope that the results presented in this article will prompt institutions across the nation, including those that declined to participate, to evaluate their own SOPs and identify potential opportunities for improvement.

Limitations

Given that this survey had a 57% response rate, the results gathered are not necessarily representative of all BDPs in the United States, and it is possible that there is nonresponse bias present. Also, due to the qualitative nature of some of the questions included in the survey, the responses gathered were often rough estimates or subjective to the experience of the individual answering the question. Respondents were not asked to provide proof of hard data to verify quantitative responses, such as the proportion of donors from various racial groups, thus these numbers could be estimates and therefore may be biased.

CONCLUSION

Overall, the results of the survey illustrate the current status of body donation in the United States and indicate that there is little to no standardization of the SOPs of the American BDPs sampled for this study. While many programs do not have trouble receiving enough donations to meet their institutional needs, others saw donor numbers fall and struggle to meet demands. Over 26,000 Americans enroll as body donors each year, and depending on where an individual chooses to enroll, they can expect a vastly different experience from the options given during the consent process, through the care and usage of their donation, and finally for the disposition of their remains. For this reason, it is important for BDPs to share experiences and develop best practices that could be utilized across the nation. It is also critical to develop policies and procedures that ensure oversight over the operation of BDPs at the institutional level while also advocating for state and national oversight. Establishing

accountability can further develop trust between BDPs, donors, and their next of kin while also ensuring ethical conduct. Finally, a lack of diversity was observed in the donor demographics reported by the BDPs. The racial homogeneity in the donor population is problematic, and further research is needed to explore the root of this finding and ways in which it may be addressed. Future investigation of the opinions and preferences of body donors may help elucidate which particular areas of improvement are most important to those who graciously elect to participate in these programs.

ACKNOWLEDGEMENTS

The authors acknowledge all of the body donation program personnel that completed our survey. They also thank Danielle Davis, Courtney Thiele, Dr. Gabriel Venne, and Amanda Gentile for their help with this project, as well as all members of the Balta Lab for their feedback and support. Finally, the authors thank the donors involved in our research and teaching in the past and in the years to come.

CONFLICT OF INTEREST STATEMENT

None.

ETHICS STATEMENT

Ethical approval for this project was waived by The Ohio State University Institutional Review Board.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Bagian LK, Wyatt TB, Mosley CF, Balta JY. Investigating the status of whole-body donation across the United States of America. *Anat Sci Educ.* 2024;17:646–659. <https://doi.org/10.1002/ase.2387>