


ORIGINAL COMMUNICATION

Human body donation: How informed are the donors?

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Abstract

Deceased human bodies are donated for education and research. Informed consent has become the standard for research on the living. A question could be asked on how informed are the donors and their families about the process before this generous gift is given. The aim of this study is to evaluate and compare the published donation forms used by body donation programs in the United States and assess them according to the guidelines published by the American Association of Clinical Anatomists. The findings of this study shows that the level of information given to donors and families, before consenting to whole body donation, varies greatly throughout the United States. Many of the forms fail to include the recommendations made by professional societies. Additional information needs to be added to whole body donation forms to better inform donors and families about the donation process, what happens to the body, and the final disposition of the bodies once studies are completed. Overall, it was concluded that in some cases consent is being obtained but much more needs to be done before institutions can claim to obtain informed consent.

KEYWORDS

anatomy, body donation, education, informed consent, research

1 | INTRODUCTION

Students and medical practitioners rely on the use of human body donors in order to learn and improve their skills and techniques in the care of the living (Ghosh, 2017). The manner in which these bodies have been obtained has varied over the past several hundred years (Ghosh, 2015). Whereas the current practice in the United States is generally to obtain consent from the donor or their family, it used to be common practice to use the bodies of executed criminals, those who died in jail, and the indigent (Habicht et al., 2018; Noel et al., 2020). Grave robbers were willing to engage in this nefarious practice in order to make money and were employed by anatomists, medical students, and physicians (Burrows, 2019). Prior to the enactment of the United Kingdom's Anatomy Act of 1832, the only legally available bodies for dissection were those of executed criminals

(Ghosh, 2015). The Anatomy Act permitted authorized parties, such as physicians, surgeons, anatomy professors, and medical students to have lawful possession of bodies so long as the individual had not made it known in writing or verbally during their illness that his body should not be used for anatomical purposes. In an effort to dissuade body snatching, the Act also stipulated the removal of corpses from graves to be unlawful (Burrows, 2019). Consent, or at least the absence of any objection of being donated, became the norm in Great Britain and the United States.

In the United States, in an effort to regulate the donation of organs, tissues, body parts, and bodies, the Uniform Anatomical Gift Act (UAGA) was passed in 1968 and was revised in 1987 and 2006. Prior to its passage, each state had its own laws regulating these donations. With the exception of a few modifications, every state and the District of Columbia adopted the 1968 UAGA. When the Act was

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revised in 1987, it created a uniform manner of obtaining consent from individuals and allowed for an individual's wishes to donate to take precedence over the wishes of their family. Primarily in an effort to increase the number of organ donations, the UAGA was revised in 2006. While no significant changes affecting body donation were made, the wishes of an individual to donate were reaffirmed to take precedence over those of their next of kin (DeVita & Caplan, 2006). The value of receiving consent from the donor or their family was becoming increasingly preferred across the nation.

In the United States, human bodies used for education and research are donated, either by the individual whose body will be donated or by their family. Bodies can be donated to educational institutions, state anatomical boards, and private body broker companies (Champney, 2016; Gunderman, 2008). Procedures vary among institutions and states and a list of 134 educational institutions with donor programs and state anatomical boards in the United States is available from the Anatomical Board of the State of Florida (ABSF, 2018).

Current recommendations as to what could be included on whole body donation forms have been made by the American Association of Clinical Anatomists (AACA), the International Federation of Associations of Anatomists (IFAA), and the American Association for Anatomy (AAA). The AACA's suggestions are in its 2017 "Best Practices Guide for Donation Programs" (AACA, 2017). In 2014, the IFAA published "Recommendations of good practice for the donation and study of human bodies and tissues for anatomical examination" (IFAA, 2014) and the AAA's website recommends donation literature to describe all possible uses of donor bodies at an institution (AAA, 2019). The aim of this study is to evaluate and compare the published donation forms used by body donation programs in the United States and assess them according to the guidelines published by the professional societies. Our goal is to improve the informed consent process that donors go through when donating their bodies to education and research. This can help improve the trust between body donors and the scientific community especially when it comes to donors who have historical distrust in science. Engaging in a discussion between scientists, donors, and families could help discover how current practices could be improved, what donors and families feel they should know in advance and compare and contrast consent for body donation to other types of medical research projects. The term "donation form" is used throughout this article acknowledging the similarity to "consent form."

2 | MATERIALS AND METHODS

2.1 | Collection of donation forms

Body donation forms were gathered from institutions and state anatomical boards in 46 states and Washington, DC. In states where educational institutions accept whole body donations, each institution has its own donation form. In states where an anatomical board coordinates body donations, a singular form is used throughout the state. The donation forms were obtained from the websites of

92 institutions and anatomical boards. Since not every institution posts their donation forms online, copies of 18 additional donation forms were received after being requested by email or telephone phone calls. Donation forms from 110 of the 134 institutions that accept body donations were included in the review. The forms came from every state and the District of Columbia, with the exceptions of Alaska, Delaware, and Wyoming, which do not have body donation programs, and one other state where access was not provided to their donation form. Data were not collected from private sector organizations. They were not included in the study as the focus of the research was to evaluate donation forms used at educational institutions.

2.2 | Review of consent forms

Currently, there are no laws or official guidelines on what information needs to be included in the donation form related to the donation of a human body. For the purpose of this study, a checklist was created using the "Best Practices Guide for Donation Programs" (AACA, 2017) published by American Association of Clinical Anatomists (AACA) in 2017. The checklist was divided into four main sections. Section one included general information about the donation process such as:

- a. Entity receiving the donation
- b. Donation time frame (including permanent teaching collections)
- c. Applicable fees, if any
- d. Serology testing/disclosure of test results
- e. Medical records/information gathering/release practices
- f. Results/rights to direct donation/release of information
- g. Possibility of declining the donation during the registration process or time of death and the potential reasons for decline

Section two was related to how and where the body may be used. Below is a list of items related to this section:

- a. Donation purpose/uses (research/education/plastination/display/training)
- b. End users of anatomical materials
- c. Use location (off campus/out of state) and possibility of transfer
- d. Images (acquisition/use)
- e. Preparation methodologies (recovery, disarticulation, embalming, plastination, etc.)

Section three was related to the authorization requirements and included the following:

- a. Age/competency status/classes of the donor or the person signing the forms on behalf of the donor if they are unable to self-register
- b. Two witness signatures, one being a disinterested witness in cases of before death donations made on behalf of another person.

The final section included information about the disposition of remains after donation (cremation, alkaline hydrolysis, burial,

scattering). Of the above, no tabulation results are included for two criteria. The first, end users of anatomical materials, was excluded because it was included in donation purpose/uses. The second, results/rights to direct donation/release of information, was excluded because it was a very broad criteria and from what could be found in the donation forms, results from anatomical studies are never shared with the family nor are donors or families allowed to direct the use of the donated body.

3 | RESULTS

When reviewing the 110 donation forms, it became clear that there are significant inconsistencies between different institutions. While many institutions had the donation form and all the relevant information in one package, many separated those documents making the information less accessible. Only the items included on the actual donation forms were included in the findings of this study. In cases where it was apparent the donation form was part of a single publication which included a Frequently Asked Question (FAQ) section and/or additional information, it was decided anything found in the publication was part of the donation document.

3.1 | General information about the donation process

Table 1 summarizes the findings from the general information section which included data on the entity receiving the donation, donation timeframe, applicable fees, serology testing, medical records and the possibility of decline of the donation. It is worth mentioning that 38% of donation forms mention the approximate length of time the body may be kept in the anatomical program. Moreover, 35% of the forms gave no indication that the donation may not be accepted at the time of death.

While donors are most commonly informed as to the potential length of time the body may be kept by the institution, one university

TABLE 1 Findings on general information in donation forms

General information	Percentage (n)
Entity receiving the donation	100% (110)
Donation time frame (including permanent teaching collections)	38/28% (42/31)
Applicable fees, if any	36% (40)
Serology testing/disclosure of test results	7% (8)
Medical records/information gathering/release practices	25% (27)
Possibility of declining the donation during the registration process or time of death and the potential reasons for decline	65% (71)

Note: The percentage (number) of institutions that included general information in their donation form.

provides this option: “This donation is authorized for ___ Up to 3 years, ___ 3 Years or longer.”

Generally, there are no expenses associated with the donation. However, one school requires donors acknowledge the following: “I understand it is necessary that the family or estate of the Donor defray the transportation fees and professional service fees of the Funeral Director in making the body available for scientific study.”

As serology testing and the review of donors' medical records are both required to determine donation eligibility upon death, one university includes the following statement, “The program will determine medical suitability of a donated body through a process that may include review of medical records, a medical or social history questionnaire and/or serology testing. Testing may include obtaining a blood sample to screen for Hepatitis B, Hepatitis C, HIV, or other communicable diseases that may render the body as medically unsuitable for donation. Results of tests will not be disclosed to the donor's designated survivor/responsible party but will be reported to the [state] Department of Health Services if mandated by law.”

One school's form, in disclosing that a body may not be accepted at the time of death, says the school “may decline an anatomical gift for any reason. Several reasons a donation may be denied include but are not limited to...” and then provides a substantial list of examples.

3.2 | Scope of utility

Table 2 summarizes how and where the body may be used in their donation form. As some institutions lend bodies to others, an assuring statement found on one donation form says, “Each individual donor is tracked throughout the process and returned to [the college] for individual cremation.” Another gives donors this option: “I (do) (do not) object to the utilization of my body for medical research and education in an approved institution outside the state.”

One university's image disclosure informs donors that “for the purposes of education or research, the Program reserves the right to create and share/distribute photographic, video, extended reality renderings, or other multimedia of [the] donation in ways that are de-identified.”

TABLE 2 Findings on how and where body may be used in donation form

How and where the body may be used	Percentage (n)
Donation purpose/uses	89% (98)
Use location (off campus/out of state) and possibility of transfer	46% (51)
Images (acquisition/use)	10% (11)
Preparation methodologies	17% (29)

Note: The percentage (number) of institutions disclosing how and where the body may be used in their donation form.

A body preparation disclosure found on one form requires donors to verify they “understand that [the institution] may embalm and/or perform dissection for the purposes of education and/or research.”

3.3 | Signature requirements

The signature requirements on donation consent forms vary from institution to institution. Most require the signatures of two witnesses, and some require an attestation of the age and competency of the person(s) signing the form. Every consent form requires a signature, however, only 29% of them stipulate the signature be of someone who is at least 18 years old *and* of sound mind/competent. Of the 110 forms, 94% (103) require two witnesses to sign in order to validate the donor's signature. Rather than allowing the donor to verify their age and competency, one institution goes a step further by asking verification from the two witnesses: “We, the undersigned, have witnessed the donor, whom is eighteen years of age or over and of sound mind and under no duress or coercion...”

3.4 | Disposition of remains

When looking at the disposition of remains, 81% ($n = 89$) of the investigated institutions disclosed the method of disposition (cremation, alkaline hydrolysis, burial, scattering) on their donation forms. Many notable statements regarding disposition were found on donation forms. One university informs donors “remains or cremains will not include tissues that have been removed for medical research or educational purposes.” Another states “I hereby authorize the disposal of any cremated remains of said gift by the School of Medicine” but does not say how they will be disposed. While the option to return cremated remains to the family is commonly included, one form wisely has the donor identify to whom the remains should be released. One university, which is capable of receiving about 300 donations a year says “due to the number of donors we receive each year” they are not capable of returning cremated remains to the family. One of the donation form asks donors to acknowledge they “understand that organs, tissues, or parts of the body may be removed or separated and sent to different entities and these parts may be disposed of at different times and at different locations.”

4 | DISCUSSION

A review of the donation forms revealed that of the 12 items for which results were tabulated, only four were included on more than 50% of the forms and four were included on fewer than 25%. It was noted that 40 (36.4%) of the donation forms, consisted of five or fewer sentences. The briefest form consisted of one sentence: “I hereby donate my body, after death, to the Anatomical Donation Program of the Medical College.” While additional information may be provided to the donor on other documents, the consent form does

not verify that it has been provided, reviewed, and approved. The AACA recommends 14 items to be included on a donation form, an institution's document ought to be far more detailed than what can be written in five sentences. Besides the guidelines provided by the AACA, suggestions as to what should be provided to potential donors in order to obtain informed consent for body donation are not provided by other anatomical associations or the UAGA.

Many institutions post their donation form on their website along with other informational documents, the donation form should include all relevant information to ensure donors and families are fully informed. The AAA's Institutional Policies recommend that each institution should have an oversight committee and that body donation programs should be reviewed annually by the Institutional Oversight Committee (IOC) but none of the documents reviewed mention the existence of an IOC. Statements such as the “body shall be utilized by the University for teaching, scientific research, or such purposes as the University shall, in its sole discretion, deem advisable” (Abbott et al., 2000) do not mention the involvement of an IOC nor do they describe all possible uses of the body. In 2014, the International Federation of Associations of Anatomists (IFAA) published “Recommendations of good practice for the donation and study of human bodies and tissues for anatomical examination.” The first recommendation is “Informed consent from donors must be obtained in writing before any bequest can be accepted” (Jones, 2016). Although the AAA and the American Association of Clinical Anatomists' (AACA) are members of the IFAA, neither organization recommends obtaining informed consent in their policies. Another concern is that the IFAA has not defined informed consent. As one of the purposes of this article is to encourage a greater level of informed consent, institutions are encouraged to achieve the minimum standards recommended by the AACA.

4.1 | General information about the donation process

4.1.1 | Entity receiving the donation

As expected, this item had 100% compliancy. The donation document needs to include the name of the receiving institution. Contact information for the anatomical program should also be included but in several instances it was not.

4.1.2 | Donation time frame

Only 38% of the donation forms mention the approximate length of time the body may be kept in the anatomical program. Donation time frames were usually from 1 to 3 years. Though this detail may be conveyed to the family at the time of death, it is important to include this on the donation form. It should be remembered that the “donation,” in most cases, is more accurately a loan in that the remains are not permanently retained by the institution. As such, the length of time a body will be used ought to be disclosed on the donation form. Some

anatomical programs keep body parts longer than the rest of the body. The review found 31 institutions mention this possibility and of those, approximately one third (35%) allow the donor to opt out of this. In that permanent retention is not an uncommon practice in the United States, consensus between the various anatomical associations as to whether donation forms should mention if body parts might be retained long term by the institution would help bring about consistency in what is expected to obtain informed consent.

4.1.3 | Applicable fees

Donation forms should indicate any costs the family may incur when the body is donated, such as costs of transporting the body, death certificates, and cremation. Some institutions provide these at no charge while others charge for some or all of these. Specific fee amounts are not on donation forms as fees vary and it is quite possible for prices to change over time. Considering the donor is providing a gift to an anatomical program, they and their family deserve to be notified in advance of any expenses they may incur that are associated with their gift.

4.1.4 | Serology testing/disclosure of results and medical records/information gathering/release practices

These two items are combined in the discussion as they are closely related. Serologic tests determine if a person has been exposed to specific pathogens such as Human Immunodeficiency Virus or Hepatitis C. Medical records, on the other hand, may disclose a wide spectrum of health-related information about the individual including surgeries, mental health issues, radiographic images, findings from routine examinations, to name but a few. As donors are protected by the Health Insurance Portability and Accountability Act (HIPAA), they are entitled to be informed of the serology and medical records policies of the institution.

4.1.5 | Results/rights to direct donation/release of information

When mentioned, the donation forms always informed families that neither how the body was used nor results of the studies would be released to the family. However, this is not always disclosed and should be to ensure the family does not have unrealistic expectations. Families are not permitted to direct how a body may be used for several reasons including the fact that the desired use may not coincide with the needs, timetable, or plans of the institution.

4.1.6 | Possibility of declining the donation

Donation forms should inform donors their body may not be accepted when they die along with potential reasons for refusal. A

statement such as “Your donation may be declined” is too simplistic and vague. Providing a list of reasons why a donation may not be accepted can help donors and their families understand, in advance, more details about the requirements for acceptance. When it is known that particular diseases, conditions, or other factors may preclude the donation from occurring, other arrangements can be made before the death occurs. Some of the potential reasons for refusal included on donation forms included autopsy, excessive trauma, suicide, amputations, organ transplants, unhealed major surgery, obesity, excessive edema, extreme jaundice, decomposition, colostomy, decubitus ulcers, deformity, contagious or highly infectious diseases, extreme emaciation, and objection to the donation by a close family member. When donors and families are only told the donation may be declined, unless they ask for more details, there is the possibility they assume the donation will be accepted. Receiving notification at the time of death the donation cannot be accepted is the most inopportune time as it leaves the family unprepared and puts them in a situation where they have to quickly make decisions regarding the disposition when they thought all was taken care of in advance. If one of the goals of a donation form is to provide *informed* consent, more detailed information besides “may be declined” is needed. It would be more helpful if donation forms included a statement such as “other arrangements for disposition of the body must be made by the family” if the donor's body cannot be accepted at the time of death. Over a third (35%) of the donation forms fail to mention that a body may not be accepted for donation, which can lead people to believe acceptance of the body at the time of death is guaranteed.

4.2 | Scope and utility

4.2.1 | How and where the body may be used

Donation purposes/uses and end users of anatomical materials

These two items are combined in the discussion as the purpose and use of donated bodies are often determined by the users of the anatomical materials. These items may be the most complex of those recommended by the AACA. While many donors understand body donation aids research and education, it is recommended to include the intended use on the donation form. Although the donation forms indicate a body may be used for education (89%) and/or research (77%), only 2% provided examples of the types of research. The American Association for Anatomy (AAA) website says “donation literature should describe all possible uses of donated bodies at that institution” (AAA, 2019) yet a review of 110 donation documents revealed that only in rare instances was more said than a body may be used for education and research. Several gave no indication as to what the bodies would be used for. Knowing what type of research will be conducted on a donor's body can impact their decision to donate or not. For example, when it was discovered that bodies donated to one university were loaned to the military and used in land mine tests, some protested (Meyer, 2004). Later, the “Army Policy for Use of Human

Cadavers for Research, Development, Test and Evaluation, Education or Training (RDT&E)” was written.

Some can argue that just as the living are entitled to be informed about the purpose of research projects, this should also apply to research conducted on human body donors. This will ensure that the values of body donors are respected after their death and protect the deceased from any harm to their dignity.

Use location and possibility of transfer

Approximately, 46% of body donor programs disclose if a greater need exists at another/other institution(s), the body or body parts may be sent to another institution. Detailed information such as the remains would only be transferred to an in-state institution is not always disclosed.

Of the 51 programs that mention bodies or parts may go to another institution, only 10 allow the donor to opt out of being transferred elsewhere; four assure the body will stay in the same state as the receiving entity, and only two assure the body will remain in the United States. Two institutions indicate that bodies or parts may be sent to other countries and one allows the donor to choose to not be sent out of the country. If the receiving institution loans bodies/parts, at a minimum, donors should be informed of this possibility and be given the opportunity to opt out as they or their families may oppose the body being distributed to multiple locations or leaving the custody of the receiving institution.

Images

The AACA Statement on the Use of Images of Body Donors says that while such images are useful, it is recommended that institution have policies that are “consistent with a donor’s consent/authorization and include guidance on the distribution of the derived images” (AACA, 2017).

Considering the ease of taking photos with a cell phone, it would also be prudent for institutions to have policies prohibiting unauthorized personnel from taking photos (Hennessy et al., 2020).

Informing donors as to how the body might be prepared helps them understand what will happen when the body initially arrives at the donor program. Donors are entitled to know that depending on how the body will be used determines whether or not the body will be embalmed. This creates awareness of the probable preservation technique. Currently only 19 donation forms give an indication as to the methods of preparation.

Preparation methodologies

Informing donors as to how the body might be prepared helps them understand what will happen when the body initially arrives at the donor program. Donors are entitled to know that depending on how the body will be used determines whether or not the body will be embalmed. This creates awareness of the probable preservation technique. Even a little knowledge is better than leaving donors and families completely ignorant as to what happens to the body upon its arrival at the institution. The inclusion of this information further contributes to the informed consent process.

4.3 | Signature requirements

Signature requirements on donation forms vary among institutions. Most require two witness signatures, and some require an attestation of the age and competency of the signatory(ies). Fewer than a quarter require the signer to be a disinterested party and only four require the signer to declare their age/competency *and* the signature of two witnesses, one being a disinterested party. Every donation form requires a signature, however, only 29% stipulate the signature be of someone at least 18 years-old *and* of sound mind/competent. Of the 110 forms, 94% (103) require two witness signatures. Ideally, witnesses have known the signer for a significant period of time which helps confirm the competency and independence of the donor at the time the document is signed.

Another suggestion by the AACA is that when the donation form is signed by the donor, at least one witnesses should be a disinterested party. This mitigates the chance the donor was coerced to donate their body, perhaps by a family member who selfishly “encourages” a relative to donate their body in order to increase their share of an inheritance or minimize funeral costs. Another benefit of having an impartial party as a witness is they are typically a more reliable source of veracity should there be a need to certify the authenticity of a donation form. Although 103 donation forms require two witness signatures, fewer than a quarter (22%) require one to be a disinterested witness. Twenty forms require a disinterested witness signature and four require the donation form to be notarized. In that notaries are not typically related to the donor, they could be considered as a neutral party.

As stated in the AACA’s *Best Practices Guide for Donation Programs*, when the donor is the signer, it is suggested that the donation form include verification of their age and competency and the form to be signed by two witnesses, one of whom is a disinterested person. Of the 110 donation forms, only four comply with all of these requirements.

4.4 | Disposition of remains

At the conclusion of use, donated bodies are usually cremated, however, only 81% of the forms mention the method of disposition. The AACA suggests, “Details of the final disposition should be communicated such that potential donors or other persons legally authorized to make a donation decision on another’s behalf are aware of the method of disposition, advanced handling options of cremated or hydrolyzed remains, the possibility of comingled buried, cremated or hydrolyzed remains, and the expected time between donation and final disposition” (AACA, 2017).

One donation form asks donors to acknowledge they “understand that organs, tissues, or parts of the body may be removed or separated and sent to different entities and these parts may be disposed of at different times and at different locations.” A concern with a statement such as this is that families may wonder what exactly will happen once studies are completed and the final resting place of

those body parts. When dismemberment takes place during the course of a body's use by an institution, parts should not be commingled with parts of other donors when they are cremated. When families utilize the services of a funeral home for cremation, laws prohibit bodies being cremated together. Remains also cannot be commingled for cremation. Anatomical programs should adhere to the same standards. Commingling remains for cremation only benefits the institution financially and logistically. An assurance that remains will be cremated individually should be included on the donation form to provide peace of mind to donors and their family.

While 89 of the forms mention the method of disposition, six gave no indication. According to 83 of the donation forms, the institutions either return the remains to the family (usually after cremation), bury the cremated remains in a common grave for whole body donors, or scatter them. If the institution handles the disposition, the location of the disposition should be included as families may wish to visit the site where the remains are buried or scattered.

Six percent of the forms declare no cremated remains will be given to the family. When the remains are not going to be returned, an explanation as to why, along with a statement assuring the remains will be cremated and disposed of in a dignified and respectful manner should be included. Since only seven programs never return cremated remains to the family, their policy of never returning the donor's cremated remains to their families seems to be a decision of not *wanting* to return them rather than an issue not being *able* to return them.

Surprisingly, 20 (18%) of the forms make no mention of what happens with the cremated remains. The donation form should always contain instructions as to where or to whom cremated remains ought to go.

5 | CONCLUSION

The findings of this article show that much needs to be done before there is uniformity in compliance among the anatomical programs in the United States. Greater collaboration among anatomical societies and their members would serve to improve the level informed consent provided to donors and their families. Besides the items recommended by the AACA, more can be done to ensure a higher level of informed consent. However, it is best to start with what is currently recommended. Working together toward providing better informed consent, institutions will bestow a greater degree of ethical care to donors and their families and could reap the benefits of more donations. Further research needs

to investigate the input of the donors on this process and how to protect their best interest.

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