

Body donation and digital technology: the ethical issues

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Abstract

Digital technology influences many different areas of society, including body donation and the use of bodies donated to science. It affects the manner in which information arising from bodies donated to science can be generated, gathered and utilised. This includes information arising from medical imaging procedures, photographs, and genomic investigation. However many issues remain unclear in relation to this transaction, including the appropriate level of informed consent, family involvement in decision-making and information sharing, and how commercialisation should be addressed. Highlighting these issues shows there is a distinct lack of empirical evidence with which to guide appropriate use of digital information arising from bodies donated to science, and caution is suggested in regard to the acquisition, distribution, and possible commercialisation of such data.

Keywords: body donation; digital technology; education; commercialisation; informed consent; images

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Introduction

Digital technology has become widely embedded in society, and has revolutionised mass communication around the world. Given the widespread use of digital technology across higher education institutions, it is highly likely that such technology will eventually impact upon body donation programmes. In fact, evidence of such impact has already been seen in the uptake of 3-D printing^[1] and exome analysis^[2] of bodies that have been donated to science. As the use of digital technology becomes more common, it is perhaps pertinent to ask - how will digital technology impact upon body donation, and how can higher education institutions responsibly address this topic?

The Potential Benefits of Digital Technology to Body Donation

Collecting digital information from bodies donated to science has numerous benefits, with such information able to be used widely across teaching and research. Health-related imaging procedures such as magnetic resonance imag-

ing, computer tomography, and ultrasound all use digital platforms and could be utilised to scan donated bodies; such data is useful in teaching students both how to use and interpret images arising from different diagnostic imaging modalities. Researchers can also use imaging in conjunction with dissection to explore different aspects of gross anatomy. Students can correlate digital information with physical findings and may have a patient history to guide anatomical examination, and researchers can have access to an information source that can be easily stored and accessed.

Digital images from donated bodies can also be distributed and shared widely with little effort,^[3] or stored for long (potentially infinite) periods of time. Outside of medical imaging, most photographs are now digital, and 3D printing is also based on digitally acquired information via computer scans. For 3D scanning and printing of bodies donated to science, this format provides a novel way of preserving anatomical anomalies that are identified, and for increasing anatomical teaching resources when the

supply of bodies may be compromised. Data from exome sequencing, or any genomic investigation, is also stored digitally. Storage of medical and health records are also being digitised in many countries, with some nations using their medical record database for research in order to improve healthcare outcomes.^[4] It is possible that in some instances, the digitised healthcare information of a donated body may become available to the institution, and this may make up part of the information transferred to a body donation programme when they receive a body.

It is feasible that digital information from bodies donated to science may facilitate the creation of large data sets, either from newly generated digital information or from that digital healthcare information that accompanies a donated body. This information could be combined with data sets from other national or international collections, with the downstream benefit of such large data sets being the increase in power and value of the gathered information. There are obvious opportunities and benefits for the creation of such combined data sets. As an example, scans of all bodies donated to science could be acquired with a data set created and shared between researchers in order to explore variations in the morphology of various anatomical structures. Such a database could potentially be contributed to, and accessed, on a global scale. While this scenario is unlikely to occur in the immediate future for reasons of access and funding, it may be possible at some point in the future when imaging technology becomes cheaper and more widely available.

Cautions Surrounding Use of Digital Information Arising from Donated Bodies

Despite the many benefits that digital technology may offer in relation to body donation programmes, many elements of the intersection between body donation and digitisation remain unexplored. Digital information has the potential to be e-mortal (electronically immortal), and with this status comes the possibility that any acquired digital information may remain almost indefinitely accessible and usable. Because digital information can probably exist far longer than older forms of recording such as photographs and researcher notations, it is yet unclear how best to deal with many of the issues that are now more visible than in previous, pre-digital eras.

Digital information is able to be shared almost instantaneously around the world, and such widespread utilisation of information does have enormous potential. Because of this potential, the information and the databases storing it are now more likely to have a dollar value, and this attracts its own problems. For information that

has a 'value', there are several questions to which there are not yet adequate answers. In the instance of digital information from bodies donated to science, who does the information 'belong' to?^[5] How long are they able to keep it? How should it be used, and if it has a financial value, who should profit? How should families be involved, if at all, in the decision making process involving digital information that is derived from their loved ones? In addition, there are also medical questions and responsibilities to consider: if exome analysis of donated bodies is undertaken, how should we address incidental findings that could impact on family members?^[6,7] Topics such as incidental findings, commercialisation,^[8] informed consent, family consent, distribution of digital information, and intellectual property are all arguably more visible topics to consider today than in previous eras.

At present, there is little guidance on how digital information arising from bodies donated to science should be utilised or regulated. The guidelines on body donation from the International Federation of Association of Anatomists (IFAA) are silent on the specific issue of digital information,^[9] however they do clearly state that there should be no commercialisation in relation to bequests of human remains. This statement has already been challenged ethically, if not legally, with 3D printed models from donated cadavers already being created^[1] and made commercially available. In addition, textbook images and some educational software programmes utilise images from bodies donated to science, and it is unclear how this has been addressed in relation to informed consent and possible downstream generation of revenue. Further questions about commercialisation of donated bodies remain in regards to the capacity of body donation programmes to generate enough funding to support the cost of expensive donor programmes. It is unclear whether there exists a cost-recovery framework that outlines what is an 'ethically acceptable' profit margin, so that programmes can ethically cover the costs of their operations without exploiting the precious resource they acquire.

Guidance on the topic of body donation as it relates to informed consent and commercialisation is guided not only by ethical frameworks such as that produced by the IFAA, but also the laws of each country. However, laws in many countries may not yet provide adequate guidance on issues of informed consent or profit as they relate to digitisation of bodies donated to science. This may be for several reasons, and perhaps simply because the law may have been developed in a period where the technology did not exist or present the current range of issues. What is now clear is that digital technology has highlighted the necessity for the scientific and academic communities to engage

with the donor populations and their families, to extend our understanding of how issues such as commercialisation and informed consent should be addressed. The Guidelines of the IFAA do attempt to address good practice and ethical behaviour by body donation programmes, however when these guidelines are ignored it highlights the difficulties surrounding global adoption and enforcement of ethical practice and frameworks. Despite the non-uniform adherence to the IFAA Guidelines, transparent frameworks for the use of digital information arising from bodies donated to science should be developed by organisations like the IFAA to ensure good practice is - at the very least - visible to all involved in body donation practice. The unfortunate case of Henrietta Lacks, whose cancer cells were taken without consent and utilised for decades prior to a public backlash against such exploitation,^[10] reminds us of the potential downfalls of unethical behaviour in the medical and anatomical sciences, and it remains imperative that emerging issues are considered in a timely and transparent fashion in order to guide the development of good ethical practice and standards in regards to the future use of digital information.

Where to from Here?

There are many questions surrounding how we should ethically use the various forms of digital information that can be acquired from bodies donated to science, be they images, diagnostic scans, exome analysis, or within medical records that may accompany a donation. However, it is not that the problems we now face are entirely new issues; we are revisiting these topics because the instantaneous transfer of information and consequent opportunity exploitation of data are perhaps more prevalent now because thanks to digital technology. As a consequence, with the increase in opportunities to embrace the various positive uses of digital technology comes the added potential for exploitation and unethical use of bodies donated to science; this is accompanied by the risk of compromising the relationships between established body donation programmes and the generous members of society that underpin the success of body donation programmes worldwide. In a digital age, where information transfer is worldwide and almost instantaneous, such risks are a not just a regional issue, but a global one. It is unclear how previous instances of negative press involving inappropriate conduct with donated cadavers have affected body donation programmes on a local scale,^[11,12] however it is safe to suggest that adverse publicity of any kind is not beneficial to long-term sustainability of body donation programmes around the world.

The increasing use of digital technology has illuminated several ethical issues with respect to body donation, including the necessity to revisit those of informed consent and commercialisation, as well as new issues such as incidental findings that will become an important consideration with exome analysis of bodies donated to science. Mostly these are not new issues, however the rapid development of digital technology has provided the stimulus for these to be revisited in the near future. What is now required are publicly informed findings to guide how institutions implement evidence-based frameworks to guide sustainable and responsible use of digital technology within body donation programmes. This should be undertaken by exploring these issues with registered body donors and their families, in a manner similar to a recent exploration in Denmark,^[13] to ask how digital technology can be most ethically utilised at its juncture with body donation. It is important that the issues surrounding digitisation of donated bodies are addressed in a timely manner, so as to inform not only ethical behaviour for donor programmes, but also to inform the shaping of new law and regulatory frameworks in an era of widespread digitisation.

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