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# Cancer As Rubbish: Donation of tumor tissue for research

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### Abstract

Tissue banking (or biobanking), thought by many to be an essential form of medical research, has raised a number of ethical issues that highlight a need to understand the beliefs and values of tissue donors, including the motivations underlying consent or refusal to donate. Data from our qualitative study of the legal, social and ethical issues surrounding tumor banking in New South Wales, Australia, shows that participants' attitudes to donation of tumor tissue for research are partially captured by theories of weak altruism and social exchange. However, we argue that the psychological rewards of value transformation described by Thompson's rubbish theory provide additional insights into participants' attitudes to tumor donation. We believe our data provides sufficient justification for an approach to regulation of tumor banking that is aimed at fostering a relationship based on the notions of virtuous reassignment and social exchange.

### Keywords

Ethics; genetics; research participation; risk perceptions

Stored collections of human tissue ("tissue banks" or "biobanks"), including collections of tumor samples, are thought by many scientists to be an essential resource for medical research ("tissue banking research"; Korn, 1996). In general terms, tissue removed from patients in the course of medical diagnosis or therapy is stored in tissue banks, and this tissue provides a means by which abnormalities in tissue can be correlated with disease aetiology, prognosis and treatment responsiveness.

Tissue banking research has raised a number of challenging ethical issues particularly in response to a series of highly publicized "scandals" involving the non-consensual retention of human tissue and

organs in the United Kingdom and Australia, legal conflict over ownership of tissue used for the development of cell lines (e.g., Moore v the Regents of the University of California et al., discussed in Ashburn, Wilson, & Eisenstein, 2000), and growing sensitivity surrounding the use of DNA more generally. Areas of ethical concern include the means of obtaining consent for tissue banking, the management of donor privacy, including whether and to whom tissue-derived data can be disclosed, the ownership of tissue and the products of tissue-based research and whether tissue is “sacred” and therefore different to other types of health information (Campbell, 2000).

The current regulatory complexity in many countries including Australia (Lipworth, 2005) reflects this growing dissonance. Tissue banks are commonly governed by numerous legislative and regulatory requirements as a result of which, the legal requirements regarding consent, access, privacy and ownership in relation to tissue frequently remain unclear. Unsurprisingly, a survey of tissue (in this case tumor) collection and research facilities in New South Wales revealed significant heterogeneity of methods for ensuring donor privacy and gaining consent, of levels of consent obtained and of information provided to donors (Clark, Lipworth, Bokey, Little, & Kerridge, 2006).

Despite all of these issues, the rate of consent for the banking of tissue for research is generally high and has been demonstrated to remain so even in the wake of scandals (e.g., Seale et al., 2005). This places the onus on regulators and ethicists to ensure that people are donating their tissue for the right reasons and are not being exploited – particularly in instances in which donors are in a position of vulnerability. No better example exists of a potentially vulnerable tissue donor than a cancer patient asked to donate their excised tumor tissue for research. A patient undergoing tumor excision is not only in the midst of a traumatic experience, but is also highly dependent on the healthcare system and their interactions with clinicians, who might be the very people asking to bank their tumor tissue. Although the need to ensure protection of tissue donors has led to an explosion of research examining donor attitudes to tissue banking, only a few of these studies have specifically explored attitudes to tumor donation (Dixon-Woods, Wilson, Jackson, Cavers, & Pritchard-Jones, 2008; Kaphingst, Janoff, Harris, & Emmons, 2006).

In an attempt to better understand the issues surrounding tumor banking, we conducted a qualitative study of lay perspectives regarding tumor donation for research with a view to answering the following broad research questions:

1. What attitudes did participants express in relation to tumor donation for research?
2. What might be the implications of these results for regulation of tumor banking?

## **Materials and Methods**

This study was part of a multiple method study (Morse, 2009) of the legal, social and ethical issues surrounding tumor banking in New South Wales, Australia. The aim of this research was to improve tumor banking processes in New South Wales through generation of empirically-grounded practical recommendations that are widely acceptable to researchers and consumers. Within this mixed methods study we conducted a series of qualitative interviews with a range of lay stakeholders, which we shall report here.

### *Sampling and Recruitment*

This phase of the research involved interviews with patients (4) and parents of children (2) who had donated tissue to a tumor bank, health advocates (3), consumer representatives (2) and an indigenous

representative (1). Having received ethics approval from Sydney West Area Health Service, the University of Sydney and the appropriate hospital-specific ethics committees, we recruited lay participants by letter through one adult and one children's hospital in Sydney's western suburbs and a number of disease organizations and consumer groups. Recruitment ceased after thematic saturation had been reached.

Participants included twelve men and women aged 35 to 86. Studies of this nature typically work with small numbers of informants and are based on detailed, in-depth interviews (i.e. they trade off the number of informants for a wealth of talk from each informant). Such studies do not aim to provide a single representative or average view or opinion, but are more concerned to account for the range of views, needs, values and beliefs of informants. Views expressed by participants in this study were highly consistent and thematic saturation was quickly reached.

All participants identified themselves as Australian, although one included reference to Aboriginal descent and several to Anglo descent. Education levels of participants ranged from secondary-school to postgraduate level, although most had some tertiary education. Participants were asked to explain if and in what context they had previously encountered the idea of tumor banking. The initial degree of familiarity with the concept of tumor banking varied considerably among the participants, from those who were informed solely through media coverage, to those who had themselves banked tissue for treatment and/or research and had some knowledge of the issues involved. All participants were therefore given a brief introduction to tumor banking at the beginning of the interview to ensure that they had at least a basic understanding of the concept.

Interviews were in-depth and semi-structured. Interviewees were asked a series of open-ended questions that allowed themes to emerge. Open-ended questions were followed by a series of prompts to explore the issues in greater depth. Interviews were transcribed and anonymized using randomly assigned numbers. All identifying information was stored in locked filing cabinets and password protected computers.

#### *Coding and analysis*

Analysis of the interviews was inductive and informed by Morse's description of the generic cognitive underpinnings of qualitative research (Morse, 1994). After the interviews had been completed, members of the research team read the interviews and identified emergent themes. These themes were then abstracted into categories and concepts. Having examined the data in this manner we utilized abductive reasoning to identify a model of tumor donation that best fit the data. This is consistent with Peirce's process of abduction (Peirce, 1958), recognized as part of the development process in qualitative analysis (Reichertz, 2007).

## **Results**

Participants in our study overwhelmingly expressed their willingness to donate leftover tumor tissue for research because of "the good" that it might bring to others. One participant, for example, commented "I just always think that it's always going to be used for the good." These "others" included family, friends, disease community members (present and future), future generations, and at times simply "anyone".

*I think a lot of people will quite happily do it because it may not benefit them but people have got kids and things like that so there could be a benefit, not to them at this particular time but also to their family or friends and other people.*

Personal benefit, largely in the form of increased knowledge about one's own health, was mentioned very occasionally as an added benefit of donating tissue, rather than the key motivating factor, as was an increased sense of agency.

*Being asked I thought was good in that it made me feel involved in it, and I was contributing something to research by being the mother of a daughter with cancer, I could say, "Yes, you can use this for research", whereas everything else I was passive in a sense.*

When asked whether they would expect donors to receive a fee for their donation or a percentage of profits made, participants generally expressed that this was not only unnecessary but also undesirable. Frequently participants commented that they had not even considered the possibility that a profit might be made from their tissue when they agreed to donate.

Although participants did not appear to expect any reward for tumor donation, many took the position of viewing donation as an act of reciprocity for years of research from which they had benefitted, or for the treatment they had received to date.

*I have a view of what comes around goes around, so I benefited from years of research and technology and medically and psychologically so I'm very much into pushing that back out again and making sure that I was given the benefit, I want someone else then to have that benefit as well.*

As such, tissue donation appeared to be viewed as part of a generalized or "indirect" form of reciprocity, in which the goodwill of others was reciprocated by the donor's contribution and by which the act of donation contributes to the level of goodwill in the general community. Thus, the desire for tissue donation to benefit others and the community was an overriding theme.

Although participants expressed a great willingness to donate, the circumstances of donation were constrained by the necessity to have tissue removed to preserve life and welfare. Some participants explicitly commented that because of the circumstances surrounding the request to donate, they did not have time to think about their decision to donate. However, they did not appear to see this as problematic.

*Interviewer (I): You mentioned that those days surrounding diagnosis and surgery were quite a blur, do you think it was appropriate for them to ask at that time or . . .*

*Participant (P): Oh yes.*

*I: . . . would you prefer if they'd waited til later?*

*P: No, because when you're going through it you're thinking, "Well, that bit of research could be stopping somebody else down the track from having a problem."*

In most cases donation appeared to be a more or less automatic response to a suggestion made at the time of admission for surgery. For example, one participant, when asked “How did you feel about the idea of donating the tissue?” responded, “No worries. I just told them take whatever and do whatever.”

Despite the circumstances under which donation took place, there was no sense of compulsion or manipulation, and interviewees were generally relaxed about their attitudes toward the uses to which their tissue might be put. Not only did participants express no sense of having or needing to be persuaded or coerced into donation, a few did not even appear to feel strongly about the need to be asked for permission to use their tissue.

*I: There's been a lot of discussion about how to ask permission to store and use people's tissue samples. Do you think it's necessary to ask for permission to use samples for research if they have already been taken for diagnosis?*

*P: It wouldn't have bothered me if they hadn't asked. Personally it wouldn't have bothered me, but I could imagine that some people would prefer to be asked.*

Participants frequently expressed that their tumor tissue was of no use to them and were somewhat puzzled that they needed to be asked for permission to use tissue that would only go to waste otherwise.

*I: Do you think that patients should be informed of whether it's going to be kept, how long for, what's going to be done with it?*

*P: It wouldn't have worried me, wouldn't have cared, when you're going through that process there's bigger things that fill your mind and this little bit of tissue, who cares, I would have imagined they would have kept the slide, whatever tissue existed on that slide and everything else thrown away, so that slide is sitting somewhere for future reference, like evidence in a murder case or something is just kept there. I would have thought that, but if they had have asked me “Can we keep this for twenty years”, I probably would have said, “Why? It's bad! No throw it out, don't want it!” I was very happy for it to be out of me.*

It was mentioned only occasionally that donors would be “giving up” part of their body. One participant commented that “to them it's part of their body, it's something that's been taken away from them.”. These comments were largely made by an Aboriginal liaison officer who was interviewed, highlighting the role that culture and ethnicity might play in such issues.

Overwhelmingly participants demonstrated a pervasive lack of concern, at times bordering on total indifference, when asked about donation of tissue for research. They commented that it was “a lot of fuss about nothing”, that “it wouldn't really matter”, they had “no worries”, “no hesitations” and “no problems”, and even that they “really didn't care”.

To ensure that this lack of concern was not because of a lack of awareness of the potential risks involved in tumor banking the interviewer introduced a series of examples, in the form of hypothetical scenarios, throughout the interview. However, the participants' lack of concern generally held firm.

*I: Obviously one of the types of information that scientists can get from your tissue is to do with genetics as you mentioned before. So by looking at the genes in cells we can tell a lot of information about what you've inherited from your parents and what you might pass on to your children and*

*also what might happen with your health in the future, so would you have any concerns about that genetic information being contained in the tissue and made available to researchers?*

*P: No I don't have any concerns.*

*I: So there's a lot of different types of research that can be done on tissue, for example a researcher might want to look at whether people with a particular gene are more likely to get a certain disease, or whether people with different types of disease respond better to treatment. Sometimes tissue is collected for a specific research project but then once that project and those particular questions are finished and answered another researcher might want to use it for a totally different research project. So how would you feel if you'd given permission, for your tissue to be used for a particular project and then someone else wanted to use it for something different?*

*P: No problem.*

*I: Would you want them to ask you?*

*P: No. Quite happy.*

It appeared that participants were aware of possible risks but were not concerned about those risks themselves. This was demonstrated by their ability to acknowledge that other people might have concerns about certain issues although they themselves did not.

In the few instances where participants did express concern about the possibility of future risk they responded in several different ways. Some issues, such as possible private company involvement and third-party access worried a couple of participants but did not appear to jeopardize their willingness to donate. For example, one participant commented, "I can see there will be slip-ups, there'll be people who do the wrong thing for profit, I think it's a risk you've got to run." Where willingness to participate did waver, this seemed to be associated with fears about the potential use of their tissue for embryonic stem cell research or reproductive cloning. However, in general there seemed to be a strong belief that risks, though concerning, were not in fact substantive. Possibilities such as cloning were considered "science fiction" examples of "weird research" that were highly unlikely to eventuate in reality.

*But I could not imagine them cloning, I think that might have even crossed my mind at the time, and I just thought no one is going to clone something from a tumor cell that I can imagine.*

## **Summary**

Analysis of the empirical data in this study therefore indicates that donors had a high level of willingness to donate tumor tissue for research. Donation was often considered to be "no big deal", given that it involved the use of tissue which would be discarded anyway and was perceived as involving little or no credible risk. At times donation appeared to be nothing more than an automatic response or afterthought made by an individual facing more urgent and threatening health concerns. Despite the sense that tumor donation was "a lot of fuss about nothing" donors expressed considerable satisfaction at the thought that their donation might benefit others and contribute to a generalized system of reciprocity.

## Discussion

How do our results relate to models of tissue donation previously discussed in the literature? Perhaps owing to Titmuss's celebrated concept of the gift relationship in blood donation (Titmuss, 1970), the majority of empirical studies regarding tissue donation focus on altruism (Barr, 2006; Boe & Ponder, 1981; Hoeyer, 2003; Hoeyer & Lynoe, 2006; Kettis-Lindblad, Ring, Viberth, & Hansson, 2005; Medical Research Council & the Wellcome Trust, 2000; Medical Research Council & the Wellcome Trust, 2002; Zaller, et al., 2005; ) and social exchange (Barr, 2006; Dixon-Woods et al., 2008; Lipworth, 2005; Ormond, Cirino, Helenowski, Chisholm, & Wolf, 2009) as models of tissue donation. As mentioned above, few researchers have reported exploring the ways in which attitudes to donation of tumor tissue might differ from that of other tissues. Definitions of altruism and social exchange resonated with many of our results. We found, however, that neither of these theories adequately explained the nuances of participants' responses.

### *Altruism*

The precise definition of altruism has been heavily debated by scholars in numerous fields including economics, psychology, evolutionary biology and sociology. In the context of tissue donation for both research and therapeutic purposes, altruism has been variously interpreted as the desire to help a stranger (Hantcheff, 1963), service to the community (Phillips, 1961), recognition of a need to help others (Boskovic, 1964; Hocking et al., 1974) and benefit future patients (Kettis-Lindblad et al., 2005), having a sense of duty, a belief that it is the right thing to do or that it is a worthy cause (American National Red Cross, 1964; Hemphill, 1969; Medical Research Council & the Wellcome Trust, 2002), gratitude (Boe & Timmens, 1966) and humanitarian interests (London & Hemphill, 1965; Oswalt & Napoliello, 1974). The variable and often atheoretical manner in which altruism is defined (or not defined) in these studies, has resulted in a lack of clarity regarding the significance and implications of their findings.

A definition of altruism put forward by Simmons, which is drawn from a comprehensive review of the altruism literature and includes four characteristics common to many writers and consistent with her own research requires that altruism (a) seeks to increase another's welfare, not one's own; (b) is voluntary; (c) is intentional; and (d) expects no reward (Simmons, 1991). Many of the elements contained in these definitions of altruism were present in our data. Donors spontaneously expressed concern that their donations should benefit others. They were firm in stating that their donations were voluntary and uncoerced. Mention of benefit resulting from donation was made in reference to others rather than themselves.

However, participants did not perceive that they would be assuming a cost through the act of donation. Perceptions of "risk" and therefore potential self-sacrifice are not essential to establish the presence of altruism, but they do provide some measure of its intensity (Monroe, 2004). Monroe, for example, has argued that altruism must include willingness to assume cost (in the form of risk or sacrifice). The necessity for altruism to include risk or sacrifice has been heavily debated. This issue is particularly relevant in the case of donation of left-over surgical waste, such as tumor tissue, which requires no further action on the part of the participant and no additional procedure and which, as we have seen, is generally not seen by donors as placing them at risk of future harm. It has been previously suggested that altruism is influenced by the ease of donation (Haimes & Whong-Barr, 2004) and that decision-making and consent in the case of donation of surgical waste is perceived as easier and of less importance by donors (Medical Research Council & the Wellcome Trust, 2000). Indeed, fear of injury, fear of after-effects, fear of pain and needles, time and inconvenience—the dominant reasons reported

for non-donation of healthy tissue (Boe & Ponder, 1981)—are largely irrelevant in the case of tumor donation.

Intentionality in the context of tumor donation is also problematic given the compelling circumstances that led to the removal of tumor tissue i.e. the necessity to preserve life and welfare of the patient. Although the satisfaction that donors appeared to draw from the sense that they were contributing to “the good” resonates with theories of altruism, intentionality was neither strongly nor spontaneously expressed. Participants did not express a pre-existing desire to do good by contributing to research, that was subsequently fulfilled by a request to donate tissue. Rather, donation appeared to be a more or less automatic response to a specific request to donate tissue, made in the context of ridding themselves of something that was unwanted and would be thrown away anyway. The intention to benefit others consequently appeared to emerge as part of a post-hoc rationalization or “reconstructed logic”—a reflective recognition or explanation for the satisfaction of feeling involved.

Although some more inclusive definitions of altruism might allow for the inclusion of acts which do not involve cost to the donor and which involve only weak intentionality, it is certainly the case that many stronger definitions of altruism would exclude such acts. We would therefore argue that the attitudes expressed by participants in our study could, at most, be characterized as “weak altruism” (Dahl, 1980; Hornstein, 1976; Monroe, 2004; Simmons, 1991).

#### *Social exchange*

In the sense that participants saw tumor donation as an act of reciprocation, tumor donation might be considered a form of social exchange. Donations were frequently viewed as reciprocating the contributions of citizens in the past, as well as contributing to treatment of future patients. Our data indicates that this system of exchange involves weak, indirect reciprocity between groups rather than individuals, as described by Levi-Strauss (Levi-Strauss, 1949). This is not the first time that donors have been identified as having a sense of contributing to a collective of others who have contributed to previous research and thereby engaging in a form of indirect, non-monetary exchange (Dixon-Woods, Wilson, Jackson, Cavers, & Pritchard-Jones, 2008; Felt, Bister, Strassnig, & Wagner, 2009; Svendsen, 2007).

However, social exchange theory is based on the notion that one gives up something of enduring social and symbolic value (Ekeh, 1994). Participants in this study frequently made comments that suggest that their tumor tissue held low intrinsic value for them. Their tissue was “useless”, “waste” and was intended to be “thrown away”. This is not necessarily inconsistent with social exchange. Waldby (2002), for example, has pointed to the potential for tissues to be imbued with differing value, depending on their position in a social network of tissue exchange. However, social exchange theory alone does not appear to provide a complete explanation of participants’ attitudes to tumor donation. In particular, we recognized that tumor tissue appeared to gain a new status (changing from something of no value to something of value) through the act of donation, and we wished to understand the process by which waste material might come to have value within a system of social exchange. This process of revalorization led us to consider a lesser known theory which incorporates elements of both altruism and social exchange theory and which appears to better capture the nuances of our results than either of these theories in isolation.

#### *Rubbish theory*

Cultural theorist Michael Thompson classified the “things” that people have in their lives as falling into three socially defined categories (Thompson, 1979).



1. Durable items have lasting value that either holds or increases over time, for example, a Monet painting (Thompson, 1979, p. 7). Durable items are widely valued financially, emotionally and cognitively in a relatively stable way. They are awarded a social status that determines appropriate social and individual actions such as preservation, protection and regulated sale.
2. Items in a state of flux are those whose value shifts around (Thompson, 1979, p. 8). Values in this category are dependent on social actions and choices, such as what collectors determine the desirability of a new artist's work to be. Items in flux might at length graduate to become durable items or they might be relegated to the third category.
3. Transient items represent things with falling or fallen value, such as second hand computers (Thompson, 1979, p. 7). As with durable items they have a stable social status that determines social and individual actions such as removing and remaindering.

Thompson (1979) points out that durable and transient items have achieved stable social status at opposite ends of a scale of approval. It is the items in flux that still carry the possibility of "innovation and creativity". But he also stresses that there is another category of objects that continue to exist "in a timeless and valueless limbo where at some later date it has the chance to be rediscovered" (Thompson, 1979, p. 10). This category is rubbish. Rubbish might be valueless at the time it is socially defined, but yesterday's rubbish might become today's archaeological treasures. Time and social interest can turn rubbish into durable objects of value.

Thompson makes a special case of body products. There is "waste material" (feces or urine), which is rapidly construed as rubbish (as distinct from durable material, such as body parts). In between are body products, such as milk and tears, which may be subject to social revision of values. Tumor tissue is a particularly interesting example of a body product. It is, in a sense, rubbish, to be discarded at all costs, and donors in this study frequently make the point that the tissue they are being asked to donate is "useless" to them and would be "thrown away" or "go to waste" otherwise. However, in recent years, tumor tissue has had a "social status-promotion" as a source of medical wisdom, an object of study, a way toward future benefits for "mankind" (Janin, 2004). As such, the status of a piece of tumor tissue may be redeemed and transferred to something durable. Of course, unlike a masterpiece that has been rediscovered, tumor tissue only has value in a particular context (an issue not explicitly dealt with by Thompson). Nonetheless, the notion of revalorized rubbish does have particular explanatory power in the context of our study.

In light of rubbish theory we would argue that donors retrospectively construct the meanings of their donations from three perspectives—weak altruism, social exchange and revalorization of rubbish: they have a desire to contribute to the creation of a good society through the benefits which will accrue to the public as a result of the reconstrual of their "hostile waste" as something beneficial to others, something that has status as a medium of social exchange. The addition of the notion of category reassignment to existing models of altruism and social exchange more adequately explains the ambiguity and weakness of intentionality apparent in our interviews, the sense that the desire to benefit others was more of an afterthought than a clear intention, as well as the lack of concern, bordering on un-interestedness surrounding the use of a piece of tissue that donors were anxious to be rid of. Furthermore, rubbish theory helps to explain the retrospective sense of satisfaction that participants gained from the act of donating that which would have been disposed of anyway. To have the tumour

tissue donation reconstrued as something positive, is to have the status of a piece of rubbish redeemed and transferred to the status of something durable. In our study, patients referred to this transformation with appreciation. Their rubbish had become someone else's potential for prevention or healing. To be a donor is to be reconstrued socially as a benefactor, a source of something durable and valuable rather than of something transient and horrible.

Unfortunately, rubbish theory has fallen into some disrepute (Benthall, 1979; Culler, 1985; Fararo, 1981; Goodin, 1981; Smith 1980). Thompson's original work has been criticised for his move from the qualitative domains of sociology and anthropology to the quantitative domain of catastrophe theory (Thom, 1975). His projected topological models fail to convince his critics completely, however much they have been persuaded by his detailed description and explanation of value assignment and its revisions. However, for all its weaknesses in Thompson's formulation, his sociological and anthropological theorizing does provide a way enrich our understanding of the mechanisms and psychological implications of tumor donation.

### **Implications**

If indeed rubbish theory is an appropriate model for tumor donation, there should be important psychological consequences for the ways in which donors perceive the value of their donations (Geyer-Ryan, 1992). Geyer-Ryan links rubbish and its redemption into something of value to psychological responses:

In everyday life the psychic position of the object is fused with a social value system of purity and filth. Under ultimately contingent circumstances, objects normally categorized as rubbish can be elevated into positivity, and are thus "sublimated" into a collector's item, for example, or any other value of distinction. The zero-position of garbage within the realm of real and symbolic objects is analogous to the position of the object in the psychic domain (p. 503).

Alienation of the body in illness is a familiar theme of the illness experience literature (Frank, 1995; Frank, 1998; Hyden, 1997; McKenzie & Crouch, 2004; Mechanic & Meyer, 2000; Taylor, 1983; Toombs, 1992) and it has been linked to the stigma attached to specific illnesses such as acquired immunodeficiency syndrome (AIDS) and cancer (Fife & Wright, 2000). Abjection has been explicitly linked to the cancer experience (Waskul & Riet, 2002) and its positive reconceptualization to posttraumatic growth (Joseph & Linley, 2008). Donors of tumor tissue in the present study experienced the elevation of their tumor tissue's status from private and rubbish, to social and virtuous—the tissue and the act of handing it over have undergone revalorization. The process of revalorization offers at least some confirmation that the whole challenging and disruptive episode can have a larger epistemological and moral meaning. As a result, tumor donation might reinforce the process of posttraumatic growth, thus contributing to the restoration of the patient's identity and sense of inclusion in society.

This model of tumor donation might also have implications for the legal, social and ethical management of tumor banking and research. To begin with, it appears that some of the key concerns that have been widely discussed in relation to organ donation for therapeutic purposes are less relevant in the context of donation of surgical waste for tissue research. Unlike therapeutic donation, the problem of increasing donation rates is not an issue in this context. Consent for tissue donation is very

high and our participants expressed an almost unfailing willingness to donate their tissue. The issue is one of opportunity rather than of influence.

Indeed, in light of the insights gained from rubbish theory, ensuring that cancer patients are given every opportunity to donate discarded tissue whenever possible may be a moral imperative. The opportunity to donate provides cancer patients with the prospect of feeling that they are contributing to and thus maintaining the creative possibility of converting potential rubbish into something of enduring worth, thereby contributing to the possibility of posttraumatic growth. Ongoing communication between tumor banking institutions and donors, might further enhance the opportunity for posttraumatic growth by allowing donors to see the benefits that result from their donation. We would argue for such things as websites and public meetings to inform those who are interested, and the inclusion of interested members of the public on tissue bank advisory committees as suggested previously by Ashburn and colleagues (Ashburn et al., 2000).

Finally, if we consider that donors of surgical waste are motivated by the redemptive ideal that their “hostile waste” can be reconstrued as something beneficial to society and that their donation can become part of a general, reciprocal system of good citizenship, then it is vital that this system of revalorization be maintained. It is probably no coincidence that our findings emerged in the context of the Australian health system in which there is universal health coverage under a national tax-based scheme. The participants in our study believed that benefits provided in exchange for the donation of “disposable” tissue would be distributed to society generally, rather than to individual donors. However, if the nature of the healthcare system and thus the system of exchange or reassignment between biomedical science and the public were to change, so would the approach to tumor banking regulation. Given that there are already complex relationships between commerce and academic biomedicine, tissue banks would need to be clear who could use donated tissue and for what purpose, as such information might change the nature of public attitudes to donation.

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There are a number of important limitations to this study. Being a qualitative study, it is based on a detailed analysis of interviews with a small number of participants, and in the absence of confirmatory studies that use more representative (i.e. more random) methods of sampling, the findings should not be generalised to any wider population. Although other studies do exist which have explored the status of tissue (Barr, 2006; Dixon-Woods et al., 2008; Gustafsson Stolta, Lissb, Svenssonc, & Ludvigsson, 2002; Hoeyer, 2006), they are scarce and have not utilised a rubbish theory framework of analysis. Our study, and others examining the status of tissue, was also conducted in a western (or westernised) population, and tissue is likely to have different significance in other settings. Indeed, the process of revalorisation

we have proposed might be meaningless in a context in which tissue always has profound status. We therefore present our findings as hypotheses that need to be replicated by studies conducted in other settings and in relation to other tissue types.

## **Conclusion**

In this article we have argued, based on empirical data, that lay attitudes to donation of tumor tissue for research in New South Wales, Australia, are more adequately captured by rubbish theory, than by theories of altruism and social exchange alone. We believe that our data provides sufficient justification for an approach to regulation of tumor banking that is aimed at fostering a relationship based on the notion of virtuous reassignment and social exchange. We have suggested that this relationship can be maintained and encouraged by ensuring that tumor banking research continues to benefit the public and by ensuring that cancer patients are given every opportunity to donate their tumor tissue to research and thus to facilitate their posttraumatic growth. We believe that this approach is not only consistent with the values of tumor donors but will serve to promote progress in research.

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