

Post-Print

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Ethics as an act of listening

Peer commentary

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Over the past fifty years concerns regarding ethical and human rights abuses arising from biomedical research have led to the establishment of sophisticated processes for ethical oversight of research and to increasing regulation of many aspects of the research endeavour. Research using human tissue collections (tissue banking research) is no exception, with ever-more stringent regulations emerging in response to concerns about consent, privacy and commercialisation. These measures are perfectly compatible with central bioethical concerns such as the need to ensure autonomy and the right to control one's body and personal information, and the need to protect vulnerable research subjects from harm. So why, one might ask, are scientists so resentful of these regulations and so concerned about their potential adverse impact (e.g. Furness 2004)? Does this mean that the scientific community is dangerously insensitive to the public's mistrust and desire for autonomy? Or are they more aware of public values? It is possible to theorise endlessly about such matters, but at some point it is necessary to carry out empirical research into public attitudes and values. While the 'empirical turn' in bioethics has its limitations and is primarily descriptive, rather than normative (Sugarman 2004), as Chandros Hull *et al* remind us, if bioethics does not accurately reflect community values may impede science and misrepresent the needs of "vulnerable" populations.

In an effort to determine whether scientists' concerns about regulation are reflective of community values, we undertook a qualitative study (as part of a larger mixed methods study) of the legal, social and ethical issues surrounding tumour banking in New South Wales, Australia. The aim of this research was to improve the tumour banking process through generation of empirically-grounded practical recommendations for the establishment of tumour banks that would be widely acceptable to researchers and consumers.

Our research (unpublished data under review) has revealed two key findings which challenge widely held assumptions about research and about the retention of tissue for research. First, we found that academic tumour banking researchers and their institutions were generally held to be highly trustworthy (as defined by O'Neill, to refer to entities that are perceived to be beneficent, non-maleficent and not in need of restrictive observation and control) (O'Neill

2001). This finding challenges the assumption that, in a “risk society”, the general public is increasingly distrustful of tumour banking researchers and of academic biomedicine more generally (e.g. Mason and Laurie 2001). We also found that the general public regarded tumour banking research as posing little, if any, risk to the donor, in part because it involved the donation of biological material that would otherwise be regarded as waste. A perception that, somewhat surprisingly, remained remarkably stable even when people were explicitly alerted to all potential dangers associated with this kind of research. This suggests that donation to tumour banks is not, as is commonly assumed (e.g. Williams and Schroeder, 2004) a strongly altruistic act (i.e. a voluntary and intentional act that seeks to increase another’s welfare without immediate reward (Simmons 1991) while carrying a known risk or involving a significant personal sacrifice (Monroe 2004) but is, at best, a weakly altruistic act (i.e. altruism associated with little or no risk or sacrifice). But even weak altruism fails to fully account for the disproportionate sense of virtue that the donors to tumour banks in our study appeared to gain from their donation, given the lack of attachment they had to their own pathological tissue and the limited sense of risk they felt associated with the act of donation. This suggests that tumour donation is an act more akin to the charitable revalorisation and virtuous reassignment of “rubbish” (Thompson 1979). This proposition, that tumour tissue is regarded as ‘rubbish’ is supported by the fact that our informants did not see the need for detailed consent procedures, and most certainly saw no need or desire for recurrent, project-specific consent—a finding in keeping with a number of other quantitative studies (e.g. Chen et al. 2005) and with Chandros Hull *et al* (who have shown that “notification may well serve as an appropriate compromise between the dual goals of advancing patient autonomy and promoting the conduct of research”).

If we take seriously the findings of our research, and of other studies of the attitudes and values of tissue donors, and avoid the temptation to explain them away by arguing that the general public is ignorant, hopelessly naïve and misguided in its trust and charitable instincts (as one might argue on the basis of the “deficit model” of public understandings of science), then the current regulatory trend needs to be viewed with some reservation. And this may lead us to place more, rather than less control in the hands of academic researchers, institutional ethics committees and advisory boards. A critical examination of the imperatives driving regulation of tissue banking informed by such empirical research may also lead us to ask whether it is paternalistic and ultimately unjustifiable to insist that tissue donors are given detailed information, and are asked for recurrent, project-specific consent, when they are expressing no such desire. At the very least, the burden of justification should rest with those who assume both the presence and appropriateness of public *distrust* and who insist that tissue donation is a risky act, and is therefore strongly altruistic.

This does not in any way suggest that tissue donation should be treated lightly, that we should return to paternalism or that research should be unregulated. For trust in research and academic biomedicine is a precious resource, and one that needs to be both protected and earned. Just because donors may perceive that their tissue is ‘rubbish’ does not mean that it, and the act of donation, is of no socio-cultural or moral significance. The donation of “rubbish”

in the context of, for example, cancer treatment and tumour donation, may be the only good that can come out of an abject, alienating and traumatic illness experience, and may even provide a path to post-traumatic growth (Joseph and Linley 2008). And 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, then it is vital that this system of re-valorisation is acknowledged and maintained.

While we believe strongly that bioethics is an act of listening and that this listening involves close attention to the expressed beliefs and values of research participants through well-designed empirical research, we would stress that this does not mean simply taking at face value what is said, nor leaving behind logic or philosophical analysis. As Chandros Hull *et al* rightly observe: "Data regarding preferences comprise one factor to be balanced with other competing considerations". Empirical research in this, or in any other area relevant to bioethics may not necessarily provide the kinds of insights that are required for the design of policy and processes in health and science. Simplistic and 'question-begging' studies can be just as disconnected from public values as are pronouncements made on the basis of theory alone. In contrast, there is a pressing need for the type of research done by Chandros Hull *et al*, research that has the potential to identify disconnects between the assumptions of regulators, ethicists and the values and perceptions of the populations they represent; a willingness to be surprised by counter-intuitive research findings; and the courage to be guided at least as much by emergent values as by philosophical principles.

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