Right of the Living Dead? Consent to experimental surgery in the event of cortical death

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Abstract:

Ravelingien et al have suggested that early human xenotransplantation trials should be carried out on individuals who are in a permanent vegetative state (PVS) and who have previously granted their consent to the use of their bodies in such research in the event of their cortical death. Unfortunately, their philosophical defence of this suggestion is unsatisfactory in its current formulation, as it equivocates on the key question of the status of PVS patients. Their proposed solution rests on the idea that it should be up to individuals to determine themselves when they should be treated as dead. Yet the authors clearly believe (and state) that PVS patients are in fact dead. Finally, given the public good their proposal is intended to achieve, the moral importance they place on the consent of an individual to the use of their body in this research is ultimately only defensible insofar as this consent represents the wishes of a living person. It is thus only a gentle caricature of their position to suggest that according to their account consent to participation in xenotransplantation research is a “right of the living dead”. Ravelingien et al’s equivocation on the question of whether these individuals are living or dead means that they avoid confronting the implications of their argument. The solution that Ravelingien et al propose to the problem of how we should proceed with xenotransplantation research is therefore not as neat as first appears.

Keywords: Death, xenotransplantation, organ donation, consent, permanent vegetative state
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INTRODUCTION

The unknown magnitude of the risk of xenozoonosis, and the difficulties involved in obtaining ethical consent to experimental surgical techniques that offer little prospect of benefit to the patient, stand as substantial barriers to the development of safe and effective xenotransplantation. As xenotransplantation offers the prospect of making life-saving replacement organs available to the tens of thousands of people who currently die each year for want of an appropriate donor organ, there is an urgent necessity to proceed as quickly as is possible with research which might contribute towards the development of safe and effective xenotransplantation. Ravelingien et al are therefore to be congratulated on their contribution to resolving the difficult question as to how such research might proceed in an ethical fashion. Their controversial suggestion is that early human xenotransplantation trials should be carried out on individuals who are in a permanent vegetative state (PVS) and who have previously granted their consent to the use of their bodies in such research in the event of their cortical death. This would make it possible for xenotransplantation researchers to trial their therapies on living human bodies and closely monitor the transplant recipients for any signs of xenozoonotic infection or any other unanticipated long-term effects of receiving a xenotransplant, while avoiding the difficult ethical issues which beset any attempts to trial these therapies on living persons. While they do not discuss it, it seems that the use of the bodies of individuals who are in a PVS might also advance research into other experimental therapies which hold out the prospect of significant public benefit yet involve such a high level of risk and so little hope of benefit to the individual patient in the initial trials that it would be unethical to perform them.

Unfortunately, Ravelingien et al’s philosophical defence of their proposed solution is unsatisfactory in its current formulation, as it equivocates on the key question of the status of PVS patients. Ravelingien et al have a bet each way on the question of whether or not individuals who are in a permanent vegetative state are in fact dead. Their proposed solution rests on the idea that it should be up to individuals to determine themselves when they should be treated as dead. Yet the authors clearly believe (and state) that PVS patients are in fact dead. Finally, given the public good their proposal is intended to achieve, the moral
importance they place on the consent of an individual to the use of their body in this research is ultimately only defensible insofar as this consent represents the wishes of a living person. It is thus only a gentle caricature of their position to suggest that according to their account consent to participation in xenotransplantation research is a “right of the living dead”.

While the idea that individuals should be able to consent to experimental surgery in the event of their entering a permanent vegetative state remains defensible no matter which of the positions described above we eventually settle for, Ravelingien et al’s equivocation on the question of whether these individuals are living or dead means that they avoid confronting the implications of their argument. Each of these alternative positions on the status of PVS patients has important and somewhat unpalatable further implications for the treatment of such patients and for the ethics of performing experimental surgery of little expected benefit to the patient in similar cases. The solution that Ravelingien et al propose to the problem of how we should proceed with xenotransplantation research is therefore not as neat as first appears.

DEAD OR ALIVE?

The idea that individuals should be able to consent to the use of their bodies in xenotransplantation research in the event of entering a permanent vegetative state is suggested by current practices surrounding organ donation in the event of whole brain death (p. 96). However, the authors’ proposal is likely to meet with significantly more controversy than existing practices because the experiments that they propose should be carried out are likely to appear far more grotesque in the public imagination and because the “cadavers” on which these experiments will be performed will be living, breathing bodies.

Ravelingien et al acknowledge that the extension of the notion of death from circulatory death to whole brain death was itself controversial and that any extension to treat patients in permanent vegetative states as dead is likely to be even more so. In anticipation of this controversy, they argue—following a suggestion of Veatch’s—that individual and cultural differences in attitudes towards the moment of death should be respected by allowing individual patients to decide for themselves when they should be treated as dead (p. 96). If they decide that (for them) death occurs when they have suffered an irreversible loss of consciousness and regardless if they continue to have respiration and a pulse even in the absence of mechanical assistance, then they should be able to donate their body to xenotransplantation research just as individuals may currently donate their body to science in the event of their (circulatory or “whole brain”)
death. The advantage of this proposal is that it seemingly avoids the necessity of resolving the difficult philosophical and political debate about the status of these patients. It also explains the importance the authors place on gaining the consent of the PVS sufferer for participation in experimental xenotransplantation.

The obvious difficulty with this move is that it is \textit{prima facie} implausible that whether or not someone is dead is a matter of individual choice. While death is a more complex phenomenon than first appears, especially in the light of advances in medical technology, it remains fundamentally a category of natural science rather than of ethics. As such, it is an objective rather than a subjective matter. To the extent that the definition of death does involve making value judgements, these are primarily social rather than individual questions. That is, they are questions about how other people should treat and respond to a person in a particular condition. When is it appropriate to bury someone, or to mourn them, or to extract their organs for transplant? These are questions that societies or cultural groups, rather than individuals, have to answer. Indeed, insofar as they necessarily involve the disposition and behaviour of large numbers of strangers, they are questions that individuals \textit{cannot} answer.

Although it may not be possible for individuals to settle the question of when they are dead, it \textit{is} possible to grant them some power to determine when they should be treated as though they are dead and what can be done to them when they are. This is presumably what Ravelingien \textit{et al} intend, rather than the stronger and less plausible thesis that individuals should be allowed to determine when they \textit{are} dead. Yet, even here, there are important limits on individuals’ rights to determine when they should be treated as dead. We don’t allow people to decide that their bodies should be available to train medical students in dissection while they are still conscious, for instance. Similarly, in societies that do use a “whole brain” criteria of death, while the medical profession may respect the wishes of deceased individuals, not to procure organs from them if they should suffer whole brain death, they do not typically allow them to insist on continuing ventilation and medical support on the ground that they are still alive at this point. The question remains then, why cortical death should be held to be within the realm where it is appropriate to allow individuals to decide whether they should be treated as dead or not.

The authors suggest, again following Veatch, that an individual’s right to determine when they should be treated as dead should be confined to reasonable claims, with the clear presumption that it is reasonable to treat PVS sufferers as either dead or alive (p. 96). However, it is unclear what this restriction on claims about death would amount to, given the range of different opinions on when people are dead. Some
religious worldviews believe that dying is a process which does not reach its end until a point long after that at which an individual has stopped breathing. Other people, perhaps including a significant proportion the medical community, believe that it is clearly the case that people are dead when they have no higher cortical functions. In an age when human cloning via somatic cell nuclear transfer is close to becoming a reality, cellular death may mark an important point prior to which there is some hope of resurrection of at least part of what people care about when they think about their mortality. In the face of such wide-ranging disagreement, it is difficult to settle the bounds of the “reasonable”. Indeed, there is almost as large a range of opinion about what the bounds of the reasonable are in relation to beliefs about death as there is about the moment of death itself. Given that death is primarily a matter of natural science and, to a lesser extent, a social consensus, any attempt to settle disagreement about the limits of reasonable beliefs about death must inevitably refer to the matters of fact which underpin claims about death and the social practices which constitute our response to it. Pointing to disagreement about the status of PVS patients therefore only partially mitigates the necessity of settling the question of whether or not they are dead before we can decide whether it is reasonable to treat them as such.

However, the real problem with settling questions about the status of PVS patients by allowing people to decide for themselves when they should be treated as dead is that whatever they decide, they are in fact either dead or alive. Importantly, how we should respond to their desire as to how they should be treated depends to some extent on whether they are dead or alive. The wishes of the living and the dead have significantly different moral weights. Ravelingien et al therefore cannot avoid resolving this question.
DEAD?

In fact, Ravelingien et al do make it clear at a number of points in the paper that they believe that a person who is in a permanent vegetative state is in fact dead. To be precise, they believe that cases of PVS present us with a situation in which a person has died leaving behind a living human body. Individuals in a permanent vegetative state have lost all those properties and/or capacities (sentience, rationality, and the ability to relate to others) that may plausibly be thought to be constitutive of personhood and to justify the moral respect that persons are owed. Moreover, because persons in a permanent vegetative state lack sentience, they no longer possess interests. Consequently, they cannot be harmed in the course of xenotransplantation research (p. 95). It is merely a strange matter of circumstance that their bodies retain properties such as respiration, circulation, and other autonomic nervous reflexes, that are normally associated with people who are alive. Given that people who have entered permanent vegetative states are dead it is reasonably straightforward to conclude that individuals should be able to will their remains to xenotransplantation research in the event of their cortical death just as they may to other forms of medical research in the event of their whole brain or circulatory death (p. 95).

Amongst a philosophical readership, this conclusion will hardly appear surprising. The authors themselves note that the argument that PVS patients are in fact dead and that consequently their organs should be available to be sourced for transplantation has been made a number of times before (p. 95). But what is now thrown into question is why the authors have restricted the range of cadavers available for xenotransplantation research to those where the recently deceased had provided their explicit consent to their remains being used in such research. Why is it so important that an individual’s consent has been obtained? At the very least it seems that, in nations which operate an “opt out” rather than an “opt in” system of organ collection after death, a strong argument could be made that the bodies of individuals who are in a PVS should be made available for xenotransplantation research unless they have explicitly directed otherwise. If the benefit to the public of increasing the number of organs available for transplantation justifies a change in the presumption of consent for organ donation then the same is likely to be the case for participation in xenotransplantation research.
The moral weight of the wishes of the dead

In fact, the implication of declaring PVS patients to be dead is more radical than this. Where people do not wish their cadavers to be used for xenotransplantation research, our reason for respecting this desire involves respect for the wishes of the dead. While there are reasons for respecting the wishes of the dead, these have always been somewhat philosophically controversial, given that the dead will experience no harm if their wishes are not respected (pp. 95-97). This in turn suggests, especially to those with leanings towards utilitarianism, that the interests of the dead should be discounted somewhat when they come into conflict with the interests of the living.

As Ravelingien et al have emphasised, the living may have very substantial interests in large numbers of xenotransplantation trials being performed as quickly as is practicable. It is puzzling then why the authors are so quick to concede that the wishes of the deceased should be allowed to stand in the way of this.

Note that the balance of considerations in relation to the use of PVS cadavers in xenotransplantation research, against the wishes of the deceased individual, is significantly different than those when it is organ collection from patients who have suffered whole brain death which is at issue. Collection of organs from a cadaver may save a few lives at most. Given the revolutionary life-saving potential of xenotransplantation, research on PVS cadavers might save tens of thousands of lives. Indeed, it is precisely because Ravelingien et al believe this to be the case, that they have put forward their proposal. Of course, drafting any individual PVS cadaver into this research may not save all these lives, but it might well be the case that it will make a more important contribution to the reduction of human suffering than would the use of this cadaver’s organs alone. The reasons in favour of co-opting the remains of those who have died by entering a PVS—regardless of their consent—are therefore much stronger than those justifying the sourcing of organs for transplant without consent.

It is true that many societies do give a substantial moral weight to the wishes of the deceased in relation to the treatment and disposal of their remains. The public’s ideas about what is mandated by the notion of respect for the dead are often much stronger than the justifications usually provided for them by philosophers allow. Despite this, decisions about the treatment of the body of the deceased against the deceased’s wishes are far from unprecedented. It is already firmly established that significant and pressing public health interests may override individuals’ wishes about the disposal of their remains. Thus, for
instance, when the cause of death of a particular individual is unknown but where the involvement of a
dangerous infectious agent is suspected, or where a death has occurred as the result of a criminal act,
coroners may be required to perform an autopsy regardless of the wishes of the deceased. On the other
hand, as Ravelingien et al point out, some countries, such as New Zealand, allow that the relatives of the
dead can override the wishes of the deceased to donate their organs for transplant or research.

Our willingness to override the wishes of the deceased in other circumstances suggests that Ravelingien et al’s concern for the consent of the deceased individual for the use of their remains is exaggerated here.
Their belief that PVS sufferers are in fact dead, alongside their recognition of the large public benefit that
would be achieved by preceding quickly to human xenotransplantation trials, should push them towards the
much more radical claim that PVS cadavers should be made available for xenotransplantation research
regardless of the wishes of the deceased.

Respect for the wishes of the relatives?

One obvious and important objection at this point, of course, is that while the wishes of the deceased may be
overridden by the benefits to the public of proceeding with xenotransplantation trials, there is also the matter
of the wishes of their living relations. The partner, parents or siblings of the deceased may be
understandably distraught at witnessing the still-beating heart or working lungs of their recently dead
relative being removed from their body and replaced with the organs of genetically modified pigs.

However, again, there is a familiar range of cases where we neglect the wishes of relatives concerning the
treatment of the remains of the deceased. Ravelingien et al themselves note with approval that many
countries allow the wishes of the deceased concerning the disposal of their remains priority over the wishes
of their living relatives (p. 97) (contra the example of New Zealand, which they cite to a different purpose).
The interests of other parties may also justify denying the wishes of relatives. We do not allow relatives
to discard the body of the deceased in the street or to make ornaments out of it, no matter how strongly they
desire to. Remains may be buried or cremated without consulting relatives if failing to do so will constitute
a threat to public health or safety. Where public health, or the investigation of a possible homicide, requires
it autopsies may be performed against the wishes of relatives.

The wishes of living relatives are an important concern when we attempt to assess the balance of
considerations surrounding the treatment of the remains of the deceased, but they are not the only
consideration. Where the public interest is large enough, we may sacrifice the interests of the relatives for the greater good of the community.\textsuperscript{19} The harm to the living relatives may be minimised by ensuring that they are aware of the justification for the treatment of the deceased and the good it accomplishes, in the hope that this will cause them to reconsider their opposition to actions taken to this purpose.

**Public policy reasons for respect for the dead?**

A significant concern about policies regarding the use of cadavers is the impact that they may have on the willingness of individuals to donate their remains to science or, more importantly, to enter into a medical and/or hospital environment at all. If people suspect that their wishes concerning the disposal of their remains will not be respected after they die they may be reluctant to remain in hospital if they are dying.

However, the relative frequency of the PVS condition compared to circulatory or whole brain death will have a significant impact on consequentialist calculations about the effects that compulsory requisition of cadavers will have on the living. Policies concerning the treatment of the cortically dead are likely to affect far fewer people than policies regarding those who have suffered circulatory or whole brain death. The vast majority of people will not end up in a permanent vegetative state and, to the extent that they recognise this, may judge that what might happen to them if they do enter into such a state is not of sufficient concern to prevent them from seeking medical care when they need it.\textsuperscript{20} While the impact of proceeding with xenotransplantation research involving PVS cadavers without the consent of the deceased on the willingness of individuals to enter a medical setting would need to be monitored, there is little reason to believe that this will be so significant as to outweigh the public benefits to be gained by carrying out xenotransplantation trials.

Another, I think more pressing, concern is that if xenotransplantation was to become associated in the public mind with such macabre practices as transplanting animal organs into the living bodies of the recently deceased against the wishes of the deceased, this might have disastrous impact on public support and therefore funding for xenotransplantation research. Proceeding with xenotransplantation trials involving PVS cadavers without the consent of the deceased (and perhaps also their relatives) would then be self-defeating, as it would undercut support for the very research it was aiming to advance.

However, this reason to respect the wishes of the dead concerning the disposal of their remains depends crucially both on some empirical facts about the link between experimentation on PVS cadavers and public
support for xenotransplantation and on resisting alternative courses of action that might sever this link. It may simply not be the case that public support for xenotransplantation will collapse if the research necessary to prove its safety involves experimenting on deceased individuals in permanent vegetative states against their previously declared wishes. The prospect of resolving the problem of the scarcity of donor organs available for transplantation that xenotransplantation holds out may be sufficiently attractive to the public that they would continue to support xenotransplantation research involving PVS cadavers even if this takes place against the wishes of those whose remains are being used for this purpose.

More problematically, it may be possible for xenotransplantation research involving PVS cadavers to proceed without any impact on popular support for xenotransplantation if the public remains unaware of it. If the expected public benefit from xenotransplantation research is large enough, it seems as though researchers may have reason to ignore even the explicit instructions of relatives and proceed with xenotransplantation research involving PVS cadavers without their consent and without their knowledge. That is, they may be justified in proceeding with clandestine xenotransplantation research. This might involve, for instance, telling the relatives that their relation had died (and providing them with a body for burial) and then abducting the PVS cadaver for research at a secure location.

The argument here is analogous to an argument that might have been made in favour of the theft of corpses for early medical research and dissection in the 17th, 18th and 19th centuries. The methods used to procure cadavers for dissection, which included theft, deception and perhaps—in some cases—murder, were prima facie immoral. However, it might well be argued that the apparently immoral actions of these researchers and their body snatching accomplices were ultimately justified by the immense public benefit that has been secured by modern medicine on the basis of knowledge gained from their activities. Dedicated xenotransplantation researchers might reason that they are in a similar position today. While it is normally wrong to deceive people about the fate of their (or their relations) remains, the benefits of proving xenotransplantation safe are so great that if the only way to carry out the necessary trials without xenotransplantation research falling victim to a public backlash which would prevent it from reaching its goals is to do so clandestinely, then such deception may well be justified. The consequentialist tone of Ravelingien et al’s paper suggests that they may have difficulty resisting this conclusion.

Of course, there may be many other good ethical reasons not to pursue this policy. I am not seriously proposing it as a way forward for xenotransplantation research. My purpose in raising the possibility has solely been to show that there is a significant tension between Ravelingien et al’s claims that individuals
who are in a permanent vegetative state are dead and that there is an enormous public benefit to be gained by performing xenotransplantation research on the “living dead”, and their claim that it is essential to secure the prior consent of the deceased for participation in such research.

**ALIVE?**

One way to justify the authors’ concern for the consent of PVS patients is to concede that these individuals are still alive. By virtue of the fact that their heart beats and their lungs respire unaided, they are still “one of us”, a living human being and as such a member of a community whose respect for each other in a medical context is expressed in a concern for consent to treatment. In some ways this is not a terribly attractive philosophical position to hold given that, as we observed above, persons who are in a permanent vegetative state seem to have so few of the morally significant properties that ground respect for living human beings. In defence of this position, however, it should be noted that PVS sufferers remain legal persons. We also have strong intuitions that despite their lack of sentience they are—in some sense at least—alive and that for this reason to experiment upon them while they are in this state without their consent is more morally problematic than if they were dead.

If PVS patients are in fact alive this need not lead to the conclusion that they may not volunteer their bodies for xenotransplantation trials. It might be argued, for instance, that while they are alive and that their previously expressed wishes are worthy of respect because of this, they are also in the unique position of having very few, if any interests, once they are in a permanent vegetative state. They will not suffer any harm even if participation in xenotransplantation research leads to their death. Thus as long as they consent to such research taking place there are no reasons of a paternalistic nature to object to their participation in it.

However, any argument that it is legitimate for PVS sufferers to consent to participation in xenotransplantation research is likely to lead to further, stronger conclusions about the rights of individuals to volunteer for experimental surgery when doing so is unlikely to harm their interests. There are, after all, other circumstances in which—it might be argued—that people are unlikely to be harmed by participation in experimental research even when it offers them little hope of benefit. Most obviously, if individuals are dying of organ failure, with no prospect of sourcing a human organ for transplant surgery, then receiving a xenotransplant is unlikely to make them worse off. Despite this, they may be willing to consent to
participate in research for altruistic reasons in the hope that their participation will assist in the development of a technology which will provide benefits to others in the future. If what justifies experimentation on persons in a permanent vegetative state is that they are unlikely to suffer any harm in the process then consent to altruistic participation in experimental medical research in cases of medical extremity will also be permissible.  

This conclusion in itself is not especially surprising. There is an ongoing debate about the morality of allowing patients to participate in research which is unlikely to provide them with any benefit if their motives are altruistic. However, altruistic participation in research in a situation of medical extremity is also generally recognised to be ethically fraught and to open individuals to the danger of exploitation. Further argument is therefore required before we can accept this possible implication of the authors’ argument. More importantly, for the purposes of this discussion, the conclusion that it is ethical to allow individuals to volunteer for participation in research in a situation of medical extremity will remove much of the need for xenotransplantation trials to involve individuals who are in a permanent vegetative state in the first place, as research into the dangers of xenozooonosis and other long-term health effects on transplant recipients could now be performed on living patients with their consent.

CONCLUSION

None of this discussion is intended as a direct criticism of Ravelingien et al’s proposal as to how xenotransplantation research might proceed past the current ethical impasse. From a public policy perspective, it seems likely that the proposal that we attempt to secure the consent of individuals to allow their remains to be used for research purposes should they enter into a permanent vegetative state is indeed the best way of ensuring public support for xenotransplantation research involving human bodies in a permanent vegetative state. However, the argumentative route that they take to this conclusion is confused. The existence of controversy concerning the status of individuals who are in a permanent vegetative state is itself insufficient to justify the conclusion that it is legitimate to trial experimental surgery on them as long as their consent is secured. The underlying philosophical question remains the status of these individuals. If we decide that they are in fact dead then it seems that the requirement for their consent is weaker than Ravelingien et al indicate and that, given the large public benefit to be gained from developing xenotransplantation technology, we may need to look further at the possibility that research would be justified without the consent of the deceased. If we decide that they are in fact alive then the authors’
concern that we seek their consent is better founded. However, allowing that such research is ethical suggests that it may also be ethical to proceed with experimental surgery involving consenting individuals in other circumstances of medical extremity and consequently that the need for xenotransplantation trials to be conducted on individuals who are in permanent vegetative states is less pressing than the authors suggest. Significant philosophical work therefore remains to be done before we can properly assess the ethics of proceeding to human trials of xenotransplantation involving individuals in a permanent vegetative state. By drawing attention to the issues, Ravelingien et al have made an important contribution to this project.
REFERENCES


2 The Lancet. Xenotransplantation: Time to Leave the Laboratory. Lancet 1999;354:1657. This is not to deny that significant ethical issues concerning the use and treatment of sentient nonhuman animals in xenotransplantation research and practice exist and remain to be resolved. For a survey, see Daar AS. Ethics of Xenotransplantation: Animal Issues, Consent, and Likely Transformation of Transplant Ethics. World J Surg 1997;21:975-982.


4 Fost also discusses the possibility that we might proceed with sourcing organs from persons in a PVS, if they had previously consented to such. Fost N. Reconsidering the Dead Donor Rule: Is it Important That Organ Donors Be Dead? Kennedy Inst Ethics J 2004;14:249-260, at 253-4.


6 Singer P. Rethinking Life and Death. Melbourne: The Text Publishing Company, 1997:20-22. This is not to deny for a moment the extent of the controversy surrounding the definition of death, or the possibility that there is more than one reasonable position on the matter. However, it is to insist that what the controversy is about is a distinction which plays a fundamental role in the life sciences and which requires a definite resolution (Russell T. Brain Death: Philosophical Concepts and Problems. Aldershot, UK: Ashgate Publishing Ltd, 2000, cited in Campbell CS. A No-Brainer: Criticisms of Brain-Based Standards of Death. J Med Philos 2001;26:539-551 at 548).


16 It is difficult to know how to refer to the bodies of individuals who are in PVS, as their status is the central issue in the controversy under discussion. However, in this section, where I am discussing the possibility that such individuals are dead, “cadavers” does not seem inappropriate.

17 In Victoria, Australia, the circumstances in which autopsies are permitted and/or required are set out in the Coroners Act 1985. A discussion of the legal status of bodies and the circumstances in which the consent of the individual can be overridden in the


20 They may also rightly reason that if such experiments are performed on them they will remain unaware of it and, arguably, unharmed by it.


22 Indeed, recent scandals in the UK suggest that at least some in the medical and research communities have embraced it. MacDonald H *Human Remains: Episodes in human dissection* Melbourne: Melbourne University Press, 2005:186-89.


24 I owe this point to Neil Levy who made it in a seminar at the Centre for Applied Philosophy and Public Ethics, at the University of Melbourne, at which An Ravelingien presented her and her co-authors’ ideas.

25 The argument here presumes that harm that is measured according to a baseline of interests which would exist independently of the action being considered.