

# Returning to the Alder Hey report and its reporting: addressing confusions and improving inquiries

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*J Med Ethics* 2004;30:463–469. doi: 10.1136/jme.2002.002774

The Royal Liverpool Children's Inquiry investigated the circumstances leading to the removal, retention, and disposal of human tissue, including children's organs, at the Royal Liverpool Children's NHS Trust (the Alder Hey Hospital). It recommended changes to procedures for obtaining consent for postmortems and retaining organs and tissues for research or education. However, the report contains five areas of confusion. Firstly, it allowed the cultural and historical traditions of horror over the use and misuse of body parts to suffuse the logical analysis of past wrongs and future rights. Secondly, it makes an inappropriate conflation between seeking redress for past wrongs and shaping future policy. Thirdly, the report takes a muddled stance over the value of bodily integrity at burial. Fourthly, the report is inconsistent over the justification for future organ and tissue collections. Fifthly, the notion of "respect" is used with troublesome looseness. The extent to which subsequent policy work has furthered the search for greater ethical clarity over these difficult issues is discussed, together with reflection on three particular improvements that could be made to the process of such an inquiry.

We have undertaken to review the report and its reporting, to understand its approach to organ retention in context. Reactions to the report are as telling as the report itself in revealing cultural attitudes to organ retention—which both reflect and reinforce the perspective taken by the inquiry. Examination of both the report and the reporting reveals a confused picture of the ethical issues. Our analysis suggests that five important sources of confusion underlie its judgements. In the development of subsequent policy, a process of teasing out these difficult issues has begun. Unravelling the intertwined and problematical ethical issues involved will help frame emerging policy. It also raises important questions about the best way to use inquiry and investigation to drive policy development in emotive and ethically complex areas.

We examine each of the five main areas of confusion and specifically consider: the weaknesses in the report; the way policy has moved away from underlying assumptions articulated, or implied by the public commentary at the time; and how the difficulties faced by inquiries might be minimised in the future.

## THE FIRST CONFUSION: THE POWER OF HORROR OVER LOGIC

Images and metaphors exert a powerful influence on human reaction, often establishing the context in which judgements are made or explained. Small details of wording reveal and evoke metaphors which often imply and bring to bear a particular set of basic assumptions to the process of inquiry. Without conscious analysis of their applicability, these images and their associated metaphors can limit the boundaries of judgement. They can reinforce or project a particular mindset. When implicit and unchallenged they limit thinking, serving as a substitute for explicit analysis and a transparent statement of the underlying values and assumptions that are central to judgement. Examining these images and metaphors can assist in unravelling the conceptual base for the perspective taken by the report and its reporting, to the ethical problems of organ retention.

A certain set of images present themselves here in the powerful cultural and historical context for any inquiry into the use and misuse of body parts. The tradition of the macabre, the horror genre of film and literature, and the real history of grave robbing and body snatching are capable of exerting a powerful pull over our imagination and our response to the events at Alder Hey Hospital, an impact that is compounded by our joint and heartfelt

The Royal Liverpool Children's Inquiry investigated the circumstances leading to the removal, retention, and disposal of human tissue, including children's organs, at the Royal Liverpool Children's NHS Trust (the Alder Hey Hospital). The publication of its report in January 2001<sup>1</sup> generated a huge emotional and political reaction.<sup>2–3</sup> Public, professionals, and politicians acknowledged wrongdoing at Alder Hey Hospital and agreed that the practices of the past needed to change.

The Alder Hey report was a catalyst to that process of change particularly with regard to the procedures for obtaining consent to post mortems, and retaining tissue and organ samples for use in education and research. Subsequent working groups in England and Wales, as well as Scotland, published proposals for how healthcare professionals might approach obtaining consent for postmortems and the possible retention and use of organs and tissues for research or education.<sup>4–6</sup> Similarly, other countries (particularly Australia and New Zealand) have conducted similar inquiries and policy processes to review and update professional practice in this area.<sup>7</sup>

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Received 13 December 2002  
Revised version received 19 July 2003  
Accepted for publication 7 August 2003

responsibilities either as parents or members of society to protect children from harm.

This tradition of the macabre includes two particularly powerful myths. The first myth is based on the image of the mad and bad scientist and the second on a fantasy of residual feeling or human sentience in the dead, or parts of the dead. There is evidence that the Alder Hey report has (consciously or not) drawn upon this horror tradition. Its presence in the report adds a layer of sensationalism, something that blurs the edges of the logical analysis required to address such problematic ethical issues. Both myths also pull the analysis and the reader towards an assumption of wrongdoing, based not so much on the facts of the case, but on an assumption of wicked intent in the very process of examining, removing, storing, and using material from the dead.

The report (and its reporting) uses images that evoke such powerful “stories”. For example, the report provides photographs of the building at Myrtle Street that was used by Professor Van Velzen to store retained organs. The report tells us that the photographs are included “to give some idea of the nature of the building”<sup>8</sup>—a somewhat ramshackle, grubby, late Victorian building—which contrasts sharply with the modern Institute of Child Health, photographs of which appear on the next page. The unfavourable impression of Myrtle Street will for some play into a fantasy about the kind of place where “bad” science takes place. This is reinforced by an accompanying narrative that tells us that van Velzen “enjoyed the seclusion Myrtle Street afforded him”.<sup>9</sup> Although it may well be true that van Velzen did enjoy the location of his workplace, the wording and context of this comment fits well with the highly charged fantasy of a lone scientist needing secrecy for his underhand deeds. Similarly, references to van Velzen’s “modus operandi” and a reference to the Professor “Munchausen” nickname (occasionally applied by staff in the Trust) reinforce a powerful image.<sup>10</sup>

Similarly, the history of the medical use of dead bodies, which is highly coloured by their misuse, can never be far away from the language used by families to tell of their experiences. The concerns of some parents, that organs were stolen: “the hospital stole something from me”; “Alder Hey stole 90% of my child”; “it feels like body snatching”<sup>11</sup> speaks directly to this history. The parents’ reactions are understandable; what is important to note however are the metaphors used and how they specifically echo a history where the use of human organs and tissues was itself suspect. Indeed, Liverpool plays a key role in this history. Fear of body snatching was rife in Liverpool during the cholera riots of 1832. Public distrust of the medical profession was extreme in the widespread panic that doctors were deliberately killing cholera victims in order to keep their bodies for anatomy work.<sup>12</sup>

The second powerful set of images concerns human sentience in the dead. Here too, we find the report and particularly its reporting conflating the notion of retained organs as, of course, biologically human, with the idea that they might be imbued with some (poorly specified) fundamental human nature. Even the language used risks this confusion—sometimes the term “human” is used to imply “belonging to a certain biological species”, on other occasions it signifies humanity, personality, consciousness, culture, individuality—human in a social, emotional, and spiritual sense.

A *Lancet* editorial on Alder Hey, for example, told readers that “stored material should be reviewed regularly, and anything not being used with dignity for a scientific or educational purpose should be disposed of in an acceptable way, not left to languish unattended”.<sup>13</sup> Can anything that is not sentient languish? And what defines dignity in the use of a pathology slide? There is a further echo of this in the *BMJ*

editorial of the time, which speaks of organs “unexamined and uncared for”.<sup>14</sup> It is arguable that inanimate things can be the proper recipients of care but the more usual use of the term would imply the imbuing of portions of a dead body with personality.

Similarly, in the light of the Alder Hey report, the CMO recommended that “for tissues and organs donated for teaching, families should be invited to prepare a ‘life book’ on the child (or adult) who has died”.<sup>15</sup> His contention was that the book “would be shown to students in conjunction with the tissue or organ used for teaching”. This “... would encourage an attitude of respect and awareness of *the fundamental human nature* of the tissues and organs being used for teaching and avoid them becoming dehumanised objects” [authors’ italics].<sup>16</sup> Again the underlying desire to promote an appreciation of the need to view the material as a gift is well made (although the consequential obligations for respect and dignity are undefined) but the confusion over the “human” status of retained material is unhelpful. There is confusion, too, about different ways of according respect and dignity to human material. The protective urge to ensure that (for teaching) “wherever possible, tissue samples should be anonymised or pseudonomised” seems directly at odds with provision of life books.<sup>17 18</sup>

## THE SECOND CONFUSION: A PROBLEM WITH PERSPECTIVE

The report—like many others—faces two directions: looking to the past to understand what happened; then looking to the future to recommend ways of avoiding a repetition of the past. Where future public interest and remedying the cause of prior wrongdoing coincide then this approach can provide a powerful impetus for appropriate change. In the Alder Hey case this can be seen in the impetus given to the need to reassert the central role of consent. At Alder Hey the families’ legitimate grievance rested on the lack of informed consent for organ retention. The summaries of their evidence to the inquiry constantly reveal this to be at the centre of their concern. They did not know that tissues and organs had been taken from the bodies of their dead children, nor did they know the extent of what was taken. On this issue of consent their perspective and the future public interest perspective are as one.<sup>19</sup>

However, the problem with this brief (to address the past and learn lessons for the future) is the temptation to turn judgements about past failure (where the perspective of the wronged might well legitimately predominate) into inappropriate assumptions about the future (where a widely drawn and subtly different public interest perspective should apply). In the same way that “victim impact statements” may be invaluable in understanding the harm caused as a result of crime and provide a basis for compensation, they may not provide a measured and balanced basis for preventing future wrongdoing.

The debate over other aspects of the rights and wrongs of organ retention would benefit from an acknowledgement of a plurality of perspectives on the ethical issues involved. Our aim in exposing the metaphors and images of the report and its reporting is precisely to open up the possibility of a plurality of ways of seeing. Instead, however, the Alder Hey report approaches this wider domain solely from the perspective of the families who were wronged in this case. The report often endorses its position on organ retention by referring to the views of this group of parents. It gives parents’ comments a prominent place at the start of the report, it devotes a chapter to a summary of their evidence and explicitly gives them special status “as a mark of respect and also as a permanent memory of their involvement in and contribution to the inquiry”.<sup>20</sup>

This may help to explain assumptions that underlie the report (and the commentary that surrounded its publication) but are not explicitly spelt out within it, or challenged in the subsequent public debate. For example, the notion that organ retention is inherently wrong and unprofessional: “This strategy ignored the potential for a maverick professor continuing undiscovered and *unprofessional* practices” [authors’ italics].<sup>21</sup> Similarly, the Secretary of State called the practice “unethical”.<sup>22</sup>

Does such an assumption reflect the perspectives of those who have been wronged? And are such assumptions, however relevant to the judgement of past events, a useful basis upon which to build a framework for future decisions about organ retention? If in the future informed consent is at the centre and forefront of discussion with parents and families, would similar implied judgements concerning the potential value of retention, and the disrespect inherent in a loss of bodily integrity at burial, still apply?

The wishes of the parents and families of those children from whom organs were retained should have been put at the centre of decisions about organ retention in the first place. It is understandable that putting them at the centre of judgements about what happened in the past might be considered the very least that could be done to begin to address that prior wrong. But future policy should be judged against a wider public interest. The issue of how to put right prior wrongdoing is an important but separate concern.

A different approach has been taken in Scotland where the Independent Review Group on Retention of Organs at Post-Mortem, expressly separated their work into two phases. “Phase 1 was essentially about helping families come to terms with the consequences of past practice, by restoring to them as much as possible the control of which they felt they has been robbed, particularly in relation to children .... Phase 1 was very much about helping individuals. Phase 2 has been undertaken in the interests of public good. Phase 2 is about the future; about moving forward from the uncertain legal basis which has underpinned hospital post mortem practice ...”.<sup>23</sup>

### THE THIRD CONFUSION: THE VALUE OF BODILY INTEGRITY AT BURIAL

Parents belonging to the Alder Hey based campaigning group PITY II (Parents who have Interred Their Young Twice) told of how they had buried only “empty shells”. This is echoed in the report: “organs were retained so that parents unwittingly buried ‘shells’ of their children”.<sup>24</sup> Similarly, the Secretary of State told of parents discovering that many children’s bodies “had not been buried intact as they believed, but had been stripped of their entire internal organs—leaving the body a shell”.<sup>25</sup>

For the wronged parents it was a discovery that led to understandable expressions of betrayal. Many expressed views that there had been an assault on the integrity of their dead child’s body. This led some families to attempt to track the fate of every small specimen of tissue collected. The need for these families to go back and put right a perceived wrong, to themselves and to their child is, in such circumstances, keenly felt.

However, the desire to restore the integrity of the buried child or to make real what families imagined they had been doing at the time of the first burial should not influence an ethical position on the value of bodily integrity at death. On this question a very real range of views exists. Understanding the wrongdoing should centre on the issues of consent and deceit (sometimes with intent and sometimes without). It need not rest on any assumed ethical consensus over the inviolate nature of the dead.

The Alder Hey report confuses this point. To give an example of this, the report tells us that “a decision was taken at the outset to inform parents of the retention of either whole organs and substantial parts of organs, but not the many small pieces of fragments, some of which were unidentifiable. Small fragments would have been present in most of the containers. The stated justification was to avoid misleading parents into thinking whole organs had been retained when they had not”. However, the report goes on to suggest that the “real significance of the concealment of the fragments lies in the inherent disrespect shown to the children’s organs”.<sup>26</sup> Underlying this concept of “inherent disrespect” to the dead is an apparent endorsement of the view that absolutely all fragments of a body must be reunited to avoid disrespect.

Again the Scottish Independent Review Group On Retention of Organs Final Report avoids this confusion. For example, the Scottish report takes a distinctive approach to the issue of tissue blocks and slides. It notes that “we believe that they raise personal and professional issues which may be quite distinct from those associated with organs and major tissues”.<sup>27</sup> It recognises that for the time being, families should be able to retrieve tissue blocks and slides, in recognition of their distress and the need of many to achieve a sense of closure. However it explicitly states that in the future different rules should apply. It argues that the preparation of a slide involves a mass of work that transforms the tissue “so that it is well-nigh impossible to regard the material on the slide as meaningful human material; it is more rational to compare the status of a slide with that of a retained x ray film ... they should, in fact, and in law, be seen as part of the medical record”.<sup>28</sup>

This stands in contrast to the tenor of the Alder Hey report where any such distinction between addressing past wrongs and stating the ethical arguments that might apply to future policy are blurred. In the Alder Hey report it is unclear whether an endorsement of the wishes of wronged parents to recover all retained organs, tissues, and fragments extends into an implicit ethical judgement that values bodily integrity—including minute parts of the body—as a good thing in its own right.

### THE FOURTH CONFUSION: JUSTIFYING ORGAN AND TISSUE COLLECTIONS

The Alder Hey report cites the reactions of Professor Johnson, Dean of the Faculty of Medicine at Liverpool University, on coming across a collection of children’s body parts. He reported being “saddened at what I had seen, and also confused”.<sup>29</sup> A few days later on learning of the fetal eye collection, he says he was “somewhat taken aback” but his initial reaction “was tempered by the fact that the research work in ophthalmology was generally of an excellent standard, and the clinical work of the Royal Liverpool hospital was excellent”.<sup>30</sup>

The reaction of the report to the various organ collections at Liverpool is similarly confused and tempered. It makes a clear delineation between van Velzen’s collection at Myrtle Street, discussed in the extensive chapter 8, and several others, discussed together in chapter 7. This is so despite the fact that the report acknowledges that problems with obtaining consent occurred throughout the collections, referring to a “cult of expectation” that hearts would be forwarded to the collection at the Institute of Child Health which “may well have been such that the issue of consent from parents became, if not a secondary consideration, something viewed as a mere formality”,<sup>31</sup> and notes that the fetal collections failed to comply with the Polkingham recommendations with regard to consent.<sup>32</sup> Moreover, the report acknowledges that scant consideration to consent

occurred nationwide. It tells the reader “the simple fact” that “the retention of organs was commonplace over the country. Doctors had been brought up to expect it. The doctors at Alder Hey no more considered the validity of the collection at Myrtle Street than they did of the Heart Collection in the ICH”.<sup>33</sup> The report also notes that there were problems with documentation with some collections. There were clearly particular problems with van Velzen’s collection at Myrtle Street. What is instructive to consider is why, given the existence of widespread problems of varying degrees with organ and tissue collections, van Velzen’s collection was subject to particular criticism. Asking this question helps reveal unanswered and difficult questions about our attitudes to organ retention.

The first part of the answer seems to lie in the scale of van Velzen’s collection. Indeed, it is on the issue of size that an unfavourable contrast is made with the ICH heart collection—the report refers to the need to consider the heart collection alongside “the huge store of body parts which accumulated in Professor van Velzen’s time”.<sup>34</sup> However, the two collections were of a similar order of magnitude—van Velzen’s collection was of about 2000 pots of organs and tissues; the ICH collection at October 1999 was of 2087 hearts and related organs. Later, the report says of the ICH heart collection: “the collection is considered to be one of the two leading collections in the country ... and one of the most extensive in the world”.<sup>35</sup> Here, “extensive” acts as a positive attribute, rendering the collection more useful. There is an illogical approach to the way that “size matters” in the report; in one place, a pragmatic marker of usefulness, in another, an attribute that seems to stand for something “bad”.

A second point of unfavourable contrast rests on the characterisation of van Velzen’s collection as a consequence of a “systematic stripping” of bodies. The idea that the retention of whole organ systems is ethically harder to justify than the retention of one organ, part of an organ or a set of tissue samples hovers in the background. The power of horror seems to be operating here, with “horror” deepening as more is seen to be taken from bodies—more from the same body, or from many bodies. There is no explanation of how the extent of retention from any one body might impact on the judgements involved. Readers are often left simply with an impression of greedy desecration. Indeed, the ICH heart collection in many cases also included lungs and other organs such as thyroid, trachea, tongue, and larynx—something the report presented as relatively unproblematic.

The final point of contrast between collections concerns the different research benefits accrued. The report implies that medical benefit can go a long way towards justification of the use of organs and tissues. For example, the heart collection at the ICH is spoken of favourably for its contribution to medical research and education. The report tells the reader: “there are now more than 1,600 living children who would have died in infancy or childhood without the improvements in surgical techniques and care which were pioneered in Liverpool. Whilst it would be disingenuous to suggest that the lowering of the mortality rate is solely due to the use of the heart collection alone, there can be no doubt that pioneering positive developments have resulted directly from work undertaken surrounding the heart collection”.<sup>36</sup> This is in contrast to the asserted lack of useful research outcomes for van Velzen’s collection—despite peer review publication. However, a valuable research outcome can only justify a collection after the fact; this cannot, as a matter of logic, be used to validate the way a collection was created.

Is it sufficient to assume (probably correctly) that a majority of people would think there was a difference between retaining a small amount of tissue, some organs,

or all the organs from a child’s body? Although it may be beyond the remit of an inquiry report to address such questions directly, clarity of these issues is necessary for the development of value based and ethically transparent public policy. Attempting to draw distinctions between different collections of organs is one way into the central issue concerning the future protection of the personal and the public interest: under what conditions is the removal and collection of organs for medical research ethical?

It is encouraging that where the Alder Hey report feared to tread, subsequent policy development is making progress towards a clearer statement of the circumstances that determine legitimacy for all such collections—not least of which are the need for consent in order to justify research endeavours, which must themselves be at the outset of creditable scientific value.<sup>37</sup>

### THE FIFTH CONFUSION: UNRAVELLING RESPECT

The report and the wider debate on organ retention puts the concept of respect centre stage. The examples are legion. The Alder Hey Inquiry is characterised as revealing a fundamental “lack of respect”.<sup>38</sup> Any ethical position would underscore the need for respect. The question is what respect in this context should mean in practice.

Unfortunately, the report, as well as debate around it, uses the term loosely. As one correspondent to the *BMJ* asserted, “the fact that retained organs exist in pathology laboratories does not in any way mean that pathologists or any other group of doctors are disrespectful of any patient, living or dead, whose organs have been stored”.<sup>39</sup> Respect means many things to different people. Clarity is crucial if it is to fulfil all that is asked of it. There are two areas where this is paramount: the process for obtaining consent and the management of expectations over the process of retaining and using organs.

Without consent, respect is compromised. Parents who testify in the Alder Hey report speak first and foremost of their lack of knowledge about informed consent to the retention of organs and tissues. However, achieving consent in a way that ensures respect is problematic. Scotland’s Independent Review Group’s Final Report makes the recommendation that the word “authorisation” be used in place of “consent” for two reasons. Firstly, the power to consent to a procedure upon a child should rest on *their* best interests, and this cannot be the case regarding a post-mortem. Secondly, consent implies a decision based on full information, but postmortem presents a situation where many families may not want to be confronted with full and potentially distressing detail at the time of bereavement. There is a move towards greater patient (and family) autonomy within medicine. But an emphasis can be put on different aspects of autonomy. One approach foregrounds rationality as a basis for autonomous decision making, requiring patients and families to take full responsibility for decisions; these must be based on full relevant information, as anything else would be less than maximally autonomous. However, an alternative approach brings choice and individual freedom to the forefront, respecting an individual’s authority to control his or her life in whatever way he or she chooses. The Scottish proposal allows parents to authorise a postmortem, having explicitly declined to be given details of what exactly will happen.<sup>40</sup>

To turn the call for respect into real and practical outcomes more clarity has to be brought to bear on what constitutes respectful treatment of organs and tissues. Without this, promises to treat with respect may mean something different to the parties involved. This is illustrated by the Alder Hey report’s consideration of whether human organs had ever been stored alongside, or in the same container as, animal

organs.<sup>41</sup> The report assumes that this would have been disrespectful had it occurred. But others may be mystified by such concern, and may never have thought that the action of storing human tissue on the same shelf as animal tissue could arouse such deep emotions and calls of “disrespect”.

There are immense difficulties in presenting information on postmortems but there is a danger that blanket reference to “respect” may paper over differences. Responses to consultations show awareness of the danger that euphemistic language may give false impressions and highlight differences in attitude—for instance, some respondents objecting to words such as “reverent” because of religious overtones.<sup>42</sup> It is right and proper that different parties have different relations with the dead and hence different ways of showing respect. We are used to the idea that different religions and different cultures show their respect in different ways. Close relatives will show respect in different ways to strangers. In the same way it would be inappropriate to expect professionals dealing with dead bodies (or parts of them) to show or feel respect in the same way as those who knew the person when alive. It may be necessary for society to recognise their actions as respectful, in context; but the difference in context must also be acknowledged.

Sorting out different contexts for showing respect can help to cast light on many of the wrongs the Alder Hey report identifies. For instance, many organs and tissues were kept but not actually used for research, or in some cases, used in poor research. This waste of material can be seen as disrespectful to the organs and tissues as valuable material and disrespectful to those who consented to their use, without necessarily involving any further notion of disrespect. So, if organs and tissues have been given for research and education, showing them respect may primarily involve making good use of them for these purposes.

### CONCLUSION: WHERE DOES THIS LEAVE US?

The Alder Hey inquiry had an unenviable task. It had to grapple with twin issues of immense psychological difficulty: child death and the treatment of the dead. Understandably, the authors of the report allied themselves with the families involved and their responses to the wrongdoing in the past. In so doing, the report focused minds on the crucial and overwhelmingly important issue of consent. But it has also been unclear about the basis for many of its (often implied) judgements concerning the process of consent, the value of bodily integrity after death, the circumstances that justify organ retention, and the characteristics that would define a respectful environment. Subsequent policy development is still grappling with the need for clarity—both ethical and practical—in these areas. We end by reflecting on three areas of concern where there is the potential for improving the approach to inquiry.

### Working with different types of truth

The letter from the inquiry team to the Secretary of State presenting the Royal Liverpool Children’s Inquiry Report states “We set ourselves the standard of leaving no stone unturned in our search for the truth and will leave it to the reader to determine whether or not we have succeeded”.<sup>43</sup> But what is the best way of achieving a good grasp of such truths? “Truth” can mean many different things from ensuring factual accuracy, asserting principles relevant to a shared understanding of the world, to ensuring honesty, faithfulness, or authenticity.

The Alder Hey inquiry strove for factual accuracy through a rigorous process of collecting evidence and hearing testimony. The confusion arises from the way the report itself mixes the consequent account with a set of judgements that hint at, but are not explicit about, the values upon which they

are based. It is hard to contest the truth of these judgements when their value base is unarticulated. Similarly, it is difficult to inculcate such unstated underlying principles in subsequent public policy. The starting point for the policy development process in England and Wales has proved to be a clearer definition of values such as respect.<sup>44</sup> This process is now beginning to bring greater clarity to the areas of confusion that pervade the report that triggered their work.

If this is a flaw of the inquiry process then it seems to arise from a concern to achieve that aspect of truthfulness that is concerned with a faithful representation of the views and perspective of those wronged by the events at Alder Hey. Although this perspective is central to the issue of wrongdoing, it is only one viewpoint on future policy. There is a tension between different approaches to establishing the truth of a situation. One approach attempts to achieve a grasp of truth by emotional involvement with a situation—putting oneself in a position to empathise, to feel another person’s pain, and therefore give true weight to its significance. A contrasting approach attempts to grasp the truth by maintaining a distance, a route of attempted impartiality that might gain a better vision by taking a longer perspective.

The Alder Hey report veers close to the first approach, whereas subsequent work, at a greater distance from events, has achieved a more balanced vision. The issues with which the Alder Hey report had to deal are emotive. Often, the report reflects reactions of shock and horror. But how could the report have been more balanced? The three authors of the report were all heavily involved in hearing testimony—generally highly distressing, emotionally charged testimony—firsthand from involved families.

An alternative approach might be to ensure two distinct elements to the inquiry process. The first focusing on the perceived wrongdoing that prompted the inquiry—obtaining the account that enables a full understanding of what went on (something that raises its own issues of fairness), while the second would address issues of organisational learning and policy development. Here, due process would need to be measured against tests of clarity, openness, and broad participation. Such a two phase approach emerged through the Bristol Inquiry and has been adopted for the ongoing Shipman Inquiry. The promised future guidance to standardise the conducting of inquiries should make a separation between the best ways of inquiring into the past and the most constructive ways of addressing the future.<sup>45</sup>

### Recognising and respecting diversity

Underlying the arrogance and detachment that led to the wrongdoing at Alder Hey, the report identified a culture of paternalism, concluding that “restricted vision is an inevitable consequence of a paternalistic attitude”.<sup>46</sup> The response to this diagnosis (both in the report and by politicians at the time) was to emphasise a new and different values base for the NHS. As Alan Milburn put it at the time, “I want the balance of power in the NHS to shift decisively in favour of the patient. ... Our task today is to forge a new bond of trust between patients and the health service ... where patients come first”.<sup>47</sup> In short, a shift of autonomy and power from professional to patient.

Of course, the public hold a range of opinions and different cultural and ethical standpoints exist over issues as complex and emotive as death and child death in particular. People will make different judgements over the relative value of organ or tissue retention as opposed to the value that they attach to the integrity of the physical body after death. So, at the centre of any new engagement with patient and public is the need to recognise and respect diversity.

The Alder Hey report and the immediate response to it dramatised a shift from one set of monolithic assumptions to

another, moving from a medical paternalism to an interpretation of patient and public wishes, itself determined on the public's behalf by an inquiry team and politicians. The version of patient autonomy and respect implied in the immediate aftermath of the report suggested that families take full responsibility for decisions on the basis of a rational model supported by full information. But that may not be relevant for everyone—some patients and families may choose to know less rather than more, or to ask for a joint decision making process with the healthcare professional. When it comes to building greater respect for patients and families, as well as a more constructive engagement with their wishes, there needs to be an acknowledgement of the differences between people and an acceptance of different processes that are tailored to different needs.

When it comes to the conduct of inquiries, the recognition of such diversity needs to be put centre stage. Capturing this diversity in the inquiry process means broad participation particularly in the examination of public policy implications. Before the Alder Hey report's call for respect can be incorporated into public policy, the many different interpretations and understandings of what really constitutes respect need to be articulated. Only through an appreciation of diversity can the process of public policy formulation (to which the process of investigation is central) stay in step with real rather than assumed social values.

### Uncovering and contesting values

The position anyone takes on questions of consent, the value of organ retention, and the meaning of respect will all be linked to a deeper response to the meaning of death (and life). These deeper issues can be seen in the range of responses to Professor Gunther von Hagens' exhibition of plasticised corpses, "Body Worlds". Reactions have varied widely, from praise to the deliberate destruction of exhibits "to make the point that you cannot turn bodies into commercial exhibits".<sup>48</sup> Supporters of the exhibition, including von Hagens himself, appeal to the notion that it helps to "democratise anatomy" and to undo the very secrecy around anatomy that helped produce the scandal at Alder Hey.<sup>49</sup>

There is a sense in the Alder Hey report and the response to it that there is something wrong about taking and retaining organs, while at the same time acknowledging the value of some organ collections. This position is consistent with a historical and hypocritical ambivalence noticeable even in commentary on the introduction of the 1832 Anatomy Act:

"I am quite ready to admit that the mode of obtaining subjects for dissection up to the year 1832, when the Anatomy Act came into operation, was most disgraceful, most abhorrent to all our best and dearest feelings, and had reached such a pitch of atrocity and wickedness that it could not be longer borne with, and was most righteously put down for ever. But ... neither the Government nor those gentlemen, who were so shocked by the conduct of the resurrectionists, devised by their Anatomy Act the means for enabling medical students to acquire the necessary practical anatomical knowledge on which alone can be grounded all the medical and surgical science."<sup>50</sup>

The roots of such a position may lie deeper than judgements on the particulars of consent, or values attached to research and education. Such deep rooted values in relation to death and the dead are not a matter of social consensus, yet they are the unseen framework for many judgements in this area. The role of inquiry should be to question and uncover (even if only to reassert) such pivotal values.

An inquiry invariably pays attention to fairness in the way it obtains an account of what happened. Similarly, future inquiries should address the relevant values that inform their judgements and recommendations, and devise suitable ways for doing this in an open fashion. Although the inquiry process acknowledges the relevant expertise of a legal member of the team in relation to due process, it is perhaps in the area of values and ethics that more explicit attention needs to be paid. We are not alone in advocating the role of ethical consideration in the management of complex healthcare systems.<sup>51</sup>

One important function of an inquiry is its ability to enable public scrutiny of professional practice and policy—it can bring public voices into previously closed areas of policy. Indeed, when it comes to matters of policy, inquiries should positively seek out alternative perspectives: exposure to such alternatives is a hallmark of good public policy. Now that time has passed since the publication of the Alder Hey report, and the stifling atmosphere of horror that surrounded it, a broader debate framed by emerging policies on consent in England and Wales, as well as Scotland, needs to flourish.

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## ECHO

### Attitudes to carrier screening for deafness genes



Please visit the *Journal of Medical Ethics* website [[www.jmedethics.com](http://www.jmedethics.com)] for a link to the full text of this article.

About one child in a thousand in Britain is born deaf. The cause is genetic in about 60% of cases (0.6 per 1000 births) and about 30% of genetic deafness (0.18 per thousand births) is syndromic and 70% (0.42 per 1000 births) non-syndromic (no other clinical features). About 80% of non-syndromic genetic deafness (about a third of all congenital deafness) is thought to be caused by recessive genes. About 33 recessive genes for non-syndromic deafness have been mapped and 17 identified. Mutations in the connexin26 gene are responsible for about 17% of severe and 30% of moderate non-syndromic congenital deafness in Britain. One mutation, the 35delG allele, is more common in Mediterranean countries than in northern Europe. Testing for connexin26 mutations is possible but unlikely to be used in the UK because it would detect only a minority of cases of non-syndromic deafness. Advances in genetic testing, however, will probably make screening for several recessive deafness mutations feasible and increase the detection rate.

There is insufficient knowledge about public attitudes to carrier screening for recessive non-syndromic deafness and antenatal detection. Deaf people who belong to deaf communities may be against screening and some may prefer to have a deaf child. People with close family members who are deaf are more likely to be in favour of screening, antenatal diagnosis, and possible termination of pregnancy. Researchers in Aberdeen have surveyed non-deaf pregnant women.

One hundred and four women completed a questionnaire after reading an information sheet about genetic deafness. Only four knew of a family member having been born deaf but 26 knew somebody who had been born deaf. None believed themselves to have a high risk of having a deaf child. Twenty five would definitely, and 48 probably, have carrier screening for a recessive deafness gene and if both partners were shown to be carriers 32 women (definitely) and 45 (probably) would want antenatal diagnosis. With a positive antenatal diagnosis, however, only one woman would definitely want termination (6 probably). The mean value placed on carrier screening (willingness to pay) was £42. This value was significantly related to perception of risk, intention to have other antenatal screening tests, low maternal age, and positive attitudes to screening in general.

Most women would value carrier screening and antenatal diagnosis for deafness but few would wish to abort an affected fetus.

▲ *Journal of Medical Genetics* 2003;**40**:e80 (<http://www.jmedgenet.com/cgi/content/full/40/6/e80>).