

Open Research Online

The Open University's repository of research publications and other research outputs

Vaccination and other altruistic medical treatments: should autonomy or communitarianism prevail?

Journal Item

How to cite:

Pywell, Stephanie (2000). Vaccination and other altruistic medical treatments: should autonomy or communitarianism prevail? *Medical Law International*, 4(3-4) pp. 223–243.

For guidance on citations see [FAQs](#).

© 2000 A B Academic Publisher

Version: Accepted Manuscript

Copyright and Moral Rights for the articles on this site are retained by the individual authors and/or other copyright owners. For more information on Open Research Online's [data policy](#) on reuse of materials please consult the policies page.

oro.open.ac.uk

Vaccination and other altruistic medical treatments: should autonomy or communitarianism prevail?

by Stephanie Pywell, PhD Student and Part-Time Lecturer in Law, University of Hertfordshire

Introduction

If a person undergoes medical treatment wholly or partly for the benefit of another person, questions arise as to whether priority should be given to individual autonomy - the right to make free and informed choices - or to communitarian principles. This issue has been recently brought to public attention by the publication of the Department of Health's report ("the DoH Report") into a 1998 case where body organs were accepted for transplantation into white recipients only¹.

Some medical procedures, such as cadaveric and live organ donation, bone marrow donation, gamete donation and blood donation, are unquestionably altruistic. It is possible to discern some semblance of order in the respective weight given in these procedures to autonomy - which is supported by the liberal philosophies of utilitarianism and deontology - and communitarianism.

There is an argument that vaccination is also an altruistic medical procedure because vaccines' benefits to individuals are frequently outweighed by their benefit to society. The autonomy/communitarianism balance is therefore relevant to vaccination.

This article outlines the nature and purpose of vaccination, and current vaccination policy in England and Wales. It explains why it is appropriate to regard vaccination as an altruistic medical procedure. It reviews the relative importance given to autonomy and communitarianism in the current laws governing altruistic medical procedures in England and Wales, making some comparisons with other Western jurisdictions.

Infant Vaccination

The nature and purpose of vaccination

Vaccination involves the introduction into the body of a small amount of an infectious organism attached to an adjuvant. The adjuvant is typically a relatively large molecule, such as alum, which triggers an immune response. Immunisation occurs when the alerted immune system produces antibodies to the infectious agent. Thereafter, whenever a vaccinee is exposed to a natural occurrence of the agent, her antibodies will prevent her from contracting the disease. Although often used interchangeably, "vaccination" and "immunisation" are not synonymous: vaccination is the process whose desired outcome is immunisation. Government spokespersons and public health physicians invariably use the term "immunisation", inherently stressing the intended positive outcome of the process.

There are two aims of mass vaccination. One is to protect each individual vaccinee from contracting infectious diseases which may cause permanent harm. The other, more important, aim is to ensure "herd immunity". This is the effective elimination of a disease from a whole community. When this occurs, those rare individuals for whom vaccination is definitely contra-indicated are protected because there is no-one from whom they will contract infections. Public health physicians and textbooks are unanimous that this second aim is the more important, because it protects both society and the individuals within it².

Current practice in England and Wales

Vaccination is not compulsory in England and Wales. Parents or guardians have the right to consent to or refuse the administration to their pre-school children of a "primary schedule" consisting of the following vaccines:

Diphtheria-tetanus-pertussis-Hib (DTP-Hib), polio and meningitis C at 2, 3 and 4

months;

Meningitis C at 13 months for babies who were over 4 months old when the three-vaccine Meningitis C schedule was introduced in autumn 1999;

Measles-mumps-rubella (MMR) vaccines at 13 months and 4 years;

Diphtheria-tetanus (DT) and polio at 4 years.

Why vaccination is altruistic

When a disease is rife within a society, the balance of advantage falls to the individual; the vulnerable patient who does not contract influenza during an epidemic, for example.

When a disease has been almost eradicated from a society, however, there is little advantage to any individual in being immunised against it. Society nonetheless benefits from the contribution made by each vaccinee to keeping the disease at bay.

Indigenous polio has been virtually eradicated from England and Wales. The benefit of polio vaccination for each vaccinee is therefore extremely small. This risk would admittedly increase if vaccination ceased, as has happened with tuberculosis, but the present situation is that the risks of polio vaccine are not balanced by individual benefits.

Nineteen of the twenty-five cases of polio reported in 1985 - 1995 were due to unimmunised individuals coming into contact with the faeces of recently-vaccinated infants³. In about one in two million cases, the vaccine is thought to lead to the vaccinee contracting polio. Despite this risk, and the negligible benefit, four doses of polio vaccine are given to children under five years old whose parents accept the whole primary schedule of vaccines.

Rubella vaccination for males is another example of the non-coincidence of individual and societal interests. Rubella has few long-term severe consequences, and little attention was paid to the disease until the 1940s, when it was first linked with the catalogue of birth defects now termed Congenital Rubella Syndrome (CRS)^{4,5}. Vaccination for women and teenage girls was introduced in 1970, and 97-98% coverage of this population had been achieved by 1987. Because this did not result in the elimination of rubella in pregnancy, rubella was included in the trivalent measles,

mumps and rubella (MMR) vaccine recommended for all infants since 1988, and offered twice to each child since 1994. Is it reasonable to ask any male to run small but unquantified health risks⁶ solely to protect the health of potential unborn children?

These examples show that some vaccines are of little or no benefit to their recipients. There is a significant number of people who claim that they, or more usually their children, have been significantly and permanently damaged by the powerful biological agents introduced into their bodies during vaccination. Although such claims are often officially dismissed, it is widely accepted that vaccines appear to cause serious harm to a small minority of vaccinees⁷.

This brief discussion about benefits and risks demonstrates the altruistic nature of some vaccinations. In consenting to vaccination, parents subject their children to personal harm for the good of society. Their public-spiritedness is officially recognised by the Vaccine Damage Payments Act 1979, which established the statutory Vaccine Damage Payments Scheme (VDPS). Parliamentary debates about the Act are notable for their cross-party harmony. It was the unanimous view of MPs that vaccine victims deserved to be treated as a special case because their injuries had been occasioned in the public interest. It was decided that an interim payment of £10,000 should be made to anyone who could prove that they had been at least 80% damaged by one of a specified range of vaccines. The debates made clear that provisions needed to be made for more substantial compensation to be paid. It was recently announced that the payment is to rise to £100,000, and that the disability threshold will be lowered to 60%⁸. No statutory compensation has been introduced, so the sum is a one-off payment.

Altruistic Medical Procedures

Cadaveric Organ Donation

The potential incompatibility of communitarianism and respect for autonomy is one of the aspects of the 1998 case where a donated liver and kidneys were specified as being available only to white recipients. The case first came to public notice in July 1999⁹.

Posthumous organ donation is voluntary, so each person - or her close relatives - freely chooses whether her organs may be used to prolong or improve another's life. It could be argued as a logical extension of that autonomy that donors may impose conditions about whom they wish to help. Strict respect for the deceased's autonomy would permit her organs to be used only in accordance with her expressed wishes¹⁰. Communitarian principles, however, require that the organs be given to the person most likely to be able to benefit from them. Published commentaries on the case suggest that most people subscribe to the latter approach.

It is the stated practice of the United Kingdom Transplant Support Service Authority (UKTSSA) to allocate cadaveric organs to the most medically suitable potential recipient. The criteria for allocation are multi-factorial, involving factors such as blood and tissue matches, the risk of organ rejection and the length of time the patient has been waiting. The UKTSSA does not consider social factors, since the medical criteria usually reveal only one "best" candidate for each organ. If publicity about a particular potential recipient results in additional donors, their organs would be allocated as described, with the patient in the publicised case waiting her turn. The wishes of a donor who made it known that she had signed a donor card to help a particular patient would not be respected. Cadaveric organ donation is thus not governed by unconditional respect for donor autonomy. The principles of allocation are essentially communitarian.

The DoH Report into the 1998 case makes it clear that, ultimately, the liver and kidneys in that case were transplanted into patients who would have received them even if no conditions had been attached. There is nonetheless concern that the standard protocol was not followed. The left kidney should have been offered to two children with Asian-sounding names, but this did not happen because of the imposition of the condition. The authors of the DoH Report have since been told by the duty consultant that the children would not have been suitable because of clinical criteria, so they were not in fact disadvantaged.

When the story of the 1998 case was first reported, Frank Dobson, then Secretary of

State for Health, suggested possible legislation to govern cadaveric organ donation by the same principles as blood donation. This would involve an autonomous decision whether to become a donor, but permit no constraints as to potential recipients¹¹. The DoH Report recommends that this proposal be formalised in clear guidance.

The DoH Report concludes that the organs in the 1998 case should not have been accepted for donation because of the conditions attached to them. It expresses concern that no-one involved, apart from the UKTSSA's duty officers, who are clerical staff, objected at the time to the acceptance of the organs. It recommends that such occurrences be prevented in the future by ensuring that all NHS staff are fully instructed on this point, and that all NHS training programmes include discussion of the requirements of the Race Relations Act 1976.

The Health Minister, Lord Hunt, has announced changes arising from a quinquennial review of the operation of the UKTSSA which was published on the same day as the DoH Report¹². The service is to be re-named UK Transplant, and measures are to be taken to improve the service and increase the number of organs available for transplant. The chief executive of the authority is shortly to be replaced¹³ following what Lord Hunt termed "an isolated, dreadful case ... I am determined that nothing like this will ever happen again". This emphasises the government's view that the allocation of organs for transplant should be governed by purely communitarian principles.

Posthumous organ transplant is more blatantly communitarian in principle in those hospitals where there is a strong culture of organ donation. "Beating heart transplants" are obtained by either moving a dying patient to a life support system, or by ventilating what would otherwise be a corpse while seeking relatives' permission for organ donation. These procedures are necessary if the organs are to be usable, because they deteriorate very rapidly after death. This approach demonstrates scant regard for autonomy, because the deceased has not given her own permission for organ donation. Advocates of the procedures point out that they increase the pool of organs available for transplant, thereby saving substantial numbers of lives.

Over thirty American states¹⁴ have legislated for "required request" in respect of cadaveric organ donation. Hospital staff must ask families of deceased persons for permission to remove transplantable organs, regardless of whether the deceased carried a donor card. Some European countries such as France, Belgium and Austria presume consent to such donation unless the deceased or relatives have expressly objected. These practices are essentially communitarian. They are probably also utilitarian because a bereaved family's increased happiness at knowing they are burying an intact corpse is unlikely to exceed that of a family whose loved one has enhanced life expectancy. Recently there have been calls for the law of presumed consent to obtain in England and Wales¹⁵, in order to rectify the acute shortage of organs available for transplant¹⁶. The resultant public debate highlights the political difficulties of such legislation in a liberal culture.

Live Organ Donation

The donation of organs, usually kidneys, during life is governed by the Human Organ Transplants Act 1989. The Act outlaws payment for organs, and ensures that in all but exceptional cases the donor and recipient are genetically related. In most cases there is no conflict between autonomy and utilitarianism: the donor chooses to donate, and the happiness of both parties is increased by the improved health of the recipient. Communitarianism is irrelevant since the procedure involves a named blood relation.

The Human Organ Transplants (Unrelated Persons) Regulations 1989 (SI 1989/2480) establish the Unrelated Live Transplant Regulatory Authority, which ensures that no payment is made for any organ and that the donor gives free and fully informed consent to the donation. The recipient is usually a named person specified by the donor, who may withdraw consent at any time until organ removal. After removal, the donor has no rights over the organ. This practice initially gives priority to donor autonomy, which has included considerations about the needs of the intended recipient. Autonomy ceases to be paramount when the organ becomes physically separated from the donor's body. At this point the common good, represented by the needs and expectations of the potential recipient, prevails.

A woman in Baltimore, USA, has recently taken advantage of less radical surgical practices to donate a kidney for transplant into any person in need¹⁷. This puts her at substantial risk if her other kidney fails. Her decision was taken entirely autonomously - "I felt as if God had tapped me on the shoulder" - and from that point she voluntarily surrendered her autonomy. A man from Northamptonshire recently donated the lower lobe of one lung to a young cystic fibrosis sufferer whom he had never met¹⁸. This involved flying to the USA, where the recipient lived¹⁹, and entailed a 20% reduction in his lung capacity. If such wholly altruistic practices were to become widespread, it would be necessary to develop ethical guidelines striking an appropriate balance between the rights of donors and the needs of potential recipients.

It is unlikely that communitarian principles could ever prevail in this area, because the procedures involved are so invasive and potentially detrimental to donors.

Bone Marrow Donation

Bone marrow donors in England and Wales are volunteers. They are not admitted to the registers held by the Anthony Nolan Bone Marrow Trust or the British Bone Marrow Register if they state that they would wish their bone marrow to be given only to a particular named recipient, or to a recipient meeting particular criteria. Removal of bone marrow is, however, carried out only after establishing compatibility with a specific potential recipient. Donor and recipient must be of the same broad ethnic origin, so there is potential compatibility between, for example, Greek and Turkish Cypriots. The British registries follow the international practice of withholding information about recipients' ethnicity and religion, but will tell donors the recipient's sex, age group and country of residence. The donor can at any stage decline to undergo the marrow-removing surgery if she does not wish to proceed. Early withdrawal is encouraged because potential recipients undergo radiotherapy and chemotherapy - "conditioning" - in the days before the expected date of transplant. A misogynist could thus be admitted to a register if he did not disclose his intention to donate only to a male, and could decline to proceed once he discovered that the potential recipient was female.

The autonomy of the donor therefore prevails over communitarianism. Like live organ donation, this procedure is so invasive that it seems unlikely that communitarian principles could ever prevail.

Gamete Donation

Third party gamete donation is a prerequisite for some in-vitro fertilisation (IVF) patients. The law governing this practice is the Human Fertilisation and Embryology Act 1990 (HFE Act) whose operation is overseen by the Human Fertilisation and Embryology Authority (HFEA). The invasiveness of the donation procedure is significantly different for female and male donors. Most female donors need to take hormonal drugs to stimulate ovulation, and all females must undergo minor surgery to remove the ova. Male donation involves no pharmacological or surgical intervention. The law makes no distinction between the rights afforded to male and female donors beyond acknowledging that preparation for egg donation can be protracted.

Ss 27 and 28 of the HFE Act specify that the mother and father of any child born following IVF shall be the woman who carried the child and, where applicable, her husband or other partner with whom she sought IVF treatment. If there is no such partner, the child has no legal father. Gamete donors are thus statutorily deprived of parental rights. They are told that they will be subject to scrutiny of their medical and family histories and genetically screened for serious inherited disorders including HIV. They are given specified information, including the pain and risks of donation, their potential legal liability for knowing non-disclosure of any fact leading to the birth of a disabled child, and their freedom to withdraw their consent at any time without penalty until the gametes are used²⁰. "Used" in this context means that the embryo created from the gametes has been either implanted into a patient's uterus or used for research²¹. There are requirements that donors' consent should not be pressurised or given without due reflection²², and treatment centres must bear any financial losses resulting from a withdrawal of consent after preparations for ovum recovery have begun²³.

Donors must consent in writing to use of their gametes for treatment for themselves and/or treatment for others and/or research. They may also specify additional conditions subject to which their gametes or embryos produced from them may be used or stored, and may withdraw or vary these conditions at any time until the gametes are used. This includes the immediate post-fertilisation period: withdrawal of consent by either gamete donor results in the foetus being destroyed. It is therefore permissible under the Code for donors to specify that their gametes are to be used only to produce an embryo for a patient of a specified race, religion or age. Donors' conditions would not be overridden, but treatment centres may decline to accept or use gametes to which repugnant conditions are attached. The Code ensures that rejected would-be donors are sensitively made aware of the reasons for their non-acceptance²⁴.

The HFEA's Code ensures absolute respect for donors' autonomy whilst permitting treatment centres to refuse unacceptable constraints²⁵. Legal protection for autonomy is justifiable because people are involved in the altruistic creation of life, rather than helping a pre-existing person. It would be unacceptable to permit other principles to prevail.

Blood Donation

Blood donation is inherently less emotive than gamete donation and is governed by different principles. Donated blood may be given to any needy recipient or separated into its component parts and used for the benefit of several patients. The donor voluntarily signs a pre-donation Declaration which concludes: "I entrust my donation to the UK Blood Services to be used for the benefit of patients". She has no means of finding out what happened to her blood.

The donor's autonomy is not compromised because the decision to sign the Declaration is freely taken. After donation, communitarian principles based upon clinical need prevail.

A communitarian policy of presumed consent to blood donation could be acceptable. The process is quick and virtually painless, involving the insertion into the body of two needles, one to test for anaemia and one to withdraw the blood. Legislation could compel the disclosure of necessary personal medical information, and make provision for exemption on religious, conscientious or health grounds. This would resolve problems of blood shortages. In cultures where communitarianism is already apparent in some health policies, such as France and the USA, laws requiring annual or bi-annual blood donation might be readily accepted. They would, however, be likely to invoke objections from wide sections of the traditionally liberal society in England and Wales.

Infant Vaccination Re-Visited

Do children have autonomy?

Because the primary schedule vaccines are administered to pre-school children, we must briefly consider whether these patients can be said to possess autonomy. There is an academic debate about whether children's autonomy exists²⁶, but the assumption in English law is that it does not. Apart from those children, usually teenagers, who are "Gillick competent"²⁷, the child has no right to consent to or refuse any medical treatment, and the legal parent has the right to take decisions on her behalf.

In S v S, W v Official Solicitor (1972)²⁸, Lord Reid, having referred to the unlawfulness of "constraint" overriding an adult's wishes, remarked:

"...it is not and could not be a legal wrong for a parent or person authorised by him to use constraint to his young child provided it is not cruel or excessive. There are differences of opinion as to the age beyond which it is unwise to use constraint, but that cannot apply to infants or young children. So it seems to me to be impossible to deny that a parent can lawfully require that his young child can submit to a blood test. And if the parent can require that, why not the court? There is no overriding requirement of public policy as there is with an adult."

The overriding consideration in cases where proxies make decisions on behalf of children is the child's best interests. Vaccination is a treatment about whose benefits and risks a pre-school child cannot make a reasoned decision. Since routine vaccinations are non-urgent, and some are not directly beneficial, it is arguable that parents thereby violate the autonomy of their children.

Free consent?

Because vaccination in England and Wales is optional, it is ostensibly a procedure in which priority is given to patient autonomy. For true autonomy, however, the decision whether to accept treatment must be made freely and after receiving all relevant information in a comprehensible form. Neither condition applies in the present situation.

In my research into parents' experiences of, and views on, infant vaccination, several respondents indicated that they thought vaccination in England and Wales was compulsory. Others commented "I just did what I was told" or "I felt I had no choice". Such remarks indicate the power of the pervasive presumption that parents will agree to vaccination for their children. My findings suggest that 25% of parents have felt under pressure to vaccinate one or more of their children, and virtually all of these regarded medical professionals as one source of such pressure²⁹. This suggests that many doctors, health visitors and nurses are urging parents to accept vaccines despite parental doubts about safety. Given the imbalance of power inherent in the doctor-patient relationship, this pressure can be decisive. Some parents are thus participating less than freely in an inherently communitarian vaccination regime.

Additional pressure on parents is derived from the fact that there are virtually no alternative vaccines to those in the primary schedule. It was formerly possible to obtain single measles, mumps and rubella vaccines if parents did not want their children to receive MMR. This option became unavailable in August 1999 when the Medicines Control Agency withdrew the import licence from IDIS, the main importer of single vaccines³⁰. My research showed that most requests for monovalent diphtheria, tetanus,

pertussis and Hib vaccines were met, but that over 90% of requests for the monovalent components of MMR were refused. 84% of respondents whose requests for single vaccines were refused subsequently accepted the trivalent alternatives, even though these were not their first choice. This is a further indication of a decision made less than freely, and a further erosion of autonomy.

In a culture where the victims of disease are often blamed for their own misfortunes, it is possible that maintenance of one's health to minimise demands upon society will become a moral, if not a legal, obligation. With typhoid and smallpox eliminated from England and Wales, official attention has turned to measles, mumps, rubella, pertussis, polio, diphtheria, tetanus and Hib. Parents are widely perceived as having a social duty to comply with the primary vaccination schedule against these diseases. 3.4% of all my respondents had been told by their doctor, health visitor or nurse that vaccination was a social duty. This represents 13% of those who had felt under some form of pressure to accept vaccination.

The desire of significant numbers of health professionals to maximise vaccine uptake is potentially explicable in a number of ways. One is that the risks of any infectious disease epidemic resulting from a reduction in vaccine coverage far outweigh the risks of harm from the vaccine. Another is that it is politically essential to be seen at least to maintain public health triumphs such as low levels of measles infection. A third is that health-related communitarianism is officially sanctioned in England and Wales, so individuals should be prepared to accept statistically small risks in the public interest.

A more sceptical view is that there are vested interests in promoting vaccination regardless of the cost to a small minority of vaccinees. This suggestion is made because of the incentive scheme under which doctors receive payments for achieving vaccination coverage targets. Rates range from £265, for vaccinating 70% of four-year-old patients with the diphtheria-tetanus and polio boosters and the second dose of MMR vaccine, to £2685 for administering three doses of diphtheria-tetanus-pertussis-Hib and one dose of MMR to 90% of patients before their second birthdays. A bonus of £6.45 is paid for every fully-vaccinated four-year-old. The incentive payment system was

introduced by a Conservative government. The New Labour administration which has been in power for over two years has not sought to change it, save for annual increases in quanta. This shows that the desire for a high level of vaccination coverage transcends political divisions.

The importance of these payments to doctors is illustrated by reports that GPs are seeking £2 million compensation because their income has reduced due to a decline in the number of children being given MMR vaccine³¹. One doctor has reported that, rather than being added to existing salaries if targets are met, the bonus payments are deducted from payments if targets are not met³². This approach increases the sense of necessity to achieve the targets, thereby exerting on GPs pressure unrelated to patients' clinical needs. This transgresses the spirit, though not the letter, of the GMC's ruling that, in relationships between doctors and the pharmaceutical industry:

"It may be improper for a doctor to accept payment or money in kind which could influence his professional assessment of the therapeutic value of a new drug."³³

It is significant that 79% of respondents in my survey were unaware of the existence of these payments. These patients did not realise that GPs, who inevitably influence the health visitors and nurses who work in their practices, were placed under substantial financial pressure to persuade them to accept vaccination for their children. The autonomy of some parents was compromised because their decisions were taken under pressure, and because they were unaware of one of the root sources of that pressure.

Informed consent?

The communitarian arguments for vaccination assume that it is desirable that young children are protected from infectious diseases such as whooping cough and measles.

Vaccination is widely credited with having played a significant part in the virtual

elimination of mortality from infectious diseases in developed countries. Doubt is cast on this, however, by McKeown (1976), who demonstrated that the steep decline in the incidence of pertussis and measles preceded widespread vaccination, and found that diphtheria declined in US states without vaccination at approximately the same rate as in those with vaccination. His overall conclusion is that "over the whole period since the cause of death was first registered (in 1838) [immunization and treatment] were much less important than other influences [on the reduction of deaths from infectious diseases]"³⁴. Baggott (1994) cites McKeown's 1979 work drawing similar conclusions to the stated 1976 results as "the definitive statement of the modern public health perspective", and he uncritically accepts its conclusions about the small part which immunisation against measles and whooping cough has played in reducing such mortality³⁵. Szreter (1988) criticises McKeown's methodology and assumptions, but does not take issue with his assertion that most vaccines became available too late to account for most of the decline in mortality from the diseases stated³⁶.

Although reduced mortality is attributable to other public health measures such as antibiotics, vaccines have certainly reduced morbidity from infectious diseases. They are therefore a valuable part of the public health armoury, but it is important that the public is given complete and accurate information about their benefits and risks.

Dr David Salisbury³⁷ has spoken publicly of the need for active promotion of immunisation³⁸. It is necessary to create a demand for, and acceptance of, vaccines. One means of doing this is using advertising campaigns designed to convey fear of infection, knowledge of vaccines and a sense of the value of vaccines. Such campaigns stress the protection of "your child", rather than "children". This emphasis is inconsistent with the fact that, in countries with a low incidence of disease - such as the UK at present - the primary objective of mass vaccination is herd immunity³⁹.

My research included a question about the most important reason for vaccinating children. 18.3% of respondents answered "to help get rid of childhood diseases from this country". 79.4% stated that the protection of their own child(ren) from childhood diseases was their most important reason. The advertising strategy of the Public Health

Laboratory Service (PHLS) is thus demonstrably successful. It is, however, ethically questionable because it deliberately misrepresents the balance of personal and societal benefits accruing from vaccination. Parents who act on these misrepresentation are not acting truly autonomously.

In November 1994 the government ran a campaign to vaccinate all children aged five to sixteen against measles and rubella. The stated reason for this was that an epidemic of measles was expected, and it was not certain that one dose of the MMR vaccine would afford sufficient protection. The ethics of the campaign were the subject of detailed and serious criticism in the *Bulletin of Medical Ethics*⁴⁰. The campaign was preceded by a television advertising campaign designed to instill into parents a fear of the possible dangers of measles infection - "blindness, brain damage, and even death". The advertisements did not mention that 90% of children who had received an MMR vaccine were believed already to have lifelong immunity to measles and rubella⁴¹, nor that mortality amongst children who caught measles had been virtually zero in England and Wales since 1968⁴².

Deliberate omissions of relevant information are ethically unacceptable in matters as serious as children's health. Misleading parents about risks and benefits compromises their autonomy by depriving them of important aspects of the information upon which their decisions should be based.

Another important aspect of information about vaccines is the risk of undesirable side-effects. From the mid-1970s to the mid-1980s there was widespread concern about a link between pertussis vaccine and brain damage. Most current public attention is focussed on whether the measles-mumps-rubella (MMR) vaccine is linked with autism and bowel disorders. The most widely publicised study was published by Wakefield and colleagues in February 1998⁴³. The paper postulated an aetiology by which MMR vaccine could lead to bowel and autistic-spectrum disorders. It contained valid criticisms of its own scope methodology, and states that more research is necessary to confirm or deny its findings.

Four weeks after its publication the Chief Medical Officer issued the expected reassurance about vaccine safety. Sir Kenneth Calman spoke to the press following a specially-convened meeting of thirty-seven scientists who had reviewed the Royal Free study. It was their view that there was 'absolutely no scientifically sound evidence to show a link between the MMR vaccine and autism, Crohn's disease or ulcerative colitis'⁴⁴. Government advice remained that all children should receive the triple vaccine while research continued. Various papers supporting each side of the debate were subsequently published.

In September 1999 Dr Ken Aitken, a clinical neuropsychologist who had attended the review meeting, publicly stated that he had "changed [his] view somewhat", and that "a small number of children may have been affected by the vaccine". His altered stance was due to a US study into links between the MMR vaccine and Heller's Syndrome, a form of autism⁴⁵. Dr Aitken stressed that the original review meeting had called for further research, and he highlighted the potential dangers of natural measles infection. The Department of Health's immediate response was that there is no evidence of a link between MMR and autism or bowel disease.

One obvious reality is that no-one knows the truth. A more startling reality is that this is because there has never been a long-term, large-scale prospective study to investigate what, if anything, happens to the health of young children after they have been vaccinated with MMR.

Detailed medical arguments are beyond the scope of this article, but my research suggests that official sources are sometimes selective about the studies to which they give credence. An example of this is the question of whether rubella vaccine causes acute arthritis. A 1991 meta-analytical study carried out for the US government found that the evidence from case series and experimental studies is consistent with a causal relationship. The incidence of acute arthritis was 13 - 15% in adult females, with much lower rates for children, adolescents and adult males⁴⁶. Although the UK's official vaccination handbook for practitioners acknowledges the existence of this work, it states: "One recent retrospective case control study showed no increase in arthropathy

(arthritis and arthralgia) in women immunised post-partum compared with their immune (unimmunised) controls"⁴⁷. The one study is thus given greater prominence than the meta-analytical work. Elsewhere, however, Dr Robert Aston, "a member of the Government's expert vaccination committee" (presumably the JCVI) has publicly criticised this selective approach. Denouncing vaccine "scare stories", he said: "[s]cience doesn't work by saying 'so-and-so produced a paper in 1980 saying there's a link between measles and Crohn's disease or whatever it is and therefore you believe it'. You look at the whole body of scientific evidence and ... come to logical conclusions based on all the scientific evidence, not selective."⁴⁸. Selective reporting is clearly officially acceptable only if the selected reports suggest that vaccines are entirely safe.

The lack of research into vaccine safety appears to be pervasive. The dominant message from Howson, Howe and Fineberg⁴⁹ and a similar work published in 1994⁵⁰ is that more research is urgently needed. In July 1999 I wrote to Dr Elizabeth Miller, Head of the Immunisation Division at the PHLS, expressly requesting details of which vaccines were currently being studied by Vaccine Study Nurses, and the length of the follow-up periods for each vaccine. Dr Miller's response made no mention of studies of adverse reactions. She states that Phase II trials of antibody responses and immediate reactions sometimes last for 4 - 6 weeks, and sometimes longer. Phase III trials of attack rates of the diseases were generally several years. Dr Miller did "not think it would be very helpful to document each trial that we have conducted over the last 12 years and the formal follow-up period per protocol for each"⁵¹.

This apparent lack of long-term research into adverse effects means that the government and its medical advisers can honestly tell the public that "there is no solid scientific evidence to support any causal link" between any given vaccine and any postulated adverse effect. This is disingenuous. There is no evidence because the evidence has not been sought, not necessarily because it does not exist. This is another vital omission from the information which autonomous parents should receive before they decide whether to accept vaccination for their children.

My research shows that the majority of parents are eager to be fully informed about

vaccination, as shown by Table 1, below.

Amount of information desired	% responses	Number of responses
All published information, even if not proved to be reliable	11.8	41
All well-researched published information	60.6	211
All the government's advisers believe doctors should know	3.4	12
All your family doctor or health visitor believes is important	21.8	76
None	2.3	8

Table 1: Amount of information desired by parents before deciding whether to accept vaccination for their children

The information routinely given to parents is what GPs or health visitors believe is important. 75.8% of respondents would have liked more information than this. Doctor Norman Begg, then Consultant Paediatrician at the PHLS, has reported that more detailed leaflets are being made available for parents who seek more than the usual amount of information about vaccination⁵². This information was received too late to be included in my survey, and the improved leaflets were not mentioned by any respondent.

If the government wishes to maintain a high uptake of a voluntarily communitarian vaccination policy, it must earn public confidence in the vaccination process. This involves offering a real choice of vaccine programmes and providing parents with adequate information upon which to base their choices. It must also provide an adequate statutory compensation mechanism: the £100,000 available under the VDPS

is derisory for a child facing a lifetime of severe psychological injury. Recent cases of children brain-damaged at birth have resulted in awards of damages up to £8 million. This element of reciprocity is essential in a communitarian regime.

Conclusion

In England and Wales there is no consistent philosophical approach towards altruistic medical procedures. Our law does not compel any person to undergo a medical procedure wholly or mainly for another's benefit, and courts and jurists pay extensive lip service to respect for autonomy. A spectrum of attitudes exists, however, towards the practical recognition of autonomy, depending upon the medical procedure in question.

Acts of altruism involving surgery, such as bone marrow or live organ donation, encompass genuine freedom to withdraw consent, and the right to some knowledge of the identity of the intended beneficiary. It is appropriate that autonomy should be respected where a person is running the risks of undergoing general anaesthesia and sacrificing part of her body.

Gamete donation recognises donor autonomy as paramount, outweighing the desire for motherhood of a patient who does not meet the donor's expressed conditions. In practice, this is normally an age constraint; many clinics are prepared to respect donors' views on this issue. It is likely that many clinics would deem unacceptable a donor's race- or religion-based restriction on gamete usage, reflecting values widely held in our multi-racial society. Male and female gamete donors have equal rights, despite the differences in the invasiveness of the donation procedures and the gametes' replaceability. It is appropriate that the law protects the autonomy of those altruistically assisting in the creation of life.

Blood donation, a minor and almost risk-free procedure, encompasses autonomy in deciding whether to donate; thereafter, blood is allocated according to decisions made on the basis of clinical need. A satisfactory balance appears to have been struck

between autonomy and communitarianism, and it might be theoretically acceptable to introduce communitarian laws requiring donation in most circumstances.

The problem areas are posthumous organ donation and vaccination, which waver between respect for autonomy and communitarian principles. A relevant similarity between these procedures is that, in the majority of cases, the patient undergoing the procedure is unable to speak for himself at the material time. The unresolved question is therefore the extent to which the views of close relatives should be respected.

In the case of posthumous organ donation there is no risk to the health or happiness of the potential donor, with the possible exception of the "beating heart" cases. Family members have a moral claim to respect for their feelings if they regard the continuing physical integrity of the corpse as important. Their emotional damage needs to be considered in the light of the health and happiness of the potential recipients, and the feelings of their families. Well-publicised laws of presumed consent appear to satisfy all the obligations which exist in such a situation. Those strongly opposed to donation are able to opt out; all other people know that after their death their bodies will provide valuable resources. Perhaps, therefore, England and Wales should follow the example of much of continental Europe and adopt this overtly communitarian stance to cadaveric donation.

Vaccination is consistent with other areas of English law in taking the views of a parent or guardian as determinative, because they normally represent the best available articulation of a young child's best interests. The optional nature of vaccination theoretically respects parental autonomy. This autonomy is, however, seriously compromised in some cases by pressure and misinformation.

Since vaccination is regarded as so important that some of the normal tenets of medical ethics are set aside to encourage it, maybe the Public Health Laboratory Service should have the courage of its apparent convictions and render vaccination compulsory in all but exceptional circumstances^{53,54}. This would undoubtedly offend those parents who believe they should have a choice about vaccination. It would also bring pressure to

bear for more extensive research into vaccine safety, for a choice of vaccination programmes, and for the establishment of a just and adequate compensation system for those believed to be damaged by vaccines.

This option would have the advantage of transparency. This quality is missing from the present situation where many parents' theoretical freedom of choice is curtailed by the non-availability of single vaccines, pressure from medical professionals, and the perception that they cannot opt out of the process. If communitarianism is to be paramount, policy-makers should declare that this is so; if not, vaccination practices should be modified so that all parents are genuinely able to make fully autonomous choices on behalf of their infant children.

The latter option appears vastly preferable, given current standards of public health in England and Wales. Communitarianism masquerading as autonomy is ethically unacceptable, and blatant communitarianism cannot be justified unless there is a much greater risk to public health than exists at present.

ACKNOWLEDGEMENTS

I am most grateful to Professor Robyn Martin, Associate Dean of the Faculty of Law at the University of Hertfordshire, for her comments on earlier drafts of this article.

Thanks are also due to the following people for their assistance with my research:

Mr John Evans, Chairman, British Organ Donor Society

Dr Deirdre Fehily, Head of Tissue Services for London and the South-East, National Blood Service

Mrs Mary Goose, a bone marrow donor

Ms Marjorie Gordon-Box, Donor Welfare Officer, The Anthony Nolan Bone Marrow Trust

Dr Joan Heyse-Moore, Medical Officer, Donor Care, National Blood Service

Ms Alison Pitts-Bland, Senior Press Officer, Department of Health

Mr James Yeandel, Director of Communications, Human Fertilisation and Embryology Authority

The views expressed above are my own, and I retain responsibility for all errors and omissions.

NOTES

-
1. Department of Health, 2000. *An Investigation into Conditional Organ Donation The Report of the Panel*. Obtained from www.doh.gov.uk, 23 February.
 2. Ref Professor Peter Beverley, Scientific Head of the Edward Jenner Institute for Vaccine Research, speaking at the Healthcare Forum *Vaccines and Health*, University of Hertfordshire, 10 December 1999.
 3. Great Britain: Department of Health, Welsh Office, Scottish Office Department of Health and DHSS Northern Ireland, 1996. Salisbury, D M & Begg, N T (Eds). *1996 Immunisation Against Infectious Disease*. London: HMSO, pp 173 - 5.
 4. Howson, C, Howe, C & Fineberg, H (Eds), 1991. *Adverse Effects of Pertussis and Rubella Vaccines*. Washington DC: National Academy Press, p 20.
 5. Great Britain: Department of Health, Welsh Office, Scottish Office Department of Health and DHSS Northern Ireland, 1996. Salisbury, D M & Begg, N T (Eds). *1996 Immunisation Against Infectious Disease*. London: HMSO, p 132.
 6. The risks of rubella and MMR vaccines are discussed below.
 7. See, eg, Great Britain: Department of Health, Welsh Office, Scottish Office Department of Health and DHSS Northern Ireland, 1996. Salisbury, D M & Begg, N T (Eds). *1996 Immunisation Against Infectious Disease*. London: HMSO, p32.
 8. Alistair Darling, Secretary of State for Social Security, announced these changes in the House of Commons on 27 June 2000 as this article was going to press. They are not yet officially published or in force. and it is too early to evaluate their likely impact. They do not, however, affect the fact that the statutory scheme provides for a one-off lump sum substantially below the level of compensation which would be awarded by a court, and that there is an absolute threshold of disability below which no payment is made. The increase in the time limit available to make a claim - any time until a child is 21, rather than within 6 years of the later of the child's 2nd birthday and the date of vaccination - is a welcome improvement to the statutory scheme, but

is still a shorter time than accrues under common law to a person under a disability.

9. Murray, I & Paterson, M, 1999. White only transplant case sparks enquiry. *The Times*, 7 July. The story was first reported by BBC *Newsnight* on 6 July.
10. Maclean (1999) suggests that donors and doctors who respectively attach and accept race-related conditions to donated organs are probably contravening the Race Relations Act 1976 (RRA). See further Maclean, A R, 1999. Organ donation, racism and the Race Relations Act. 149 (6901) *New Law Journal*, 1250 - 1252. This point seems to be accepted by the DoH report, para 1.10, although it is not discussed in detail.
11. Woodward, W & Boseley, S, 1999. Dobson threatens new law to halt organ 'apartheid'. *The Guardian*, 8 July.
12. Department of Health, 2000. *Lord Hunt announces modernisation of transplant services*. Press Release 2000/0106, obtained from www.doh.gov.uk, 22 February.
13. Boseley, S, 2000. Transplant chief loses job over racism row. *The Guardian*, 23 February.
14. For example New York.
15. Professor Sheila McLean said on BBC Radio 4's *The World at One* on 7 July 1999 that she would favour this situation. The annual conference of the British Medical Association agreed on 8 July 1999 that it, too, was in favour.
16. The DoH Report shows that there were 5,631 patients awaiting kidney transplants at 31 December 1998, and that only 1,769 transplants were carried out during that year. As at 29 September 1999, the waiting list was 4,745, of whom 63% had been waiting more than one year, and 14% more than five years.
17. Burnett, V (1999). Does anyone want my kidney? *The Guardian*, 12 October.
18. BBC Radio 4 (1999). *Today*, 24 November.
19. The past tense is used because the recipient died a few weeks after receiving the donation.
20. Human Fertilisation and Embryology Authority, 1998. *Code of Practice*. Fourth Edition, paragraph 4.5. Obtained from www.hfea.gov.uk/frame.htm, August 1999.
21. Human Fertilisation and Embryology Act 1990, c 37, Schedule 3, s4(2).
22. Human Fertilisation and Embryology Authority, 1998. *Op cit*, Note 19, paragraphs 5.17 and 5.18.
23. Human Fertilisation and Embryology Authority, 1998. *Op cit*, Note 19, paragraphs 5.12 - 5.20.
24. Human Fertilisation and Embryology Authority, 1998. *Op cit*, Note 19, paragraph 3.56.
25. Maclean's arguments (Note 9) regarding breaches of the RRA would presumably apply equally to gamete donation.
26. See, eg:
Nicholson, H (Ed), 1986. *Medical Research with Children: Ethics, Law and Practice*. Oxford: Oxford University Press, P 131. This argues that children's autonomy is protected and maximised by their parents' right to consent to treatment on their behalf.
Alderson, P, 1990. Consent to Children's Surgery and Intensive Medical Treatment. *Journal of Law and Society*, 17(1), 52 - 65 at pp 53 - 4. This argues that proxy consent inevitably contradicts the notion of personal autonomy, and that children have a much greater understanding or treatment than adults normally attribute to them.
27. Gillick v West Norfolk and Wisbech Area Health Authority [1986] AC 112

-
28. S v S, W v Official Solicitor [1972] AC 24 (HL)
 29. This survey involved 377 parents of children, mainly under five years old, in North Hertfordshire. It was conducted between April and November 1999, and sought parents' views on a range of aspects of vaccination policy and practice.
 30. Laurance, J, 1999. Ban on vaccines sparks new alert. *The Independent*, 28 August.
 31. Anonymous, 1999. GPs seek jabs cash. *The Daily Telegraph*, 7 February.
 32. Personal conversation, February 2000.
 33. General Medical Council, 1983. *Professional Conduct and Discipline: Fitness to Practice*. London: General Medical Council, p 27.
 34. McKeown, T, 1976. "The Medical Contribution". In Davey, B, Gray, A and Seale, C (Eds). *Health and Disease: A Reader*. Second Edition. Buckingham: Open University Press, 1995, 182 - 190.
 35. Baggott, R, 1994. *Health and Health Care in Britain*. New York: St Martin's Press, p 31.
 36. Szreter, S, 1988. "The importance of social intervention in Britain's mortality decline c. 1850 - 1914: a re-interpretation of the role of public health". In Davey, B, Gray, A & Seale, C (Eds). *Health and Disease: A Reader*. Second Edition. Buckingham: Open University Press, 1995, 191 - 199.
 37. Principal Medical Officer, Communicable Disease Branch, Department of Health.
 38. At a Healthcare Forum *Vaccines and Health*. University of Hertfordshire, 10 December 1999.
 39. See Note 2.
 40. See *Bulletin of Medical Ethics* as follows: No 102, October 1994, pp 3 - 5; No 104, January 1995, pp 3 - 4; No 110, August 1995, pp 3 - 9; No 114, January 1996, pp 13 - 23.
 41. *Hansard*. Parliamentary Debates (House of Commons). Vol 265, Col 608. Tom Sackville, Parliamentary Under-Secretary of State at the Department of Health, said studies on the duration of protection from measles vaccine have been under way for 30 years, and those for rubella for 25 years. No decrease in protection against either disease had been discovered.
 42. McKeown, T, 1976. *Op cit*, Note 33.
 43. Wakefield, A, et al, 1998. Ileal-lymphoid-nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children, *Lancet*, 351, 637 - 641.
 44. Murray, I, 1998. Triple baby vaccine is safe, experts tell parents. *The Times*, 25 March.
 45. Hall, C, 1999. New fear over autism link to triple vaccine. *The Daily Telegraph*, 8 September.
 46. Howson, C, Howe, C & Fineberg, H (Eds), 1991. *Adverse Effects of Pertussis and Rubella Vaccines*. Washington DC: National Academy Press, p 197.
 47. Great Britain: Department of Health, Welsh Office, Scottish Office Department of Health and DHSS Northern Ireland, 1996. Salisbury, D M & Begg, N T (Eds). *1996 Immunisation Against Infectious Disease*. London: HMSO, p 198.
 48. BBC Radio 4, 1997. *File on Four*. 9 December.
 49. See Note 8.

-
50. Stratton, K, Howe, C & Johnston, R (Eds), 1994. *Adverse Events Associated with Childhood Vaccines: Evidence Bearing on Causality*. Washington DC: National Academy Press.
 51. Personal communication dated 23 July 1999.
 52. Semi-structured recorded interview, 13 July 1999.
 53. Professor Margaret Brazier was asked on BBC Radio 4's *Law in Action*, 24 October 1999, whether she thought vaccination could be made compulsory. Professor Brazier noted the situations in the USA, where unvaccinated children may not go to publicly-funded schools, and some European countries, where child benefit is not paid in respect of unvaccinated children. She expressed the view that compulsory vaccination might involve a breach of Article 8 of the European Convention on Human Rights - the respect for private and family life - unless it could be shown that the risks to society of non-vaccination were such as to create a risk to health. Whilst stressing that this situation did not obtain in England and Wales at present, Professor Brazier felt that any putative compulsory vaccination should be made an absolute obligation backed by criminal sanctions. This suggestion is based on the moral point that those who do not rely upon State-funded benefits or education should not be able to "buy out" of their obligation to contribute to the well-being of society.
 54. Bradley (1999) concludes, in an article evaluating the rights, risks and benefits of vaccination, that the situation in the UK at present does not justify a policy of compulsory vaccination. See further Bradley, P, 1999. Should childhood immunisation be compulsory? *Journal of Medical Ethics*, 25, 330 - 334.