

# UK CLINICAL ETHICS NETWORK NEWSLETTER

Issue 12, Summer 2004



## **Welcome to the Summer Edition of the UK Clinical Ethics Network Newsletter**

Since the last edition the Network has had a successful AGM and Annual Conference.

The issues of the future direction and funding of the Network were discussed at the AGM and a very helpful presentation was given about options for its constitution. Detailed reports on the AGM and options for the Network constitution appear on page 8.

The Annual Conference, held in London in May focussed on end of life issues, comparing the position in the UK with that in the Netherlands. There was also an interesting presentation on clinical ethics support in Germany. A report on the Annual Conference appears at page 12.

Given the recent debate on the Human Tissue Bill we have devoted this issue to exploring the ethical issues it raises and the areas that may be of particular relevance to clinical ethics committees.

We are grateful to those who have contributed interesting papers on different aspects of the human tissue/organ donation debate, and also to Sally Newman, Head of Legal Services, Oxford Radcliffe Hospitals NHS Trust, for her useful comments.

As this is such a complex and wide-ranging area we are hoping to deal with it in more detail on the UK Clinical Ethics Network website ([www.ethics-network.org.uk](http://www.ethics-network.org.uk))

If you would like to suggest a topic to be covered by a future edition of the newsletter, please let us know.

With best wishes

Carolyn Johnston & Jane Goodall

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## THE HUMAN TISSUE BILL

### **Background**

The Bristol Royal Infirmary Inquiry, which examined the high death rate of children who had heart operations at the hospital, raised concerns that organs had been routinely removed for research without consent of the parents.

In December 1999 an Inquiry Panel was appointed to investigate the removal, retention and disposal of human organs and tissues following post mortem examination at The Royal Liverpool Children's Hospital, Alder Hey.

In the piece below **Jonathan Zimmern** identifies the key issues that arose in the group litigation regarding the lawfulness of the removal of organs and considers the relevant ethical issues.

### **A B and Others v Leeds Teaching Hospital NHS Trust, Cardiff and Vale NHS Trust**

#### **Legal Issues**

On 26 March 2004, Mr Justice Gage gave judgment in the trial of the three test cases in the Nationwide Organ Group Litigation (NOGL) made in respect of claims that organs had been removed, retained and subsequently destroyed following hospital and coroners post mortems on children without this information being discussed with parents/relatives. In each of the three cases, the parents alleged that in removing and retaining organs from their babies the defendant hospitals (1) committed the tort of wrongful interference with a body; (2) were negligent in a number of respects, resulting in psychiatric injury to the parents: and (3) breached Article 8 of the Human Rights Act.

(The judge found against the claimants in the coroners post mortem cases as the coroner does not require consent, whereas the hospital post mortems require the doctors to check for lack of objection)

#### **(1)Wrongful Interference with a Body<sup>1</sup>**

The claimants submitted that the requirements of this novel tort<sup>2</sup> are two-fold:

1. The claimants must establish a duty/right to possess the body of his or her deceased child, pursuant to their duty to bury the body.
2. It must be proved that the defendant interfered with that duty/right by retaining and/or disposing of body parts without lawful authority.

All three test cases failed on their facts. The Judge held that where the claimants had no right of burial and possession of organs lawfully removed at post-mortem and retained, there was no action for wrongful interference with the body of the child. The parents had consented to the post-mortems and the application of work and skill during the post-mortem and histopathological process entitled the hospitals to lawful possession of the organs.<sup>3</sup> There was therefore no right to possession. The Judge suggested that were a parent to expressly stipulate that all organs were to be returned, a tort of wrongful interference with a body might, in principle, exist. However, he further added that in those circumstances a claim in negligence would also lie and he therefore saw no reason or justification for the creation of a novel tort.

#### **(2)Negligence**

Negligence was only alleged in the Hospital Post-Mortem (HPM) cases. The Human Tissue Act 1961 imposes a duty on doctors to check for lack of objection to a post mortem. Coroner's post mortems do not require consent. Despite evidence that usual clinical practice did not include a discussion about organ retention and that very few parents, if any, asked questions about the post mortem or organ retention, it was held that doctors could owe a duty of care to a mother after the death of her baby and that therefore the practice of not warning parents that a post-mortem might involve the removal and retention of an organ could not be justified. Taking consent for a post-mortem was not just an administrative

matter. It was part of the continuing duty of care owed by the clinicians to the mother. It is perhaps worth noting that although only one of the two claimants succeeded, Mrs Harris's claim only failed because the judge found, as a matter of fact, that she was such a 'robust person' that it was not reasonably foreseeable that her paediatrician would foresee psychiatric injury.

### **(3) Human Rights – Article 8**

It was held that a (hypothetical) decision to use a brain taken during a lawful post-mortem for *research* without authority under s.1(2) Human Tissue Act 1961 is capable of engaging, and of breaching, Article 8(1). The Judge indicated that the circumstances in which such a use could be justified under Article 8(2), on the grounds of public interest, will be rare.

In summary the case raised the following important points:

- Work & skill involved in a post-mortem sufficient to allow hospital/coroner to acquire proprietary rights over removed organs
- Continuing duty of care owed by clinicians to parents following a child's death
- Potential for Article 8 claim based on use of lawfully retained organ for research

### **Ethical Issues**

The Nationwide Organ Group Litigation is just one element in the much wider context of the discussions surrounding the use of human tissue for donation, research, diagnosis and post-mortems. The judgment must be read against the background of a move away from paternalism within the medical profession and against the government's efforts to regulate the area with the new Human Tissue Bill. With this in mind, I have noted some of the ethical concepts that underpinned the factual matters raised in the case:

#### **Consent and Autonomy**

The medical profession has been moving steadily away from paternalistic practices for many years, championing a patient's right to choose his or her own treatment. Of course this process is far from simple and questions of what constitutes a valid, informed and fully autonomous decision remain controversial. Furthermore, although apparently universally accepted as such, it is not immediately self-evident that the consent of a living relative should be considered either morally relevant or the most appropriate way of making decisions in regard to the use of a deceased's tissue. If one weighs up possible harms against benefits, one might argue that the claims of grieving relatives deserve no such 'trump card status.'

#### **Human Dignity and Respect for the Dead**

One of the fundamental questions that underpins medical ethics is the search for what it is that makes human life valuable and morally relevant. It is our understanding of this issue that is the cornerstone of why we believe people should be treated with dignity and respect. Whilst one might be tempted to assume that this is both an obvious and universal position, questions still arise in relation to the use of tissue from a deceased's body. Many of the traditional arguments that distinguish a person as a morally relevant being – consciousness, awareness of self, ability to reason, rationality etc – do not apply to the dead. Therefore, if it is shown that tissue from a deceased can help a living person it might be arguable that respect for the living actually requires such tissue be used. These arguments notwithstanding, it seems that any ethical system that respects human dignity must show proper respect in the manner in which the dead are treated.

#### **Religious or Cultural Beliefs**

In a multi-national and multi-cultural society it is important that differences in belief systems are taken into account when decisions regarding death, burial and post-mortems are made.

#### **Privacy and the Right to a family Life – The Human Rights Act**

Article 8 has been interpreted as protecting the individual against arbitrary interference by public authorities in his or her private or family life. The concept of 'family life' has been

construed widely and Gage J's decision seems to anticipate that the removal, retention and use of tissue from a deceased member of a family can, in principle, amount to interference with family life.

*Jonathan Zimmern, MA student, Medical Law & Ethics, King's College, London  
Pupil barrister, at 7, Bedford Row, London*

<sup>1</sup> The case is set against the accepted legal principle that there is no property in a corpse, save in certain circumstances, i.e. the right to bury a deceased child

<sup>2</sup> It was accepted that such a tort is recognised in Scotland, Canada and the USA

<sup>3</sup> Following *Doodeward v Spence [1908] 6CLR 40*

The legal action and the Bristol and Alder Hey inquiries served to raise questions about the issue of consent to be given by next of kin for retention of tissue for medical research. The Human Tissue Bill was introduced to Parliament to update the law and to provide a uniform legislative framework covering issues relating to whole body donation, post mortems, and the taking, storage and use of human organs and tissues.

### **Key Issues of the Human Tissue Bill that may be of Relevance to Clinical Ethics Committees / Groups**

As the Bill is in draft form the following is a summary of how the law is likely to appear.

#### **Samples from living individuals**

As originally drafted the Bill required the consent of patients for storage / use for research and education purposes of any human tissue or bodily fluids taken from living persons. A doctor who used any material without consent would commit a criminal offence. This would have included surplus tissue following surgery, left over blood and urine and would have covered samples taken in primary care and in hospitals.

The Royal College of Pathologists raised concerns about the practicalities and cost of obtaining explicit consent for every sample taken from a living patient. It is estimated that over 100 million such samples are taken in the UK every year. The Wellcome Trust and the Royal Society had also stated that the Bill as originally drafted was too restrictive and would hamper research.

The government responded to these concerns and the Bill has been amended so that human tissue samples can be used for education and training without the need for individual explicit consent.

Explicit consent will still be required for use of tissue for research unless;

- the research has been approved by a research ethics committee and
- the researcher will not be able to identify the person from whom the material has been obtained

In such cases, as the ethical issues will have been addressed by a research ethics committee, it remains to be seen whether a *clinical ethics committee* will be asked to discuss the ethics of use of samples for research.

#### **Tissue /organs from dead individuals**

Quite apart from the difficult issues that arise when samples are obtained from living individuals an entirely different set of considerations comes into play regarding the use of tissue and organs from individuals who have died.

In *The Removal, Retention and Use of Human Organs and Tissue from Post Mortem Examination* published in 2001, the Chief Medical Officer for England recommended that there should be a fundamental and broad revision of the law on human organs and tissues

taken from adults or children, either during surgery or after death. A consultation document, *Human Bodies, Human Choices* launched in July 2002, reviewed the current law in England and Wales.

The Human Tissue Bill requires that 'appropriate consent' be obtained for various uses of the body or material from the body including anatomical examination, research and transplantation.

#### **Deceased child**

If he/she was competent and made an advance decision, that will apply. Otherwise appropriate consent for the carrying out of a post mortem examination or use of organs for transplantation must be obtained from someone with parental responsibility.

#### **Deceased adult**

'Appropriate consent' is required in relation to activities concerning the body or relevant material of a deceased adult. 'Appropriate consent' means a decision to consent or not to consent in force immediately before he died. If an adult has made no prior decision then a person nominated by him/her to make a decision after his/her death or, failing that, someone in a 'qualifying relationship' may give consent in relation to the body or relevant material from the body. Those in a qualifying relationship include:

- Spouse
- Partner
- Parent
- Child
- Brother/sister

Consent should be obtained from the person with the highest-ranking relationship. Regulations will be made regarding adult patients who lack capacity.

#### **Organ Donation**

The BMA amongst others had strongly urged for an amendment to the Human Tissue Bill to allow for presumed consent for organ donation to address the lack of organs available for transplantation. The amendment was defeated so the Bill as drafted states that with respect to organ donation an adult must make a prior decision, or the decision should be made by someone nominated by him or a person in a qualifying relationship may give consent.

Clause 48 of the Bill provides that it is lawful for hospital authorities to take the minimum steps to preserve the organs of deceased persons whilst appropriate consent to transplantation is sought.

The following two papers consider some issues regarding the ethics of organ donation. **Heather Draper** considers mandated choice and **Bob Brecher** discusses the issues of a market in organs for transplant.

#### **Mandated Choice and Organ / Tissue Donation: The Pros and Cons**

Mandated choice for organ donation requires citizens to register a decision about whether or not to be an organ/tissue donor. It does not require them to choose to donate; it only requires that a choice be made. The number of choices available can depend upon the system of mandated choice operating; citizens could simply register consent or refusal of consent, or choices could be extended to letting relatives/next of kin decide, to specifying which tissue (if any) can be taken or even the kind of recipients preferred. The principle that seems to govern mandated choice is that whilst individuals should be free to decide whether or not to consent, this decision is so important that it must be made – one way or another (it could be compared to mandatory voting where citizens are considered to have a duty to vote, irrespective of what party they intend to vote for). Penalties are imposed if citizens do not register a choice, if there were no penalties the system could not be described as mandatory.

Theoretically these could include fines or even imprisonment, but it is more likely that registration would be linked with applications for driving licenses, tax returns, applications for state benefits etc.

Mandated choice is preferred by its supporters for two main reasons: first is the disparity between the apparent willingness of individuals to donate (around 70% of people say that in principle they would be willing to act as organ donors) and the rates at which individuals actually register consent (around 20%) and relatives give consent post-mortem; second is the desire to maximise the number of organs available. Clearly the second reason is premised on the first: it assumes that people will register their consent at the rate at which they claim to support donation in surveys and this would in turn result in more organs being available. But there are also ethical reasons to support mandated choice: it removes the burden of consenting from relatives and it ensures the potential donors' autonomy (the current system permits relatives to decide whether or not their decision reflects what the potential donor wanted – if indeed their wishes were known).

There are at least three arguments against mandated choice: it undermines autonomy when people are forced to choose, relatives will be harmed if organs are removed against their wishes – irrespective of what the donor wanted – and this will in turn undermine faith in the transplantation system in general making people less likely to donate in the future, and finally, a more effective and ethical system for maximising the number of organs available would be mandatory donation. There are also practical concerns related to how the system is imposed. For instance it is not clear how to best to ensure that the duty is one shared by all citizens when not all will be drivers or fill out tax returns or be recipients of state benefits etc.

In such a short paper, it is impossible to do justice to either the arguments for or against mandated choice. Chouhan and I proposed a system of modified mandated choice that took into account some of the objections to traditional mandated choice, especially the view that people should not be permitted to make the 'bad' choice of not donating (see Chouhan P Draper H, Modified mandated choice for organ procurement. (2003) *Journal of Medical Ethics* 29: 157 – 162).

*Heather Draper*

*Senior Lecturer in Biomedical Ethics, Centre for Biomedical Ethics, University of Birmingham  
Member of the Advisory Group on Ethics, Assisted Conception Unit, Birmingham Women's Hospital Trust. Member of the Clinical Ethics Group, Birmingham Children's Hospital  
Member of the Clinical Ethics Committee, Heartlands Hospital.*

### **Organs for Transplant: Against a Market**

The BMA has recently been reported to be thinking of advocating a market in organs for transplant; and one of Britain's leading medical ethicists, John Harris, has written in the *Guardian* in support of such a proposal (1). His arguments are central to the issue: and so, much more though there is to be said about it, I shall restrict myself to those.

First, though, I need to make it clear that my own view does not rest on any sort of "sanctity of life" position. For even if, on a thoroughly secular view, the body could be shown to be in some special way intrinsic to our identity, it still would not follow that there was anything necessarily degrading in removing part of it. After all, as Ruth Chadwick pointed out 15 years ago, 'If I can have my foot amputated to save my life, why not sell my kidney to pacify the loan sharks from whom I am in fear of my life?' (2)

Harris's two main arguments are these: (a) being paid for something doesn't undermine its ethical value; and (b) it is, at best, patronising to dictate to people how they choose to make a living. Let us consider these in turn.

(a) 'Sellers of organs would know that they had saved a life and would be reasonably compensated for their risk, time and altruism, which would not be compromised by sale: we do not, after all, regard medicine as any the less a caring profession because doctors are paid.'

But this analogy fails, since the reasons for seeking payment are different in the two cases: being paid for expertise is quite different from being paid for something unacquired, like time or a part of one's body. In the case of expertise there is an element of voluntariness, namely in the acquisition of such expertise; in the latter case, such voluntariness is absent. Having no expertise to sell, one sells all one has to sell, namely one's body. And that takes us straight to the second argument.

(b) 'Some people say such a market would exploit the poor. [First,] it is hypocritical to think that denying poor people an opportunity to sell one of their few saleable assets is doing them any favours, at least so long as no attempt is made to alleviate their poverty in other ways. ... So long as would-be organ vendors freely choose to provide an organ, knowing the risks and aware of the benefits, then they are not exploited, even if they would not provide the organ but for the money.'

This is the nub of the marketeers' case: to deny poor people the opportunity to make the most of what they deny other people similar sorts of opportunities – to rent their genitalia out, perhaps, or to sell their time and labour. This argument cuts both ways, however: hypocrisy arises only if we oppose the sale of organs for transplant but not, for example, the renting of genitalia or the sale of labour under similar conditions. Harris thinks that so long as 'would-be organ vendors [prostitutes; labourers] freely choose to' sell their kidney, rent their genitalia or sell their labour, they are not being exploited, since they 'freely' choose to sell or not to sell. I disagree. As things are, the sex-market, the labour market and the would-be market in organs are all exploitative, and in exactly the same way: the real choice is sell or starve, and that is not a free choice at all.

But Harris adds a crucial qualification to the charge of hypocrisy: denying people the opportunity to sell a saleable asset is hypocritical 'at least so long as no attempt is made to alleviate their poverty in other ways'. And that brings us to the core of what is wrong with the proposal. Whether or not capitalism is necessarily exploitative, a market in organs for transplant would have, as a matter of fact, and among other consequences, that of directly discouraging just that effort to alleviate people's poverty that Harris himself demands. And that is objection enough. The more we commercialise and commodify our relations with each other, the more aspects of our relations with each other are organised on market principles, the more readily we reject values, and of course policies too, that run counter to those principles. In short, the fewer practices we regard as exploitative, the more exploitative our society is likely to become. And to treat each other, and more specifically each others needs, as commodities is to exploit each other.

(1) "This won't hurt your bank balance', *Guardian*, 4 Dec. 2003, G2, pp. 2-3.

(2) 'The market for bodily parts: Kant and duties to oneself', *Journal of Applied Philosophy*, 6, 1989, pp. 129-40, at 134.

The longer talk of which this is a summary may be obtained from Bob Brecher:

email [r.brecher@bton.ac.uk](mailto:r.brecher@bton.ac.uk).

*Reader in Philosophy in the School of Historical & Critical Studies, University of Brighton*

### **Relevant reading and contacts:**

BMA response to the Human Tissue Bill  
Press release date: Saturday, 26 Jun 2004 (BMA London)

Medical Research Council  
Human Tissue Bill web consultation  
<http://www.mrc.ac.uk/index/>

Cambridge Genetics Knowledge Park – Human Tissue Bill  
[http://www.cgkp.org.uk/topics/human\\_tissue](http://www.cgkp.org.uk/topics/human_tissue)

The Royal College of Pathologists, comments on the Human Tissue Bill  
<http://www.rcpath.org>

The Bristol Royal Infirmary Inquiry  
<http://www.bristol-inquiry.org.uk/>

The Report of The Royal Liverpool Children's Inquiry  
<http://www.rlcinquiry.org.uk/>

Furness and Sullivan, Editorial, The human tissue bill, Criminal sanctions linked to opaque legislation threaten research. *BMJ*, 2004; **328**: 533-4

English V, Sommerville A. Presumed consent for transplantation: a dead issue after Alder Hey? *J Med Ethics* 2003; **29**:147-152

Dyer C. Human Tissue Bill is modified because of research needs. *BMJ* 2004; **328**: 1518

Human Tissue Bill  
<http://www.publications.parliament.uk/pa/ld200304/ldbills/094/2004094.htm>

Explanatory notes  
<http://www.publications.parliament.uk/pa/ld200304/ldbills/094/en/04094x--.htm>



## UK CLINICAL ETHICS NETWORK ANNUAL GENERAL MEETING

**Thursday 6<sup>th</sup> May 2004 2.00pm – 5.00pm**

**St Mary's Hospital, London**

The 2004 Annual General Meeting was attended by 25 people and chaired by Dr Alan Watson.

### **The Relationship between The Ethox Centre and the UK Clinical Ethics Network Anne Slowther**

Anne Slowther gave a brief history of the development of the UK Clinical Ethics Network from its inception in 2001. The Network has a close relationship with the Ethox Centre, partly because it was initially formed in response to an expressed need for a network by Chairs of clinical ethics committees during a study conducted by the Ethox Centre, and partly because the Ethox Centre has been able to obtain two short term grants from the Department of Health to develop the Network and provide support for CECs (including the Network website and newsletters). The close collaboration between the Network and the Ethox Centre has advantages for both groups. However, this relationship may change in the future, and will to some extent depend on the status of the Network and the source of future funding to support the Network.

### **Funding**

A key issue is to identify long term funding for the Network. Both the Ethox Centre and the Network need to identify sources of funding, as each will have different strengths that may attract a wide range of funders. The relationship between the Ethox Centre and the Network will then depend on the source of funding. If the Ethox Centre secures funding then it is likely that the current arrangement will continue. If the Network secures independent funding it could then commission academic and administrative support from the Ethox Centre, or another institution.

There is a clear need for the Network to develop its own constitution so that its relationship with other organisations, including the Ethox Centre, can be clarified and agreed.

## **Report on the options available to the Network for the development of a constitution**

**Liz Mulvaney**

*Liz Mulvaney is a solicitor at Weightman Vizards in Nottingham, and a member of the Nottingham City and University Hospitals Ethics of Clinical Practice Committee. The Network wishes to thank Liz for her hard work.*

Liz presented a synopsis of the various options open to the Network in developing a constitution and becoming a formal body. These include

- becoming an unincorporated association;
- becoming an incorporated company;
- becoming a charitable company or association.

The pros and cons of the various options were discussed, and the consensus was that the most suitable option appeared to be becoming a charitable company or association. However, Liz cautioned that a first step in this decision making process should be to develop a document outlining where the Network wishes to be in five years time, articulating the key functions and aims of the Network. This will inform both the drafting of the constitution and the final decision on what form the organisation should take.

It was decided that the Network needed to develop a brief document. The constitution options available to the Network are as follows:

### **1. Unincorporated Association**

An Unincorporated Association only has to follow general legal principles. They are generally for small groups with short term goals and low incomes and do not employ staff or acquire property.

#### **Advantages**

- Cheap to set up
- Quick to set up
- Cheap to run
- Flexible Democratic Structure

#### **Disadvantages**

- Cannot hold property in its own name
- Cannot enter into contracts in its own name
- Legal proceedings cannot be taken in the name of the organisation
- Individuals may be held personally liable for obligations and debts

### **2. Incorporated Company Limiting Liability by Shares or Guarantee**

Unlike an Unincorporated Association this option provides a company with a legal identity separate from the members and office holders, making the company responsible for its commitments rather than the members or office holders. Companies limited by shares usually only operate in the commercial sector investing funds to make profit. Companies limited by guarantee re-invest the profits into the company.

#### **Advantages**

- Members liability may be restricted
- Organisation can hold property, borrow money and enter contracts in its own name
- Directors / Committee members must follow management procedures laid down in the constitution which must accord with Company Law

#### **Disadvantages**

- Bound by terms of Companies Act and controls
- Costs of setting up are higher
- Changes of Directors details must be filed at Companies House, and there are fines for late filing
- A bespoke constitution will be required in the form of articles and separate

- Organisation is subject to democratic control
- Companies can employ staff
- Corporation tax is paid at a lower rate than income tax
- memorandum of association
- Companies must operate PAYE system on all salaries and pay NI
- Running costs are higher and will involve an external auditor/accountant
- There is no VAT exemption
- Formalities relating to meetings are more complex
- Dissolution procedure is complex

### 3. Charitable Company or Association

Organisations are charitable if all its aims and objectives are charitable, that is non-profit-making and benefits the public. Charities can only raise funding through trading if the trade can be described as ancillary to the charity's main purpose.

#### Advantages

- Charity may hold assets in its own name
- Charities may enter into contracts
- Office holders/trustees/board of management only become personally liable if they act imprudently, unlawfully or in breach of the charities constitution
- Charities do not pay income tax, corporation tax, capital gains tax, stamp duty, inheritance tax and get at least 80% relief from business rates
- May be some VAT relief
- Funding may be easier to attract from a greater variety of sources
- Charity is subject to democratic control by regulation by the Charity Commission
- Business may be conducted by phone, fax, internet or circulation of papers

#### Disadvantages

- Most charities need to be registered
- Office holders/trustees are not generally entitled to remuneration
- A charity must serve a public benefit
- Constitution and charity law may restrict future development plans
- Indemnity cover is only permitted in respect of managers "*honest and reasonable mistakes*"
- Setting up and administrative costs are higher than an unincorporated association but not as high as setting up and running a company
- The organisation must not pursue a political purpose but may engage in limited political activity aimed at securing or opposing a change in the law or government policy
- Trading for profit must be conducted under a separately established trading arm subject to the Charities Commission's approval
- Accounts must be prepared annually in format required by statute and checked externally where the gross expenditure/income exceeds £10,000

In order to develop the constitution the Network needs to decide how it wishes to develop and answer the question, 'where do we want to be in five years time?' Stephen Louw volunteered to draft this document, in liaison with Anne Slowther and the Network Committee. This process is expected to take 3 months.

*If anyone has any ideas or comments on the status and future of the Network, please contact us on [admin@ethics-network.org.uk](mailto:admin@ethics-network.org.uk)*

### **Future funding for the Network**

### **Graham Walker**

Graham Walker presented a short summary on his fund raising activities for the Network, The fund raising success has been held back by the Network not having a bank account or a constitution. The Network can not have a bank account until we have a constitution. Many potential funders also wanted a document describing the function and activities of the

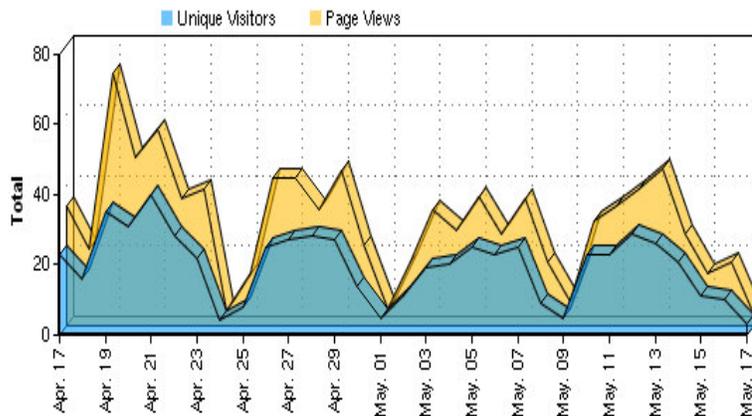
Network, this is being developed. It was stated that any revenue source would have to be reliable and respectable.

Graham was congratulated on his fund raising efforts.

### Update on the web site

**Jane Goodall**

After the launch of the web site on the 30th September 2003, we bought a counter service to monitor web traffic. So far we have had nearly 4500 hits.



### Homepage Hit Counter

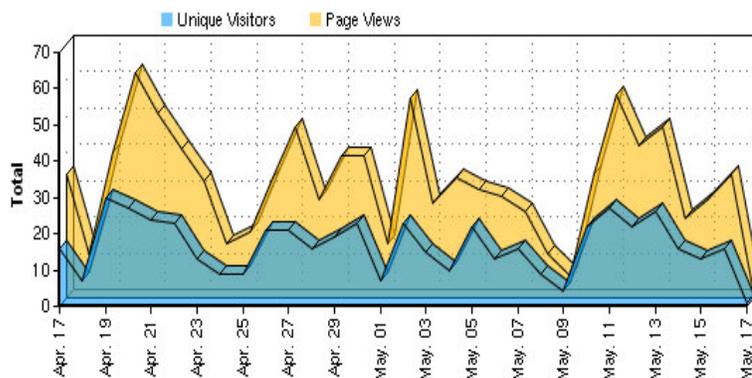
Page Views = 4435

Total Uniques = 2833

Uniques / Page Views = 64%

Counter Start Date = 20th October

Figures taken 17<sup>th</sup> May 2004



### Cases Studies Hit Counter

Page Views = 4100

Total Uniques = 2333

Uniques / Page Views = 57%

Counter Start Date = 16<sup>th</sup> December

Figures taken 17<sup>th</sup> May 2004

### Site Expansion

The site has been expanded considerably. The courses and conferences section shows events throughout the UK. There is a new feature allowing event organisers to send their events details via the web with their advertising flier attached.

Resource Allocation in Healthcare was added to the Ethical Issues page in March this year. And has so far had 449 hits. We have also re-developed the International section to include international perspectives on clinical ethics committees – for which we have views from Norway and Estonia so far. There are international clinical ethics committee details, international courses and conferences and links. This is an area that we want to continue to expand. This page has had 545 hits, with 65% returning.

The further reading section has also been re-developed to include an archive of all the Network newsletters and summaries of these on clinical ethics committees. *It would be useful if all committees could check their online details to ensure that they are correct. I would also like to receive any comments or suggestions on the web site. Comments should be sent to [admin@ethics-network.org.uk](mailto:admin@ethics-network.org.uk) or via the web site feedback forms.*

Alan Watson closed the meeting and thanked everyone for coming. The next AGM will be before the 5<sup>th</sup> annual conference to be held in Newcastle on 19<sup>th</sup>/20<sup>th</sup> May 2005.



## UK CLINICAL ETHICS NETWORK 4<sup>TH</sup> ANNUAL CONFERENCE Friday 7<sup>th</sup> May 2004 Mostyn Hotel, London

The Annual Conference this year was very successful with just under one hundred people attending. The Conference had an international flavour with speakers from The Netherlands and Germany, as well as delegates from Taiwan, Norway, India and Australia.

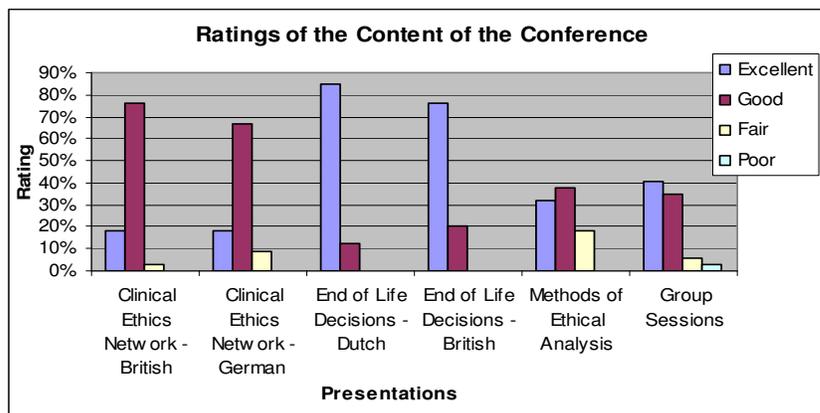
The Conference began with an introduction by Dr Richard Lancaster, a Consultant Physician, Chair of the St Mary's Hospital Clinical Ethics Committee, member of the Network Committee and host for this year's conference.

Dr Anne Slowther, Director of the UK Clinical Ethics Network, began with a presentation on the British experience of setting up a clinical ethics network. The issues discussed included the progress of both the Network and clinical ethics committee development, the functions of clinical ethics committees and future plans. This was followed by a presentation on the German experience of setting up clinical ethics committees by Dr Thela Wernstedt from the Institute of Medical Ethics, Erlangen-Nuremberg University, Germany. The talks were concluded with a joint discussion on both their experiences and the way forward.

After a short break the second session on end of life decision-making got underway with a short introduction by Dr Alan Watson, Chair of the Network Committee. Professor Guy Widdershoven of the University of Maastricht, The Netherlands, gave a presentation on the Dutch perspective on end of life decision making, including the law and practice of euthanasia. Dr Julian Hughes, from the Centre of the Health of the Elderly, Newcastle General Hospital, followed with a presentation on the British perspective on end of life decision making, including the potential impact of the draft Mental Capacity Bill. This session was followed by a lively discussion on the experiences and practice of end of life decision making in both countries.

The afternoon session was dedicated to case discussion. Mr Don Hill and Dr Mike Parker, both from The Ethox Centre, Oxford, gave a short presentation on Virtue Ethics, Kant, Utilitarianism and the Four Principles and how each theory could be applied to a case. Cases were discussed in small groups followed by a plenary session discussion

The Conference was very highly rated amongst the delegates. The feedback forms were very positive with each session either rated good or excellent. Some of the delegates expressed a desire for more time for each session, suggesting that the Conference should either run longer or go over into two days.



The Conference delegate packs are available from the Network at a cost of £10.00, made payable to The Ethox Foundation, to cover copying, postage and packing. If you would like a delegate pack from the Conference please contact the Network at [admin@ethics-network.org.uk](mailto:admin@ethics-network.org.uk)



## ENQUIRIES TO THE NETWORK

### **Committee Membership and Terms of Office**

The St Mary's Hospital Clinical Ethics Committee is currently reviewing its membership and operating procedures as their current Chair is retiring. An enquiry was sent to the Network to see if any other clinical ethics committee had a 'code of practice' for their members and terms of office.

Replies were received from 8 committees.

Great Ormond Street Hospital Clinical Ethics Committee do not have a procedure for electing a new Chair, but their membership and procedures are stated in their terms of reference:

- membership should generally be for 3 years, reviewable after that time
- the Chair and Vice-Chair should serve for a period of not less than 3 years

Sheffield Teaching Hospitals Clinical Ethics Group terms of reference provide details of membership and terms of office:

- the Chair and Vice-Chair are appointed by the group and serves for a term of 3 years at the end of which there is a review of the position
- members also serve for 3 years, which may be renewable if there are no new members ready to join the group
- new members may join when current members retire

Royal United Hospital Clinical Ethics Committee terms of reference also details member's terms of office:

- if a member does not attend three consecutive meetings their membership will lapse
- the Chair is elected by the group and serves for a minimum of 2 years
- no person can act as Chair for more than 4 consecutive years

The St Mary's Clinical Ethics Committee reported that these responses proved very useful and their new Chair, Dr Andrew Hartle, has been appointed for 3 years. They are currently involved in up-dating and producing a more detailed document than their current terms of reference. They expressed their thanks for the responses.

### **Medical Student – Patient Interaction**

A round robin email regarding medical student involvement with patients was sent to all Chairs of CECs known to the UK Clinical Ethics Network in March. The request asked if any CECs had been involved in decisions relating to, or developed policies regarding, medical student involvement with patients. The issues raised were:

- Policy on consent to medical students taking part in teaching, history taking or examinations of patients
- Medical student involvement in patient care
- Opt out provisions for the patients
- Intimate examinations of patients
- Examination of patients under anaesthetic

One response reported a situation where a family refused to have students (nurses in this case) taking part in the care of the child impacting on clinical care for other sick children

where there was a lack of qualified nurses. Therefore there are risks of not having students involved in this case - busy staff / more pressure on qualified staff.

Another response referred to the hospital information leaflet which explains that medical students may be involved in a patient's care. Patients have the right to refuse, especially in outpatients. The leaflet specifies the opt out options.

The Oxford Radcliffe CEC has developed two policies in association with the medical school office and students:

- Guidelines to medical students about proper conduct with regard to physical examination of adult patients
- Guidelines to medical students about proper conduct with regard to physical examination of patients who are under the age of 18 years old (minors)

For further reading there is an interesting article in the BMJ (BMJ 2001;322:685-686 (24 March), by Len Doyal 'Closing the gap between professional teaching and practice' which refers to other papers on the same topic.

### **Accountability of 'service users' sitting on clinical ethics committees**

A CEC at a Mental Health Trust contacted the Network with an enquiry in May to ask if any other committee had dealt with the issue of service users sitting on CECs and their accountability. The main issue was one of confidentiality, which also applies to lay members of a committee, as other members of a CEC have professional codes of conduct to adhere to.

The CEC wanted to know if any other committee thought the presence of a service user would deter case referrals by clinicians, or if any other CEC had experience of service users sitting on their committee, their selection procedures and any problems / benefits experienced. The Network received 7 replies.

One committee, whose Trust also includes Adult Mental Health and Learning Disability Units, have recently considered this and decided to not use individuals but user organisations due to the difficulty of selecting users. This difficulty included issues of confidentiality, competence and the problems of selecting 'users with an agenda', such as those from pressure groups. Instead they invite user organisations, such as the Alzheimer's Society and Mencap, to act as consultants when a specific issue is being discussed.

A CEC that operates within a Learning Disability Directorate also decided not to use service users. Instead there are 4 parent-carers in the group, who are given training on how the CEC operates and the issues of confidentiality. Before cases are referred to the CEC they are anonymised, to further reduce the risk of a breach of confidentiality.

The use of anonymised referrals was also highlighted by other committees as an effective tool. One Committee also highlighted the usefulness of PALS as a source of advice on any trends or common issues / concerns that may be relevant to the case as an alternative to service users and lay members.

One CEC does not have any lay representation as they feel that the group should be populated by healthcare professionals with an interest, and training, in medical ethics rather than representatives of groups.



## FRANK HONIGSBAUM

Frank Honigsbaum, an editor of the UK Clinical Ethics Network website and lay member of the Clinical Ethics Committee, St Mary's NHS Trust sadly has died. He was an expert on the National Health Service and a leading medical historian who campaigned for reform in Britain and the United States.

His obituary appears in The Guardian, Thursday 1<sup>st</sup> July, 2004



## USEFUL WEBSITES

- 📄 UK Clinical Ethics Network <http://www.ethics-network.org.uk>
- 📄 Journal of Medical Ethics: <http://jme.bmjournals.com/>
- 📄 Journal of Medical Ethics pre-published papers:  
<http://jme.bmjournals.com/misc/ecurrent.shtml>
- 📄 British Medical Journal: <http://bmj.com/>
- 📄 British Medical Association: <http://www.bma.org.uk>
- 📄 General Medical Council: <http://www.gmc-uk.org/>
- 📄 Cardiff Centre for Ethics, Law and Society: <http://www.ccels.cardiff.ac.uk/>

## DATES FOR YOUR DIARY

- ✍ **Ethics and Mental Health Workshop - Thursday 23<sup>rd</sup> September**  
The workshop will be held at Old Road Campus, Oxford, and will cost £50.00. For an agenda and registration form contact Jane Goodall at [admin@ethics-network.org.uk](mailto:admin@ethics-network.org.uk)
- ✍ **Ethics and Resource Allocation Workshop - Wednesday 10<sup>th</sup> November**  
The workshop will be held at Old Road Campus, Oxford, and will cost £50.00. For an agenda and registration form contact Jane Goodall at [admin@ethics-network.org.uk](mailto:admin@ethics-network.org.uk)
- ✍ **Ethics in Clinical Practice Workshops - Monday 18<sup>th</sup> and Tuesday 19<sup>th</sup> October**  
Held by The Ethox Centre at the Old Road Campus, Oxford. The agenda for the workshop is available on the website or from Jane Goodall at [admin@ethics-network.org.uk](mailto:admin@ethics-network.org.uk).
- ✍ **2<sup>nd</sup> Conference of the Science of Morality – Friday 24<sup>th</sup> & Saturday 25<sup>th</sup> September**  
The Conference will be held at The Royal College of Physicians, London, and will cost £250 for both days and £150 for students. Further information is available on their web site, [www.thescienceofmorality.com](http://www.thescienceofmorality.com) or by contacting [booking@thescienceofmorality.com](mailto:booking@thescienceofmorality.com)



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# UK CLINICAL ETHICS NETWORK NEWSLETTER

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