

# UK CLINICAL ETHICS NETWORK NEWSLETTER

Issue 13, Autumn 2004



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

The network support team have had a busy few months since publication of the last newsletter. A major undertaking has been the production of a guide for clinical ethics committees. This should be available before the end of the year and all CEC chairs will receive a copy. There have also been an increasing number of requests for advice and information using the 'round robin' facility of the network. The Network Support Project comes to an end this month but the newsletter and website will continue to be maintained by Jane Goodall and Anne Slowther. The Ethox Centre is currently seeking further funding to continue this support. A final report explaining the aims and outcomes of the Network Support Project appears on page 7.

A questionnaire to find out the effectiveness of ethics training for PRHOs during their induction programme at Sheffield Teaching Hospitals NHS Foundation Trust was carried out by Mark Cobb and Steve Baker. They have written a very interesting report which appears on page 3.

The Network is often contacted by CECs to ask for further information on a point that has arisen for consideration by the committee and to elucidate whether the Network is aware of any other CECs which have addressed the topic. To this end we prepare round robin emails for circulation to all CECs known to the Network. A write up of recent requests about the ethical issues relevant to the use of 'Wanderguard' and the use of drugs of porcine origin can be seen on page 10.

There have been a number of important relevant legal cases in recent months and you can see a brief resume in 'Issues of Interest' on page 13.

The Network is organising a Joint Conference with the Association of Research Ethics Committees to be held on 18<sup>th</sup> March 2005. Further information is available from the Network website: [www.ethics-network.org.uk](http://www.ethics-network.org.uk) where you can also see information about the next Network Annual Conference, centred on Resource Allocation, which Stephen Louw and the Newcastle upon Tyne Clinical Ethics Advisory Group is hosting on 20<sup>th</sup> May 2005.

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## 2005 AGM AND CONFERENCE

The details for the 2005 AGM and Annual Conference have now been finalised. The agenda and registration forms for both events are enclosed with this newsletter and can also be found on the Network web site at:

[www.ethics-network.org.uk/Course/conference.htm](http://www.ethics-network.org.uk/Course/conference.htm)

Both events are being hosted by the Newcastle-upon-Tyne Clinical Ethics Advisory Group.

### **Annual General Meeting**

The AGM will be held on **Thursday 19<sup>th</sup> May 2005** at the Royal Victoria Infirmary, Newcastle upon Tyne.

### **Network Meal**

The AGM will be followed by a meal to be held at the Copthorne Hotel, The Close, Quayside, Newcastle upon Tyne. The meal will be held in a private room in the hotel, and due to constraints on the room size there will be a maximum number of 30 places available. Places will be given on a first come first served basis. The meal will cost £25 a head. Please indicate if you would like to attend this meal on your registration form for the AGM.

### **Annual Conference**

The UK Clinical Ethics Network 5<sup>th</sup> Annual Conference will be held on **Friday 20<sup>th</sup> May 2005** at the Centre for Life, Times Square, Newcastle upon Tyne. The Conference will be themed around the ethical issues of resource allocation. The talks being given are:

'Resource allocation decision-making: reasons and process.' Professor Tony Hope of The Ethox Centre

'CECs and resource allocation: what are the issues and should we be considering them?' Dr Neil Snowden, Chair, Pennine Acute Clinical Ethics (PACE) Committee

'The views of primary care physicians on ethical issues in resource allocation. A European comparison.' Dr Samia Hurst of the University of Geneva

The lunch session will be extended to allow for viewing of posters being displayed. The poster presentations will be themed towards the activities of clinical ethics committees. Anyone wishing to submit a poster should send the Network an abstract of their poster by mid-January 2005. We will inform you if your poster has been accepted by the end of February 2005.

The afternoon session will consist of a panel discussion chaired by Dr Tom Shakespeare of the Policy Ethics and Life Research Institute (PEALS). The day's speakers will be joined by Dr Simon Woods, also of PEALS, Professor Sir Michael Rawlins of the Royal Victoria Infirmary, and Dr Alan Watson, Chair of the UK Clinical Ethics Network Committee.

There will be an opportunity for delegates to submit questions for the panel both on the day and at registration. If you already have a question you would like to be asked, please complete the appropriate form and send it with your registration form for the Conference. There will be another opportunity to submit questions on the day.



## ETHICAL AWARENESS OF NEW HOUSE OFFICERS: A QUESTIONNAIRE SURVEY

MARK COBB AND STEVE BAKER

The GMC recognises that medical graduates must know about and understand the main ethical and legal issues they will come across and be able to take account of medical ethics when making decisions<sup>1</sup>. Consequently ethics is increasingly emphasised within the curriculum of medical schools and there is a recognised need for continuing professional education in ethics<sup>2</sup>. To consider the needs of new doctors in an acute hospital setting we investigated how well prepared Pre-Registration House Officers (PRHOs) were in dealing with ethical issues in clinical practice.

### **Participants, methods, and results**

We conducted a questionnaire survey of new PRHOs during their induction programme at Sheffield Teaching Hospitals NHS Foundation Trust. The questionnaire contained four components: 15 multiple-choice questions designed to evaluate knowledge of the core topics proposed in the UK consensus statement on medical ethics and law<sup>3</sup>; 2 self-rated assessments for respondents to indicate their overall knowledge of clinical ethics and confidence in addressing ethical issues; a multiple-response question for respondents to indicate the sources from which they had learnt about ethics; and a question about further learning.

All new PRHOs in the Trust were invited to participate anonymously and the response rate was 60% (52/87). The mean score was 11.1 out of a possible 15 (SD=1.4). 11 of the multiple-choice questions were answered by all respondents. The question with the lowest response rate, answered by 44/52 (85%) of respondents, tested their knowledge of research governance. The two questions that all respondents answered correctly were about euthanasia and withholding information. Not more than 75% of respondents gave correct answers for questions relating to mental capacity (39/52), prioritisation of resources (39/52) and proxy consent (35/51). Three questions were answered incorrectly by more than half of those who provided an answer and these related to human reproduction (22/52), research governance (19/44) and whistle blowing (11/52).

When asked to indicate sources from which they had learnt about ethics the mean response was 5 out of a possible 9 sources shown in figure 1. The top three most frequently cited were lectures (90%, 47/52), television and radio programmes (73%, 38/52) and reflection on personal experience (64%, 33/52). Journals were a source for 17/52 (33%), books for 10/52 (19%) and the internet for 5/52 respondents (10%). Respondents were asked to rate their overall knowledge of clinical ethics on a 5-point scale [*Poor – Excellent*] resulting in a mean score of 2.6 (SD=0.68). They also rated their confidence in addressing ethical issues on a 5 point scale [*Not at all – Completely*] resulting in a mean score of 2.5 (SD=0.8). Finally, all the PRHOs considered that they needed to learn more about ethics for their clinical practice.

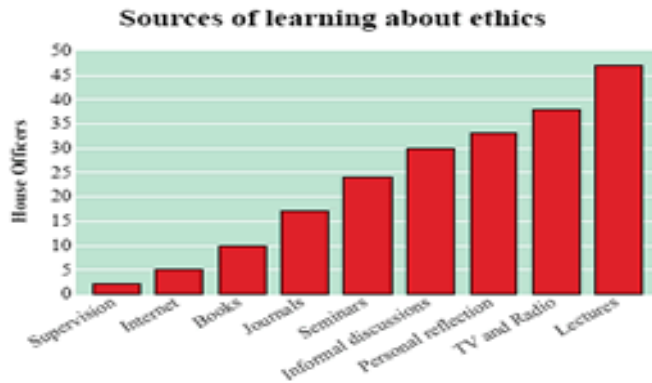


Figure 1.

### Comment

The survey provides a snap-shot of the ethical knowledge of a single cohort of medical graduates in the UK and gives an indication of where they learn about ethics. This provides useful feedback to those delivering the medical curriculum as well as information to shape the ongoing content and form of learning opportunities aimed at developing ethical competence. The questionnaire did not assess skills of reasoning and critical reflection which are essential for integrating ethical knowledge into clinical practice. However the survey results provide a starting point for discussing how these skills can be developed in doctors and suggest some areas that require greater attention in the current curriculum. What is perhaps particularly significant is that for these PRHOs major sources of learning are beyond the confines of the lecture theatre; but then ethics by its nature is a social issue as much as it is a subject for didactic education.

MC & SB designed and coordinated the study, analysed data and wrote the paper as members of the Trust's Clinical Ethics Group (CEG). We should like to thank other CEG members, firstly Caroline Altounyan for contributing to the study design, also George Helsby, Vincent Kirkbride, Jane Liddle and Tony Moore for their comments on the pilot questionnaire.

1. GMC *Tomorrow's doctors*. London: GMC, 2003
2. Parker M. Getting ethics into practice. *BMJ* 2004;329:126
3. Teaching medical ethics and law within medical education: a model for the UK core curriculum. *JME* 1998; 24:188-192

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# UK CLINICAL ETHICS NETWORK WEB SITE ANNUAL REPORT

[www.ethics-network.org.uk](http://www.ethics-network.org.uk)

## Introduction

The UK Clinical Ethics Network was created to provide help and support to established and new clinical ethics committees (CECs) in the UK. One of the most effective methods of sharing good practice and disseminating information is through the creation of a web site.

The development of the Network and the web site has been maintained by the UK Clinical Ethics Network Support Project. This project is run by the Ethox Centre and supported by grants from the Department of Health, Institute of Medical Ethics and the Ethox Foundation. These grants have allowed the web site to have unrestricted access and to be open to CECs, clinicians, patients and individuals with an interest in clinical ethics and the work of the Network. It is hoped that this openness will continue in the future.

## Launch

The UK Clinical Ethics Network web site was launched on Tuesday 30<sup>th</sup> September 2003 at Regent's College, London.

The event was well attended by members of the Network and other interested parties and was opened by Professor Tony Hope, Director of The Ethox Centre. Professor Hope introduced the evening and gave a brief explanation of The Ethox Centre's support of, and role within, the UK Clinical Ethics Network. Professor Aidan Halligan, the Deputy Chief Medical Officer of the Department of Health addressed the meeting. Professor Halligan emphasised the importance of ethics education for healthcare professionals and expressed his support for the new website, which provides many useful tools for promoting ethical education and debate.

Mrs Mary Judge and Dr Alan Watson commented on the website from a patient and clinician perspective. Both welcomed it as a useful and relevant innovation. The launch concluded with a demonstration of the website and the opportunity of those present to familiarise themselves with its resources.

## Counter Statistics

On the 7<sup>th</sup> October 2003 a counter service was introduced to the web site and counters were placed on specific pages. One year on, the site has received 7166 page views,<sup>1</sup> 3897 first time visitors with 4883 returning after 24 hours.

The web site has been extremely effective for publicising the work of the Network. Since the launch the number of CECs has increased from 20 identified in 2001<sup>2</sup>, to 60 identified by a questionnaire survey conducted by the Network in 2003<sup>3</sup>, to the current figure of 69. Of the new CECs, nine registered directly via the web site. The Network has also received 17 individual registration forms, and 12 feedback forms.

## Site Expansion

Following the launch the site has been extensively up-dated and expanded.

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<sup>1</sup> All web site visitor figures in this annual report were taken on the 7<sup>th</sup> October 2004

<sup>2</sup> Slowther A, Bunch C, Woolnough B, Hope T. *Clinical ethics support in the UK: a review of the current position and likely development*. London: Nuffield Trust, 2001.

<sup>3</sup> UK Clinical Ethics Network, *Report on the Network Questionnaire, 2003*

### *Courses and Conferences*

The courses and conferences section shows events throughout the UK, and has had 1562 page views. In February 2004 a new feature was created, allowing event organisers to send their event details via the web site with their advertising flier attached. So far details for 30 courses have been submitted.

### *Site Navigation*

In July 2004 the web site was updated to include drop down menus on the main navigation bar. This permits a much easier navigation of the web site.

### *Annual Conference*

In 2004 the annual conference was advertised online for the first time, the page was viewed 718 times. This method of advertising has been very successful, there were 87 delegates at the conference compared to 68 delegates in 2003, with 21 delegates registering for the conference via the web site.

Three delegates were international visitors, coming from Taiwan, India and Norway. Graph 1 shows a steady increase in visitors to the web site prior to the conference, indicating the effectiveness of the web site in advertising and providing extra information about Network events.

### *Ethical Issues*

A discussion of Resource Allocation in Healthcare was added to the Ethical Issues pages in March 2004, and has had 1117 page views.

### *International Section*

The International section has been re-developed to include global perspectives on clinical ethics committees – for which we have views from Norway and Estonia. There are international clinical ethics committee details, international courses and conferences, and links to medical ethics centres worldwide. This is an area that we want to continue to expand. This page has had 731 page views.

### *Reading*

The further reading section has also been re-developed to include an archive of Network newsletters and summaries of theses on clinical ethics committees. This page has had 1338 page views.

### **Accessibility**

In July 2004 the site was up-dated to include a new navigation system and adapted to conform to the Web Content Accessibility Guidelines of the World Wide Web Consortium's (WC3) Web Access Initiative. This has resulted in the site being awarded AAA rating, meaning that the site meets all the Priority checks for accessibility. The guidelines are intended to allow web designers to create web sites that can be viewed by anyone, regardless of ability.

### **Site Feedback**

We have received a great deal of positive feedback from people, from both the online feedback form and direct emails.



## NETWORK SUPPORT PROJECT: END OF PROJECT REPORT

I started work as Project Officer for the UK Clinical Ethics Network in December 2002. This post was funded by a Department of Health grant awarded to further facilitate the development of the national network for clinical ethics committees in the UK.

This two year project is now coming to an end and so it is timely to reflect on what we have achieved, and perhaps the future of clinical ethics groups in the UK.

### **Questionnaire**

At the beginning of 2003 we sent out a questionnaire to all Chairs of CECs known to the Network. We wanted to find out more about what CECs do and how they operate. The questionnaire asked about frequency of meetings, the types of issues arising for discussion by CECs, the range of members and their level of ethics education. A report was presented to the Annual Conference held in Bath in May 2003.

This information helped us to assess the type of support CECs required and how best to meet those needs. We wanted to ensure that the Network facilitates the sharing of information and experience of CECs so that individually each CEC can benefit and does not have to 'reinvent the wheel'. This has been achieved in a number of ways, particularly by way of round robin emails generated by the Network and through the website.

### **Website**

One of the key outcomes of the project has been the creation of the UK Clinical Ethics Network website ([www.ethics-network.org.uk](http://www.ethics-network.org.uk)) which was launched in September 2003. The aim of the website is to provide accessible information on issues of interest to members of CECs. Four key topics are discussed; Patient Confidentiality, Consent and Refusal of treatment, Resource Allocation and End of Life. Jane Goodall has worked very hard to ensure that the website is accessible, user friendly and up to date. Jane will continue to manage the website. I have received very complimentary comments on the website through meeting with members of CECs. It would be wonderful if the experience of members could be used to generate more topics, for example ethical issues surrounding the beginning of life.

### **Manual**

In 2001 a review of clinical ethics support in the UK identified twenty NHS trusts (4%) that had CECs and a further twenty which were thinking of setting one up. Since then there has been a great expansion in the number of CECs. An important outcome of the Network support project is a Manual to provide information to those thinking of establishing a CEC and also to address those issues that frequently arise for consideration by existing CECs.

In March 2004 I spoke to Sue Eckstein at King's College London, who edited the Manual for Research Ethics Committees. The manual for CECs was never intended to be as sizeable as that but nevertheless it has been a big project and has taken longer to produce than was originally envisaged. The Manual will be a loose leaf document in a ring binder so that it can be readily updated and expanded. It includes sections on the following:

- Clinical Ethics support in the UK and internationally
- Information about the UK Clinical Ethics Network
- Ethical frameworks
- Professional guidelines, law and ethics
- Examples of professional guidelines

- Legal issues and clinical ethics committees
- Patient organisations
- Reading list
- Key web sites

The topics are cross referenced and expanded by way of appended documents of interest. I am very grateful to all of those who have contributed to the Manual. It will be ready for distribution during December (hopefully!).

### **Round robins**

The Network has responded to a large number of queries raised by CECs on ethical issues that have been brought for consideration where the view of other CECs is sought or further information required. The Network has generally responded by drafting a question for consideration and then circulating it to members for consideration. We have collated the responses and replied to the CEC requesting the information and those who have responded. Where appropriate we have written up the topic in the newsletter.

The following issues have been the subject of round robin enquiries:

- Rationing of services due to lack of staff
- Ethical scrutiny of management decisions
- Developing a framework for ethical discussions
- Patients access to minutes of CEC meetings
- Medical student interaction with patients
- Committee membership and terms of office
- Service users sitting on mental health CECs
- Use of drugs of porcine origin
- Neonatal circumcision for religious reasons
- Developing a Do Not Attempt Resuscitation policy
- Case Consultation and Access to Minutes
- Electronic Tagging of Vulnerable Patients

### **Annual conferences**

The Network Annual Conferences have provided an excellent way to generate interest in clinical ethics, as a way to educate and provide information and to get to know others in the field.

Since I have been involved in the Network support project, conferences have been hosted by Royal United Hospital, Bath and St Mary's NHS Trust, London. In May 2005 Newcastle Upon Tyne Hospitals NHS Trust Clinical Ethics Advisory group will host the conference on the theme of Ethical Issues of Resource Allocation in Healthcare.

### **Newsletters**

The Network produces a newsletter three times a year. It is distributed in hard copy, or by email where requested, to all chairs known to the Network and to individual members by email where we have their details.

We have covered particular topics in some issues:

- Spring 2003 Assisted Reproduction Issue
- Winter 2003 Data Protection and CECs
- Spring 2004 Mental Capacity
- Summer 2004 Human Tissue Bill, organ donation and transplantation

We are very grateful to those who have written articles for the Newsletter.



### **Training and Presentations to new committees**

As part of the Support Project presentations have been made to groups interested in developing clinical ethics support within the Trust.

This often results in a request for ethics training to meet the requirements of the individual committee. It has been very satisfying to observe the enthusiasm and commitment for ethics support.

### **Ongoing issues for the Network**

The Network Committee, chaired by Dr Alan Watson, has considered the future direction of the UK Clinical Ethics Network. In order to ensure the continuing development of the Network the issue of future funding has been addressed. In this context it has been relevant to discuss the constitution of the Network. Stephen Louw and Richard Lancaster have worked hard to consider the options with Liz Mulvaney, a member of the Ethics in Clinical Practice Committee at Nottingham City Hospital and a partner in Weightmans Solicitors.

A number of contacts have been made with other bodies including the Ethics Committee of the British Transplantation Society and the Jehovah's Witness Hospital Liaison Service.

### **The Future of clinical ethics**

Although the Network support project is coming to an end, clinical ethics will continue to be a developing issue.

The Network was asked by the GMC to seek and collate responses from Chairs of CECs on the ethical issues raised by the judicial review of the GMC guidelines on Withholding and Withdrawing medical treatment (R (Burke) v GMC).

Michael Parker, Professor of Medical Ethics at Oxford is a member of the Royal College of Physicians working party on clinical ethics committees. It will report later this year.

I have enjoyed working on this project enormously. I have learnt a lot about the application of ethics to issues arising in clinical practice and feel very privileged to have had the opportunity to work in such a dynamic and interesting area.

I will be continuing with the Education and Training project until the end of March 2005, and I am sure I will be contacting you about that in the near future!

Carolyn Johnston  
November 2004



## ENQUIRIES TO THE NETWORK

### Drugs of Porcine Origin

#### Introduction

The Network received an enquiry from a clinical ethics committee (CEC) regarding the use of drugs of porcine origin and the implications for both Muslim and Jewish patients. The questions raised were:

- Is the porcine origin of some elements of a drug of religious and moral significance?
- Should the porcine elements of a drug be disclosed to a patient?

Following the enquiry a 'round robin' email was sent to the Chairs of CECs known to the Network to ascertain whether this issue had been discussed by other committees and what the committee opinions were.

#### Views of the Clinical Ethics Committees

Of the eight CECs that responded to the 'round robin' query, the majority had not considered the issue of prescribing drugs of porcine, or bovine, origin, but the common response suggested that committees thought that the patient should be told. Reasons given included respecting patients' autonomy and maintaining the trust involved in a doctor-patient relationship, which would be undermined if it came to light that the doctor was aware, and had failed to inform the patient, that the prescribed drug was of porcine origin.

The two CECs that had reached a conclusion on these issues, based upon advice from relevant religious groups, found that the prescription of such drugs *is* acceptable as they are primarily for health care and not for nutritional reasons.

#### Summary

A patient should be given information about treatment that is necessary for him or her to make an informed choice about treatment. A patient's religious beliefs will have a bearing on what is considered relevant information. In this case the porcine origin of a drug would be seen to have relevance for the patient, at least in so far as they may wish to consult with a religious leader about the treatment.<sup>4</sup> A medicine that contains a porcine content may not be prohibited by Islamic and Jewish religious laws, as these laws usually pertain to ingestion in the food sense.<sup>1, 2, 3</sup> However, it is recommended that religious leaders should be consulted if the patient is unsure of the religious significance of the porcine content.

A competent patient has the right to refuse a treatment for any reason, even if the decision could be life threatening.<sup>4</sup> The religious views of a patient are relevant to the 'best interest test' and should be taken into account when making a treatment decision for an incompetent patient.<sup>4</sup>

If the Trust is not willing to provide funding for the alternative source of treatment, or allow the patient to fund themselves, this decision must be fair and transparent to scrutiny and disclosed to the patient.<sup>5</sup>

#### References

1. Daar AS, Khitamy BA. Bioethics for Clinicians: 21. Islamic Bioethics. *CMAJ*2001;**164**(1):60-63
2. Goldsand G, Rosenberg ZRS, Gordon M. Bioethics for Clinicians: 22. Jewish Bioethics. *CMAJ*2001;**164**(2):219-222

3. Mynors et al. 2004. Informed Choice in Medicine Taking: Drugs of Porcine Origin & Clinical Alternatives. Medicines Partnership.
4. UK Clinical Ethics Network, Ethical Issues: Consent.  
<http://www.ethics-network.org.uk/Ethics/econsent.htm>
5. UK Clinical Ethics Network, Ethical Issues: Resource Allocation  
<http://www.ethics-network.org.uk/Ethics/eresource.htm>

**A copy of the full report is available from the Network.**

## **Electronic Tagging of Vulnerable Patients**

### **Introduction**

The Network received an enquiry from a CEC about the ethical issues raised by the use of the product Wanderguard within its Trust.

Wanderguard is an electronic tag, worn as a wristband, on patients who are at risk of wandering and falling, for example patients with dementia. The tag enables the patient's movements to be monitored. Without the use of the Wanderguard it is argued that there would not be adequate human resources to watch patients who wanted to go outside the ward to ensure that they didn't wander too far and to prevent risk of falling. Instead they would be required to stay within the ward for their own safety.

The Network facilitated a round robin enquiry.

### **Views of the Clinical Ethics Committees**

A total of ten CECs responded to the round robin enquiry. Four CECs had not considered the issue previously, one CEC had not considered the issue but a tagging system is used in its Trust, and another CEC had considered the issue and decided it was not ethical to implement a tagging system within the Trust.

Three CECs were able to discuss the issue at their next meeting. The outcomes of which were:

- If the patient has the capacity to give informed consent, his /her decision has to be adhered to.
- If the patient does not have capacity the case would need to be discussed with the healthcare team and the relatives to determine what would be in the patient's best interests.

Of these CECs, only one concluded that it is ethical to tag patients at risk, as a failure to use such a system could put a patient in danger.

Another CEC concluded that it would not be ethical to use a tagging device to prevent a patient from falling because summoning help would be more practical and effective. This CEC was also concerned not only about the stigma attached to the wearing of a tagging device but also the reasons for using a tagging system - the resources used for the tagging system could perhaps be used to fund adequate supervision of patients.

One CEC also expressed concern over the use of the technology from a resource allocation perspective. The technology could be seen as a method of reducing current care arrangements and caution should be used to ensure that the technology supplements patients' care and is not used as an alternative.

## Ethical Issues

In the UK there are an estimated 600 000 people with dementia.<sup>5</sup> A symptom of dementia is wandering which causes concern to both the patients and the carers, and can increase injury risks, particularly from traffic accidents.<sup>3</sup> A telephone survey of carers for people with dementia conducted by McShane *et al*<sup>6</sup> found that 45% of patients were at a risk of wandering and getting lost, and 20% were at a risk of traffic accidents. The ethical issues have been considered by Hughes and Louw in their article 'Electronic tagging of people with dementia who wander'<sup>1</sup>.

Key ethical considerations include:

- Autonomy: does the patient express a view about whether he/she is willing to be tagged?
- Beneficence: will the use of Wanderguard for a particular patient produce a greater benefit in comparison with alternative forms of supervision e.g. observation by staff?
- Non-maleficence: what harms may occur with use of the Wanderguard e.g. harm to dignity of the patient and harm if the patient wanders and falls?
- Justice: is the use of Wanderguard the best use of resources? How would patients be treated if tagging is not available?

## Further Considerations

- Would it be possible to reduce the stigma attached to wearing an electronic tagging device by investing in more discreet technology?
- Would the device have an alarm button so the patient could call for help? (particularly in the case of patients at risk of falling).
- Would the device only indicate when a patient had left a specific area, or would it include a tracking device to help locate the patient?

## Reading:

1. Hughes JC and Louw SL Electronic tagging of people with dementia who wander. *BMJ* 2002;325:847-8
2. Various Authors. Rapid Responses to Hughes and Louw. *BMJ* 2002;326:281
3. McShane R, Gedling K, Kenward B, Kenward R, Hope T, Jacoby R. Related (1998) The feasibility of electronic tracking devices in dementia: a telephone survey and case series. *J Int Geriatr Psychiatry* 1998;13:556-63
4. McShane R, Hope T and Wilkinson J Tracking patients who wander: Ethics and technology. *Lancet* 1994;343:1274
5. Miskelly F A novel system of electronic tagging in patients with dementia and wandering. *Age and Ageing* 2004;33:304-306
6. Moss L Satellite System to Track Lost Dementia Patients. Scotsman.com <http://news.scotsman.com/latest.cfm?id=3517731>
7. Welsh S, Hassiotis A, O'Mahoney G and Deahl M Big brother is watching you – the ethical implications of electronic surveillance measures in the elderly with dementia and in adults with learning difficulties. *Ageing and Mental Health* 2003;7:372-375
8. UK Clinical Ethics Network. Ethical Issues: Consent and Refusal of Treatment <http://www.ethics-network.org.uk/Ethics/econsent.htm>

## **Guidelines**

BMA. 2002 Medical treatment for adults with incapacity : guidance on ethical & medico-legal issues in Scotland

<http://www.bma.org.uk/ap.nsf/Content/adults+with+incapacity+-+scotland>

GMC. 1998 Seeking patients' consent: the ethical considerations

<http://www.gmc-uk.org/standards/consent.htm>

Department of Health. Consent Documents

<http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/Consent/ConsentGeneralInformation/fs/en>

**A copy of the full report is available from the Network.**



## **ISSUES OF INTEREST**

### **Human Fertilisation and Embryology Authority grants licence for PGD for colon cancer.**

On the 1<sup>st</sup> November 2004 the HFEA granted a licence to the Assisted Conception Unit at University College Hospital, London for preimplantation genetic diagnosis (PGD) for Familial Adenomatous Polyposis Coli (FAP). FAP is an inherited serious colon condition with onset occurring frequently in teenage children. Those affected by the condition suffer from rectal and colon cancers requiring surgery to remove the colon. Diagnosis has been by way of investigative colonoscopy from the age of 10 every one or two years.

Families with the genetic condition have a 50 per cent chance of passing it on to their children.

PGD is a technique whereby an embryo created by IVF is tested for the gene that causes the disease. Only embryos free from the disease are transferred to the womb. As PGD involves the creation of an embryo outside the womb, the clinic carrying out the technique requires a licence issued by the HFE Authority.

Other conditions which have been licensed for PGD include Beta Thalassaemia, Cystic Fibrosis, Duchenne Muscular Dystrophy, Huntington's disease and Haemophilia.

In deciding whether to issue a licence for PGD the HFEA will consider factors such as the likely degree of suffering associated with the condition, the availability of effective therapy now and in the future and the speed of degeneration in progressive disorders.

The HFEA and the Human Genetic Commission undertook a public consultation on attitudes to PGD. A report was issued in November 2001.

[www.hfea.gov.uk](http://www.hfea.gov.uk)

## **“Patients tagged to cut NHS mistakes”**

The Times 1<sup>st</sup> November 2004, page 30. Anna Patty

A Birmingham hospital has become the first in the world to tag its patients electronically to avoid the spread of infection and to avoid medical mishaps. Patients are fitted with a wireless tag which tracks their movements in the hospital. It triggers display of patient records on VDU screens in theatre and waiting rooms.

## **GMC guidance - Withholding and Withdrawing Life-Prolonging Treatment.**

In August 2004 the GMC's guidance 'Withholding and Withdrawing Life-Prolonging Treatment' was subject to judicial review. The High Court declared that key sections of the guidance are unlawful (*R (on the Application of Burke) v General Medical Council [2004] EWHC 1879 (Admin)*).

A summary of the issues raised in the case is available on the Network website: <http://www.ethics-network.org.uk/comment/mulvaney.htm>

The GMC asked for responses to the judgment and so on 12<sup>th</sup> October the Network made an email request to the Chairs of all clinical ethics committees in the UK Clinical Ethics Network asking for the views of their committees, or their personal views, on the judgment.

A summary of responses from clinical ethics committees is available from the Network:

The GMC is now appealing aspects of the judgment:

<http://www.gmcpressoffice.org.uk/apps/news/mediabrief/print.php?key=72>

### **Reading:**

Gillon R. Why the GMC is right to appeal over life prolonging treatment. *BMJ*,2004;**329**: 810 - 811

## **Withholding treatment from babies**

Two recent decisions of the High Court have deliberated the issues of termination of treatment for babies and young children. In both cases the medical team did not consider that it was in the best interest of the babies to continue treatment. The judgment of the European Court in *Glass v UK* provides that where there is a disagreement between the clinical team and the parents of the child patient regarding the proposed course of treatment or non treatment then the matter should go to court to determine what is in the child's best interests.

### **Charlotte Wyatt**

Baby Charlotte was born at 26 weeks gestation. She was placed in an incubator and had never left hospital. She had chronic respiratory and kidney problems and had profound brain damage that left her blind, deaf and incapable of voluntary movement or response. According to medical evidence she experienced pain. The most optimistic prognosis for survival for 12 months was 25%, although oral evidence indicated about 5%.

Unanimous medical opinion was that artificial ventilation would not be in Charlotte's best interests. Her parents disagreed and the matter came before Mr Justice Hedley to resolve the issue.

*He concluded that further aggressive treatment would not be in her best interests. Nevertheless he expressed the hope that in reaching that conclusion he "looked much wider than[ the medical evidence] and seen not just a physical being but a body, mind and spirit expressed in a human personality of unique worth who is profoundly precious to her parents. It is for that personality of unique worth that I have striven to discern her best interests"*

Portsmouth NHS Trust v Wyatt [2004] EWHC 2247 paragraph 39.

### **Luke Winston Jones**

In October Dame Butler-Sloss gave the decision of the High Court that it would not be in Luke's best interests to be resuscitated if he stopped breathing again. Luke had Edwards syndrome, a severe chromosomal abnormality. He had never left hospital. His mother did not want any proposed treatment be ruled out in advance.

These cases and the Burke judgment are important in clarifying the extent to which the views of parents or the patient him/herself can determine best interests in the face of opposing medical opinion.

## **British Transplantation Society Ethics Committee**

The Network has now established a link with the BTS Ethics Committee.

Dr Peter Rowe, the Chairman, has kindly agreed to provide input to any Network discussion on current developments on behalf of the transplant community. This is particularly timely as the Human Tissue Act received Royal Assent on 15th November. We hope to develop the link with the BTS Ethics Committee in the near future.









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BTS website: <http://www.bts.org.uk/ethics.htm>

For an update on the Human Tissue Act 2004: [http://www.cgkp.org.uk/topics/human\\_tissue/](http://www.cgkp.org.uk/topics/human_tissue/)







## 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/>
-  International Journal of Healthcare Ethics:  
[http://titles.cambridge.org/journals/journal\\_catalogue.asp?mnemonic=cgh](http://titles.cambridge.org/journals/journal_catalogue.asp?mnemonic=cgh)
-  Cardiff Centre for Ethics, Law and Society: <http://www.ccels.cardiff.ac.uk/>



## DATES FOR YOUR DIARY

-  **Association of Research Ethics Committees and UK Clinical Ethics Network Joint Conference**  
**Friday 18<sup>th</sup> March 2005**  
Will focus on issues of joint interest between CECs and RECs
-  **UK Clinical Ethics Network Annual General Meeting**  
**Thursday 19<sup>th</sup> May 2005**  
Open to Chairs of Clinical Ethics Committees. The AGM will be held at the Royal Victoria Infirmary, Newcastle upon Tyne. Further details will be distributed soon.
-  **UK Clinical Ethics Network Annual Conference**  
**Friday 20<sup>th</sup> May 2005**  
Themed around Ethics and Resource Allocation this conference will be hosted by the Newcastle upon Tyne Clinical Ethics Advisory Group and held at the Centre for Life, Newcastle upon Tyne. Full details of the programme, location, travel, accommodation and a registration form are available on the Network website or from Jane Goodall at [admin@ethics-network.org.uk](mailto:admin@ethics-network.org.uk)
-  For details of other courses go to the Courses and Conferences page on the website. If you would like to advertise an event with us please contact Jane Goodall.





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