

UK CLINICAL ETHICS NETWORK NEWSLETTER

Issue 18: New Year 2007



Welcome to the New Year 2007 Issue of the UK Clinical Ethics Network Newsletter

Welcome to the first issue of 2007 of the UK Clinical Ethics Network newsletter. Last year was a time of some uncertainty for the Network with regard to both the status of the Network itself and the support service offered by Ethox, hence the absence of newsletters later in the year. However, despite the uncertainty the Network continued to develop with some new committees registering, a very successful annual conference, and the production of a discussion document on core competencies for clinical ethics committees.

Fortunately the prospects for the Network over the next twelve to eighteen months are bright. The Ethox Foundation has agreed to fund a Clinical Ethics Support Project run by Anne Slowther at the Ethox Centre, which includes provision of support for the Network (including newsletters, round robin services and maintenance of the website). This project will run until December 2008 by which time the aim will be for the Network to be self supporting financially. The Ethox Project will also include other work in the area of clinical ethics support not directly linked to the Network. Anne will be working on the project one day a week and we have recently appointed Andy Copper who will be working two days a week as project administrator. Andy will be in charge of all administrative matters relating to the Network and is therefore likely to be in touch with you on a regular basis.

In this issue Dr Vic Larcher describes his experience of setting up a clinical ethics service at Great Ormond Street Hospital. Vic is unique in the UK in having a combined NHS post as a consultant paediatrician and clinical ethicist. His insights into the development of a clinical ethics post will be of interest to anyone thinking of developing this model of clinical ethics support in their Trust. Pandemic influenza is a subject that has come to the attention of several CECs in the Network (and was the subject of a round robin some months ago). Clive Richards is a member of the Department of Health Committee on Ethical Aspects of Pandemic Influenza, and in this issue describes the role of this committee and comments on the implications of its findings for local clinical ethics committees. The Committee will be publishing a report which we will circulate to the Network as soon as it is available.

We hope you enjoy the Newsletter. Please feel free to make suggestions for future issues (or volunteer to contribute a piece!) We look forward to seeing many of you in Portsmouth in May for our 2007 conference.

Anne Slowther

Editor: Anne Slowther,

The Ethox Centre, Department of Public Health and Primary Care, University of Oxford, Gibson Building/Block 21 Radcliffe Infirmary Woodstock Road Oxford OX2 6HE. Telephone 01865 287887 E-mail: admin@ethics-network.org.uk Web Site: www.ethics-network.org.uk



NETWORK CONFERENCE 2007

The 7th Network Conference will be held in Portsmouth on **Tuesday 22nd May 2007**. The theme of the conference is Rights and Responsibilities in Health Care. Topics covered will include patient choice; individual rights and distributive justice, professional responsibilities in the new NHS; and the role of families in clinical decision-making. The Network AGM will be held during the meeting. This is an extremely important AGM as we need to vote on the Constitution prior to obtaining Charitable status from the Charity Commission. There will also be a Network dinner on the evening of Monday 21st May.

A conference flier and registration form will be circulated in early February but please make sure the date is in your diaries. The 2006 conference was a great success and received excellent feedback from the delegates. I am sure that the 2007 conference will be equally interesting and stimulating.



SUBSCRIPTIONS TO NETWORK

Several committees have responded positively to the letter requesting an annual subscription to the Network to support its continuing work and development. We appreciate that many committees find it difficult to obtain financial support from their Trust but we hope that this situation will improve as CECs become more established within the fabric of the NHS. Nottingham University Hospitals NHS Trust Ethics of Clinical Practice Committee has secured a commitment to regular funding from the Trust in response to a submission by the committee to the Trust management outlining the advantages of a clinical ethics committee to the Trust. The Committee in Nottingham has kindly agreed to share this document with the Network for other committees to use as a model in negotiations with their own Trust.



CORE COMPETENCIES FOR CLINICAL ETHICS COMMITTEES

At a meeting of the network Committee in 2005 it was agreed that the Network should develop a discussion document on the core competencies required for members of clinical ethics committees. This was in response to the Report of the Royal College of Physicians' Working Party, Ethics in Practice, published in June 2005 which identified a need for a statement of core competencies and appropriate education for clinical ethics committees. A sub group of the Committee, led by Dr Vic Larcher, has worked on this issue and produced a discussion document which was circulated to all CECs in December 2006. Once we have received comments from CECs the sub group will amend the document prior to publication. The competencies set out in the document are a guide for CECs and it is not expected that all CEC members will possess all competencies. The document can be used to assist CECs in identifying learning needs of the committee. The next step will be to identify and/or develop appropriate educational programmes for CEC members to meet these competencies.

It is important that we have the views of CEC members on this document so we can ensure that we have covered all aspects and that the document is relevant to CECs. If you have not had an electronic copy of the document please contact Andy Cooper at admin@ethics-network.org.uk.



DEVELOPING A CLINICAL ETHICS SERVICE IN A CHILDREN'S HOSPITAL: THE EXPERIENCE AT GREAT ORMOND STREET

Dr Vic Larcher Consultant in General Paediatrics and in Clinical Ethics, Great Ormond Street Hospital NHS Trust

In June 2005 I took up a consultant post that is unique in having time dedicated (3 programmed activities- equivalent to 12 hours /week) to clinical ethics. The post was created at Great Ormond Street Hospital for Children (GOSH) NHS Trust to raise the profile of clinical ethics and to provide:-

- (a) prospective and retrospective review of individual cases and issues,
- (b) staff support & training,
- (c) input to policy development and
- (d) support for Clinical Ethics Committee (CEC).

GOSH provides a wide range of highly technical specialist services for children with complex medical conditions. Staff surveys in 1996, 2000/1:- defined a high prevalence of recurring ethical issues and need for ethics support. There has been a CEC/Forum in the Trust since 1995.

My first task was to determine what other resources were available to provide staff & parental support and what ethical expertise was available in individual units. Other services having supportive and humanitarian functions included Chaplaincy, Clinical Governance, Family Support, Legal, Mediation and Patient Advocacy. I met with all to clarify roles, establish co-operative working patterns and discuss academic and service developments.

I identified ethical interest/expertise by developing personal links with specialist units e.g. critical care, neurosciences, nephrology genetics, palliative care. Postgraduates (e.g. MA's) or PhD/MA students in ethics were identified in 5/11 clinical units whilst administrative support (0.05 WTE) was provided by a postgraduate in Ethics.

In the first year 49cases (29 active, 20 retrospective) from a wide range of specialities were referred. All case discussions involved multidisciplinary teams, or small groups (median duration > 60mins), with the CEC providing additional input in 25%. Important outcomes of retrospective discussions were to limit or withhold future life sustaining treatments (LST) or change goals of care in 12.

Discussions in 29 active cases resulted in decisions to withhold or withdraw LST (4), to limit its use (10), or to continue or escalate active treatment in 15.

Palliative care was instituted, often as outreach, in 10 of 14 cases in whom goals of care were changed.

Most cases involves a substantial number of secondary ethical issues of which communication difficulties, consent, exposure of the trust to risk and resource allocation were the most frequent. A library of cases has been created to provide precedents and a teaching resource.

All case discussions included an educational component but in addition over 40 formal training opportunities including seminars lectures and workshops were delivered with positive evaluations. Detailed ethical debriefings on particularly difficult case were an increasing feature of the service, and numerous informal discussions were held.

Cost-benefit evaluation of the post has been complex. Whilst costly interventions e.g. intensive care were withheld or withdrawn in some cases, in others discussions lead to the

instigation of palliative care or even innovative therapies e.g. the compassionate use of “off trial” therapies for malignancies. However, ethical guidelines for the latter use have been developed.

A small core group has been formed to develop techniques for formal evaluation of the Clinical Ethics Service, and to take forwards other academic and educational initiatives. The recent appointment of a half time (0.5 WTE) administrator for the service will provide a valuable resource for this.

Vic Larcher
Consultant in General Paediatrics and in Clinical Ethics
Great Ormond Street Hospital NHS Trust
December 2006



PANDEMIC INFLUENZA – NATIONAL ETHICAL GUIDANCE AND THE ROLE OF CLINICAL ETHICAL COMMITTEES

Dr Clive Richards Chair Nottingham University Hospitals HS Trust Ethics of Clinical Practice Committee and member of the Department of Health Committee on Ethical Aspects of Pandemic Influenza.

Pandemic influenza will generate serious problems for society and for the formal and informal health systems providing care. It will also generate significant ethical dilemmas, such as negotiating the balance between public good and individual freedoms, choosing how to allocate limited resources, or deciding on the extent of professional obligations against conflicting personal priorities. None of these are easy questions to answer. From my perspective as member and chair of the Clinical Ethics Committee of a teaching hospital trust, I can see that these will be unfamiliar and uncomfortable issues for clinicians and carers.

The Department of Health has recognised this and as part of its pandemic influenza planning, has set up a Committee on the Ethical Aspects of Pandemic Influenza, to consider these issues. The Committee has a wide membership including representatives from ethical, lay, legal, faith and clinical backgrounds. It will be publishing an ethical framework designed for use by planners at national, regional and local level both before and during a pandemic. It is also designed to assist clinicians and others in thinking about the ethical dimensions of their work in relation to a pandemic, as well as members of the public who want to think about the ethical implication of their own behaviour during a pandemic. Underlying this framework is a fundamental principle of equal concern and respect which would underpin everything else that follows.

The framework when published (probably early in 2007) will not be an ethical cookery book in which clinicians can look up the answers to specific dilemmas. Rather it will provide an ethical basis against which local decisions and plans can be tested. This will highlight the important contribution that will be required from Clinical Ethics Committees in testing and evaluating the local response plans. Although some clinical groups, for example, intensive care physicians have already developed advanced plans for circumstances where there might be more patients requiring ventilatory support than facilities to provide this, the majority of clinicians will still need extensive support in making difficult treatment and non-treatment, decisions. This is where the role of Clinical Ethics Committees may well be crucial. An ethical basis to difficult decision making is the only way to enlist public support for painful measures that may be needed if a severe pandemic hits.



ISSUES OF INTEREST

New revised issue of Good Medical Practice issued by General Medical Council in October 2006

In October 2006 the General Medical Council published a new edition of its core guidance for doctors, Good Medical Practice (GMP). New areas of guidance include working in partnership with patients, the care and treatment of children and equality and diversity. The review of GMP, which began in 2004, is the first comprehensive re-drafting of the guidance since its publication in 1995 and was informed by a wide ranging consultation. The Guidance can be obtained from the GMC website http://www.gmc-uk.org/guidance/good_medical_practice/index.asp

Nuffield Council on Bioethics report on ethical issues in critical care of neonates.

The Nuffield Council on Bioethics has published the report of its consultation on critical care decisions in fetal and neonatal medicine. The report Critical Care decisions in fetal and neonatal medicine: ethical issues includes a set of recommendations for health professionals and NHS Trusts on how these decisions should be made and supported. The recommendations include specific reference to the role of clinical ethics committees in this process and a recommendation that the NHS *'should identify the best mechanism for the operation of clinical ethics committees able to provide advice on ethical dilemmas in fetal and neonatal medicine'*. The recommendation also states that *'the chosen model(s) should be implemented on the basis of equal accessibility for parents and all health professionals involved in the health or social welfare of the child.'*

[Nuffield Council on Bioethics Report](#)

Review of the Human Fertilisation and Embryology Act

In December 2006, the Department of Health published proposals for revised legislation, including establishment of a Regulatory Authority for Tissues and Embryos. The proposals were developed following a public consultation exercise that took place in 2005. The proposals uphold the need for a statutory authority to license activity within the bounds set by parliament. This independent regulatory authority would replace the Human Fertilisation and Embryology Authority and would encompass the roles of the current HFEA and Human Tissue Authority. The requirement for treatment centres to consider the welfare of the child who may be born as a result of treatment (or any other child who may be affected) will remain but the reference to the future child's need for a father will be removed. There is a proposal to revise the confidentiality restrictions in the HFE Act relating to the use of data on assisted reproduction treatments to increase accessibility for activities such as research. In all there are 25 proposals which will be put before parliament in a Bill published for pre legislative scrutiny.

http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4141311&chk=GJrzug



DATES FOR YOUR DIARY

29th-30th March **Ethics in Clinical Practice Workshop. Ethox Centre**
Two day introductory workshop for members of clinical ethics committees

For further information contact
Andy Cooper
Telephone 01865 287887
E-mail: admin@ethics-network.org.uk

22nd May 2007 **7th Annual Conference of the UK Clinical Ethics network**
Rights and responsibilities in health care
Hosted by the Portsmouth Hospital NHS Trust Clinical Ethics Committee

For further information contact
Andy Cooper
Telephone 01865 287887
E-mail: admin@ethics-network.org.uk

1st-3rd June 2007 **3rd International Conference on Clinical Ethics Consultation.**
Toronto.

For further information contact
University of Toronto Joint Centre for Bioethics
88 College Street
Toronto, Ontario, Canada, M5G 1L4
E-mail: joint_centre_for_bioethics
Telephone: (416) 978-2709
Fax: (416) 978-1911
[conference website](#)

5th June 2007 **Cardiff and Vale Clinical Ethics Committee Second Annual**
Conference. 'Is it ethical?...'
Park Inn, Circle Way Llanedeyrn, Cardiff

For further information contact:
Delyth Alldrick delyth.alldrick@cardiffandvale.wales.nhs.uk



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/>



CONTACT DETAILS

Listed below are the names of the CEC grouped by geographical area in the UK. All the details are now available online.

If you do not have access to the website, and would like the contact details of any clinical ethics committee, please contact the Network.

Scotland

Dundee Medical Forum
Grampian NHS Board

North East

Newcastle Upon Tyne NHS Trust
Northgate and Prudhoe NHS Trust

North West

Calderstones NHS Trust
Lancashire Teaching Hospitals NHS Trust
Pennine Acute Clinical Ethics Committee
Royal Manchester Children's Hospital
Wythenshawe Hospital
Cheshire and Wirral Partnership NHS Trust
Wirral Hospital NHS Trust

Yorkshire and Humberside

Doncaster Royal Infirmary
Hull and East Yorkshire Hospitals NHS Trust
Leeds Teaching Hospitals
Mid Yorkshire Hospitals NHS Trust
South Tees Hospitals NHS Trust

Northern Ireland

Royal Hospitals Belfast
Altnagelvin H&SS Trust

Wales

Cardiff and Vale NHS Trust
North East Wales NHS Trust

West Midlands

Birmingham Children's Hospital
Birmingham Heartlands and Solihull NHS Trust
Birmingham Women's Health Care NHS Trust

Mid Staffs General Hospitals NHS Trust
Shelton Hospitals
University Hospitals Coventry and Warwickshire NHS Trust

East Midlands

Derbyshire Mental Health Services NHS Trust
Highbury Hospital
Nottingham City and University Hospitals
Sheffield Childrens Hospital NHS Trust
Sheffield Teaching Hospitals Trust
Sherwood Forest Hospitals NHS Trust
St Andrews Hospital
Southern Derbyshire Acute Hospitals NHS Trust
University Hospitals of Leicester NHS Trust

Eastern

Addenbrooke's Hospital
East Anglian Ambulance NHS Trust
King's Lynn and Wisbech Hospitals NHS Trust
James Paget Healthcare NHS Trust
Norfolk and Norwich University Hospital
Princess Alexandra Hospital NHS Trust
Peterborough Hospitals NHS Trust
Queen Elizabeth II Hospital
Southend Acute Hospital Trust
St Johns Hospital

London

Barts and the London NHS Trust
Central and North West London Mental Health NHS Trust
Cromwell Hospital
Great Ormond Street Hospital for Children NHS Trust
Homerton University Hospital NHS Trust
King Edward VII Hospital
Kingston Hospital NHS Trust
Northwick Park Hospital
Queen Elizabeth Hospital NHS Trust
Royal College of Anaesthetists
Royal College of General Practitioners
Royal College of Nurses
Royal College of Obstetrics and Gynaecology
Royal College of Ophthalmologists
Royal College of Paediatrics and Child Health
Royal College of Pathologists
Royal College of Physicians
Royal College of Psychiatrists
Royal College of Surgeons of England
Royal Free Hospital
St Christophers Hospice
St Georges Hospital
St Marys Hospital
The London Clinic
UCLH NHS Trust

South East

Brighton and Sussex University Hospitals NHS Trust
Dartford, Gravesham and Swanley PCT
Hastings and Rother NHS Trust
Helen and Douglas House Oxford
Oxford Radcliffe Hospitals NHS Trust
West Kent NHS and Social Care Trust

South

British Association of Paediatric Surgeons
High Wycombe General Hospital
Poole Hospital NHS Trust
Portsmouth Hospitals NHS Trust
Royal Berkshire Hospital
Salisbury Health Care NHS Trust
Southampton University Hospitals Trust
UK Genethics Club

South West

Plymouth Primary Care Trust
Royal Devon and Exeter Hospital
Royal United Hospital NHS Trust
Taunton and Somerset Hospital



UK CLINICAL ETHICS NETWORK NEWSLETTER

Issue 17, January 2007

Index of Contents

| | |
|---------|--|
| Page 1 | Editorial |
| Page 2 | Network Conference 2007 |
| Page 2 | Network subscriptions |
| Page 2 | Core competencies for clinical ethics committees |
| Page 3 | Clinical ethics at Great Ormond Street Hospital |
| Page 4 | Ethics and pandemic influenza |
| Page 5 | Issues of interest |
| Page 6 | Dates for your diary |
| Page 7 | List of clinical ethics committees by region |
| Page 10 | Index |

Editor: Anne Slowther

**The Ethox Centre, Department of Public Health and Primary Care, University of Oxford,
Gibson Building/Block 21 Radcliffe Infirmary Woodstock Road Oxford OX2 6HE.**

Telephone 01865 287887

E-mail: admin@ethics-network.org.uk Web Site: www.ethics-network.org.uk