

UK CLINICAL ETHICS NETWORK NEWSLETTER

Issue 19: Summer 2008



Welcome to the Summer 2008 Issue of the UK Clinical Ethics Network Newsletter

Welcome to the UK Clinical Ethics Network Newsletter. Those of you who have been Network members for some time will have noticed that there has been a hiatus of eighteen months since the publication of the last newsletter. This has been due to a variety of reasons largely related to the perennial problem of too much to do in too little time. This is partly a function of the success of the Network in that the support team at Ethox have had an increasing number of requests for training from clinical ethics committees. We have also been successful in obtaining funding for projects to develop web based resources on the Network website. All exciting developments but the newsletter has therefore taken a back seat. However we now plan to recommence a regular newsletter for UKCEN members every four months and in this first issue of the re-launched newsletter we will bring you up to date on all the developments and achievements of the Network over the past eighteen months. For future issues we would like to encourage individual committees to contribute short pieces on subjects that might be of interest to other committees. For example if your committee runs a conference or a workshop then a short report on the proceedings and what you learnt from it would be interesting, or your committee might have had success in obtaining financial support from your Trust and can share your strategy/tactics with other committees who have had less success. One recurring theme at clinical ethics workshops is the difficulty in raising awareness of the CEC within the Trust in which it sits, particularly among the health professionals working in the Trust. Perhaps your committee has developed some innovative approaches for engaging clinical staff in work of the committee. If you would like to contribute to the newsletter please let Andy Cooper know (admin@ethics-network.org.uk).

Following ratification of its constitution at an extraordinary AGM in May 2007 the UK Clinical Ethics Network is now a registered Charity. This new status will allow us to develop on a more secure footing, to seek external funding and to raise the profile of clinical ethics in the UK more widely. We now have a Board of Trustees and at the 2008 AGM Dr Stephen who took over as Chair of the Board. He replaces Professor Alan Watson who was Chair of the Network steering committee for eight years and who successfully guided the Network through its infancy. Stephen reflects on some of Alan's achievements in his Chair's letter on page 2.

We hope that you find the newsletter informative. Please feel free to make suggestions for future issues (or volunteer to contribute a piece!)

Anne Slowther

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Message from the Chair of the UKCEN Board

Since its inception, UKCEN has held annual conferences of increasing quality and popularity. The 2008 conference in Sheffield, organised by Paul Gerrish and his committee, was no exception, attracting a record number of attendees with an outstanding programme including distinguished speakers. We have been brought to this point by the energetic and able leadership of Professor Alan Watson over the past 8 years. And the unrelenting support of the Ethox Foundation, spearheaded by the indefatigable Anne-Marie Slowther (Editor of this Newsletter), who have provided financial and infrastructure support for the establishment of the UKCEN/Ethox website and many other facets of UKCEN's development.

For the next 3 years I shall have the honour of heading UKCEN as a well-established organisation, which incorporates some 75 Clinical Ethics Committees (CECs) as members. The organisation has consolidated its position as the premier ethics organisation for clinicians in the UK and continues in its efforts to bring the functioning of CECs to a more professional standing (by establishing standards and accountability). The core competencies statement sets the standard - and we are working on a linked training programme for CEC members. Following consultation with UKCEN member CECs during 2007, the editorial group of the core competencies (Vic Larcher, Ann Slowther and Alan Watson) are set to publish the document in the public domain in the near future.

In this climate, the Board has agreed that our goal for the next 3 years should be to work steadily towards achieving formal recognition of the necessity for every health trust in the UK to have a CEC as part of its clinical governance structure. Though this sounds daunting, I believe the time is ripe for such recognition by the Department of Health.

What do CEC's do? Polls show that health professionals value the opportunity to have their *clinical cases* discussed in a neutral forum, where the best interests of the patient are always foremost – this process almost certainly reduces the likelihood of litigation and enhances the consistency of approach in unfamiliar clinical scenarios. In addition, polls have shown that CECs spend a high proportion of their meetings considering the implications of *health policy*. If recent news headlines are anything to go by, CECs will be confronted by some fairly radical questions over the next year or two: "Doctors back top-up drugs" – top-ups were previously thought anathema, striking at the very root of the egalitarian ethos of the NHS; "British Woman Wins High Court Right to Challenge Assisted Suicide Guidelines" - potentially striking at the heart of the public's trust in the medical profession; "Brain-death test dropped to boost organ donation" – (ditto). Can any trust afford not to have a CEC?

Stephen Louw
Chair: UKCEN Board of Trustees



Alan Watson receives a memento of his Chairmanship of UKCEN from the new Chair Stephen Louw



Network developments 2007/8



Core competencies document

The position paper on core competencies for clinical ethics committees, developed by a sub group of the then Network Committee was ratified at the 2007 AGM. Vic Larcher, Alan Watson and Anne Slowther have now submitted a paper to the British Medical Journal describing the development of the position statement and its key recommendations. We will keep you posted on its progress. Many of you have asked us when we will have a curriculum for training of clinical ethics committees based on the core competencies document. At its meeting in May 2006 the Board of Trustees agreed to commission Dr Martin Tweeddale to develop a curriculum which will then be sent out for consultation and which can be piloted with individual CECs. Until recently Martin was a member of the Network steering committee and he has many years experience of chairing clinical ethics committees in both the UK and Canada. He was involved in developing educational materials for clinical ethics committees when he worked in Vancouver and has led ethics workshops and seminars in his role as the Chair of Portsmouth NHS Trust Clinical Ethics Committee.



Website projects

A key project which has taken up much of the time of the Ethox Clinical Ethics Support team in the past 12 months had been the updating of the Network website. As you will all have seen we have a new look website which we hope you agree is visually pleasing and easy to navigate. Now that we have transferred to a different website platform the system is much easier for us to update and modify but it took much time and many teething problems before we achieved an efficient and effective product. Andy Cooper has devoted a great deal of time and energy to updating our database of contact details so hopefully we now have your correct details on the website. If you notice any mistakes please let us know. We are hoping to further develop the content of the site further over the next year.

MCA project

In 2007 the Department of Health awarded a project grant to the Ethox Foundation to develop web based and workshop materials to raise awareness of the Mental Capacity Act initially among clinical ethics committees but with the intention of this then disseminating through CECs to health professionals in NHS Trusts. Some of you will have taken part in one of the three workshops that we held and which were hosted by the ethics committees of

- Central and North West London Mental Health NHS Trust
- Nottingham University Hospitals NHS Trust
- Leeds Teaching Hospitals NHS Trust

The web materials have been reviewed by members of the website editorial committee and by members of CECs, and are now available online on the Network website <http://www.ethics-network.org.uk/educational-resources/mental-capacity-act-2005>. Your comments and feedback are welcome. We plan to develop some case discussions based on the materials in the near future and these will also be available on line.

GMC project

In the last month we have also secured an agreement with the General Medical Council to develop a similar project based on their new guidance for treating children, '0-18 years: Guidance for all doctors'. We will be working with Dr Vic Larcher from Great Ormond Street and Charles Foster a barrister and visiting academic at the Ethox Centre to develop the materials. You will be hearing from us shortly as we look for volunteer CECs to host the workshops!



UK Clinical Ethics Network Annual Conference 2008 Sheffield Teaching Hospitals and Sheffield Children's Hospitals CECs

Sheffield was host to the UK Clinical Ethics Network 7th Annual Conference which took place on 21st May 2008. This was the Network's most well attended conference with over 180 delegates. The conference was superbly organised and the programme was both interesting and challenging. An innovative and very effective addition to the more usual lectures and case discussions was the use of brief video clips of parents talking about their experiences of facing life and death decisions about their child. It reminded us all that clinical ethics is not simply an abstract discussion but is about very real and agonising decisions with lasting consequences for patients and their families.

Synopsis of the day

The conference was opened by Dr Eve Garrard, Senior Lecturer in the Centre for Professional Ethics at Keele University. The title of her talk was 'Value of life and death', which as she said in her introduction is a huge topic, encompassing almost the whole of medical ethics. While acknowledging the impossibility of unravelling the complexities of concepts such as rights, duties and values in a 30 minute presentation Eve provided an excellent and insightful overview of some of the key questions such as what makes life valuable, what is a person and when is personhood lost, and is there a right to life, among others. While not providing answers she presented a range of perspectives on the questions and provided a vivid and entertaining example of the difficulties of defining personhood with a tale of aliens, spaceships and maternal instinct.

The second speaker, Dr Daniele Bryden, Consultant in Critical Care Medicine and Anaesthesia at Sheffield, provided a contrasting perspective on life and death looking at the clinical and legal difficulties in defining death. Dr Bryden began her talk with a conundrum. The traditional criteria for diagnosing death are also the criteria used for initiating advanced life support, the only difference being the assumption of irreversibility in the former and reversibility in the latter. But how do we judge irreversibility? She then went on to discuss the various definitions of death used in different legal jurisdictions and professional guidance. She finds the definitions inadequate for clinicians who are often "working beyond the areas encompassed or considered by these definitions". In her conclusion she called for a move away from what she termed operational definitions of death as described in the current definitions, towards a more functional definition that takes into account the process of death, informed by ethical debate.

A legal perspective in death and end of life issues was then provided by Dr Margaret Branthwaite, retired barrister and former consultant physician and anaesthetist at the Royal Brompton Hospital. Dr Branthwaite began by commenting on the fact that until the 20th Century the Law had done little to supervise or regulate medical practice in end of life care but that in recent years this had changed in response to the demand by individuals and society for a greater role in medical decision-making. She characterised the law as having no special authority to resolve questions of morality but as being empowered to regulate moral disputes and as such to provide a reasoned commentary on issues that are often emotive. She described both statute and case law that has mapped out the territory of legally acceptable decision-making in areas of assisted suicide, defiling brain stem death, withholding and withdrawing life sustaining treatment and the relevance of personal preferences in end of life decision-making. Her agreement with Justice Holman in *Re MB* ([2006] EWHC 507 (Fam)) that the law decides whether a treatment is in a patient's best

interests but the doctors make the decision about whether to continue the treatment was challenged during questions from the floor. It would suggest that a judgement about withdrawing life sustaining treatment includes factors other than what is in the patient's best interests. This is an interesting point for ethical debate but alas time did not permit further exploration of the issue.

The morning concluded with small group discussions of cases focusing on decisions at the end of life. At the beginning of the session delegates were asked to indicate how much weight they would give to patients' views and how much to the views of the family in end of life decision-making. They were then asked to repeat the exercise after the case discussions. The group that I was in had some lively discussion on the cases. It seemed we would respect a competent patient's wishes but were not so keen to respect their former wishes once they lost competence, particularly if our own perception was that the patient was suffering without treatment.

The afternoon session began with a plenary presentation by Sir James Mumby. To the disappointment of some in the audience he was not prepared to be drawn on the judicial review of the GMC Guidance on withholding and withdrawing treatment sought by Mr Leslie Burke and over which he presided in the High Court. However the presentation included some interesting reflections on the law in relation to suicide and assisted suicide. This was followed by another lively case based discussion on issues of parents requesting treatment for their child that the clinicians regarded as either futile or not in the child's best interests. The day was rounded off by Professor Mike Parker from the Ethox Centre who considered the important question of who makes these difficult decisions and the implications of this for clinical ethics committees. Mike argued that the questions of who makes the decision and how the decision is made are important moral questions and therefore we need to consider these from a moral perspective in the same way that we consider the moral question of what is the right thing to do. He suggested a theoretical approach of deliberative ethics as a model for approaching these questions. This approach stresses the importance of reason, impartiality and a search for consensus. It allows for marginalised views to be taken into account and includes the question of who should decide (or be involved in the decision) as a substantive moral question. Implications of this approach, and the moral questions of who decides and how, for CECs include consideration of the role of families and patients in CEC deliberations, recording of discussions and broader issues of membership of CECs.

Feedback from the day has been extremely positive and I am sure the Network would wish thank Paul Gerrish and his team of volunteers from both the Sheffield CECs for bringing off such a successful conference.



The 2009 conference will be in Oxford on Monday 29th and Tuesday 30th June at St Hugh's College. Initial programme details will be on the Network website in early September. The theme of the conference will be 'Capacity, Responsibility and Authenticity'. We will be trying out a two day model for this conference in view of the feedback that we have had from previous conferences highlighting the need for more time. As well as plenary presentations and case discussion related to the conference theme we will have a half day focussing on methods of clinical ethics case consultation. We are very pleased that Professor Guy Widdershoven and Dr Bert Molewijk from Maastrich University have agreed to lead this session. They have extensive research and practical experience of ethics case consultation in the Netherlands, particularly in the setting of mental health practice.



Ethics news

New GMC guidance on consent

The GMC has published new guidance for doctors on consent and decision-making. The guidance sets out the key principles of good decision-making about patient care, takes into account changes in the Law particularly in relation to the mental Capacity Act and Human Tissue Act. The guidance includes advice on discussing, sharing information, and discussing treatment options. It reflects the shift in public and professional attitudes towards a more patient centered approach to health care.

This is a key piece of guidance for all practicing doctors in the UK and CECs will need to be familiar with it when providing support to health professionals.

The guidance can be downloaded at http://www.gmc-uk.org/guidance/ethical_guidance/consent_guidance/index.asp

BMA annual conference calls for Royal Commission on co-payment for treatment

Doctors at the BMA annual conference on the 8th July passed a motion that was broadly supportive of patients being able to pay for treatment that was not available on the NHS while still receiving NHS treatment for the same condition. However the conference recognized that the issue of co-payments was a complex one which raised several concerns. Rather than vote outright for co-payments they called for a Royal Commission to investigate the issue with public consultation and consideration of appropriate safeguards.

<http://www.bma.org.uk/pressrel.nsf/wlu/SGOY-7GDJGJ?OpenDocument>

A BMJ personal view on the issue of top up charges can be found at

http://www.bmj.com/cgi/content/full/337/jun30_1/a578



Dates for your diary

15th-19th September Imperial College course on medical ethics

Further details at <http://www3.imperial.ac.uk/cpd/courses/subject/medical/medeth>

4th September 4th International conference on clinical ethics: Rijeka

Further details available at

http://www.bioethics2008rijeka.info/en/fourth_international_conference_on_clinical_ethics



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

Grampian NHS Board

North East

Newcastle Upon Tyne NHS Trust

Northgate and Prudhoe NHS Trust

Northumbria Health Care NHS Foundation Trust Clinical Ethics Advisory Group

South Tees Hospitals NHS Trust

North West

Calderstones NHS Trust

Lancashire Teaching Hospitals NHS Trust

Royal Manchester Children's Hospital

Wythenshawe Hospital

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

Sheffield Childrens Hospital NHS Trust

Northern Ireland

Altnagelvin H&SS Trust

Belfast Health and Social Care Trust

Nothern Ireland Hospice

Wales

Cardiff and Vale NHS Trust

North East Wales NHS Trust

Swansea NHS Trust

West Midlands

Birmingham Children's Hospital

Birmingham Women's Health Care NHS Trust

Heart of England NHS Foundation Trust

Mid Staffs General Hospitals NHS Trust

St Andrews Hospital

University Hospitals Coventry and Warwickshire NHS Trust

East Midlands

Derbyshire Mental Health Trust
Derbyshire Royal infirmary
Highbury Hospital
Nottingham City and University Hospitals
Sherwood Forest Hospitals NHS Trust
Southern Derbyshire Acute Hospitals NHS Trust
University Hospitals of Leicester NHS Trust

Eastern

Cambridge University Teaching Hospital NHS Foundation Trust
East and North Hertfordshire NHS Trust
East Anglia 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
Shelton Hospital
Southend University Hospital NHS Foundation Trust

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
Imperial College Healthcare Clinical Ethics Committee
King Edward VII's Hospital
Kingston Hospital NHS Trust
London Clinic
Luton and Dunstable Hospital NHS Foundation Trust
Northwick Park Hospital
Queen Elizabeth Hospital NHS Trust
St Christophers Hospice
St Georges Hospital
The London Clinic
UCLH NHS Trust
West Herts Clinical Ethics Committee
Whittingham NHS Trust

South East

Brighton and Sussex University Hospitals NHS Trust
Dartford, Gravesham and Swanley PCT
Helen and Douglas House Oxford
John Radcliffe Hospital
Oxfordshire and Buckinghamshire Mental Health Partnership NHS Trust
Princess Alice Hospice

West Kent Primary Care Trust

South

Poole Hospital NHS Trust

Portsmouth Hospitals NHS Trust

Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust

Salisbury Health Care NHS Trust

Southampton University Hospitals Trust

UK Genethics Club

South West

Bristol Royal Infirmary

Gloucestershire Hospitals

Plymouth Health Community

Royal Devon and Exeter Hospital

Royal United Hospital NHS Trust

Taunton and Somerset Hospital

Yeovil District Hospital