

UK CLINICAL ETHICS NETWORK NEWSLETTER

Issue 20 Spring 2009



Welcome to Spring 2009 Issue of the UK Clinical Ethics Network Newsletter

Welcome to the UK Clinical Ethics Network Newsletter. Since our last newsletter in July 2008 we have been busy on a variety of fronts. As mentioned in the last newsletter the Network Board of Trustees commissioned Dr Martin Tweeddale to prepare a discussion document and proposal for a core curriculum for CECs. Martin presented this to the Trustees meeting in December.

The GMC project to develop web based materials and accompanying workshops on ethical issues in caring for children has been running since August. Many of you will have attended one of the workshops that we have been running for this project. Vic Larcher and I have been travelling the country with these workshops and feedback has in general been very positive. We have visited Derby, Bath, Belfast, Tyneside, and Glasgow. The web materials should be on line in late April. On the subject of the website, developments are taking place within the Clinical Ethics Support team at Ethox which will mean that more time can be spent on improving the content of the website for the benefit of Network members. More news of these changes can be found later in this newsletter.

We have two external contributions to the Newsletter this edition. Dr Peter Lepping, consultant psychiatrist and Associate Medical Director for Ethics, Capacity and Consent in the North Wales Trust describes his role as a Trust appointed Director for ethics, possibly the first in the UK. This could be a model for other Trusts and something CECs could pursue with their own Trust management. Dr Andrew Tillyard, consultant in intensive care at Derrisford Hospital comments on one aspect off the ethical issues raised by pandemic influenza planning, that of triage for intensive care beds. This is an increasingly topical issue for CECs. We have had a round robin request to discuss the issue and most CECs who responded commented on the difficulties of developing a policy prior to the event. Because of the interest and concern on this topic we are exploring the possibility of having a specific meeting to discuss the role of CECs in policy development for pandemic influenza planning, with some additional material on the website.

Finally don't forget the 9th Annual Network Conference which is being held in Oxford on 29th and 30th June. We hope to see many of you there. Information and registration forms are available on the website

<http://www.ethics-network.org.uk/courses-and-conferences/ukcen-annual-conference-2009>

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Message from the UKCEN Chairman of the Board of Trustees

UKCEN's first Patron

I am delighted to be able to announce that Baroness Sally Greengross has agreed to be the Patron of our organisation. Lady Greengross has a distinguished record as an advocate for Age Concern, and was director general of that organisation for 13 years. More recently her interests include her co-chairmanship of the Alliance for Health & the Future. In Parliament she is a member of subcommittee F (Social Affairs, Education and Home Affairs). She expressed great enthusiasm for supporting UKCEN in achieving our objectives and we hope she will be able to attend our next conference.

The annual conference in Oxford in June 2009 promises to be a premier event in the life of UKCEN. This is the first truly international conference, with several speakers from abroad. Spread over two days, the programme will be diverse and challenging, promising much food for thought for those attending, whatever their level of experience in medical ethics. I appeal to CEC members to register early (it will facilitate planning) and to bring your colleagues along. We should make a special effort to promote attendance by professionals allied to medicine and also the legal profession.

Hope to see you there!

Stephen Louw Chair UKCEN Board of Trustees



Associate Medical Director for Ethics: A way forward for ethics in NHS Trusts

Dr Peter Lepping

Consultant Psychiatrist/Associate Medical Director/Honorary Senior Lecturer

Central Community Mental Health Team

My name is Peter Lepping, I have been appointed Associate Medical Director for Ethics, Capacity and Consent in the North Wales Trust in June 2008. I believe that this is the first such post in the country. Should there be any other Associate Medical Directors for Ethics I would be delighted to hear from you and your experiences. I was appointed Consultant Psychiatrist and Honorary Senior Lecturer with the University of Wales in 2004. Wales does not have any Mental Health Trusts so Psychiatry is still part of the overall Acute Trust system. I was employed partly with a role in ethics in mind because I had done my MSC in Medical Ethics and it has long been an interest of mine. Many Trusts have been trying to increase awareness of ethical issues across their staff groups in order to make ethical considerations a fundamental pillar of our day to day medical decision-making. Much progress has been made across the country but much more would be desirable. In my Trust the appointment of an Associate Medical Director for Ethics was a deliberate decision by the Trust Board to emphasise the importance of ethics for the Trust. I started in my role about 2 years prior to my formal appointment, and in the middle of several years

of efforts to build up a base of people interested in medical ethics who would help to make ethics important on the ground. We created an Ethics Committee as well as an Ethics Interest Group in order to bring people together from various professions as well as various specialities. The Ethics Committee was primarily concerned with internal Trust issues such as protocols, ethical dilemmas and new legislation whilst the Ethics Interest Group developed interest for ethical issues outside the Trust with public debates as well as Grand Round debates. The two committees have now merged but they remain a centrepiece of our attempts to try and disseminate ethical knowledge and thinking throughout the Trust and beyond.

My new role includes chairing this Ethics Committee. It also involves the planning and ratification of protocols and procedures that have ethical implications. This is particularly everything to do with capacity and consent but also end of life issues, restraint and resuscitation. We have been very lucky in our timing because of the advent of the Mental Capacity Act as well as the Human Rights Act, the Mental Health Act and the Human Tissue Act. It was really paramount for our ability to get ethical issues across to Trust staff to have the vehicle of the introduction of new pieces of legislation. It freed up training resources and money, it got people talking and it vastly increased the awareness of especially capacity issues across the staff. We used training on the new legislation to raise awareness for ethical issues in general and increase skills of how to solve ethical dilemmas. We increased awareness of the Human Rights Act at the time. We also managed to bring together Local Authorities, Local Health Boards (PCT's in England) and the Trust to pool our resources in order to provide training, which allowed us to disseminate knowledge and raise awareness beyond the Trust boundaries. This collaboration has pretty much survived and is being utilised for other projects.

Many Trusts still see ethics as a matter for litigation and clinical governance. However, in my opinion, ethics is a vital part of every day medical decision-making. We are trying to increase awareness of this across the Trust and I believe that the creation of the Associate Medical Director post has helped with this. It has also been vital to have Trust Board and Chief Executive support from the very beginning. In fact I think that my job would have been much more difficult had it not been for the immense support from the top. The other vital ingredient was to find people in different positions and professions to join a group of particularly interested people in order to disseminate enthusiasm, knowledge and awareness.



Pandemic planning public accountability and clip board rationing

Dr Andrew Tillyard, Consultant in Intensive Care Medicine at Plymouth Hospitals NHS Trust, Clinical Academic Lead For Medical Ethics at the Peninsula Medical School

The World Health Organisation states that it is not a case of if but when the next pandemic will come. Intensive care involvement, along with much of the health service in general, is predicted to be overwhelmed using the government's statistics. In 2005, it was estimated that the requirement for intensive care beds would be 231% of the total number of intensive care beds actually available in the event of an influenza pandemic(1).

Given this scenario, there is going to be a need to ration intensive care. One suggested means which has gained significant support is a triage criteria which aims to prioritise treatment for all

patients being assessed for critical care regardless of aetiology (trauma, pancreatitis, flu) based on objective measurable values, age and co-morbidities (2). However despite being developed over 3 years ago and being recommended by various international consensus groups, there are no published studies investigating the effect of this triage protocol on a population of people who require intensive care. We have recently conducted such a study in a District General Hospital and found that 31% of all emergency admissions to intensive care would have been excluded on the basis of this criteria, of whom 46% would have survived. This also does not take account of the elective patients that would be cancelled during a pandemic potentially leading to 'collateral damage', nor the 26% of patients who could have had their treatment stopped at any time if someone more likely to benefit presented on the basis of their triage score. This introduces the concept of clipboard physicians – doctors adding up a score to decide if they provide patients with further therapy or not.

Despite the vast majority of governmental, medical and ethical bodies all stating the importance of public awareness and accountability regarding the plans for a pandemic, little actual evidence of public consultation has occurred. In Ontario, Canada with a population of approximately 12million people, public consultation regarding a mechanism of triaging intensive care during a pandemic consisted of two groups of approximately 25 people which was considered 'enough to get a flavour of the public perspective' (3). These two groups disagreed with some of the exclusion criteria but deciding what to do in response to this is still being considered. At a recent European Pandemic Preparedness conference it was highlighted that individual European states had or were developing different plans for allocating resources amongst different sub-group populations (refugees, children) as well as different plans for keeping their international borders open or closed. This may lead to significant 'postcode' differences and population migration in response to what treatment is available for individuals, which in-turn may be exacerbated by the fact that not all countries have the facilities to produce vaccines and oseltamivir and some borders may be closed. The conflict between a clinician's responsibility for individual patient admissions and refusals to critical care, versus the role of governmental and professional bodies trying to ensure equity of access for all during a pandemic was also highlighted at this conference. If pandemic flu arises in significant numbers, society needs to decide whether they want physicians using their individual clinical acumen to determine admission to critical care with the attendant risk of physician exhaustion, emotional distress and 'postcode' variations in care. Or would they prefer 'clipboard physicians or managers' rationing care on the basis of some arbitrary scoring system?

Whilst some form of 'prioritisation' of health services will be necessary in the event of a pandemic, I believe the concept of population accountability and understanding of what triage really means for some individuals has only been paid lip service too rather than there being any meaningful stakeholder engagement. This needs to be addressed, not just for the population at large but also for the physicians. Otherwise we may have the instance of Dr Pou, repeating itself. Dr Pou is currently the subject of litigation in America due to treatment decisions resulting in patient death during hurricane Katrina, when normal 'resources' were not available[8].

1. Menon D, Taylor B, Ridley S. Modelling the impact of an influenza pandemic on critical care services in England. *Anaesthesia* 2005;60(10):952-954.

2. Christian MD, Hawryluck L, Wax RS, Cook T, Lazar NM, Herridge MS, et al. Development of a triage protocol for critical care during an influenza pandemic. *CMAJ* : 2006;175(11):1377-81.

3 Personal communication with Assistant Deputy Minister, Public Health Division Ontario, Canada. July 2008

4. . Okie S. Dr. Pou and the hurricane - implications for patient care during disasters. *N Engl J Med* 2008;358(1):1-5.



Network 2009 conference

The 2009 conference will be in Oxford on Monday 29th and Tuesday 30th June at St Hugh's College. You should all have received a flyer advertising the conference so you can put the dates in your diaries. Further information and registration details are available on the Network website. CECs who have paid their annual subscription to the Network will be entitled to a £50 reduction in the conference fee for one member of the committee. The focus of the conference will be on capacity and responsibility for medical decision making. We will also have a half day focussing on ethics case consultation with colleagues from Maastricht in the Netherlands. Speakers at the conference include Professor Jonathan Glover and Professor Genevra Richardson, both highly regarded experts in their respective fields of moral philosophy and Mental Health Law. The conference runs over two days which is a new venture for the Network. We hope many people will attend both days although it is possible to register for only one of the days. There is also the opportunity to attend the conference dinner in the dining hall of St Hugh's College. We look forward to seeing many of you in Oxford in June.



Developments with the Clinical Ethics Support Project at Ethox

The Clinical Ethics Support Project which has run at the Ethox Centre in Oxford since 2001 and which has provided academic and administrative support to Network activities at various levels (including publication of the newsletter) is undergoing further development. The Ethox Foundation which has supported the project since its inception has donated funding to Warwick Medical School to further develop clinical ethics in the UK. The funding will provide a full time academic post with administrative support to work with Anne Slowther in developing an educational and research programme in clinical ethics. Proposed research will include evaluation of clinical ethic support (an issue that has been discussed in the Network and more broadly in the literature recently). Educational work will build on the work already done at Ethox in developing workshops for CECs and include development of materials, workshops, and longer courses in clinical ethics for health professionals and CEC members. The team at Warwick will be working closely with the Ethox Centre and the Network website will continue to be hosted in Oxford with Andy Cooper responsible for maintaining and updating the site, including registration of new CECs. With more academic time we hope to expand the materials available on the website and provide an up to date information and commentary service on ethics developments and issues of relevance to CECs. We will continue to run workshops for CECs and hope to work closely with the Network on its programme of development of a core curriculum and training programme. The Warwick team will also develop the round robin discussion forums with a view to having an on line discussion forum in the near future. While the Clinical Ethics Support Project will continue to have a close relationship with the Network we envisage that over the next few years our separate roles

will become more distinct as the Network establishes its own identity and key areas of interest, and the Support Project expands its focus to clinical ethics more widely.



Ethics news

New government guidance on ‘top up fees’

In November the Government published guidance on NHS patients who wish to pay for private care as an addition to their NHS care. This guidance was the outcome of a consultation on ‘top up payments’ commissioned by the Government in response to public concern about the issue following several high profile cases of patients with cancer being denied an opportunity to pay for a treatment that was not paid for by the NHS while still receiving their routine NHS treatment. The review was led by Professor Mike Richards. The guidance is available at:

<http://nds.coi.gov.uk/environment/fullDetail.asp?ReleaseID=383246&NewsAreaID=2&NavigatedFromDepartment=False>

A summary of a CEC discussion of this topic will be available on the Network website in April.

Report of the International Bioethics Committee of UNESCO on consent

This is the first in a new series of publications that are intended to disseminate the IBC reflection and deliberations on the principles set out in the Universal Declaration on Bioethics and Human Rights (2005). The document is available at:

<http://unesdoc.unesco.org/images/0017/001781/178124E.pdf>

Physician assisted suicide debate returns to the news

In recent months there have been further high profile cases highlighting the issue of physician assisted suicide. In October Debbie Purdy lost her case in the High Court to have a guarantee that her husband would not be prosecuted if he assisted her in seeking Physician Assisted Suicide (PAS) if her medical condition deteriorated. In December the Director of Public Prosecutions announced that charges would not be pursued against the parents of Daniel James, a young man who died by PAS having travelled to Switzerland with his parents in September. In February this year the case of a husband and wife who also traveled to Switzerland for PAS was given much media attention. These cases have reignited the debate on PAS in the UK. In March the Health Secretary Patricia Hewitt tabled an amendment to the Coroners and Justice Bill which would grant immunity from prosecution for relatives who traveled to Switzerland with a person seeking PAS. No doubt the debate will continue during 2009.

High court ruling on withdrawing life sustaining treatment from a severely disabled child

In March the parents of a seriously ill child lost their case against withdrawing of ventilation from their seriously ill child. The clinicians argued that the burdens of treatment were intolerable and it was not in the child’s interests for treatment to continue. The parents argued that their child was able to experience pleasure and had long periods when he was peaceful and pain free. The decision in this case contrasts with that of MB in 2006 when a High Court ruling agreed with the parents of a child that ventilation should be continued. These cases highlight the difficulty of deciding about best interests and conflicts between clinicians and relatives at the end of life.

Ethics committees, while not a substitute for the Courts, can sometimes be helpful in facilitating discussion and reducing conflict in such cases. <http://news.bbc.co.uk/1/hi/uk/7956845.stm>

GMC consultation on End of life treatment and care

The GMC have opened a consultation on new guidance for doctors on end of life treatment and care. The guidance updates and builds on the existing GMC guidance, *Withholding and withdrawing life-prolonging treatment*, but also provides more general advice on end of life care, covering issues such as advance care planning, palliative care, bereavement issues and organ donation.

You can read the draft guidance and take part in the consultation online at:

www.gmc-uk.org/end_of_life_care. If you are unable to access the internet, paper copies are available on request (please telephone 020 7189 5404 or email standards.consult@gmc-uk.org).

The consultation will run until 13 July 2009.



Dates for your diary

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| 24 th April 2009 | Lincolnshire Clinical Ethics Conference |
| 19 th May | Third Annual Confernece Plymouth Health Community Clinical Ethics group |
| 29 th and 30 th June | 9 th UK Clinical Ethics Network Conference and Annual General Meeting |

Details of all these meetings are on the Network website courses and conferences section <http://www.ethics-network.org.uk/courses-and-conferences>



CONTACT DETAILS

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

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

Alder Hey Children's NHS Foundation Trust Clinical Ethics Committee

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

Sheffield Teaching Hospitals Clinical Ethics Group

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

St Andrews Hospital

University Hospitals Coventry and Warwickshire NHS Trust

East Midlands

Derbyshire Royal infirmary
Nottingham City and University Hospitals
Nottinghamshire Healthcare NHS: Adult Mental Health Clinical Ethics Committee
Nottinghamshire Healthcare NHS Learning Disabilities Service Advisory Group
Sherwood Forest Hospitals NHS Trust
Southern Derbyshire Acute Hospitals NHS Trust
United Lincolnshire Hospitals Trust Clinical Ethics Committee
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
Queen Elizabeth II Hospital Clinical Ethics Committee
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
Northwick Park Hospital
Queen Elizabeth Hospital NHS Trust
Royal Hospital for Neurodisability
St Christophers Hospice
St Georges Hospital
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 Clinical Ethics Committee
Helen and Douglas House Oxford
John Radcliffe Hospital
Luton and Dunstable Hospital NHS Foundation Trust

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
Guernsey Health and Social Services Department Ethics Committee

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