UKCEN NEWSLETTER

Volume 2, Issue 26, Summer 2012

UKCEN Conference Success

New Advanced Workshops

2013 Conference Announced

Clinical Ethics in Europe

Editor
Anne Slowther
Division of Health Sciences
Warwick Medical School
University of Warwick
Coventry
CV4 7AL

Tel: 024 76 151607
Email: info@ukcen.net
Website: www.ukcen.net

UKCEN is supported by
the Ethox Foundation through the Warwick Clinical Ethics Project
Welcome to the latest UKCEN newsletter. I hope you have all had an enjoyable summer despite it being the wettest one for a hundred years. Fortunately the sun shone on the UKCEN conference in June, both literally and metaphorically. The setting in Greenwich University was stunning and the conference content lived up to our high expectations. I would like to thank on behalf of UKCEN Dr Karen Le Ball and her team for doing such a great job in organising this successful day. You can read a full report of the conference on pages 2-4. Don't forget to keep 18th and 19th June 2013 free for the next conference which will be in Birmingham.

We also had an excellent and well attended pre-conference workshop organised by the Great Ormond Street clinical ethics committee who shared with us their experience in developing a framework for tackling requests for innovative treatments. The workshop included lively case discussions around resource allocation and concluded with a challenging presentation by Professor Janet Radcliffe Richards asking the question, what are clinical ethics committees for? We will be running a workshop linked to our 2013 conference in Birmingham so if any of you have ideas for a specific topic you would like to see covered please get in touch.

Our new website has attracted many complimentary comments and we are now working to launch the member’s only section. The UKCEN Board is also working on ideas for providing education and training support for member CECs linked to our core competencies document. We should have further news on this in our next newsletter.

Ethical issues in health care continue to feature regularly in the media highlighting the need for ethics support. We look forward to continuing to work with you in improving this support and welcome any suggestions on how we as a Network might increase the profile and impact of the work of CECs.

Anne Slowther, Chair UKCEN
The 12th UK Clinical Ethics Network Annual Conference ‘Inequalities in Healthcare’ took place in the stunning surroundings of the Queen Anne Building, Greenwich University, London.

This was the first conference where UKCEN had offered bursaries to students giving them the opportunity to attend and present their own work on an ethical theme. This was made possible by a generous grant from the Institute of Medical Ethics and assistance was offered to seven students to attend.

The quality of the posters they submitted were extremely high and very reflective.

Poster judges Dr Andrew Long and Dr Jenny Selway had a hard job to decide who should take the accolade of best poster but in the end the prize was awarded to Hannah Baird, a medical student from Manchester for her poster on Paediatric long term ventilation; the right or wrong move?

We were also lucky to have a broad range of posters from other colleagues, the prize winner in this section being Dr Nisha Morar for her poster on Ethical Dilemmas of Medical Certificates in Primary Care.

Dr Vic Larcher skilfully ran the preconference workshop on 14th June on behalf of the Great Ormond Street clinical ethics committee.

They were exploring methods that they were in the process of introducing in their committee of making decisions regarding
resource allocation. The workshop was well attended by thirty delegates and we were particularly lucky at the end to have a lecture from Professor Janet Radcliffe-Richards of the Uehiro Centre at Oxford University who gave an interesting oversight into resource allocation and justice from a philosophical perspective.

In the evening following the workshop we enjoyed a relaxing dinner where delegates and speakers were able to chat over the events thus far.

The following days conference Inequalities in Healthcare got off to a flying start with a morning of philosophical debate on the meaning of Justice, equality and inequality and professionalism in context, with extremely interesting perspectives forward by Dr Carwyn Rhys Hooper, Dr Ann Gallagher and Professor Jonathan Wolff.

This was followed by breakout sessions giving delegates the opportunity to choose a clinical area to explore in more detail what inequality may mean in the clinical context.
Following lunch our Keynote speaker Professor Stella Reiter-Theil Head of Clinical Ethics Support University of Basel, delivered a very interesting lecture explaining how resource and other ethical dilemmas can be brought to the bedside and explained to delegates the interesting project she has been steering in her local health economy to help make these decisions.

Subsequent to that the conference was admirably concluded with a more general societal perspective. Dr David Erdal spoke on employer ownership; Dr Robert Elias spoke on the relevance of inequalities for ethics committees and Professor Peter Goldblatt finished the conference speaking about the social determinant of ill health.

We now look forward to next year’s conference, which is being held by our colleagues in Birmingham on the 18th & 19th June.

Our thanks to the joint hosting ethics committees of South London Healthcare NHS Trust and Oxleas Foundation NHS Trust.

Dr David Erdal

Dr Robert Elias

Professor Stella Reiter-Theil
Clinical ethics services are developing in many countries in Europe and it is interesting to see some of the different approaches to ethics support.

In Norway all hospitals are required to have a clinical ethics committee and work is now progressing on developing models of support for nursing homes and community health care.

In 2011 the Norwegian government issued a mandate setting out minimum standards for clinical ethics committees including membership, access, and organisation of committees. It specifically includes a requirement that CECs have appropriate resources to ensure ethical competency of its members and that the Chair and secretary have protected tie within their hospital work to carry out CEC business.

We will circulate a translation of this mandate to CEC chairs as they may find it useful in discussions with their own organisations.

UKCEN will also be looking at how we can use this example in our efforts to engage the Department of Health in recognising CECs in the UK.

Norway’s model of ethics support is very similar to the UK model of CECs. In the Netherlands and Sweden a model of moral deliberation groups is more common. This model uses facilitated discussion with members of the health care team involved in the particular case or issue to be discussed.

Despite the different methods it is not clear if the overarching objectives of the two approaches are significantly different.

Within the European Clinical Ethics Network members are working on models of evaluation of different approaches to clinical ethics support and it will be interesting to see how much variation there is between different countries and different models.

In 2011 the Norwegian government issued a mandate setting out minimum standards for clinical ethics committees including membership, access, and organisation of committees.
Patients with 'locked in syndrome' lose court case to allow a doctor to help them end their life.
The High Court has ruled that the current law and DPP guidance on prosecution of assisted suicide cannot be changed except by Parliament. The current situation where health professionals who assist a patient who wishes to take their own life are liable to prosecution was challenged by lawyers acting for two men with 'locked in syndrome'.

Currently the guidance issued by the Director of Public prosecutions specifies when relatives or friends may not be prosecuted in these situations but specifically excludes professionals from assisting suicide.

To see the guidance issued by the Director of Public prosecutions visit: http://www.cps.gov.uk/publications/prosecution/assisted_suicide_policy.html

For more information on the case see the report on the BBC website 16th August 2012: http://www.bbc.co.uk/news/health-19249680

Parents withholds information about terminal illness from their 12 year old son.
The recent death of Adam Lewis in May 2012 from a brain tumour has sparked a debate about disclosure of terminal illness in children. The parents of Adam Lewis made a decision not to reveal to their son that his cancer was terminal. They wanted Adam to enjoy the last year of life and did not want him to feel depressed if he knew there was no hope.

The case raises issues around truth telling, best interests, competence of young people and the role of the family in medical decision making.

Parents of Down’s Syndrome patient challenge resuscitation order.

A man with Down’s syndrome is suing an NHS trust over a hospital’s decision to issue a do-not-resuscitate order giving his disability as one of the reasons. The man’s family were unaware of the DNAR order until he returned to his care home. This is just one of a number of cases where families of patients have taken legal action or made a complaint in relation to DNAR orders.
Earlier this year a PCT apologised to relatives who were not informed of a DNACPR order in place for a care home resident. The apology followed investigations into a complaint by the daughter of a 77-year-old man after she found out by chance that he had such a form in his medical notes.

Resuscitation Council guidance (2007) states 'Where the expected benefit of attempted CPR may be outweighed by the burdens, the patient's informed views are of paramount importance. If the patient lacks capacity, those close to the patient should be involved in discussions to explore the patient's wishes, feelings, beliefs and values.'

Read this news item: http://www.bbc.co.uk/news/health-19570364
To view the full statement visit http://www.resus.org.uk/pages/dnar.pdf

Transplant watchdog launches crackdown on illegal trade of organs.

The Human Tissue Authority has said that it will examine the legality of a US donor matching website that launched its British version on 30th August and which allows people seeking organs to speak directly with potential living donors. Under the NHS transplant scheme, altruistic living donors are not told who receives their kidney. While it is not unlawful to specify who should receive an organ from a living donor (directed donation) unlike in cadaveric donation, donors cannot receive any financial incentive. The HTA will be publishing a framework for the assessment of altruistic directed-donations in September. Read this news item: http://www.independent.co.uk/life-style/health-and-families/health-news/transplant-watchdog-launches-crackdown-on-illegal-trade-of-organs-8098876.html

Read the HTA statement on matching donors website: http://www.hta.gov.uk/media/mediareleases.cfm/1083-Human-Tissue-Authority-statement-on-matching-donors-website.html

Complaints about doctors have hit a record high with patients more prepared to raise concerns about their treatment, a General Medical Council report says. GMC, 18th September 2012.

Read more: http://www.gmc-uk.org/news/13895.asp

A panel of experts discuss real-life cases to explore the workings of clinical ethics committees.

Broadcast on Radio Four, listed below are the issues that this the 8th series has covered:

◆ Programme 1: Restraining Patients in intensive care.

◆ Programme 2: Too Old to donate?

◆ Programme 3: Preventing Pregnancy in Homeless Women.

◆ Programme 4: Should children with degenerative, life-limiting conditions be kept alive at all costs?

You can download podcasts of the current series and some of the previous series discussions here:
http://www.bbc.co.uk/programmes/b007xbtd
Round Robin

Since our last newsletter we have had several round robin requests to the Network on a range of issues including:

- Contracts for egg donation between UK and European fertility clinics.
- Patients’ requests to make a co-payment to receive a drug not funded by the NHS.
- Recruitment and training of lay members of CECs.

Thank you to all those CECS who took time to respond. Currently we are not reporting on case specific queries in the newsletter due to issues of confidentiality. The discussion on the general issue of contracts for egg donation with European clinics is summarised below.

A committee asked for views on the establishment of contracts between UK fertility units and European clinics for the provision of egg donation to UK couples who have difficulty in obtaining a suitable egg donation.

In general responding committees were supportive of a practice that would increase the opportunities for infertile women to conceive with egg donation, acknowledging that the shortage of egg donors in the UK meant that many women either suffered considerable distress at not being able to have a child, or sought treatment overseas, possibly in unregulated clinics. Overseas IVF centres readily advertise their services in print and on the internet. The principles of respect for autonomy and beneficence would seem to support the fertility clinic’s attempts to improve this situation. However concerns were expressed on a number of issues outlined below:

Responding committees expressed some concern over how a contract between a UK clinic and a European clinic would work in practice. For example if a woman or her foetus was harmed as a result of negligence on the part of the European clinic where would the legal liability lie? Would the UK clinic be legally responsible for the care provided in Europe or would the woman have to seek redress in the country in which the egg donation took place? While these are legal issues rather than ethical they raise the ethical issue of a doctor’s duty of care to her patient and the scope of that duty. Linked to this was a concern regarding potential coercion of women awaiting NHS IVF with egg donation who might feel pressured to transfer to the new model which is not publicly funded.

Possible reasons for an increase in donor availability in European clinics compared to the UK were considered including whether this related to higher levels of

Overseas IVF centres readily advertise their services in print and on the internet.
Round Robin

payments to donors than reimbursement of expenses which is the regulatory requirement in the UK. The reason for the UK cap on donor payment is a concern to avoid undue coercion of donors from financial incentives. If this is thought to be an ethical concern then a UK clinic providing treatment for women that includes egg donation achieved through financial incentives would appear to conflict with the ethical principles underpinning UK regulation. Several committees stated that they would support the clinic’s proposal providing it was consistent with UK regulatory and ethical guidance. One responder however commented that there are different regulatory requirements regarding organ donation across Europe (for example Spain has an opt out system and the UK has an opt in system) but organs are shared across Europe and a UK transplant team could accept a kidney donated in Spain. This is an interesting case comparison raising the question of whether there is a morally relevant difference between organ donation and egg donation. It is not clear whether the children born as a result of the proposed treatment model would have a legal right to know the identity of their genetic parent as children of UK egg donors now have. If this was not the case the question would then be whether the argument of beneficence for the couple who would be able to have a child outweighs the harm to that future child of not knowing their genetic parent. If this argument is accepted it raises interesting questions for UK policy on this issue. Responding committees agreed that the regulatory criteria regarding payment of donors and access to donor information applicable in the UK should also apply to situations where treatment was under the care of a UK clinic even if the egg donation occurred in another regulatory environment.

The HFEA has recently released updated guidance on gamete donation following a public consultation. The amended guidance can be accessed at http://www.hfea.gov.uk/6966.html.
Dates for your Diary

12th and 13th November 2012
Advanced Moral Decision Making Skills Workshops
Radcliffe Training and Conference Centre,
The University of Warwick
Further details—see opposite page

19th November 2012
Clinical Ethics Groups in Wales Annual Conference,
‘Interests in Ethics: how, why... and whose?’
Village Hotel, Swansea
http://www.ukcen.net/index.php/main/courses_conferences/
clinical_ethics_groups_in_wales

24th and 25th November 2012
Medicine Unboxed , Belief
Parabola Arts Centre, Cheltenham
Visit: http://www.medicineunboxed.com/#about-medicine-
unboxed-1/

14th to 16th March 2013
International Conference Clinical Ethics and
Consultation
Munich
Visit: http://www.clinical-ethics.org/

19th June 2013
13th UK Clinical Ethics Network
Annual Conference
Pre-Conference Workshop (18th June 2013)
Birmingham

If you would like us to advertise any courses or conferences in relation to medical ethics please
email details to: info@ukcen.net
Monday 12th November 2012

**Moral reasoning and case analysis in clinical ethics**

This day will build on our introductory workshop focussing on the theoretical underpinnings of good ethical reasoning and the critical appraisal of frameworks for ethics case consultation. The format will be interactive and use case discussions for delegates to specifically develop the skills discussed in the lectures.

- Facts, values, and moral argument
- Concepts, principles and theories
- Analysis and comparison of ethical frameworks for clinical cases
- Reflection on use of frameworks & their value in clinical practice

Tuesday 13th November 2012

**End of life ethical issues**

This day will build on the end of life session in our introductory workshop. The programme combines in depth analysis of the underlying ethical concepts that inform decisions and debates on end of life issues, discussion of legal and professional guidance and the opportunity for delegates to apply their learning through in depth case analysis.

- Ethical reasoning in end-of-life care
- Group discussion of case scenarios
  - Invited speaker
- Advance care planning, proxy decision making and do-not-resuscitate orders
- Physician-assisted suicide: Legal, ethical and social considerations

Course registration fees: 1 day £100; 2 days £180. Fees include full attendance at each day’s workshop, morning and afternoon refreshments, lunch and workshop literature. Location: Radcliffe Training & Conference Centre, The University of Warwick. To register for the workshop please download the registration form from [http://www.ukcen.net/index.php/main/courses_conferences/advanced_moral_decision_making](http://www.ukcen.net/index.php/main/courses_conferences/advanced_moral_decision_making)
Area List of Clinical Ethics Committees

**Scotland**
Grampian NHS Board  
Royal Hospital for Sick Children

**North East**
City Hospitals Sunderland NHS FT Medical (Clinical) Ethics Group  
Newcastle Hospitals Clinical Ethics Advisory Group

**North West**
Alder Hey Children’s NHS Foundation Trust Clinical Ethics Committee  
Lancashire Teaching Hospitals Practical Ethics Committee  
NHS Central Lancashire Clinical Ethics Group  
Royal Liverpool & Broadgreen University Hospitals NHS Trust Clinical Ethics Committee  
Wirral Hospital NHS Trust

**Yorkshire and Humberside**
Doncaster & Bassetlaw Hospitals – Trust Ethics Advisory Committee  
Hull Royal Infirmary  
Mid Yorkshire Hospitals NHS Trust Healthcare Ethics Group  
Sheffield Children’s Hospital NHS Trust  
Sheffield Teaching Hospitals Clinical Ethics Group  
St James’s University Hospital

**Northern Ireland**
Altnagelvin Area Hospital  
Belfast Health & Social Care Trust  
Northern Ireland Hospice

**Wales**
Abertawe Bro Morgannwg University Local Health Board  
Betsi Cadwaladr University Local Health Board  
Cardiff and Vale University Health Board

**West Midlands**
Birmingham Children’s Hospital Ethics Advisory Group  
Coventry Clinical Ethics Forum, University Hospitals Coventry & Warwickshire NHS Trust  
Heart of England NHS Foundation Trust  
University Hospital of North Staffordshire Clinical Ethics Advisory Forum  
University Hospitals Birmingham NHS Foundation Trust

**East Midlands**
Derby City Hospitals  
Nottingham University Hospitals  
Nottinghamshire Healthcare NHS: Adult Mental Health Clinical Ethics Committee  
Nottinghamshire Healthcare NHS Learning Disabilities Service Advisory Group  
Sherwood Forest Hospitals NHS Foundation Trust  
United Lincolnshire Hospitals Trust Clinical Ethics Committee  
University Hospitals of Leicester NHS Trust
Area List of Clinical Ethics Committees

Eastern
Cambridge University Hospitals FT Clinical Ethics Group
East & North Hertfordshire NHS Trust
East Anglia Ambulance NHS Trust
James Paget University Hospital NHS Foundation Trust
Norfolk and Norwich University Hospital
Princess Alexandra NHS Trust Harlow
Queen Elizabeth II Hospital Joint Clinical Ethics Committee

London
Central and North West London NHS Foundation Trust
Cromwell Hospital
Great Ormond Street Hospital for Children NHS Trust
Guy’s and St Thomas’ Foundation Trust Clinical Ethics Advisory Group
Imperial College Healthcare Clinical Ethics Committee
King Edward VII’s Hospital
Kingston Hospital NHS Trust
London Clinic
Northwick Park Hospital
NRES Committee London – Hampstead
Royal Hospital for Neurodisability
South London Healthcare Trust, Oxleas NHS, Greenwich
PCT Trust (Queen Elizabeth Hospital)
Royal Surrey County Hospital NHS FT Clinical Ethics Forum
St Christopher’s Hospice
St Georges Hospital
UCLH NHS Trust
West Herts Hospitals NHS Trust Eastern Region
Whittington NHS Trust Clinical Ethics Group

South East
Brighton & Sussex University Hospitals NHS Trust
Helen & Douglas House Oxford
Luton and Dunstable Hospital NHS Foundation Trust
Oxford Health NHS Foundation Trust
Princess Alice Hospice

South
Poole Hospital NHS Foundation Trust
Portsmouth Hospitals NHS Trust
Royal Bournemouth & Christchurch Hospitals NHS Foundation Trust
Southampton University Hospitals Trust
Guernsey Health & Social Services Department Ethics Committee

South West
Gloucestershire Hospitals
Plymouth Health Community Clinical Ethics Group
Royal Devon & Exeter Hospital Clinical Ethics Reference Group Committee
Royal United Hospital NHS Trust
Taunton & Somerset Foundation Hospital
University Hospitals Bristol NHS Foundation Trust
Yeovil District Hospital

For Full contact details visit:
http://www.ukcen.net/index.php/committees/member_list