2012 UKCEN Conference
Pre-Conference Workshop
Clinical Ethics in New Zealand
New UKCEN Website
March Workshop
Evaluation Study

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UKCEN NEWSLETTER

UKCEN is supported by the Ethox Foundation through the Warwick Clinical Ethics Project
A Message from the Chair

Welcome to the first UKCEN newsletter of 2012. A happy New Year to you all. Since our last newsletter we have successfully launched our new look website at www.ukcen.net (see page 5 for further details) and our new sub editors will be working hard to make the website as interesting and informative as possible. Once the main website is working well we plan to initiate a member’s only section for CECs who subscribe to the Network so watch this space.

Plans for the 2012 annual conference in June are well under way and we have an exciting programme of speakers with a highly topical theme of resource allocation. I would encourage you to book early and get the date in your diary (14th and 15th June). The issue of how to persuade our Trusts to provide resources for their CEC will be even more pressing in the coming years given the difficult financial situation facing the NHS. Providing justification for ethics support will be one priority for the Network to consider.

A new research project at Warwick plans to look at how we can evaluate ethics services within the NHS (see page 6). We can also learn from our colleagues in New Zealand (page 4). I hope you enjoy reading the newsletter and look forward to seeing many of you in June.
We are looking forward to welcoming members to the 12th Annual Conference of UKCEN which is being held at Greenwich University on June 15th.

The subject of the conference is Inequality and we are hoping to explore a number of aspects of this concept. We start the day by setting the scene with what we understand by Inequality and Equality. There will then be an opportunity to participate in interactive workshops which will be looking at inequality in different clinical settings which many of us not only encounter in our day to day practice and lives but also within our clinical ethics committees.

There will then be some further presentations and discussion regarding the relevance of these considerations for clinical ethics committees and organisations as a whole and we finish the day with looking at inequality in the broader society and what this means for the NHS of today.

We are fortunate in that we have attracted some extremely exciting speakers including Professor Stella Reiter-Theil from Basel, Professor Jonathan Wolff (UCL) and Dr Jessica Allen from the Marmott Review group.

There is also a workshop the afternoon prior to the conference to give committee members the opportunity to discuss in depth aspects of inequality and equality in the clinical ethics context. One member of each CEC that has paid their 2012 UKCEN subscription will be eligible to attend free of charge.

The conference dinner will be held on the evening of June 14th. There will also be a competition for the best poster; instructions on how to submit posters will be found on the website: www.ukcen.net.

Do come to Greenwich to experience what will certainly be a very interesting conference in an exciting and beautiful setting.

**Hosted by South London Healthcare NHS Trust & Oxleas Trust CEC**

**Location**
Queen Anne Building Greenwich University London

**The Conference will be preceded by a half day Ethics Workshop on 14th June**

**Themes for Discussion**
Concepts of Justice and Inequality
Relevance of Inequality for CECs
Inequalities in Clinical Situations
Social context of Health Inequalities

**Speakers Include**
Dr Ann Gallagher
University of Surrey

Prof Jonathan Wolff
University College London

Prof Stella Reiter-Theil
University of Basel, Switzerland

Dr David Erdal
University of St Andrews, Scotland

Jessica Allen
Institute of Health Equity, London
Pre-Conference Workshop – 14 June 2012

The pre conference workshop this year will link to the theme of the conference and focus on the role of clinical ethics committees in responding to issues of resource allocation, either in individual cases or at a Trust policy level.

The workshop will include discussions of whether and how CECs should respond to dilemmas involving resources, how resource issues add complexity to other ethical dilemmas such as consideration of futility in decisions to withdraw or withhold treatment, and case scenarios that highlight some of these points.

A highlight of the workshop will be a presentation by members of the Great Ormond Street clinical ethics committee who will share their committees’ experience of developing a framework for considering cases of innovative treatments and how they are now building on this to engage with the difficult issue of resource allocation more generally.

Places on the workshop are limited so book early. One member of each CEC that has paid their 2012 UKCEN subscription will be eligible to attend free of charge.

To register please visit: http://www.ukcen.net/index.php/main/courses_conferences/ukcen_12th_annual_conference_inequalities_in_healthcare

Great Ormond Street Hospital for Children will be contributing to the pre-conference workshop.
Clinical Ethics in New Zealand

New Zealand has a proud history of being at the forefront of social progress. In 1893 New Zealand became the first country in the world where women had the right to vote in parliamentary elections. In 1938 the first continuously functioning public health service came into existence in New Zealand. The 75th anniversary of this momentous occurrence will be in 2013.

However, in the area of clinical ethics the availability of formal structures to support clinicians’ decision making is less than in other developed countries. In New Zealand a small number of Clinical Ethics Advisory Groups (CEAGs) have evolved in response to addressing clinical ethics problems. However, many District Health Boards (DHBs) have no such formal clinical ethics support at all. In addition there is little or no communication between DHBs on clinical ethics. Therefore; the clinical expertise and experience that currently exists, is not shared.

In the latter part of this year the Health Quality and Safety Commission (HQSC) has provided support for the concept of a National Clinical Ethics Network. Early plans to promote the idea of a network include writing a report to review international developments in clinical ethics and use this as the basis for exploring what a New Zealand clinical ethics network might look like. In addition a clinical ethics network website will be set up. These two initiatives will provide the basis for discussions with various professional bodies that are relevant to the development of a clinical ethics network.

In the short to medium term the plan is to raise the profile of clinical ethics to the extent that “Clinical ethics should be everyone’s business” in support of this aim is that ultimately all clinicians should have access to a CEAG.

The membership of a CEAG should reflect the diversity of clinical professionals. Membership should also reflect cultural diversity. Appropriate legal expertise is vital and ethical expertise is desirable. Public representation must be an integral part of such CEAGs.

A National Clinical Ethics Network will provide mutual support for smaller centres which may initially struggle to maintain a clinical ethics presence. The collective aim of the network must be to ensure that clinical ethics becomes an integral part of all health services.

In common with other countries, New Zealand will face an increasing struggle to provide health services in a resource constrained environment. Variations in availability and access to services threaten to become even more critical than they are today. Robust ways of making and justifying the hard choices that will reduce these differences will need to have a basis that complements politics and economics and the other complex components of the health system. An awareness of clinical ethics has to be an integral part of such decision making.

The formation of a clinical ethics network in New Zealand can be seen as an effective way of introducing the relatively simple (but not simplistic) language of ethics into the everyday work of health professionals.

These are grand rather than grandiose ideas. Close communication with the UK Clinical Ethics Network has helped with the development of a nascent Clinical Ethics Network in New Zealand. Continued close collaboration with UKCEN now and in the future will ensure that our network thrives.

Alastair Macdonald, Chair of the Capital and Coast CEAG Wellington, New Zealand
Welcome to the new look Website

Editorial Board:

**Ethicists**
- Richard Ashcroft, Professor of Bioethics, Queen Mary University of London
- Alastair Campbell, Professor of Bioethics, National University of Singapore
- Mike Parker, Professor of Bioethics, University of Oxford
- Bobbie Farsides, Professor of bioethics and clinical ethics, Brighton & Sussex Medical School

**Lawyers**
- Charles Foster, Barrister and Associate Fellow, Ethox Centre, University of Oxford
- Jose Miola, Senior Lecturer Medical Law, University of Leicester
- Richard Huxtable, Reader in Medical Law University of Bristol

**Clinicians**
- Anneke Lucassen, Professor of Genetics, University of Southampton
- Vic Larcher, Consultant paediatrician & clinical ethicist Great Ormond Street Hospital
- Julian Hughes, Consultant in old age psychiatry and honorary professor of philosophy & ageing

**Lay members**
- Sarah Barclay, Founder of the Medical Mediation Foundation
- Hazel McHaffie, Author and former Research Fellow in Medical Ethics

**International**
- Stella Reiter-Theil, Professor of medical ethics and clinical ethics University of Basel
- Reidun Forde, Professor of Medical Ethics and Director Centre for Clinical Ethics University of Oslo
- Guy Widdershoven, Professor of Bioethics, Free University of Amsterdam

The network is pleased to announce the new website: www.UKCEN.net

The UKCEN website provides an up to date resource for health professionals and members of clinical ethics committees including educational materials, news items, and links to national policies and guidelines on ethical issues relating to patient care.

Our previous website has proved popular with health professionals and educators in clinical ethics and our new site will continue to develop practical resources in this field.

New section editors will ensure that each section of the website provides relevant and useful information for members of CECs and health professionals more widely. Check out our courses and conferences section for opportunities for training and updating your knowledge. A future facility will be a members only section including a discussion forum.

www.ukcen.net
Evaluation of Clinical Ethics Services Study

The Warwick Clinical Ethics Project, funded by the Ethox Foundation with the support of Warwick Medical School at the University of Warwick, is entering into a new stage of its research.

After completing a national survey mapping the current provision of clinical ethics services in the UK, the next step is an empirical research into evaluation of clinical ethics services.

The principal investigator Dr Anne-Marie Slowther, co-investigator Dr Dita Wickins-Drazilova and research secretary Mrs Louise Hutton aim to develop a consensus on the main objectives of clinical ethics support in the UK context. This will inform the development of better quality ethics support for health professionals and patients which can be evaluated against standard benchmarks.

The team is hoping to identify the range of objectives considered relevant for clinical ethics support services, and to develop a set of key outcomes that can be tested in a further study. The final result of this study will be a list of the key objectives and most appropriate outcomes that will be useful for evaluating clinical ethics services in the UK and potentially in other countries.

The method that will be used is the Delphi technique, which is widely recognised in health care research as an appropriate method for achieving consensus. The approach will use mixed methods (interviews, questionnaires and nominal groups).

The first step will be to develop a range of reasonable domains (objectives) to present to participants for ranking, which will be achieved through interviews with key informants.

The Warwick Clinical Ethics project will be working closely with Dr Leah McClimens from the University of South Carolina, who is leading a similar study in the US.

Study findings will be presented in later editions of this Newsletter, as well as circulated to NHS Trusts, published in peer reviewed journals and presented at conferences.

First results are expected to be available in autumn 2012.

This will inform the development of better quality ethics support for health professionals and patients which can be evaluated against standard benchmarks.
Since our last newsletter we have had several round robin requests to the Network on a range of issues including:

- Patients and families filming in hospitals
- Whether clinicians should request non clinically indicated x rays in cases of alleged assault
- Selection of new 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 filming in hospitals is summarised below.

Patients and families filming in hospital

A CEC asked for views about rights of patients/relatives/medical staff in relation to patients filming clinical events.

The responding committees raised several points to be considered about filming in hospitals in general and about relatives filming treatment specifically. It was pointed out that most if not all hospitals will have a policy regarding filming by commercial companies and it was considered that if images were to be placed on YouTube this would constitute broadcasting and could fall within existing policy. Committees thought that the principles underpinning policy on commercial filming probably also applied to filming for personal use and related to respect for privacy, informed consent, and acting in the best interests of the patient.

However it was also pointed out that filming already occurs in other hospital contexts, for example fathers taking pictures of or filming the birth of their child, or parents who have been involved in decisions about treatment of their dying child being able to take pictures during the dying process. Any consideration of policy in this area would need to ensure consistency across a range of different scenarios.

Both the GMC and BMA issue guidance for doctors on the use of video and audio recording of patients. These were seen as relevant to the use of such images by patients and family. One committee separated the issue into two specific points:

1. Should permission be sought for filming?
2. If permission is sought should it be granted?

The consensus was that permission should be sought by anyone wanting to film patients or staff in a hospital setting. This was for a range of reasons including the need to have the consent of the patient (if capacitous) or to protect the interests of the patient if they lacked capacity to consent. For example an unconscious patient or a young child; the need to have consent from health professionals being filmed; the need for consent from any other patients whose image may be captured by the filming; and the need for the Trust to have some control over the use of images obtained during patient care for which the Trust could be argued to have some responsibility.

Responding committees also commented on the practical difficulties of developing and implementing a policy on this kind of filming.

While the consensus was that filming and photography should not take place without the consent of those involved (patients and staff) or in the best interests of those patients who could not consent, there was concern over how the policy would be implemented in a range of different scenarios and to what lengths the Trust could go to prevent filming without consent.

Confiscation of a camera could be seen as theft and a confrontation between relatives and staff during a crucial moment of treatment could be both distressing and hazardous for the patient. A challenge for any policy development will be how to protect staff and vulnerable patients while facilitating filming or photography that can be beneficial to patients and their families.

CECs may find the following guidance helpful in considering this issue:

GMC - Making and using visual and auditory recordings of patients. 2011
http://www.gmc-uk.org/guidance/ethical_guidance/making_audiovisual.asp here is guidance for doctors but the principles can be applied to other situations.

DH Guidance on filming in the NHS 2005

A similar case was the subject of a Clinical Ethics Committee case discussion in the journal Clinical Ethics in 2010. The paper gives a detailed and carefully considered analysis of the issues and I would recommend CECs to read the paper. It can be accessed on line at http://ce.rsmjournals.com/content/vol15/issue2/#CASE_STUDIES
Judge rules that woman in minimally aware state should not be allowed to die

The Court of Protection issued a landmark ruling in the case of Ms M who is in a minimally conscious state. Her family had asked for ANH to be withdrawn saying that she would not want to be kept alive in this state. The judge ruled against the family’s wishes giving more weight to the preservation of life as it was believed that Ms M was able to have “some positive experiences”.

http://www.bmj.com/content/343/bmj.d6300.extract

The Institute of Medical Ethics (IME) launches new website to improve education and understanding of medical ethics

The Institute of Medical Ethics (IME), a charitable organisation that promotes and supports the study and understanding of medical ethics through education, research and publication, launched its new website on Wednesday, November 2nd, 2011 offering a virtual network and resource for teachers, students and clinicians interested in medical ethics.

The site will provide multimedia learning resources, the latest updates on conferences, research and teaching opportunities as well as media coverage related to medical ethics.

http://www.instituteofmedicalethics.org

The Joint Committee on Medical Genetics has issued a reviewed guide to Consent and Confidentiality in Clinical Genetic Practice

The Joint Committee on Medical Genetics has issued a reviewed version of their guidance on consent and confidentiality in clinical genetic practice.

The report contains recommendations, for example what sorts of issues should be discussed during the consent process to facilitate the sharing of data which is familial in nature, as well as discussions on a range of case scenarios.

http://www.rcplondon.ac.uk/sites/default/files/consent_and_confidentiality_2011_0.pdf

BMA publishes new guidance for doctors and medical students on using social media

The BMA has published guidance on how doctors and medical students should use social media in the context of their professional roles.


The Independent Mental Capacity Advocate publishes a report in its fourth year of service

**PIP breast implants scandal raises questions of duty of care**

The discovery that a French manufacturer of breast implants has been using industrial grade silicone has caused significant distress for up to 40,000 women in the UK and many more worldwide who have these implants and face uncertainty about their safety.

The Department of Health has accepted that the NHS as a provider of these implants has a duty of care to the women to remove them if this is appropriate.

The guidance includes a statement that private clinics that originally provided these implants also have a moral obligation to remove the implants free of charge.


**Welsh government planning to introduce opt-out system for organ donation**

The Welsh government is planning legislation to introduce an opt-out system for organ and tissue donation later this year with the aim of increasing the number of available organs for transplantation. The proposal is for the introduction of a “soft opt-out” system where organs and tissues can be used after a person has died unless they have objected during their lifetime. Although the White Paper consultation ended on January 31st, the proposals can be viewed on the government’s website.

http://wales.gov.uk/consultations/healthsocialcare/organ/?lang=en

**The Commission for Assisted suicide produces final report**

The Commission for Assisted Suicide, chaired by Lord Falconer, has now produced its final report following a year of gathering evidence and consultation. The report criticises the current law on assisted suicide calling it “inadequate and incoherent” and makes proposals for a new legal framework, including eligibility criteria and safeguards against abuse. The Commission was set up with funding from Terry Pratchett and Bernard Lewis.

http://www.commissiononassisteddying.co.uk/

**HFEA consultation on the ethics of mitochondria transfer**

A consultation on the use of techniques to prevent the transmission of certain genetic conditions from mother to child was announced in January. Currently these techniques are only permitted for use in laboratory research but the consultation will seek the public’s views on the wider use in IVF treatment for women to avoid transfer of mitochondrial disease. To register an interest in being involved in the consultation, email mitochondria@hfea.gov.uk

http://www.hfea.gov.uk/6898.htm
Conferences

5th – 6th March 2012
Ethics in Clinical Practice Workshop – Warwick Medical School, University of Warwick
See details on page 11

16th March 2012
The Intensive Care Society Conference – Law and Ethics in Intensive Care - Oxford

16th – 19th May 2012
The 8th International Conference on Clinical Ethics and Consultation – Sao Paulo, Brazil

15th June 2012
UKCEN 12th Annual Conference – Inequalities in Healthcare - Greenwich
See opposite feature
Further details are on page 2 or please visit http://www.ukcen.net/index.php/main/courses_conferences/ukcen_12th_annual_conference_inequalities_in_healthcare

24th – 25th November 2012
Medicine Unboxed – Parabola Arts Centre, Cheltenham
Medicineunboxed.com

If you would like us to advertise any courses or conferences in relation to medical ethics please email details to: info@ukcen.net
Ethics in Clinical Practice Workshop
5th and 6th March 2012

A one/two-day course aimed at members or potential members of Clinical Ethics Committees

It is possible to attend either one or both days of the course. Each day’s teaching stands alone but is complementary to the other day

**Course facilitators:**
Dr Anne Slowther and Dr Dita Wickins-Drazilova

**Invited Speaker:**
Stephen Louw, Consultant Physician & CEC Chair at Newcastle Hospitals & UKCEN Board Trustee

**Location**
Warwick Medical School, University of Warwick


**Content**

- Understanding Moral Theory
- Ethical frameworks
- Core Knowledge: Consent and best interests
- End of Life Decision making
- Systems and processes for Clinical Ethics Committees
- Promoting CECs within your trust
- Confidentiality and Data protection for CECs
- Provoking innovative approaches to ethics discussion in your CEC
- Appreciating different perspectives in a case consultation
- Ethics Committees and NHS reform; meeting the challenges

**Testimonials:**

“Many thanks for organising such an enjoyable and stimulating workshop. I would be interested to know of any other workshops you are organising in the future.”

“I enjoyed the chance to network with colleagues whose paths I would not normally cross and I have learnt lots to take back to my CEC.”
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
South Tees Hospitals NHS Trust

North West
Alder Hey Children’s NHS Foundation Trust Clinical Ethics Committee
Calderstones NHS Trust
Lancashire Teaching Hospitals Practical Ethics Committee
NHS Central Lancashire Clinical Ethics Group
Royal Liverpool & Broadgreen University Hospitals NHS Trust Clinical Ethics Committee
South Manchester 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
St Andrews Hospital
United Lincolnshire Hospitals Trust Clinical Ethics Committee
University Hospitals of Leicester NHS Trust

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
Peterborough Hospitals NHS Trust
Queen Elizabeth II Hospital Joint Clinical Ethics Committee
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