



# UK Clinical Ethics Network Newsletter



**Welcome to the Summer 2010 edition of the UK Clinical  
Ethics Network Newsletter.**

Another summer is slipping by and I am happy to be able to report that another successful Network Conference has taken place, this year in Cardiff and once again accompanied by glorious weather. Let's hope we can maintain this standard (for both conference and weather) for 2011 in Glasgow. A report of the Cardiff conference can be found on page 3. The Cardiff conference was also notable for two innovations; a train the trainers workshop held the day before the conference and sponsored by UKCEN, and a linked one day conference hosted by the Institute of Medical Ethics. Both initiatives were very successful and we will be looking to build on these for future conferences.

Since our last newsletter we have seen the publication of a paper on the Core Competencies for Clinical Ethics Committees in the Journal Clinical Medicine (followed by an editorial in the BMJ). The UKCEN Board of Trustees has been investigating options for development of our website and the proposed plans are summarised on page 5.

The next year is likely to be an ethically challenging time for the NHS as the new government implements its ideas for change and resource constraints begin to bite. So there will be much work for CECs to do in the coming months.

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### **Message from the Chairman of UKCEN Board of Trustees**

As predicted, the UKCEN Annual conference in June was a great success thanks to careful planning by the Cardiff organising committee (Wulf Stratling, Richard Hain *et al*). The day afforded delegates an immersion into the multi-faceted and deeply challenging socio-political and ethical issues surrounding disability – it was hard work, but worth it.

What really made the Cardiff experience great was the fact that this excellent UKCEN conference was sandwiched between two other really stimulating ethics events, a “Train the Trainers” workshop on the preceding day and on the following day a conference on ethics and medical education. The Board hopes that the train the trainers workshops will be a feature of future conferences and I strongly commend attendance of this workshop to any senior member who wishes to develop their CEC.

The day following the Conference, the Institute of Medical ethics held a conference with a focus on ethical and legal issues arising from a not uncommon scenario: teaching medical students on a patient who is unable to consent. The organisers (Dr Wing May Kong, Revd Bryan Vernon *et al*) had conceived the following captivating mechanism to achieve the audience’s deep engagement with the issues: A mock-trial was held, closely resembling a real Court, with a stern judge presiding, evidence was led, witnesses called and cross-examined. In the afternoon parallel working groups analysed the ethical and legal issues of the case from different perspectives. This is a highly productive way of engaging ethicists, lawyers and clinicians and I thoroughly enjoyed the day, coming away with new insights.

Some important ‘changes of the guard’ have taken place on the Board, confirmed at the June AGM: Anne-Marie Slowther was elected as Vice Chair; Peter Rudd stood down as Vice Chair, but continues as Secretary; Martin Vernon is standing down as Treasurer, which Office is being taken over by Dermot Murphy. The Board registered an enormous debt of gratitude to Peter and Martin for their sterling work. Paul Gerrish was re-elected as Board member and will continue to lead on a project to develop an autonomous website for UKCEN.

The Board was delighted to be able to entertain Professor Tony Hope and Mike Parker at the Conference dinner in Cardiff and to present each with a certificate bestowing Honorary Life Membership of UKCEN. This is in recognition of the tremendous work they have each done to develop clinical ethics in the UK and to support the UK Clinical Ethics Network. They were the first individuals honoured by UKCEN in this way.

So, the ‘Cardiff Experience’ was terrific; pretty city too. No sight of Torchwood thank goodness!

Stephen Louw, Chair UKCEN Board



## Tenth UK Clinical Ethics Network Conference



GIG  
CYMRU  
NHS  
WALES

Bwrdd Iechyd Prifysgol  
Caerdydd a'r Fro  
Cardiff and Vale  
University Health Board

The 2010 conference took place on 23<sup>rd</sup> June and was hosted by the Cardiff and Vale University Health Board Clinical Ethics Committee and Cardiff University. The theme of the conference was Disability and its ethical implications. The range of perspectives on this theme was considered by a group of excellent speakers from different service user, academic, and clinical backgrounds.

The scene was set by Dr Mikey Dunn from the Ethox Centre who provided a clear overview of different discourses on disability, pointing out that how we think of and articulate concepts of disability itself has an ethical dimension, and different discourses will engender different ethical questions and dilemmas to grapple with. This excellent introduction was followed by Professor Luke Clements from Cardiff who guided us through the legal framework within which disability is considered with particular reference to a single Equality Act and international Human Rights. Professor Clements reminded us of the impact of disability on carers as well as the person who has the disability, and the broader legal considerations arising from this recognition.

Another Cardiff speaker, Professor Stephen Edwards, provided a thoughtful analysis of a particular, high profile case which has provoked strong views and in which a clinical ethics committee (in the US) was involved. The case of Ashley is well known to most of us with an interest in medical ethics and Professor Edwards' careful description of the case and events surrounding it generated much discussion and acknowledgement of how difficult these decisions can be and the range of different perspectives that can be involved.

With our thoughts focussed on a practical dilemma, Heather Bradshaw from Bristol then took us through some of her empirical work on disability studies in medical ethics, challenging the traditional frameworks that are usually applied to ethical dilemmas in health care and suggesting that we need to look at different models to adequately engage with issues raised by the disability debate. In this spirit Professor Julian Savulescu, Director of the Uheiro Centre in Oxford, proposed a welfarist account of disability which views disability in terms of a reduction in well being caused by a combination of physical and psychological characteristics and external circumstances. Again this generated much discussion not least around the question of how we define or measure well being.

The afternoon session focussed on the experiences of people who have a disability and those caring for them. Dr Kevin Fitzpatrick from the University of Glamorgan talked about patient partnership and the need for patients to be empowered to take more responsibility for their health. This was followed by a very moving, and often humorous, account of caring for someone with a disability from Mr John Viner, a lay member of the Cardiff clinical ethics committee. The day concluded with a panel question and answer session involving many of the day's speakers during which some interesting thoughts and comments came from the delegates. Feedback from the conference has been very positive and constructive and we will take this forward to our preparations for 2011 in Glasgow. Congratulations and thanks go to Dr Wulf Stratling and his team in Cardiff for the incredible amount of effort and organisation they all put into the day. Wulf has negotiated with the Journal Clinical Ethics to produce a collection of papers based on the conference presentations for publication in the Journal in early 2011. The eleventh annual Network conference will be in Glasgow in June 2011. We will email further details in the coming months.

*Conference speakers taking part in the discussion panel*



## Train the trainers workshop

As many of you will know the Network's document on Core Competencies for Clinical Ethics Committees has been published in the Journal Clinical Medicine. This document, developed in collaboration with all CECs in the UK, sets out in broad terms what we as a Network think are the key knowledge, skills and attributes that a CEC should be able to demonstrate among its members. The Network Board of Trustees hope to build on this work to develop a suggested curriculum for training of CEC members and some preliminary work has already been done to this end. However the Network is not in a position to take on the role of training itself, at least in the short term, but is keen to facilitate training initiatives working with academic departments of ethics and others on the field to develop training opportunities for its members.

Regular readers of this newsletter will know that both the Ethox Centre, and more recently the clinical ethics group at Warwick Medical School have been active in the area of CEC education. The Warwick team are currently in the process of developing a suite of workshops to cover some of the areas of the core competencies document and are particularly interested in education of a cohort of trainers who can then take on the education of CEC members and health professionals more generally at a local and regional level.

As part of this work and in collaboration with UKCEN, a train the trainers workshop was piloted prior to the Cardiff Conference. The workshop was developed and run by Leah McClimans and Anne Slowther from Warwick and was funded by UKCEN. The workshop was free to members of CECs who were subscribers to UKCEN.

Twenty participants took part in a range of activities specifically designed for participants to take back to their CECs and use for in house training. Some of the materials and worksheets used in the workshop will be placed on the Network website in the near future. Feedback was very positive and we plan to develop the train the trainers programme further in the coming year.

The core competencies document can be found on the [website](#).



## Network website

In December 2009 the UKCEN Board of Trustees established a working group (Paul Gerrish, Martin Vernon, Anne Slowther and Sarah Barclay) to consider the future of the existing UKCEN website which is currently hosted by the Ethox Centre at University of Oxford. The working group was asked to explore options for development of the website and to address issues such as hosting the site, editorial responsibility, and collaboration with other groups in the field of clinical ethics. There was a recognition that the Network could not continue to rely on one academic department to develop and maintain the site for the Network and that there were opportunities for expanding and improving website services to Network members if UKCEN took more control.

As part of their investigations the working group conducted an online survey of the views of UKCEN members. The response rate was low but some tentative conclusions could be drawn from the findings. The current level of use of the website is variable with approximately 25% of respondents visiting once a month, 25% every 3 months and 50% rarely or not at all. There did seem a theme that respondents viewed the site as a source for "news" as an important function emphasising the need to ensure the site is regularly updated with current links and news. Respondents also thought there should be a closed section of the website accessible to members on a password basis for discussion forums and other member benefits.

The working group made a series of recommendations the Board of Trustees at its meeting on the 22<sup>nd</sup> June and the Board then presented a recommendation to the AGM on 23<sup>rd</sup> June that the Network should proceed to developing an independent website, building on the current content of the Network website but hosted and run by UKCEN either directly or through commissioning of specialist services such as web design. The working group will now take this forward and report back to the Board at its November meeting. So by the time we meet for the 2011 Annual Conference and AGM we would hope to be showcasing our new look website. Any suggestions for the website, or volunteers to be involved in its maintenance are welcome.



## Survey of clinical ethics services in the UK

In 2000 The Ethox Centre published a report on the provision of clinical ethics support in the UK. At that time there were twenty clinical ethics committees established in UK health care institutions, mainly in NHS Trusts. Since then the number of clinical ethics committees in the UK has risen to 87 with some hospitals also employing individual ethicists. In parallel to this development in the UK clinical ethics services have been developing in other European countries. The situation in the UK is now very different from that in 2000 and we currently have very little detailed knowledge of how clinical ethics committees in the UK are functioning. The clinical ethics team at Warwick are therefore conducting a survey in order to provide an up to date and accurate account of clinical ethics services in the UK. The findings will be used to inform the development of educational resources for CECs, models of evaluation, and support for further development of these services. We expect that you have all received a copy of the survey, and hopefully many of you have also completed it. Thank you to those who have and a plea to those who have not yet done so to try and find the time. Good information about CECs will help to persuade Trusts and policy makers that this is a service that can benefit the NHS, and help CECs to improve their service.



## Round robins

In April we had two round robin requests to the Network. Thank you to all those CECS who took time to respond. The queries and their responses have been circulated to CECs but are also reproduced here in case members have not seen them. We do not publish case discussions in the newsletter.

### 1. Electronic patient information boards

A Clinical Ethics Advisory Group had identified an issue in their hospitals with electronic patient information boards being displayed in publicly visible areas of wards. They asked whether any other CECs have had the same problem.

#### **Nine responses were received to this query**

Only one responding committee had experience of electronic patient information boards (in an Accident and Emergency Department). Six CECs had experience in their Trusts of white boards with patient information on display and one CEC had not discussed the issue and had no information about it. The views of committees regarding the acceptability of such information boards and the level of information on them were quite varied. Most committees reported the use of white boards in their Trust although fewer had electronic boards. Information on publicly accessible boards was generally limited to a minimum level, usually patient name (in one Trust the patient's first name was used and in others the patients' surname). The reason for this information being displayed in all cases was to allow staff and relatives to know where patients were. One CEC reported that their Trust had a policy that all boards are out of public view to preserve patient confidentiality. Two CECs reported that their Trusts had removed boards but then reinstated them because of confusion about patient location. However most CECs were clear that they thought only patient names should be displayed and no other personal information. One responder commented that any other information, for example infection risk, would be for the benefit of management and staff and not in the patients' best interest. One Trust sought patient consent for information to be displayed. The issue, as articulated succinctly by one responding CEC, is the balance between respecting patient confidentiality, patient safety and efficiency. Responses demonstrated a difference of opinion on how these competing interests should be weighed. Some responders considered that arguments for efficiency were legitimate only if related to assisting location of patients and revealed minimal information (patient name and location). Others argued that too much emphasis was placed on confidentiality at the expense of the need to use ward resources efficiently and protect patient safety.

Professional guidance and the law places great emphasis on respect for patient confidentiality, emphasising both the public and private interest in maintaining confidentiality. Any breach would need to be justified in the public interest. With respect to the use of display boards in public areas the Trust would need to demonstrate that there was a significant risk of serious harm to patients or others (either directly or indirectly due to resource implications of inefficiencies) that outweighed any harm to the patient from breach of confidentiality to justify the public display of patient related information. How these considerations are balanced will also depend on the context in which the display boards may be used. For example one CEC reported that boards were used in A&E Departments to note the time to breach of waiting time target but that on the infectious disease wards no display boards were used because of the concern about stigmatisation of patients identified as being on such a ward.

## 2. Case consultation procedures

A newly formed CEC sought information about how other CECs handle procedural issues regarding case consultation. Ten CECs responded to this query:

### a) Are the records of the discussion put in the patient's notes?

One responding CEC only considered anonymous retrospective cases so the issue of documenting the discussion on the patient notes did not apply. The other committees were evenly split in reporting two approaches. Some committees provide a written summary of the discussion to the referring clinician. How the clinician then handles the information may vary, for example two CECs do not explicitly request that the summary is recorded in the notes but one assumes it will be and the other assumes it will not be. Other committees request that the referring consultant place a copy in the notes. One committee responded to this question by setting its response in the context of the committee's role as an advisory body for clinicians. As the clinician was the decision maker the committee left the decision as to what extent the CEC consultation was recorded in the patient's notes to his or her discretion. However the clinician is asked to record the main points that they take away from the consultation in the notes. This committee documents case discussions in detailed minutes which are sent to clinical directors and to the Trust Clinical Governance and Quality Committee. A second group of committees record the summary of the case discussion directly in the patient's notes or by way of a letter to referring clinician which is then placed in the patient's notes.

*It is important to note that whether or not a summary of a CEC discussion of a current case is written in or lodged in the patient's notes it will still be considered as part of the patient record for the purposes of Access to Records and can be requested as evidence in legal proceedings.*

### b) Are patients with capacity shown a record of the discussion?

In general committees had little experience of discussing cases involving patients with capacity. Only one committee had a policy of asking the referring team to ensure that the patient knows the issue is going to be discussed and offers to speak to the patient and/or family if required. One committee undertook bedside consultations and in these cases the patient and/or their family is closely involved in the discussion.

### c) Do records include the full discussion or just the primary recommendations?

All committees who responded kept a record of the discussion for the committee records, as well as in some cases a record in the patient's notes. The level of detail appears to vary with some committees recording an outline or summary of the main points of discussion and the recommendations, some committees keeping a detailed record of the discussion but with no attribution to individual CEC members, and one CEC attributing comments or lines of argument to individual CEC members.

d) Is permission of the competent patient gained before referral to the CEC?

The responses to this question overlapped with those to question 2b. Most cases involve non competent patients. However several respondents commented that their committee would be prepared to take referrals from patients or family members although this rarely happened in practice. One CEC had experience of inviting family members to attend the discussion but no-one had accepted the invitation. Several responders viewed CEC consultations as similar to multidisciplinary team meetings or other types of clinical consultation. Thus they considered that patient consent for a consultation was not required but that the patient should be informed if a consultation was to or had taken place.

*The most recent GMC guidance on confidentiality (2009) specifically addresses the issue of sharing patient information for the benefit of individual patient care. Relevant extracts from the guiding principles include: 'You should make sure that information is readily available to patients explaining that, unless they object, their personal information may be disclosed for the sake of their own care and for local clinical audit. Patients usually understand that information about them has to be shared within the healthcare team to provide their care. But it is not always clear to patients that others who support the provision of care might also need to have access to their personal information.... You must inform patients about disclosures for purposes they would not reasonably expect, or check that they have already received information about such disclosures.'* (para 7)

*'When disclosing information about a patient, you must:*

*(a) use anonymised or coded information if practicable and if it will serve the purpose*

*(b) be satisfied that the patient:*

*(i) has ready access to information that explains that their personal information might be disclosed for the sake of their own care, or for local clinical audit, and that they can object, and*

*(ii) has not objected ' (para 9)*

*CECs may wish to consider whether patients in their Trust have access to information about the CEC and its role in considering case referrals, While personal data such as patient name is not normally disclosed in CEC referrals the nature of the case may be such that anonymity is not feasible.*

e) Are patients ever given the opportunity to put their views to the committee or is the CEC seen only as an advisory body for the clinical team?

Responses to this question varied. Most responding CECs see themselves primarily as advisors to the clinical team and therefore do not actively include patients and/or family members in the discussion. One CEC recommended an initial discussion with the team followed by a meeting with the patient's family to continue the discussion. Some CECs either consider case referrals from patients/family members or would be prepared to do so.

The response to these round robin queries was low with only ten CECS responding. However those that did respond gave considered and in some cases quite detailed responses. The range of CEC processes is considerable which is to be expected in the context of a UK system where there is no regulation or specific guidance on the role of clinical ethic support. The questions and responses to them highlight the importance of CECs clarifying their role and specific functions, justifying their processes and improving communication with patients and families regarding these processes.





## Ethics news

### **GMC publishes guidance on end of life care**

The GMC has launched new guidance for doctors on end of life decision making. [Treatment and care towards the end of life: good practice in decision making](#) came into effect on 1 July 2010 and replaces the booklet *Withholding and withdrawing life-prolonging treatments: Good practice in decision-making* (2002). The publication followed extensive public consultation and provides advice on a range of issues relating to end of life care including frameworks for decision making for people who have capacity and those who do not, the role of families, working in teams, dealing with uncertainty, emotional issues and resource constraints.

### **Director of Public Prosecutions publishes policy on prosecution for assisted suicide**

On the 25th February 2010 the DPP published a policy on assisted suicide. This was in response to a ruling by the House of Lords requiring him to clarify the position regarding prosecution in cases of assisted suicide. The policy sets out 16 factors in favour of prosecution and 6 against. The focus is on the motivation of the person assisting suicide. The policy is available on the [CPS website](#).

### **The Nuffield Council on Bioethics announces launch date for its report on the ethical issues of personalised health care.**

The Council will launch its report *Medical profiling and online medicine: The ethics of 'personalised' health care in a consumer age* on 12 October 2010 at a seminar in London. The report will identify the ethical values that are important when making decisions about interventions relating to a range of medical profiling and online medical services. More information is available from the [Nuffield Council's website](#)

### **Updates to the UK Clinical Ethics Network website**

The ethical issues pages of the website have been updated to reflect changes in the law, for example the implementation of the Mental Capacity Act, and in professional guidance. Recommended reading has also been updated. [UKCEN website](#)



## Dates for your Diary

### **September 2010**

Annual Intensive Course on Medical Ethics  
Imperial College London  
13<sup>th</sup> – 17<sup>th</sup> September 2010

### **October 2010**

Medicine Unboxed 2010 – Stories, Language and Medicine  
Cheltenham General Hospital  
11<sup>th</sup> October 2010

### **November 2010**

Ethics in Clinical Practice – Warwick Medical School Workshop  
University of Warwick  
1<sup>st</sup> and 2<sup>nd</sup> November 2010

### **May 2011**

7<sup>th</sup> International Conference on Clinical Ethics Consultation  
Amsterdam  
18<sup>th</sup> – 21<sup>st</sup> May 2011





## 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  
Royal Hospital for Sick Children

### North East

Newcastle Upon Tyne  
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  
Central Lancashire Teaching Hospitals NHS Trust  
Wirral Hospital NHS Trust

### Yorkshire and Humberside

Doncaster Royal Infirmary  
Hull and East Yorkshire Hospitals NHS Trust  
Leeds Teaching Hospitals  
Mid Yorkshire Hospitals NHS Trust  
Sheffield Children's Hospital NHS Trust  
Sheffield Teaching Hospitals Clinical Ethics Group

### Northern Ireland

Belfast Health and Social Care Trust  
Northern Ireland Hospice

### Wales

Abertawe Bro Morgannwg University Local Health Board  
Cardiff and Vale NHS Trust  
North East Wales 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  
University Hospitals of North Staffordshire

## **East Midlands**

Derby Hospitals NHS Foundation Trust  
Nottingham University Hospitals  
Nottinghamshire Healthcare NHS: Adult Mental Health Clinical Ethics Committee  
Nottinghamshire Healthcare NHS Learning Disabilities Service Advisory Group  
Sherwood Forest 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  
James Paget University Hospital NHS Foundation Trust  
Norfolk and Norwich University Hospital  
Princess Alexandra Hospital NHS Trust  
Peterborough Hospitals NHS Trust  
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  
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 Free Hospital  
Royal Hospital for Neurodisability  
St Christophers Hospice  
St Georges Hospital  
St Raphael's Hospice  
UCLH NHS Trust  
West Herts Clinical Ethics Committee  
Whittingham NHS Trust

## **South East**

Brighton and Sussex University Hospitals NHS Trust  
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**

University Hospitals Bristol NHS Foundation Trust  
Gloucestershire Hospitals  
Plymouth Health Community  
Royal Devon and Exeter Hospital  
Royal United Hospital NHS Trust  
Taunton and Somerset Hospital  
Yeovil District Hospital