

Irish Council for Bioethics
Comhairle Bitheitice na hÉireann

Minutes of Council Meeting
Thursday 13th September 2007

- In the Chair:** Dr Dolores Dooley
- Present:** Dr Alan Donnelly; Professor Andrew Green; Professor Linda Hogan; Dr Richard Hull; Dr Peter McKenna; Mr Asim Sheikh; Professor David Smith.
- Apologies for absence:** Professor John Vincent McLoughlin. Mr Stephen McMahon; Professor Cliona O'Farrelly; Dr Darina O'Flanagan; Professor Richard O'Kennedy;
- Also present:** Dr Siobhán O'Sullivan; Ms Emily de Grae; Dr Stephanie Dyke; Mr Paul Ivory

1. Minutes

The minutes of the previous meeting were adopted and signed.

2. Report from the Scientific Director

Dr O'Sullivan reported on the progress of the RTÉ radio series, explaining that the series would be launched, with the first town hall meeting, on Monday 24th September in the RTÉ studios. Dr O'Sullivan confirmed that the locations for the remaining town hall meetings would be Athlone, Castlebar, Ennis, Letterkenny and Waterford. Council members were informed that they would be invited to each of the meetings and it was hoped that at least some of them would be able to attend these events. Dr O'Sullivan stated that, the first programme in the series would be discussing the ethics of human enhancement, with the remaining topics being euthanasia, organ donation, forensic DNA databases, environmental ethics and stem cell research. Dr O'Sullivan noted that RTÉ had been coordinating the recruitment of the panelists for each of the meetings and these individuals would be drawn from both Ireland and abroad. Dr. O'Sullivan stated that full details of each of the town hall meetings and the panelists involved would be sent to Council members as soon as they were available.

Dr O'Sullivan reported that a winning playwright had been chosen for the ICB's National Playwriting Competition. The winner was Mr Paul Meade, an up and coming playwright and the co-director of the *Gúna Nua* production company. Dr O'Sullivan informed the Council that the first draft of Mr Meade's play was due to be sent to the secretariat on Friday 14th September. The play will consist of 3 separate acts each discussing a different bioethical topic, saviour siblings, assisted suicide and *in vitro* fertilisation (IVF).

Dr O'Sullivan was hopeful that a staged reading of the play would take place in Farmleigh House during the first week of February 2008.

Dr O'Sullivan confirmed that the ICB's policy conference on Environmental Ethics would be taking place on Tuesday 9th October 2007, in the RDS. Dr O'Sullivan stated that the presentations would be made available as podcasts on the ICB website. In addition, it was noted that transcripts would be made of the question and answer sessions following each presentation, which would be included in the final conference proceedings.

Dr O'Sullivan informed the Council that the Department of Health and Children, had established a steering committee in order to draft a paper on the ethical of avian influenza pandemic planning. The ICB will be represented on the steering group.

Dr O'Sullivan stated that the Council meeting in December had been moved from Thursday 6th to Wednesday the 5th. In addition, this would be an afternoon meeting followed by dinner.

3. Correspondence - Submission from Medical Council on Stem Cell Research

Dr O'Sullivan acknowledged the submission the ICB had received from the Medical Council as part of the consultation process for the ICB's report on stem cell research.

4. Submission to Medical Council from ICB on the revision of "A Guide to Ethical Conduct and Behaviour"

Dr O'Sullivan informed the Council that the ICB had been formally invited to make a submission to the Medical Council regarding their own review of their document, "A Guide to Ethical Conduct and Behaviour". Dr O'Sullivan and Dr Dooley asked for the Council's views on the submission they had drafted to be sent to the Medical Council. Council members acknowledged the importance of this opportunity for the ICB to highlight specific issues relating to bioethics that they felt should be addressed or expanded upon in the new edition of the Medical Council's guide. The Council were happy with the submission overall, but recommended that the statement relating to the refusal of medical treatment by a competent individual in an advance healthcare directive should be modified slightly. It was agreed that further explanation was required regarding the determination of competence in making such treatment decisions and that the statement should refer specifically to such treatment decisions made by adults. Dr O'Sullivan agreed to make the necessary revisions before the final submission would be made to the Medical Council.

5. Invitation from Department of Health and Children to make a submission on Human Tissue Act

Dr O'Sullivan reported that the ICB had been formally invited to make a submission to the Department of Health and Children relating to the proposed Human Tissue legislation. The Council were of the opinion that the ICB should make a submission reiterating some of the specific recommendations made in the ICB's report on Human Biological Material, which itself was related to international best practice in this area.

6. Submissions on the New ICB Work Programme

Dr Dooley introduced the discussion regarding the potential topics to be covered in the ICB's work programme for 2008. The topics proposed by both Council members and the secretariat were: Climate Change; Alternative Energy Sources; The ethics and law of Human Enhancement; Biobanking; Organ Donation; Genetic Predictive Testing for Employment/Insurance; Scientific Misconduct; Ethical Challenges in Academic/Industry Collaboration; Biometrics; and a Deliberative Conference.

Dr Dooley reiterated that a number of criteria needed to be taken into account in the final decision on the topic to be covered. These criteria were as follows:

- The topic should be discreet with a limited number of stakeholders
- The stakeholder meetings and the final report can be completed in 12-14 months
- The topic offered maximum "Add-on" value in the context of Irish policy making
- The topic involved novel, emerging issues, which are forward looking.

Following a roundtable discussion of the merits of each of the proposed topics, with particular reference to the criteria outlined above, the Council agreed that Biometrics would be the next topic covered in the ICB work programme. Furthermore, it was agreed that the stakeholder consultation process for the biometrics report should begin in November 2007 to ensure it is completed before the end of the year.

7. Any Other Business

Dr Dooley, Dr McKenna and Dr Sheikh reported on their meeting with the Law Reform Commission (LRC) on behalf of the Council. The LRC expressed an interest in collaborating with the ICB on projects of mutual interest in the future. The Council welcomed the opportunity of co-operating with the LRC in the future.

Dr O'Sullivan informed Council members that incorporation of the ICB would proceed in the next month, as all outstanding employment issues pertaining to the secretariat had been satisfactorily resolved.

8. Joint Meeting with the Norwegian Bioethics Committee

Dr Dooley welcomed the members and secretariat of the Regional Committee for Medical Research Ethics for Central Norway. Professor Arne Sandvik (Chair) and Professor Anna Bofin (Vice Chair) of the Regional Committee thanked the ICB for hosting this meeting with them.

Dr Dooley proceeded to give an overview of the terms of reference and the role of the ICB. Dr Dooley provided an overview of each of the reports and opinion documents that the ICB has produced thus far. In addition, Dr. Dolley outlined the various aspects of public outreach work that the ICB conducts. Professor Bofin gave an overview of the work of medical research ethics committees, particularly regional committees, in Norway as well as the national regulations and procedures in place relating to their operation.

This was followed by a roundtable discussion covering details relating to the work of the ICB and the Norwegian Committee, including a comparison of the work of research

ethics committees in Ireland and Norway. The view was expressed on all sides that the meeting had been very informative and that it would be beneficial for all involved to keep the channels of communication open.

9. Date of Next Meeting

Thursday 18th October. Venue to be confirmed.