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## **The Ethox Centre**

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## **1. Introduction**

The Ethox Centre is a multidisciplinary bioethics research centre in the Department of Public Health in the Medical Sciences Division of the University of Oxford. The Centre has its origins in the Oxford Practice Skills Project which piloted and evaluated the development of ethics teaching for medical students in Oxford between 1990 and 1994. This led to the publication of the Oxford Practice Skills Course by Oxford University Press in 1996 and to the creation of the first substantive post in medical ethics in Oxford in 1997. The Centre was formally established in 1998 under the directorship of Tony Hope, and was complemented by the creation, in the same year, of the Ethox Foundation – a charity established to support the work of the Ethox Centre. Michael Parker, who joined the Centre early in 1999, has been the Centre's director since January 2004. Ethox currently has a staff of around twenty researchers, administrators and doctoral students.

## **2. Aims and Approach**

The Ethox Centre aims to improve ethical standards in healthcare practice and in medical research in the United Kingdom and internationally. It does this through education, ethics research and ethics support for health professionals and medical researchers. The Centre aims, in all its activities, to be close to practice and seeks to engage with ethical issues faced by real world actors in real world settings. One implication of this is that the Centre places particular value on approaches – bringing together empirical research with rigorous ethical analysis. The Centre's focus on the improvement of ethical standards in healthcare practice and medical research means that it also places a great deal of importance on the provision of ethics support for health professionals and researchers; the development of policy and of models of good practice; and the provision of ethics training and education. These activities rarely if ever take anything approximating a linear form, running from “problem” through research to “solution.” There are many possible routes such journeys can and do take. Furthermore, while taking the view that there is particular value in bringing together empirical research with ethical analysis, Ethox does not seek to have an agreed position on the form such research should take. Indeed, the methodological and theoretical implications of engaging seriously with the relationships between empirical research and ethical analysis are a productive source of debate within the Centre.

The Centre increasingly aims to take a global perspective in all its activities and has a particularly strong interest in the ethics of collaborative global health research – bringing together research actors in developed and developing countries.

## **3. Activities and Themes**

The Centre's activities focus on education, ethics support and research. These activities are interdependent and there is no clear distinction between them.

### **3.1 Education**

Ethox provides teaching to all of the medical students passing through Oxford Medical School. This teaching is carried out in small groups to facilitate discussion and reflection. Its content is based largely on that described in *Medical Ethics and Law: The Core Curriculum* (Hope, Savulescu and Hendrick, 2008, 2nd edition). The teaching materials used are freely available on the Ethox Centre's website. The Centre also runs an ethics module on the Department's successful MSc in Global Health Science and contributes to the Global Health Summer School.

Ethox also provides ethics teaching for practising health professionals and medical researchers. This has included teaching in areas such as: clinical genetics, reproductive medicine, cardiology, anaesthetics, resuscitation, psychiatry, intensive care, emergency medicine, infectious diseases, and primary care. As a result of the growing interest in ethics training among researchers outside the Medical Sciences Division, the Ethox Centre has also – together with other bioethics centres in Oxford – established the Oxford Bioethics Network to develop and coordinate the teaching of ethics to researchers across the University (<http://oxbionet.medsci.ox.ac.uk>). The Network is co-ordinated by Karen Melham.

### **3.2 Ethics Support**

The Ethox Centre has a long-standing interest in the development of innovative forms of support to help health professionals with the ethical problems arising in their day-to-day practice. In 2001, an Ethox research project funded by the Nuffield Trust reviewed the current position and likely development of clinical ethics support in the UK. The subsequent report identified a small number of UK hospital trusts with existing forms of clinical ethics support, but also a very much larger unmet need among health professionals who said that they would find such support of value were it to become available. Shortly afterwards, with the support of the Ethox Foundation, Anne Slowther and Tony Hope established the UK Clinical Ethics Network: to support the development of clinical ethics provision in the UK; and to provide support and training to the members of existing clinical ethics committees and those thinking of establishing them. Since its establishment the UK Clinical Ethics Network has flourished and there are now more than ninety clinical ethics committees in the United Kingdom. In 2007 the Network became an independent charity. Support for the Network is now provided jointly by the Ethox Centre and Warwick Medical School. These activities are led by Anne Slowther and are funded by the Ethox Foundation.

In addition to its work with clinical ethics committees, the Ethox team provides ethics support directly to health professionals locally and nationally. An example of this is the Genethics Club: a national forum for genetics professionals, including nurses, counsellors, geneticists, and laboratory staff to present and discuss ethical issues arising in their day-to-day practice and to share models of good practice ([www.genethicsclub.org](http://www.genethicsclub.org)). Since its establishment in 2001, the Genethics Club has met twenty-three times and has discussed more than 200 cases. The Ethox Centre also provides ethics support for a wide-range of medical researchers. Much of this takes place within the context of the collaborative research projects described below.

### **3.3 Research**

The Centre has three broad areas of research interest: clinical ethics, research ethics and global health.

#### *3.3.1 Clinical Ethics*

From the beginning, Ethox has had a strong research interest in ethical issues arising in healthcare practice. In the area of mental health and neuroscience, Tony Hope, Jacinta Tan, Ray Fitzpatrick and Anne Stewart are carrying out research on competence and treatment decision-making in Anorexia Nervosa – bringing together empirical research on the experiences, decision-making and views of patients and their parents, with ethical analyses. Tony Hope is also carrying out research with Clive Baldwin at Bradford University on the ethical dilemmas arising for family carers of patients with Alzheimer's Disease. Dominic Wilkinson is investigating the ethical issues generated by the use of imaging technologies such as MRI in end of life decision-making in neonates. Virginia Bovell is exploring the ethics of treatments for autism, and Carolyn April has recently completed research on the implications of neuroscience for moral decision-making. In the area of genetics, Michael Parker is carrying out research into the ethical problems faced by genetics professionals in their day-to-day practice, such as in the sharing of family information, misattributed paternity, and the genetic testing of children and young people. With Anneke Lucassen in Southampton and Nina Hallowell in Edinburgh, he is investigating ethical issues arising out of the close relationship between clinical practice and research in cancer genetics. In the area of health and social care, Michael Dunn is leading the development of a new programme of research activities exploring ethical issues in the care and treatment of “vulnerable adults.” This programme is funded by the Ethox Foundation.

#### *3.3.2 Research Ethics*

From 2002 to 2006 Ethox was a partner in the Oxford Genetics Knowledge Park, which supported a programme of “translational” research in genetics (with a particular focus on cardiovascular disorders associated with the risk of sudden death). Ethics research carried out within the GKP by Ethox included research on the ethical review of research on rare inherited disorders; research on the testing of children and young people for inherited cardiac conditions; and research on the issues presented by the development of genetics databases. The connections created by the Genetics Knowledge Park have led to a number of subsequent research collaborations with scientists. In the area of genomics, Jane Kaye, Sue Gibbons, Catherine Heeney, Andrew Smart and Michael Parker are carrying out research on the ethical, legal and social aspects of the governance of genetic databases. As part of the Procardis network, Paula Boddington is investigating the ethical issues presented by translational genomics research on early onset coronary artery disease. As part of the EU-funded IBDChip network, Catherine Heeney and Michael Parker are exploring the ethics of research collaboration, in the context of genomic research, to develop chip technology for prognostic testing of patients with inflammatory bowel disease. More broadly, Michael Parker and Lindsey Brown, with Mary Dixon-Woods at Leicester University, are completing empirical research on the views of patients, health professionals and researchers about the use of medical records for research. Mark Sheehen is developing a new programme of ethics research exploring the ethical issues arising in the research of the new Oxford Biomedical Research Centre. Jane

Kaye, Liam Curren, Nadja Kanellopoulou and Heather Gowans are developing regulatory models for the giving and revoking of consent to the use of personal data for research. Naomi Hawkins is carrying out legal research on the implications of patents for genetic research and practice.

### *3.3.3 Global Health Ethics*

Ethox leads the ethics programme of the Malaria Genomic Epidemiology Network (MalariaGEN) – a partnership of malaria researchers in over twenty countries supported by the Bill and Melinda Gates Foundation and the Wellcome Trust through the Grand Challenges in Global Health initiative. MalariaGEN investigators are using a range of genetic epidemiological approaches to investigate mechanisms of protective immunity against malaria as part of the global effort to develop an effective malaria vaccine. Michael Parker, Susan Bull and Jantina de Vries, have provided ethics support and advice to partners, including site visits and ethics training workshops in Mali, Kenya, Vietnam, Thailand, and Ghana. They have led the development of an informed consent template, a data-release policy and mechanism for the Network, and are also carrying out a number of longer term research projects on ethical issues facing the Network. Susan Bull is carrying out research on models for the assessment and evaluation of consent processes using Mali and Ghana as case studies. Jantina de Vries is investigating the ethical issues arising in the collection, storage and use of ethnicity data using Kenya and The Gambia as case studies. Michael Parker is carrying out research on the ethics of research collaboration in the context of collaborative global health research. Other Ethox researchers focussing on global health include Geoffrey Lairumbi, who is carrying out research in Nairobi on benefit-sharing and social value in collaborative research; Vicki Marsh, who is investigating understandings of sickle cell screening in the context of genome-wide association studies in Kenya; and Aisha Malik, who is carrying out research on the ethical issues arising for health professionals in Pakistan.

In 2008, Ethox was awarded a Wellcome Trust Enhancement Award to establish an international research network on the ethics of collaborative global health research. The Network, which is a collaboration with Sassy Molyneux's group at the Wellcome-KEMRI Unit in Kilifi, Kenya, will build ethics expertise and capacity both in the United Kingdom and in developing countries. The research activities of the network will focus on: community engagement; global ethics governance; the ethics of research collaboration; and, the roles and responsibilities of research actors. The Award will fund DPhil studentships, the development of on-line resources and a range of training activities. The first Studentship has been awarded to Paulina Tindana from Ghana, who will investigate the ethical issues arising in the export and storage of biological samples from Africa for collaborative research.

## **4. More Information**

The Ethox Centre has a rich research culture, including visiting researchers, research seminars and on-going collaborative writing groups on a wide range of topics. More information about the Ethox Centre's activities, publications and sources of research funding can be found on the Centre's website at <http://www.ethox.org.uk/>, or by contacting Andrew Cooper or Susan Barrington – the Centre's administrator and secretary.