

## Imperial Ethics Newsletter

Newsletter of the Medical Ethics Unit, Imperial College London  
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### Editorial

**Dr Richard Ashcroft**

Life in the Medical Ethics Unit at Imperial College London continues to be exciting. We have new projects to tell you about, as well as information about the various visits Unit staff have made recently to other centres worldwide and the visitors we have been welcoming. It is great to be part of a truly international network of scholars and scientists!



In line with most research groups in the UK, we are reviewing our strategy in the light of the forthcoming Research Assessment Exercise. The RAE is the UK higher education sector's way of making sure all our beautiful thoughts and practical achievements actually get reported and disseminated. Attractive as this may be in principle, it has some strange consequences in practice, since "applied ethics" falls down a lot of the cracks between "panels" assessing research activity. One useful consequence of the RAE, however, is that it forces us to think about what we are really good at, and really passionate about (I hope these are the same things...).

In future, the Medical Ethics Unit will be structuring its activity around three main research areas: Psychiatry and the Neurosciences; Clinical Genetics and Genetic Research; and Public and International Health. Piers Benn is leading on psychiatric ethics, and is developing research on psychopathy and dangerousness in the light of the UK's mental health law reforms and developments in the neurosciences and psychiatric research and practice. Ainsley Newson is leading on ethics in genetics, and is continuing to develop her work on clinical ethics in clinical genetics, as well as her long-standing interests in the ethical aspects of the genetics of complex disease. I am developing a programme of work on ethical issues in international health, with a particular emphasis on the challenges posed by HIV/AIDS.

In the midst of this focus on research, we are not losing sight of our teaching, and are also taking part in a number of initiatives in the research community and public life – from membership of various committees, to contributing to the debate on asylum seekers' healthcare, to assessing the merits of banning of smoking in public places. Ethics is not a purely academic pursuit, and does not always bend easily to fit auditors' categories – but it should always be interesting and, we hope, practical. ■

Richard Ashcroft  
June 2005



## Clinical Ethics Problem

### The Scientific Use of the Imagination: Disclosing Delicate Information and the Role of Relatives in Decision-making?

Daniel Sokol

#### A Case Scenario

Yellowing skin and a complaint of fatigue accompanied the smile and sparkling eyes of the 70-year-old Greek matron. Through her family translator, she asked: "Should we try chemotherapy?"[1].

She had been told about her pancreatic cancer when it was discovered a month earlier at the hospital emergency department. However, when liver metastases were found on laparotomy (a surgical incision into the abdomen), the surgeon complied with her family's wishes and did not inform her of the metastases. Her family asked that I, too, not tell her about the metastases. They said, "she will give up hope" and "this is how the doctors do things in Greece." The patient's family seemed to have her best interests at heart, and they believed that she would not want to know.

*How can I determine what the patient really wants? What should I tell her?*

#### Commentary

Doctors, in many ways, are like detectives. Most obviously, they investigate the patients' symptoms in search of a diagnosis, eliminating options that do not match the evidence. Once identified, the diagnosis can further enlighten the quest for a treatment. Gathering all the facts, the doctor/detective can then predict with some accuracy the future course of events. We should not be surprised, perhaps, that Arthur Conan Doyle, himself a general practitioner, based the celebrated Sherlock Holmes on a real-life doctor.

There is another way in which doctors resemble detectives, reflected in the scenario's first question: "How can I determine what the patient really wants?". Osler pointed out that people "cannot be dealt with as man deals in corn and coal." [2] Although the location of the liver seldom changes, a patient's beliefs and character are unique. In the context of medical disclosure, the doctor needs to find out how much each individual patient wants to know. The GMC also recognises the changing nature of information-giving: "The amount of information you give each patient will vary, according to factors such as [...] the patient's own wishes". [3]

In this scenario, there is conflicting evidence. The family invoked three reasons to support their position:

1. She would give up hope
2. Non-disclosure is the norm in Greece
3. She would not want to know

The second reason can be quickly dismissed. The prevalence of a practice does not, in itself, make it right. To use a worn example, the observation that most people owned slaves in 17th century Virginia does not mean slavery was morally right in 17th century Virginia (although it may have been widely *regarded* as such), unless one adheres to certain forms of moral relativism.

The first reason is compelling, although many staunch truth-tellers would question the epistemological basis of the claim. "How can we know?" they might ask. Indeed, we can never know *for certain* how people will react to bad news. The patient may already know about her grim prognosis, or she may not know and, when told, decide to make the most of her remaining time or, as the relatives fear, she could give up and sink into depression. Yet, in my view, this uncertainty alone is not a strong case for disclosure. Likelihoods can be balanced against each other. In the absence of any additional evidence, a close relative's genuine belief in a loved one's anticipated response is preferable to guesswork. The presumption in favour of a patient's desire to know should be no more than a presumption. Of course, one needs to ascertain whether the relative's belief is genuine and, if so, if it is based on valid reasoning. This is why it is crucial for the doctor to discuss the issue at length with the family. In practice, the hard-nosed position on disclosure is not followed as strictly as the regulations require. Doctors do occasionally respect relatives' wishes not to disclose certain information to patients. I do not believe such violations are always wrong.

Is it a doctor's duty to maintain or enhance hope? This is a thorny question. I am inclined to say no, or at least to qualify the duty as a *prima facie* one. A doctor's duty is to act in what he believes is in the patient's best interests and this often requires some hope to be maintained. A doctor who coldly 'dumps' the truth onto patients is guilty of an

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unfeeling heart. There is, after all, an important psychological component to well-being. Yet there are times when maintaining hope (at least hope in *survival* or hope in a certain *quality of life*) can be devastating to the patient's well-being. In such cases, the doctor's duty is to extinguish that harmful, misplaced hope and replace it with more realistic expectations. Discerning the variable point when the duty to maintain hope erodes the weightier duty of beneficence is a matter of judgement.

While the first reason appeals to a doctor's duty to avoid causing net harm, the third reason appeals to the duty to respect the patient's autonomy. The GMC states that patients have a right to full information about their condition. A right to full information, however, does not entail a *duty* to be fully informed. The correlative duty deriving from the right is the doctor's 'duty to inform' and its precise nature is partly guided by the patient's desire. A patient may autonomously decide *not* to know the grim details of his condition. Without asking the patient, it is difficult to know how much information a patient wants. In consultations, doctors have exploratory strategies to unearth the informational needs of patients (such as asking open questions and using subtle cues). In this case, the patient clearly wants to know about her treatment options. Her direct question - "Should we try chemotherapy?" - indicates a) that she probably isn't aware of the severity of her condition and b) that she wants to get better or, at least, live longer. Her question severely undermines the validity of the family's third reason.

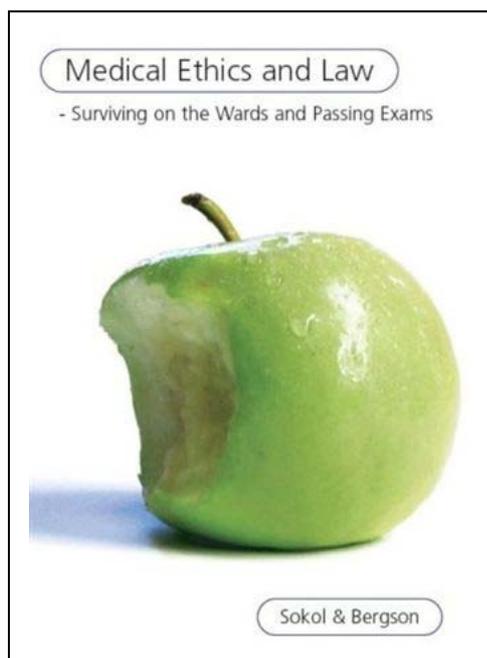
It appears, then, that the Greek matron *does* want to know more than she currently does. Respecting her autonomy would entail giving her a better idea of her condition. Is there a way to avoid the conflict between the duty not to harm

and the duty to disclose relevant information? One solution would be to offer her the *choice* of either making her own decisions regarding treatment or delegating the decision-making to her family (or indeed neither, leaving the doctor to decide). Whatever her preference, the doctor could ask her *how informed* she wants to be. This second question is routinely asked by some oncologists and palliative care doctors. The answers to these questions will provide valuable clues for the doctor's evaluation of what is in the patient's best interests. An affirmative answer to the first question and a desire to be 'fully' informed would weigh heavily in favour of disclosure, even in the knowledge that respecting her wishes may lower her spirits. In light of her self-asserted desire to know, it would be unlikely that sharing the news (in a compassionate manner) would sink her spirits below the threshold of her best interests. As Holmes declared, "we balance probabilities and choose the most likely. It is the scientific use of the imagination." [4]. ■

#### References:

- [1] Cochella, S. Pedersen, D. Negotiating a request for non-disclosure. *American Family Physician* 67 (1), 2003.
- [2] Osler W. On the educational value of the medical society. In: *Aequanimitas with other addresses to Medical Students, Nurses & Practitioners of Medicine*. 3rd ed. Philadelphia. PA:Blakiston, 1932.
- [3] GMC. Seeking patients' consent: the ethical considerations, 1998. Available at: <http://www.gmc-uk.org/standards/consent.htm> (9/5/05).
- [4] Conan Doyle A. The hound of the Baskervilles. In: *The complete Sherlock Holmes*. New Lanark: Midpoint Press, 2001.

Daniel Sokol



## Medical Ethics and Law

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## Visits and Visitors!

The Medical Ethics Unit has been busy of late, travelling and receiving visitors. Last year we were visited by:

- Professor Florencia Luna  
FLACSO, Buenos Aires, Argentina;  
President of the International Association of Bioethics
- Professor Charles Weijer  
Bioethics, Dalhousie University, Canada
- Dr Minou Friele  
European Academy for Interdisciplinary  
Technology Assessment, Bad Neuenahr-  
Ahrweiler, Germany.

We bade a fond farewell to Angela Ballantyne, our visiting PhD student from Monash University, Melbourne Australia, who is currently at the World Health Organisation working on genetics policy.

Piers, Ainsley and Richard spent an invigorating few days at the Sydney International Association of Bioethics 7<sup>th</sup> World Congress in November.

Between mid-January and early April, Richard was a Visiting Fellow at the ARC Centre for Applied Philosophy and Public Ethics (CAPPE) at the University of Melbourne, travelling on an Australian Bicentennial Fellowship. Thanks to the Fellowship Trustees, and to Assoc. Prof. Janna Thompson and her colleagues for looking after him so well! During his stay in Australia, Richard was working on rationality in ethics, and on the relationship between beneficence and justice in allocating treatment for HIV/AIDS in resource poor settings. He presented papers at the Institute of

Molecular Bioscience and at the School of Population Health at the University of Queensland (Brisbane), the Department of History and Philosophy of Science, Sydney University, the Ethics Centre of South Australia at Flinders University (Adelaide), and at CAPPE and at the Murdoch Children's Research Institute in Melbourne.

Since Richard's return in April, we have hosted a lecture by Dr Justin Oakley, Monash University Centre for Human Bioethics, on the ethics of reporting individual surgeons' performance data (jointly with the Division of Surgery, Anaesthesia and Intensive Care). We have also welcomed Dr Rachel Ankeny (HPS, Sydney University), Dr Mal Parker (Medical Ethics, University of Queensland), Prof. Anton van Niekerk (Philosophy, Stellenbosch University, South Africa), Dr Nancy Olivieri (University of Toronto), Dr Adam Hedgecoe (Sussex University), Dr Richard Huxtable (Bristol University), Prof. David Taylor (University of London School of Pharmacy), Prof. Steve Humphries (Cardiovascular Genetics, UCL), and Prof. Tony Hope (ETHOX Centre, Oxford University). Later in the year we will be welcoming Prof. Florencia Luna again, as well as Dr David Neil (Philosophy, University of Wollongong, New South Wales) and David Hunter (Massey University, New Zealand). In July Richard is visiting the University of Cape Town to act as a visiting lecturer in their research ethics diploma programme. ■

## Unit Project Summary

### Hybrids: Towards a New Typology of Beings and Animal Products

*Over the past couple of years, Richard Ashcroft has been working with a designer, Elio Caccavale, on a project exploring the ethical and aesthetic questions arising out of animal-human and animal-animal hybrids. The initial collaboration was on Elio's Royal College of Art MA dissertation on xenotransplantation, which looked at the ideas surrounding keeping genetically modified pigs as almost members of the family to insure against the possible future need for xenotransplanted organs. This project explored ideas of the pet, the human/animal distinction, and protecting one's health against future threats. In the current project, Elio and Richard had Wellcome Trust funding under its Public Engagement programme to develop these ideas through workshops involving design with medical students, and an exhibition of design products exploring children's responses to animal biotechnology at the University of London Institute of Education in collaboration with Prof. Michael Reiss. We are currently exploring a collaboration with Prof. Anthony Dunne (Royal College of Art). ■*

On Tuesday May 31 2005, the widow of a man who had died of lung cancer lost her long-running legal battle with Imperial Tobacco. Margaret McTear had claimed that the company was responsible for her husband's death. However the judge found that Mr McTear's death could not be attributed to his lack of knowledge of the links between tobacco and lung disease: he had chosen to smoke despite being aware of these dangers. [1]

This ruling will come as an immense relief to all tobacco companies, as it would have set a worrying - and expensive - precedent for them (Mrs McTear was suing for £500, 000). The ruling also demonstrates what has become more and more evident in recent years: it is no longer possible to claim ignorance of the fact that cigarette smoking is bad for you. Information on the evils of cigarettes is all-pervasive. The government has prevailed upon us to be aware of the dangers of smoking, and having done so, allows us the free exercise of our informed choice.

But this is not the whole story; in fact, the free exercise of choice for smokers is being inexorably eroded. Bans have been set on smoking in public places in Ireland and Scotland, and England looks set to follow. Many hospitals and workplaces have declared themselves smoke free zones, and staff and patients alike are obliged to sneak outside to indulge their habit. So why are these new measures necessary in the face of the very successful education of the public as to the adverse effects of smoking? Is smoking really as villainous as these measures imply?

After all, though we know that smoking is risky, those risks are a matter of open knowledge. If an adult makes an informed choice to smoke cigarettes – as did Mr McTear – why should we try to stop him/her, any more than we tried to stop Ellen MacArthur from sailing round the world, or Robert Scott from taking lethal his journey to the Antarctic? If we think that these people's choices – even if they are risky – ought to be respected, why should smokers' informed acceptance of risk be regarded so unfavourably?

The obvious answer to this is that smokers impose risks on others as well as themselves. It is often argued that those who work in pubs and other smoky venues are unfairly exposed to the risks of passive smoking. However, similar arguments might apply to staff in many environments: pub workers might find they are more likely to be attacked by drunken punters, or psychiatric nurses by violent patients. Most working environments have their hazards to a greater or lesser degree, and where these are thought by the employee to

outweigh the benefits of the job, they look elsewhere.

Conceding, however, that smoking *does* impose risks on others, it is relevant to consider the fact that most of us frequently indulge in behaviour whose risks threaten others' safety or wellbeing, as well as our own. Driving cars is one instance of our willingness to do this. Driving involves not only danger to oneself and others in terms of the chance of crashing; it also imposes a long term harm on drivers and non-drivers alike through the emissions which spew into the air, and fill our lungs. Generally, people do not feel concerned enough about these dangers to vilify cars or their drivers. Instead, we as a society accept the danger as a reasonable pay-off for the convenience of being able to get to where we want to go. Alcohol consumption is another instance of risky behaviour. It may cause people to crash their cars, lose their inhibitions, or to become so fixated that they lose jobs, homes and families and end up fuddled and reeking on street corners. Alcohol is also a factor in a huge proportion of crimes. According to a recent home office document[3], in one year alone, approximately 1.2 million episodes of alcohol-related violence occur.

So far, I have failed to find anything about smoking that makes it more obviously unacceptable than other behaviours such as drinking, driving, or taking part in extreme sports. In all these, risks are voluntarily accepted by those who enjoy these activities, but are also imposed on others, just as is the case with smoking. Yet as is evident from the media, smokers' freedoms are being encroached upon more and more: we are hounding them out of existence.

Could it be, simply that we don't feel that smoking is *virtuous*, and that this is what makes it less acceptable than other activities? After all, even though extreme sports players may take risks and impose them on others, we may see something noble in their endeavours. And drinking alcohol – while perhaps not noble – has been said to be good for the health in moderation. Driving cars, while neither noble nor good for the health, is not generally regarded a *vice* in the way that smoking is. Smoking – and smokers – are seen as weak-willed, selfish and self-indulgent.

However, that does not necessarily mean that they should be vilified. As vices go, smoking seems to me a fairly moderate one. I have no objection to the thought that there might be places where smokers can go and indulge their vice: I might not choose to frequent those places, but that is surely no reason

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to prevent other people from doing so. Similarly, if patients in hospitals have a dying wish for a cigarette, can it really be compassionate to refuse them the opportunity to be wheeled into a smoking room? It seems to me that our attitudes have become skewed. If smoking is a crime, then it should be punished. However, until we are willing to say that it is a crime, it seems self-righteous and obtrusive to adopt the kind of punitive attitude that is prevailing in our current climate. ■

[1]<http://news.bbc.co.uk/1/hi/scotland/4593571.stm> (accessed 2 June 2005)

[2][http://news.bbc.co.uk/2/hi/uk\\_news/england/north\\_york\\_shire/4232245.stm](http://news.bbc.co.uk/2/hi/uk_news/england/north_york_shire/4232245.stm) (accessed 2 June 2005)

[3]<http://www.homeoffice.gov.uk/crime/alcoholrelatedcrime/> (accessed 2 June 2005)

Anna Smajdor

*Editor's Note:*

*The issue of banning smoking in public is controversial! For an opposed perspective on this issue, readers may like to read the chapter on ethics and civil liberties in the forthcoming Royal College of Physician's report on passive smoking, written by another member of the Unit. Opinion within the Unit is divided on this question. One crucial question here is whether public policy should be consistent when it comes to questions of risk and liberties. What appears to some to be inconsistency may to others be simply a matter of weighing the relevant reasons differently under the different circumstances applying in different policy contexts. ■*

## Biography

**Dr Paquita de Zulueta**



I am a part-time general practitioner in a large West London teaching and training practice, and have worked as an 'inner city' GP since 1984.

I was made a fellow of the Royal college of GP's last year. Since 2001, I have been an honorary senior

clinical lecturer at Imperial College (having been a clinical lecturer from 1990). I took a masters degree at King's college in medical ethics and law in 1993.

I teach a diverse range of topics on the Medical Ethics MSc at Imperial College, including narrative ethics, confidentiality, pre-natal screening, and abortion. I have taught medical ethics and law to undergraduates and postgraduates since 1993, and am a personal tutor for some of the IC undergraduates.

I am chair of the Health Care Ethics Forum, a small multi-disciplinary group that broadly aims to explore and expose norms, practices and policies that threaten or erode ethical and humane clinical practice. Membership is free and is open to all. As programme director of the Health Care Ethics Forum, I organised - in collaboration with the professional development unit at Imperial College - two successful conferences:

- *Body Parts for Sale* (April 2004) – the ethics of live organ donation, infertility treatment and embryo research.
- *Exploiting the Dead?* (April 2005) – The use of human cadavers for research, teaching and spare body parts.

I have acted over the years as a GP member of the St Mary's Trust Clinical Ethics Committee, and on two research ethics committees. I have written papers and undertaken research on antenatal HIV testing as well as role models in undergraduate medicine.

I am currently writing a book entitled *Everyday Ethics in General Practice – a case-based approach* (Blackwell) with Professor Brian Hurwitz, and a chapter entitled Truth, Trust and the Therapeutic Relationship for A Reader in Primary Care Ethics (Radcliffe publications. Editors John Spicer and Deborah Bowman). I am also writing up other articles on informed consent and testing for HIV in pregnancy, use of the recently dead cadaver for teaching purposes and others.

I am on the editorial board of The New Generalist, the magazine of the Royal College of GP's and peer review for the Journal of Medical Ethics, Family Practice and the British Journal of General Practice.

My interests include narrative ethics, casuistry and primary care ethics, as well as the role of emotions in clinico-moral decisions and actions. I am also interested in medicine and literature, and believe that fiction can enrich the moral sensitivity and perception of physicians. I started a reading group three years ago and we meet up regularly to discuss the classic texts, contemporary fiction and sometimes biography. The group includes general practitioners, a professor in medicine and the arts, a professor of pharmacology, an English writer/academic and a psychologist. ■

## Medical involvement in torture – some ethical considerations

Dr Piers Benn

It has been said that without doctors, torture would hardly exist. Fortunately, this does not mean that the medical profession is the source of the abuses perpetrated by unpleasant regimes worldwide. However, torturers routinely rely upon the assistance of doctors. Such assistance includes certifying a victim's 'fitness' for torture, halting it when he can no longer withstand it, examining him, and treating him so he can be abused again. The medical profession in the Western world is aware of widespread role of doctors in human rights abuses and is adamant that involvement of doctors in torture is absolutely wrong[1].

The BMA's handbook provides a wealth of historical detail on the involvement of doctors in the abuses committed by various unsavoury regimes, and some relatively savoury ones. In it, doctors testify how they were sucked into involvement, how they couldn't protest, how they were ordered not to treat 'enemies', and how they were themselves threatened. There seem to be few limits to the ingenious cruelty of certain people with power, and many others turn a blind eye to it. But for the British medical profession, there is something particularly abhorrent about doctors' involvement in torture. Doctors are healers who must put the best interests of those in their care above all else. The last thing doctors should do is become involved in abuses.

But is this an obvious truth of medical ethics, or a vague platitude? If we are going to take an absolute or nearly absolute stance against medical involvement, we need to be armed against some familiar arguments to the contrary, rather than be content with simply re-iterating that such involvement is simply unthinkable. It is not clear that the official writings of the BMA deal with such arguments in the necessary depth.

For example, it will be said that doctors' involvement is unlikely to make torture victims any worse off than they would have been otherwise, and may even make them better off. If doctors can prevent torturers from 'going too far', this benefits the victims. The doctors can't prevent these terrible abuses, but they can at least limit the damage.

Another argument is the familiar old chestnut 'If I don't do this, someone else will'. That is, if I don't take on this admittedly nasty job, the job will still be done, and possibly by some fanatic who takes positive pleasure in it. Obviously, this argument is often used as a mere rationalisation for what one wants to do in any case. But on a theoretical level, it is not susceptible of instant refutation.

Underlying these issues is the ethics of torture itself (however defined). How we assess the ethics of medical involvement in torture will largely, though

not entirely depend on how we assess arguments for and against the absolute wrongness of torture.

Human rights bodies such as Amnesty International take it that torture is always immoral, whatever evils it may forestall. This is also the implicit view of the BMA. And it is one I am strongly inclined to support. But moral absolutism faces philosophical challenges, especially in a secular framework. Many people argue that torture is occasionally both necessary and sufficient to avoid a catastrophe. If it is necessary to torture a terrorist to find out where a bomb is planted, then perhaps that is what we should do.

To condemn torture whilst avoiding absolutism – which may well commit us to other uncomfortable absolute stances – we might resort to a refined consequentialism, and argue that in fact, torture rarely or never yields consequences that are beneficial overall. The effects of breaching our normal barriers against violence may be worse than we thought, and the force of bias and irrationality in such seemingly rational calculations is very considerable. In any case, the evidence that torture is an effective way to gain information is highly contentious.

Both absolutist and consequentialist arguments against torture can be effectively deployed. What then of medical involvement? From either perspective, we can argue that doctors should not be involved (except in caring for victims) since in the long term their involvement props up the system, even if it occasionally limits harm to victims. Absolutists, of course, will say this is not enough. There are certain acts, such as murder, rape and torture, that we simply should never commit.

What we may need to be clear about is our philosophical position. If it is absolutist, then we must ask how seriously we can take this as a general theory. It may have implications we do not like. If it is non-absolutist, we may reluctantly have to admit that torture and medical involvement could be justified in theory, even if not in practice. We just have to hope that justifying circumstances will never in fact arise. ■

[1] See the BMA's handbook (*The Medical Profession and Human Rights*, BMA publications 2001)

Piers Benn



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## Unit Project Summaries

### Race/Ethnicity and Genetics

*Richard Ashcroft is a partner in a major Wellcome Trust funded study on the implications of using race/ethnicity concepts in applied population genetics studies, such as the UK Biobank. The project research fellow is Dr Richard Tutton, and the project is led by Dr Paul Martin (Institute for the study of Genetics, Biorisk and Society, Nottingham University). The other partners are Dr Andy Smart (ETHOX Centre and Oxford Genetics Knowledge Park, Oxford), and Prof. George Ellison (St George's Hospital Medical School). The project involves literature reviews and interviews of scientists involved in both genetic epidemiology and in pharmacogenetics research. For further information, see <http://www.nottingham.ac.uk/igbis/reg/>*

## Selected Recent Unit Publications

**Ashcroft RE** "Access to Essential Medicines: A Social Contract Approach" *Developing World Bioethics* 2005; 5(2): 121-141

**Ashcroft RE** "After the trial is over: What are the sponsor's obligations?" *SciDev.Net*, June 2005  
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## **Unit Project Summaries**

### **Clinical Ethics Support for London's Clinical Genetics Centres**

*Ainsley Newsom is undertaking post-doctoral work to offer and evaluate various mechanisms of clinical ethics support for London's clinical genetics community, including case consultation, regular attendance at clinical meetings, clinical observation and an ethics workshop series. This form of ethics support is one of a number of initiatives currently being utilised by professionals to provide ethics support in the United Kingdom; other mechanisms include clinical ethics committees and the Genethics Club.*

## ***MSc in Medical Ethics***

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Telephone: +44 (0)20 7594 8093

You may discuss the course informally with the organiser:

Dr Piers Benn  
Tel: +44 (0)20 7594 3389  
Email: [p.benn@imperial.ac.uk](mailto:p.benn@imperial.ac.uk)

Please note that the course organiser cannot supply application forms.

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