SAL – BAC SYMPOSIUM

"RETHINKING INFORMED CONSENT IN BIOMEDICAL RESEARCH"

23 FEBRUARY 2012

WELCOME REMARKS
BY CHIEF JUSTICE CHAN SEK KEONG

The Baroness O'Neill of Bengarve, Dr Kon Oi Lian, Mr Gregory Vijayendran, guests, ladies and gentlemen:

Good afternoon.

1. My task here is to welcome all of you to this symposium and also to introduce the keynote speaker to you. So, welcome to all of you. Lady O'Neill needs no introduction. Her fame precedes her. The short write-up in the Programme of her professional career and work as a philosopher in academia and also in public service does not do her justice. Incidentally, justice is also a subject which is also within the scope of her scholarship. Go to Google and you will realise why a panel once described her as having brought a "terrifying but brilliant" brain to bear on problems, including freedom of speech, euthanasia and stem-cell research issues. I would therefore like to commend the Committee on Legal Education and Studies of the Singapore Academy of Law and the Bio-Ethics Advisory Committee for their initiative in organising this symposium.

2. Today's symposium is about informed consent, particularly in the field of biomedical research. In her latest book on the subject, Rethinking Informed Consent in Bioethics, published in 2007, Lady O'Neill and her co-author Neil C Manson have suggested that "informed consent is best thought of as part of a

wider ethics of communication". Lady O'Neill will no doubt elaborate on this theme in her address.

3. What more can I add, except perhaps that the concept of informed consent is still evolving. Taking a brief glance back, it's clear that the standards of informed consent that we are used to today are a far cry from what they used to be. The world's first heart transplant was an experimental surgery that involved a chimpanzee's heart being transplanted into a human patient. And that was thirty-five years ago! It must have been a rather radical surgical alternative to have taken – not only was a heart being transplanted for the first time, it was not even from a human source! Yet remarkably, the consent form was but one-paragraph long, with no mention of how novel the procedure was, and zero indication that it was going to be a xeno-transplant of a chimpanzee's heart. Such a situation cannot happen today.

4. Locally, the huge controversy that arose in 2002 over Professor Simon Shorvon's alleged professional misconduct at the National Neuroscience Institute underscores the importance of having informed consent. Prof Shorvon reportedly carried out tests on patients with Parkinson's disease without getting their consent. Patients were recruited into his medical research and their medications were altered without them knowing of it[1]. Separately, another disciplinary action recently arose where a doctor injected rabbit stem cells into a patient's body as a last ditch effort to treat a muscle-wasting disease for which there was no known cure. The doctor failed to inform the patient that such treatment was still very much in the experimental stage, and that the doctor himself actually had no specialised knowledge or skill in that treatment[2]. There is no doubt from these two cases that *having* informed consent is vital, but the question remains: *how* do we ensure that informed consent is attained*?*

[1] Professor Simon Shorvon v Singapore Medical Council [2006] 1 SLR 182

[2] Dr Wong Yoke Meng v Singapore Medical Council (OS No. 414 of 2011)

5. In shaping our consent regimes, both law and ethics have to come into play. In discussing 'informed consent' where we are more concerned about the *substance* of what it should achieve rather than just the *form* of procedures and protocols, the role of ethics should feature more prominently than legal solutions. This allows for the necessary degree of flexibility to grapple with new technologies, and to understand how these will impact the ways we think about informed consent. In this connection, the set of guidelines released by the Bio-Ethics Advisory Committee with regard to research involving human subjects is a right step in that direction.

6. We are now in a new era of biological and medical research. This is the new frontier. The completion of the human genome project in 2003 has ushered in a whole new chapter of biomedical research, and a pressing need to think about these issues. Genetic information from the individual lies at the heart of genome related research. The problem is that such information necessarily reveals information about others who share their genetic links. Entire family trees and ancestral lines are implicated. This is an exhilarating prospect for the geneticist, but at the same time a nightmare for those trying to protect privacy rights. At once, inadequacies of the traditional one-on-one consent protocols that so much of scientific research has been reliant on are instantly apparent.

7. As we move into this phase where research material can implicate not just individuals, but entire communities, our concept of "informed consent" must make a similar shift in gear. Is it still appropriate to continue placing the bulk of such choice and responsibility on the individual? Perhaps it is time to seriously consider the merits of more communitarian values like reciprocity and solidarity. Fundamentally two public interests are at stake: safeguarding individuals' privacy and enabling biomedical research that will advance the nation's health. Balancing the two would involve some form of reciprocity. Since individuals benefit from medical research which is inherent in the

medical care received, there is some form of willingness that can be expected of their participation in such research. In Singapore, especially, individuals are seen as members of society with obligations to the community at large. There is a real sense of continuality which involves having benefitted from past ones and thinking ahead for future generations. Quite clearly, the whole notion of “informed consent” is not, in and of itself, an immutable “holy grail” to be preserved at all costs. Rather, it exists within a greater matrix of values and interests, and has to be balanced delicately with them.

8. To close, let me offer a simple observation. While we are at a symposium to discuss informed consent, it pays to remember a key concept of fundamental biology. That is, successful organisms survive robustly because they do one thing very well: they adapt. And so must we. The perennial challenge for ethicists and lawmakers alike in a field that is constantly changing is simply keeping up. As the boundaries of science shift rapidly, legal and ethical frameworks must adapt nimbly to safeguard essential interests without hindering the progress of research. If we don’t, either way, we lose.

9. I wish the participants a fruitful symposium. Thank you.

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