

## **Institute of Ideas Health Forum**

### **Informed Consent Discussion**

Introducer: - Steve Bowler  
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#### Introduction:

Consent has many and varied forms, ranging from filling in complicated forms to proffering one's arm for a blood test.

The essential components, as laid out by the GMC, are that patients should be competent to give their consent, should have all of the appropriate information, and should consent voluntarily to undergo treatment or be part of research.

So far, consent issues have mainly been governed by case law, but now they are increasingly coming into the sphere of statutory legislation e.g. the Human Tissue Act, which gives lots of new powers to Local Research Ethics Committees (LRECs).

Guidelines and legislation around informed consent now applies to procedures from physiotherapy to surgery, and cover different 'client groups' from children, to unconscious people, to those with mental health problems. The common thread between the different strands of the discussion is that there is an implicit power imbalance in the relationship between expert and patient, which needs to be addressed and corrected.

This is unsurprising given that in many other areas of society today e.g. in government and churches, authority, which used to be assumed, now increasingly needs to be justified, critiqued and audited.

The doctor-patient relationship is in a state of transition. Obviously, consent is always better than coercion, so the idea of informed consent fits in well with old-fashioned models of medical ethics. But, driven by the dimming of medical authority, the pressure to formalise the relationship means that the burden of responsibility is being passed firmly on to the patient.

In defense of an older model, it could in fact be said that the inequality in the doctor patient relationship potentially has a therapeutic effect. The authority of the doctor means he is not just a technician, but helps us, when ill, to restore a sense of normality in relation to ourselves. Informed consent is an expression of the dilution of that authority.

A wide-ranging discussion ensued, covering the following areas (and more):

#### The doctor-patient relationship

One contributor pointed out that much of the pressure towards informed consent, for example about 'do not resuscitate orders', has come from patients themselves, wishing to be better informed about their condition. Another speaker raised a similar

point: isn't the fact that people are less deferential now, and more demanding of the medical profession, potentially a driver for improving standards?

On the other hand, several contributors pointed out the downside of the drive towards informed consent. The dynamic comes from professionals who are increasingly less confident, keener to subordinate themselves to guidelines, rather than addressing the actual needs of patients. As doctors become more defensive about their professional identity, so the consent form goes from being just a piece of paper to being 'a defensive screen'. Blame can't be attached because correct procedures were followed.

The use of chaperones for 'intimate examinations' was raised by a couple of speakers as symbolic of the deterioration of the doctor-patient relationship, and the defensiveness of the new medical ethics. In the past, medical codes of conduct guarded against doctors potentially taking advantage of patients, for example with strict strictures against any sexual relationships between doctors and their patients. Now the use of chaperones is explicitly referred to in the medical literature in terms of protecting doctors from patients who might make malicious allegations.

The idea of an intrinsic 'imbalance in power' between doctors and patient was discussed. One contributor raised the idea that the patient is after all an expert in her own life, so consultation should be meeting of two experts. The imbalance in the relationship can go both ways, and this is what we need to learn to negotiate. Others pointed out that an imbalance in expertise is not the same as a difference in social power. For example, we take our car to a mechanic, expecting it to be fixed without worrying about power relations.

One idea raised in a document circulated prior to the meeting was that 'sick people are not themselves', i.e. are not in a good position to make informed judgments when ill. This is when the medical profession should be helping them, not placing the burden of decision-making onto them.

One speaker raised problems with this idea, particularly in terms of patients who are acutely mentally ill, and may have little insight into their own condition. Making decisions on their behalf might be experienced as coercion.

### What has changed?

Various contributions addressed how much ideas around 'informed consent' have developed in the last ten years. Several people mentioned the transformation of Professor Sir Ian Kennedy, an academic lawyer, whose strong indictment of modern medicine didn't resonate with the wider mood of the 70's and 80s, as it does now. His profile was raised after he gave the Reith Lecture in 1980 and his ideas now are central to the direction of government policy as Chair of the Healthcare Commission – the new NHS 'watchdog'.

There have always been good and bad doctors, but now rather than just shrugging off a bad experience as due to an individual bad doctor, people identify problems as representative of a systematic failure. There are not more bad doctors now, but

people's understanding of their experience is different, and grievances can take on a new momentum.

One contributor pointed to some of the historical discussion about Nazi Germany in the introductory document. In fact Germany had fairly robust informed consent procedures in the 30s, but terrible abuses of the doctor-patient relationship came with increased state involvement and distortion of that relationship. So, rather than looking at individual doctors, we should be looking at the state generated dynamic.

Another speaker described the destructive role of the new 'bioethical' model. The simple model of medical ethics, contained in the Hippocratic Oath, contained a spontaneous idea of 'personhood' and autonomy of both doctor and patient. In contrast, the bioethical model embraces relativism. The autonomy described is more of a defensive gesture, than part of a moral order.

### Research and the Human Tissue Act

One speaker discussed several aspects of the Human Tissue Act. It has provoked a lot of bitterness in the medical profession, as it is seen to be a blatantly political Governmental gesture, which will impede research. Some of the new principles governing research, like improved data protection, might in fact be helpful for research subjects. But ironically, the HTA approaches consent in a very technical, 'tick-box' fashion, and does not provide very robust data protection. Rather it seems to be more aimed at policing doctors than protecting the public.

Several contributors raised problems with the idea that the trust implicit in the doctor-patient relationship should automatically be extended to patients' participation in research. This idea was defended by others, who pointed out that modern medicine progresses through experimentation.

One speaker raised the question as to why members of the medical profession are so defensive about their own motives in research. In Alder Hey e.g. it was apparent that doctors were not harvesting misshapen kidneys for ghoulish reasons, but with a view to future research. Others disagreed: the research imperative should not be used as a blanket justification for all actions.

### Informed choice and informed consent

Parallels were drawn by several speakers between the current popularity of 'informed choice' and informed consent. Ironically, public discussion on choice, 'supporting people to make the right decisions', could be seen as limiting choice, telling people what's good for them when they're well, whereas informed consent, when people are ill, is when they least need choice. Both phenomena were described as ways of passing on responsibility to the individual.

