Doctors breaching patient privacy: Orwell redux

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Legislative changes made without public discussion allow disclosure without patient consent

Of all the ethical principles underlying medical practice, confidentiality is so fundamental that its breach is an illegal, high-order betrayal of responsibility. Disclosing personal medical information without consent profoundly violates the autonomy, beneficence and privacy that patients have always rightly expected.[1] Although disclosure without consent has only rarely been necessitated by an urgent threat to life or health, two recent legal erosions of doctor–patient confidentiality illustrate how privacy-invading legislation can so easily and silently harm individuals who do not form sufficiently clamorous rights-demanding groups. In one, a state government directs that private medical records be lodged in an Orwellian sounding "Central Register" without regard for the individual's knowledge, and risking privacy breaches by seeking consent for disclosure to third parties. The other permits disclosures of a patient's medical information against their wishes even without any urgent threat to the life or health of another person. Both represent unreasonable intrusions on privacy and erosion of personal liberty.

Recently, the New South Wales Government made a legislative amendment, without parliamentary debate or public discussion, in the last days of their current term. This amendment to the *Assisted Reproductive Technology Act 2007* (NSW)[2] forces doctors to provide the identity of anonymous sperm donors to a central register when their genetic offspring submit a request for information to the Director-General of NSW Health. This transfer of identifying information can occur regardless of the sperm donor's consent, and overrides any prior condition of strict confidentiality guaranteed at the time of sperm donation. Although it is argued that identifying information cannot be released without the donor's consent, the Director-General's possession of donor contact details creates a situation where a stranger to the donor might try to contact him to seek consent for disclosure. The donor, however, did not ever consent to such an approach from a government instrumentality which, in itself, is virtually certain to breach the donor's strict confidentiality. Inevitably, once the Director-General possesses identifying information and this contact and consent process proves unworkable, the logical next step is eliminating the troublesome consent requirement. This retroactive legislation is starkly at variance with the recent Australian Senate's report of its inquiry into donor conception in Australia,[3] which recognised that all states' legislation on donor conception respected the time-honoured principle of rejecting legislative retrospectivity.

Sperm donors have often long forgotten their altruistic act, two decades previously, motivated by a wish to help infertile couples and thought of as akin to blood donation; certainly they would not have provided sperm without the guarantee of enduring and strict confidentiality. Now, merely expecting undisturbed privacy, they do not constitute any sort of group to oppose the persistent, vocal donor-conception lobby groups demanding involuntary disclosure that overrides donors' legal and moral rights. Sperm donors' lives over the decades since donation could have changed in every imaginable way so that forced disclosure may be unwelcome, and damaging to some. It denies natural justice to disregard the usual requirement for their consent. We hope that a new NSW Government will show regard for consent and amend the retrospectivity of this assault on the privacy and personal liberty of well intentioned individuals.

The other legal assault on privacy is highlighted in a recent update of the National Health and Medical Research Council (NHMRC) guidelines on medical genetic testing.[4] These guidelines endorse a recent amendment to Commonwealth privacy legislation that widens the legal exemption allowing disclosure of patients' genetic information to others, even against a patient's wishes. Rarely, the situation arises where a patient is unwilling to inform relatives of a genetic test result that, in a doctor's opinion, should be disclosed. Such disclosure was previously only permitted to resolve an imminent danger to another person's health. After the previous exemption for imminent medical danger created a precedent, a recent amendment has removed the requirement altogether. In effect, this now creates genetic testing without consent by proxy — a situation where the relative may be informed, against the patient's wishes, of the patient's genetic status without the relative soliciting the information and possibly without wishing to know.

The arbitrary nature of this new standard is illustrated by its vague boundaries — only a "serious threat to life, health or safety" extending to "third-degree relatives" is required to override the patient's denial of consent. The NHMRC guidelines even encourage not disclosing that the original genetic testing occurred, piling dishonesty upon breach of faith. The widened loophole creates an elastic legal excuse for the well meaning (but impatient) to breach individuals' privacy. This disavowal of patient confidentiality at a doctor's sole discretion has the net effect of allowing one individual's subjective, value-laden judgement, triggered by any remote threat to health or welfare, to override a patient's refusal of consent. Inevitably, unintended perverse outcomes should be expected — bringing to mind the legal maxim "hard cases make bad law".

In practice, this loophole will encourage the taking of the lazy path of legal coercion rather than gradual persuasion and ultimate acceptance of a patient's decision. If forced disclosure is really required, such a momentous breach of a patient's expressed wishes in the absence of genuine life-threatening circumstances should require approval from an independent legal tribunal, a standard well established for surgery on children whose parents refuse consent, or for sterilisation operations or other major elective procedures for those unable to consent.

Both these legislative assaults on privacy reflect the fashionable belief in genetic determinism prevailing over any ethical, moral and legal constraints of everyday life. But ditching the trusted confidentiality of medical information for doctors' convenience or to satisfy lobby groups permits arbitrary and damaging intrusion on personal liberty — the price of which remains eternal vigilance.

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