Peri-Gravid Genetic Screening: The Spectre of Eugenics and Medical Conscientious Non-compliance*

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Peri-gravid genetic screening is the search of populations to provide public health information on genetic disease relevant to the reproductive period. It differs from genetic testing in that it is not initiated at the request of the individuals sampled or their immediate family. It can also be distinguished from adult carrier, adult presymptomatic, workplace susceptibility, forensic and research genetic screening. Information flowing from the Human Genome Project is set to markedly increase the potential scope of peri-gravid genetic screening. This may lead to significant public benefit when it relates to an important condition, offers a clear diagnosis and prognosis, informs choice and provides reasonable opportunities to alleviate morbidity. When, however, it becomes explicitly or implicitly mandatory and involves legal or illegal abortion as the primary therapeutic option, peri-gravid genetic screening may become eugenic, supposedly beneficial to the mass, but often deleterious to the good of an individual patient, her fetus or baby. Doctors may then determine that medical loyalty and their professional ethical obligations require conscientious non-compliance. This unusual position may also arise, however, if doctors are prohibited by law from offering patients requested information (that is, relevant to trait or sex selection) derived from peri-gravid genetic screening, or, being so permitted, are prevented from discussing or offering abortion, either absolutely or solely on the ground of genetic abnormality in the fetus. Medical educators, patients and legislators require greater awareness of the complex ethical dilemmas facing physicians as a result of increased peri-gravid genetic screening and inconsistent abortion laws.

Introduction

It is axiomatic that doctors, like all citizens, must obey the law. But patients are by definition vulnerable and forced to trust. This creates an overriding ethical obligation on doctors to give their primary loyalty to protecting the good and alleviating the suffering of their patients. Where this loyalty conflicts with the doctor's loyalty to the law, as it will, rarely, in contentious legal areas such as euthanasia and abortion, it may provide a sufficient weight of independent moral reason for the doctor to consider conscientious non-compliance.

Assume a woman in her 30s, a committed Catholic and partner in a legal firm specialising in disability actions, presents to her doctor in Sydney for a pre-natal check. The patient is the foster parent of a child with severe cerebral palsy and has a sister who has suffered from multiple sclerosis since the

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age of 12. The doctor says he has by law to collect a sample of venous blood for a "routine" test. The patient asks why.

"To check if the baby is healthy."

The patient asks the doctor to elaborate.

"To prevent birth defects."

"A vaccine?"

"No, to screen for Down's syndrome or spina bifida. If the test is positive further investigations will follow so a decision can be made in the second trimester."

"How to treat the problem?"

"Well no. Gene therapy isn't available yet."

"Then what?"

"Termination of pregnancy."

The woman refuses the test. She says that under the common law in New South Wales it is illegal for the doctor to offer abortion for any fetal condition which is not a danger to her physical or mental health. She says that this attempted coercion of her into genetic screening is a eugenic invasion of her privacy. The doctor writes in the notes that the genetic screening test was refused "against medical advice". The patient seeks an obstetrician willing to forgo the genetic screening.

The following day another woman presents, at 10 weeks gestation, for the same pre-natal screening blood test. Her husband is threatening, for cultural reasons, to divorce her unless her first baby is a tall male. The woman says she had heard it was now possible to check the DNA of a fetus by isolating and amplifying a cell from the mother's blood. She wants information on whether the screening blood shows a fetal "y" chromosome and the alleged "gene" which indicates above-normal height. If both are absent she wishes to have an abortion. The doctor refuses to arrange access to the additional information and says that, even if such testing were feasible, abortion could only be recommended if the screening test showed the baby had diseases such as Down's syndrome (Trisomy 21) or a neural tube defect. The woman says any female child born to her would be unwanted and probably abused. She feels that, by denying her this information, the doctor is morally judging her and trying to direct what she does with her pregnancy. She says that any information obtained from the screening is as much her property as the sample itself. She questions the idiosyncratic and unchallenged manner in which doctors can dress up such a political determination as a purely medical decision. The physician says the test is publicly funded and he has a responsibility to the community to prevent women being devalued. He refers the woman to a colleague previously well known to the patient who, after listening closely to her story, agrees to an abortion for sex selection, if required, provided it is done in the next two weeks of the pregnancy. The colleague says she will state that the abortion was performed to protect the physical and mental health of the mother.

As well as ethical concerns about empathy in relation to doctor-patient communication, these examples highlight how insidiously the spectre of eugenics may arise in the context of peri-gravid genetic screening. This article analyses why this is so and what ethical position it requires from doctors, particularly with relation to the concept of conscientious non-compliance.

The spectre of eugenics

The term "eugenics" was possibly first used by Francis Galton early in the 20th century to refer to "the study of the agencies under social control that may improve or impair the racial qualities of future generations, either physically or mentally". More recently, "eugenics" has been defined as "the science that deals with all influences that improve the inborn quality of the human race, particularly through the control of hereditary factors". Many

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1 Adapted from L. Blumberg, "Eugenics vs Reproductive Choice" (1994) (Jan/Feb) Disability Rag & ReSource 3.


3 F Galton, "The Possible Improvement of the Human Breed Under Existing Conditions of Law and Sentiment" (1901) 64 Nature 659.

4 K L Garver and B Garver, "Eugenics: Past, Present, and the
have associated and continue to associate eugenics with state policies that coercively interfere with individual procreative choices. Here I take eugenics to mean reproduction-related decisions involving the imposition upon others of a particular conception of humanity’s biological or intellectual future good.

Eugenics may be negative and involve efforts by the state to “weed Mendel’s garden”, to minimise the transmission of “deleterious” genes among its population. Relevant techniques in this respect have included compulsory sterilisation, involuntary euthanasia and mass murder, as well as laws against interracial marriage and restrictive immigration. Tacit or overt encouragement of the abortion of any fetus with “undesirable” characteristics also falls under this head. Positive eugenics, on the other hand, describes a state’s attempts to maximise the transmission of “desirable” genes, examples being propaganda to encourage breeding among certain classes, a sperm bank accepting samples only from Nobel laureates or a premarital check for carrier conditions with a central genetic data bank.

Germany and the United States were prominent in the eugenic movement in the early part of the 20th century. In the climate of unemployment and social dislocation which followed the First World War, 32 North American States, beginning with Indiana in 1907 and ending with Georgia in 1937, passed legislation which required doctors to become involved in involuntary sterilisation of patients who were categorised as either “mentally retarded”, “insane”, “criminal habitual”, “derelict”, “morally degenerate”, “syphilitic”, “sexually perverted”, “alcoholic” or “a menace to society”. The Government of Alberta in Canada passed a Sexual Sterilization Act in 1927 which led, in the following 50 years, to the sterilisation of 2,800 Canadians.

German doctors helped draw up and enforce the 1933 Nazi Law for the Prevention of Genetically Diseased Offspring. This legislation was used subsequently to allow doctors to sterilise substantial numbers of mentally and physically handicapped patients and, later, people of “undesirable” ethnic groups who were needed as slave labourers. From 1934 doctors sat on each one of the country’s 181 Genetic Health Courts. Despite in most cases realising the consequences, they registered diagnoses of genetic illness with the state, performed abortions simply because pregnant women were of “inferior” genetic stock and encouraged parents to seek euthanasia for their abnormal or malformed children. On 18 August 1939, 14 days before the invasion of Poland, the German Committee for the Scientific Treatment of Severe, Genetically Determined Illnesses produced a secret report which was delivered to all state governments. It required midwives and doctors delivering any child suffering from “idiocy or mongolism” (especially if associated with blindness or deafness); microcephaly or hydrocephaly of a severe or progressive nature; deformities of any kind such as missing limbs, malformation of the


head, or spina bifida; or crippling deformities such as spasticity" to register that child with the local health authorities. Questionnaires returned by the physicians and midwives were assembled and passed on to Professors of Medicine, Catel, Heinze and Wentzler, to be sorted for "selection". The names of children slated to die were marked with a plus sign; those allowed to live, with a minus sign. Methods of extermination included excessive doses of morphine, cyanide gas or other poisons. Administration was initially slow, so that the cause of death could be medically disguised as pneumonia or bronchitis. Often such children were simply starved, or left to die from exposure in unheated hospital wards. This allowed doctors to argue that their actions were not a breach of Hippocratic ethical obligations to beneficience and non-malificence, but simply "withholding care" or "letting nature take its course". Relatives were informed with a standardised letter, used at all relevant institutions, that their daughter or son had died suddenly or unexpectedly from brain edema, appendicitis or some other fabricated disease. They were also told that, owing to the danger of an epidemic, the body was cremated immediately. Close to 100,000 people were murdered in this way. Doctors were never ordered to do the killing, they were simply empowered by the state to do so and complied without protest, often with initiative. By 1942, half of all the nation's doctors had voluntarily joined the eugenically-oriented Nazi Party.

The reasons why the state exerted pressure on doctors to rid it of these citizens were a mix of economics (the cost of long-term institutionalised care), strong paternalism (poor perceived quality of life) and desire to protect the long-term "health" of the community. Genetic determinism, which ascribed to faulty genes a whole range of social ills including prostitution, alcoholism, criminality and even chronic unemployment, also played a part.

Altered political and economic conditions and increased ethical awareness make it unlikely, in most contemporary constitutional democracies, that state pressure on doctors will again take the form of overt eugenic-oriented legislation, such as Linus Pauling’s suggestion that children carrying deleterious but non-expressed genes be made to have symbols tattooed on their foreheads to prevent them falling in love with an incompatible partner. Yet, in the 1980s Singapore's President Lee Kuan Yew decided that the quality of the state's populace was being reduced, because many women with university education were remaining single or declining to have children when married. Eugenic reform measures included state-funded computer-dating services, all-expenses-paid love-boat cruises, tax incentives and the introduction of courtship classes into the undergraduate curriculum.

In China marriage is reputedly prohibited for people diagnosed with genetic diseases that may totally or partially deprive the sufferer of the capacity to live independently. Under the Maternal and Infant Health Care Law 1994 (People's Republic of China) there can be no legal challenge to a physician's order for sterilisation or termination of pregnancy. The Genetical Society in Britain has withdrawn from the International Genetics Federation in protest against the 18th International Congress of Genetics taking place in Beijing in 1998 on the precondition that "eugenics and the law that enforces it" not be opposed.

Renzong, Director of the Bioethics Program at the Chinese Academy of Social Sciences, has reported: "Most Chinese geneticists are working in governmental medical schools, hospitals or institutes, and they feel they have a responsibility to do their work being not [sic] against government policies. Now the Chinese government has a basic policy, ie, reducing the quantity of population and raising its quality. Great efforts have been made for improving newborns' quality of life or preventing the birth of seriously defective newborns. Although there is no governmental directive of telling Chinese genetic counsellors what he/she has to do in providing counselling, many counsellors tend to suggest [sic] a client, for example, to abort a fetus with Down's syndrome."

The evidence suggests that Chinese physicians are directive about termination of pregnancy for a much greater range of conditions than their counterparts in the West.4

In Kentucky, a statute was still on the books in 1995 that allowed a physician examining applicants for a marriage licence to obtain blood samples to eugenically test each prospective parent for sickle cell trait or any other genetically transmitted disease that affects haemoglobin.25

Some academic commentators only in part believe in the spectre of eugenics and consider it a myth that may have an unfortunate chilling effect on beneficial scientific research, such as that involved with the multibillion dollar, international Human Genome Project.26 Others, however, have highlighted the ways in which such increased genetic surveillance can change the character and mood of a pregnancy,27 can implicitly give the state information about the parents,28 and constitute an unwanted imposition of information designed to alter future reproductive choices.29 Peri-gravid genetic screening, for example, may provide information that leads to legislation mandating abortion for certain conditions, or providing a basis for financial incentives designed to restrict childbearing in certain at-risk groups.30 Eugenics, however, may also covertly arise in physician discretions related to the severity of fetal genetic illness under specific legal grounds for abortion such as s 1(1)(b) of the Abortion Act 1967 (UK),31 s 3(2)(b)(ii) of the Medical Termination of Pregnancy Act 1971 (India),32 s 187A(1)(aa) of the Crimes Act 1961 (NZ), s 3(1)(b) of the Termination of Pregnancy Act 1972 (Zambia),33 or s 82A(1)(a)(ii) of the Criminal Law Consolidation Act 1935 (SA).34 The spectre of eugenics may one day stalk abroad from the collective effect of parental abortion decisions arising from increased information flowing from the Human Genome Project, that is, for sex or trait selection not necessarily related to severe fetal disease. Genetic enhancement technologies, though still themselves embryonic, could enhance such "backward" eugenics, some arguing that they should be permitted unless likely to result in "clearly and

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29 Bobinski, op cit n 20, p 90.
31 "[A] person shall not be guilty of an offence under the law relating to abortion when a pregnancy is terminated by a registered medical practitioner if two medical practitioners are of the opinion, formed in good faith ... that there is a substantial risk that the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped." See D Morgan, "Abortion: The Unexamined Ground" [1990] Crim LR 687.
34 This section substantially reproduces the terms of the corresponding United Kingdom Act.
significantly damaging effects on the future child.\textsuperscript{35} Both peri-gravid genetic screening and eugenics involve attempts to improve the health of a population. Assuming that the former is unquestionably justified and appropriate at the macro level, and this is contentious, it will nonetheless, at some point, operate against the good of particular people. It is probably the physician who will be most commonly faced with tempering the eugenic pressures for such legislation, by decisions for the good of individual patients. This was the insight that led, as will be explained in the next section, to the Nuremberg and Geneva Declarations and to development of the attitude, if not the fully articulated concept, of medical conscientious non-compliance.

**Conscientious non-compliance**

On 20 August 1947 an Allied Military Tribunal sentenced four German doctors to death by hanging for war crimes and crimes against humanity.\textsuperscript{36} When Brigadier General Telford Taylor concluded his opening statement for the prosecution, he accused those leaders of the German medical profession then in the dock, of having greater guilt than any other defendant: “They are the men who utterly failed their country and their profession, who showed neither courage nor wisdom, nor the vestiges of moral character.”\textsuperscript{37} This was, he said, “no mere murder trial”, because the defendants were physicians who had sworn to “do no harm” and to abide by the Hippocratic Oath. The people of the world needed to know “with conspicuous clarity” the ideas and motives that moved these doctors “to treat their fellow human beings as less than beasts”.\textsuperscript{38}

Societies have generally expected that doctors, in whom they invest so many valuable and scarce resources, must be dedicated to the good of their patients. Community dismay followed the Nazi doctors’ trial’s establishment of breach of this trust. The dissatisfaction similarly felt by the three judges of the Nuremberg tribunal, with prosecution testimony about the quality of consent previously generally required for human participation in medical research, lead to the Nuremberg Code.\textsuperscript{39} The Nuremberg Code, a statement of ten moral and legal prerequisites for the use of human beings in experimentation, pronounced in Principle 1: “The voluntary consent of the human subject is absolutely essential.” This revolutionary statement went on to create the non-delegable duty of a researching doctor to ensure that any prospective patient is “so situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, over-reaching, or other ulterior form of constraint or coercion”.\textsuperscript{40} In this document, for possibly the first time, doctors were asked to give greater weight to the patient’s perception of his or her own good (at least insofar as it related to the contemplated research) than to any alleged broader social good or law.

Dr Andrew C Ivy, one of the Nuremberg prosecution’s chief medical expert witnesses, had repeatedly emphasised in his testimony, though with dubious sincerity, the centrality of the Hippocratic injunctions to beneficence and non-malificence in guiding the ethical behaviour of all physicians.\textsuperscript{41} The Nazi doctors’ trial was a factor in

\textsuperscript{36} A Mitscherlich and F Mielke, “Epilogue: Seven Were Hanged” in Annas and Grodin, op cit n 16, p 105. Three of those hanged were not doctors.
\textsuperscript{37} T Taylor, “Opening Statement of the Prosecution, December 9, 1946” in Annas and Grodin, ibid, p 92.
\textsuperscript{38} E Shuster, “Fifty Years Later: The Significance of the Nuremberg Code” (1997) 337 (20) NEJM 1436 at 1437.
\textsuperscript{41} Katz, op cit n 40, at 1663. “I will prescribe regimen for the good of my patients according to my ability and my judgment and never do harm to anyone”: Hippocratic Oath in J K Mason and R A McCall Smith, Law and Medical Ethics (Butterworths, London, 1994), p 429. It has been argued since that, although the Oath played a meaningful role in the development of medical ethics, this requirement of “doing the best for the patient” is all that usefully can be drawn from it today: A Britton, “Hippocrates: Dead or Alive?” in K Petersen (ed), Intersections: Women on Law, Medicine and Technology (Dartmouth Publishing Co, 1997), p 1. The quotation “as to diseases, make a habit of two things – to help or at least to do no
the World Medical Association's post-war redrafting of the Hippocratic Oath as the Geneva Declaration in 1948. This emphasised to doctors that they had consecrated their lives to the service of humanity, that it was expected they will practise with conscience and dignity, that the health of their patient will be their first consideration despite any considerations of religion, nationality, race, party politics or social standing and that, even under threat, they are not to use their medical knowledge contrary to the laws of humanity. \(^{46}\) The World Medical Association's International Code of Medical Ethics 1949 declared that a doctor owes to his or her patient "complete loyalty and all the resources of his [or her] science". \(^{43}\) The American Medical Association in its most recent ethical pronouncements has not gone as far as this, but has stated that among their other ethical obligations, physicians should "serve as their patient's advocates" \(^{44}\) and "shall respect the law and also recognise a responsibility to seek changes in those requirements which are contrary to the best interests of the patient". \(^{45}\) No explicit statement of physician loyalty appears in the Australian Medical Association's Code of Medical Ethics beyond a general duty to respect the patient's right to make his or her own decisions about treatment or procedures. \(^{46}\)

The Geneva Declaration's emphasis on the primary loyalty of doctors to "conscience" and the "laws of humanity" with respect to the good of their patients, like the Nuremberg Declaration, represents a natural law position. An academic movement has recently developed which views natural law as a virtue-based approach to social regulation rather than the "caricature version" which Kelsen criticised as paving the way for the infamous totalitarian regimes of the 20th century (by grounding the authority of the state on mystico-religious ideologies rather than the rule of law). \(^{47}\) Finnis, in particular, has linked natural law with the individual's quest to define human good and the elements of practical reasonableness that are required for morally appropriate decision-making. \(^{48}\) The crucial elements of practical reasonableness, according to Finnis, are: a coherent narrative of life, no arbitrary preferences among values or between persons, detachment and commitment, efficiency in one's actions for the good, refusal to act so as to damage the basic forms of human good, fostering the good of the community and developing and exercising conscience. \(^{49}\) Some may suspect that such a list reflects the privileged existence of the academic. It is, however, appropriate that natural law jurisprudence rid itself of the notion that there is a magic formula, a DNA sequence or system of moral education, that inevitably leads to right conduct. Accepting the chaotic and unpredictable in ethical decision-making encourages non-linear regulatory structures in which virtue-oriented life narratives are augmented by abstract conceptions of obedience to law.

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\(^{46}\) Australian Medical Association, *Code of Medical Ethics* (1996) 1.3 (b), reproduced in Breen, Plueckhahn and Cordner, op cit n 42, p 316.


\(^{49}\) Ibid, pp 100-127.
Civil disobedience, set in this virtue-based context, is a non-violent (that is, not interfering with other’s civil liberties) act of public protest, at the boundaries of fidelity to the legal system, by a doctor, designed to change laws or government policies, which are perceived as being contrary to conscience, to values central to his or her life narrative, or that of others with whom he or she has a professional empathy. Conscientious objection is a refusal to obey a state’s positive command similarly determined to be, among other wrongs, against conscience. Though an overt act of public defiance to a command of the state, conscientious objection is not a form of appeal designed to harness the majority’s sense of justice to the promotion of legal change. In distinction to civil disobedience and conscientious objection, what I term conscientious non-compliance is a doctor’s decision based on conscience, on loyalty to a life plan emphasising the good of patients, to privately disobey a legal component of the regulatory framework of the doctor-patient relationship.

Childress, following Rawls, terms such acts “evasive noncompliance”. But this terminology has similarities to such morally unacceptable, self-regarding practices as tax evasion and fails to take sufficiently into account the obligation of confidentiality inherent in the doctor-patient relationship. Performing an abortion at a pregnant woman’s request and for her communicated good, though she does not fall within the strict legal guidelines, or refusing to comply with mandatory genetic screening legislation that would expose a patient to a substantial risk of discrimination or pressure her to have an abortion, are both examples of conscientious non-compliance. Medical conscientious non-compliance must involve an altruistic action.

Dr Bourne was confronted in the 1930s in the United Kingdom with a young woman pregnant as the result of a vicious multiple rape. At her request he performed an illegal termination. This was an act of conscientious non-compliance. He then handed himself in to the police who arrested him. This was now an act of civil disobedience, a public attempt (successful as it turned out) to change the law.

When Dr Henry Morgentaler, Dr Robert Scott and Dr Leslie Smoling opened a clinic in Ontario, Canada, to perform abortions, as they had done in Quebec, they did so in the knowledge that they would be arrested. This was an act of civil disobedience. Their public act of protest was designed to achieve, and did in fact lead to, a Supreme Court decision that changed the abortion laws of that country. In May 1992 the Morgentaler clinic in Toronto was bombed by pro-life activists. Such activists subsequently shot Dr Garson Romalis, a Vancouver gynaecologist, in 1994, Dr Hugh Short, a gynaecologist in Hamilton, Ontario, in 1995 and Dr Jack Fainman in Winnipeg in 1997. Non-violent “sit-ins”, obstruction of abortion clinics and bombings were also directed at doctors who became “abortion providers” in the United States. Dr Jane E Hodgson, Dr Warren M Hern and Dr Elizabeth Karlin have written of their conscientious motivations in continuing medically and emotionally to support patients who chose abortion in this difficult political and legal climate.

Childress gives as an example of an act of what I term conscientious non-compliance, a doctor deciding to misrepresent a “screening” test as a “diagnostic test” (that is, one performed after prior detection of signs of illness), in order that an indigent patient may be covered by health insurance.

54 See R v Bourne [1938] 3 All ER 619. The doctor was released as Macnaughten J created a new common law principle by indicating that an abortion was not unlawful where it was necessary to protect the physical and mental health of the mother.
59 J F Childress, “Conscience and Conscientious Actions in the
Doctors who refuse to perform or counsel for abortions, out of religious respect for the life of the fetus and mindful of the Hippocratic Oath's prohibition, are also performing acts of conscientious non-compliance. In many cases such acts arise from a deep understanding of Catholic theology on the natural law position, such as that expounded by Thomas Aquinas and his numerous interpreters. The Abortion Act 1967 (UK) has, for example, in s 4, an exception based on conscientious objection from participating in all but emergency abortions, the burden for proof of which lies on the doctor. A doctor's failure, on conscientious grounds, to make a referral for an abortion where the request has met the legal requirements would not be covered, as would failing to treat the results of an abortion.

This serves to indicate the chaotic ethical and legal complexities confronting doctors in this area. The Nazi example has encouraged many states to unequivocally champion the life of all citizens in areas such as abortion and euthanasia. This is an appropriate stance for the state, and medical conscientious non-compliance has probably been tacitly relied upon by many legislators to temper such laws to the good of individual patients. Yet for medical conscientious non-compliance to operate effectively, doctors must be selected for, educated and structurally encouraged to develop and display virtues such as empathy and loyalty. The role of literature in this respect in medical education is of particular interest to the author, but will not be discussed here. The state, however, may view it as inappropriate openly to encourage any notion of conscientious non-compliance, the first virtue of the state being justice, not loyalty. These points may be highlighted by examining in more depth the complexities of the relationship between peri-gravid genetic screening and abortion laws.

**Peri-gravid genetic screening**

Practising physicians became increasingly interested in genetic diagnosis after the publication in the 1950s of studies revealing chromosomal abnormalities in apparently inherited diseases. By the 1970s the development of amniocentesis, legalisation of abortion during the first two trimesters in many jurisdictions and greater understanding of the maternal and environmental causes of birth malformations, as well as enhanced

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**Context of HCOs** (1997) 7 (4) Kennedy Inst of Ethics J 403.

60 Carrick has argued that the Hippocratic tradition was far from united on this point, particularly when maternal health was endangered: Carrick, op cit n 41.

61 A prime overall requisite for a law from the viewpoint of Aquinas' philosophy of law, then, is that it be just ... related to the common good ... proportioned to the needs of the people ... enacted by those with lawmaking authority... If it is not just, if it lacks this essential element, it is no law at all. It is rather perversity, corruption, violence and tyranny": T E Davitt, “Law as Means to End - Thomas Aquinas” in J Finnis (ed), Natural Law (New York University Press, 1991), Vol I, p 69.


63 Mason and McCall Smith, op cit n 41, p 116. See also Criminal Law Consolidation Act 1935 (SA), s 82a(5) and Criminal Code Act 1983 (NT), s 174(2).

64 That is, by ensuring at a minimum that admission to medical school involves an interview to assess personal qualities and by emphasising a liberal education in the humanities, as well as science, as prerequisite subjects for a post-graduate medical course. Newcastle University in New South Wales has led the field in this regard in Australia for several decades.

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65 One-third of United States medical schools now have faculty teaching literature and medicine, the foundation Professor being Joanne Trautmann [Banks] at the Pennsylvania State University College of Medicine in Hershey: K M Hunter, R Charon J L Coulehan, "The Study of Literature in Medical Education" (1995) 70 (9) Academic Medicine 787.

66 That is, for example, by ensuring that Medicare rebates give a reasonable incentive for doctors to spend time explaining investigations and treatments to patients and hospitals set up pre-admission clinics for this purpose.

67 Rawls, op cit n 50, p 3.


69 The word is derived from the Greek amnion, the membrane around the fetus, and kentesis, to pierce. Fluid is withdrawn after needle perforation of the fetal sac, cultured and analysed: C B Jacobson and R H Barter, “Intrauterine Diagnosis and Management of Genetic Defects” (1967) 99 Am J Obstet Gynecol 796; T Friedman, “Prenatal Diagnosis of Genetic Disease” (1971) 225 Scientific American 34; E Nightingale and M Goodman, Before Birth: Prenatal Testing for Genetic Disease (Harvard University Press, 1990); M Steele and W Breg, “Chromosome Analysis of Human Amniotic Fluid Cells” (1966) 1 Lancet 383.


71 For example, ionising radiation and maternal infections and drug use. In Australia it is estimated that 1.44 % of all births are associated with a major congenital anomaly, though this is probably an underestimate due to under-reporting, late recognition and the derivation of data from perinatal forms.
recognition of their individual, parental and public costs, had stimulated considerable demand for perigravid genetic screening. It is now routine in developed countries for this service to be offered to pregnant women. Peri-gravid genetic screening may be divided into

1. heterozygote carrier screening of prospective parents;
2. prenatal embryonic screening (that is, by maternal blood test or fetal ultrasound); and
3. homozygote neonatal screening for particular treatable conditions.

Heterozygote carrier screening of prospective parents

In relation to carrier screening of prospective parents, the United States National Institutes of Health has recently recommended that all patients discussing a possible pregnancy with their doctor should be informed of the possibility of cystic fibrosis carrier testing and that carrier detection of 90 per cent should be the goal for the general population. Cystic fibrosis (CF) is caused, in an autosomal recessive pattern, by a variety of mutant alleles for the "gene" that sits on the long arm of chromosome 7. The most common disease-causing allele involves a three base pair deletion at amino acid position ΔF508 of the protein known as CF transmembrane regulator. This is present on only 70 to 75 per cent of chromosomes carrying cystic fibrosis mutations and results in abnormal sodium and chloride transport across airway epithelia, producing secretions that are dehydrated and poorly cleared, predisposing the patient to pneumonia. A similar process in the gut leads to retention of pancreatic enzymes and destruction of that organ, as well as intestinal obstruction. If a couple is screened and one is found to have a cystic fibrosis "gene", their risk of having a baby with cystic fibrosis increases from 1:2,500 to approximately 1:396. If the other partner has no known alleles (that is, doesn’t have the ΔF508 mutation), he or she may nonetheless have one of over 200 other "genes" causing cystic fibrosis, which are as yet "unmapped". Cystic fibrosis may also arise from spontaneous mutations which are undetectable by genetic screening. Further, of the many nucleotide variations that are known to constitute the cystic fibrosis "gene", some appear to be associated with phenotypically different symptoms, and other non-cystic fibrosis associated "genes" may produce symptoms that are indistinguishable from the disease.

To get accurate genetic screening of such a condition, extensive and lengthy population-based research needs to establish the existence and extent of correlations between specific DNA patterns and overt manifestations over time. What tests to use and how to choose them, which populations to screen, how to utilise and transfer the information, how to arrange counselling and follow up, how to obtain informed consent including, possibly, cost-effective generic consent to a panel of screening tests, how to protect patient privacy and exclude unnecessary commercial considerations, are all

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72 Although the terms genetic "testing" and "screening" are effectively synonymous in the bioethical literature, the latter go beyond the former to include population-based research to establish the existence and extent of correlations between specific DNA patterns and overt manifestations over time.
relevant issues. To save funds (especially with respect to counselling), detected carriers are often only informed of their status after screening if their partner is also a carrier and the child is thus at risk. This often unannounced fact may deceive carriers into either not seeking subsequent testing with a new partner, or not alerting relatives. Many also feel that it spoils the joy of prospective parenthood to only learn about the need for screening at that time. Each year nearly 40 per cent of patients with cystic fibrosis are hospitalised for one week or more, an impact on the health delivery system that is disproportionate to the absolute number with this disease. Some doubt that managed care health systems and insurance companies will cover the substantial costs of caring for children and adults with cystic fibrosis born to parents previously revealed to be carriers by a screening program. Population-based carrier screening for cystic fibrosis is predicated on the prevention, but if need be, the elective abortion, of an affected fetus. Can a doctor consider this a good, even if opted for by a pregnant patient, if research into the molecular pathology of cystic fibrosis yields novel therapies that extend the quality and span of life of those suffering this condition to 40 or 50 years?

The American College of Obstetricians and Gynaecologists (ACOG) has reviewed and agreed with a 1990 policy statement of the American Society of Human Genetics. This states:

"First, carrier screening should be offered to couples in which either partner has a close relative affected with CF. Second, one or a few federal, foundation, or privately supported pilot programs should be conducted as soon as possible in order to gather more data regarding laboratory, educational and counselling aspects of screening. Third, there is an immediate need for centralized quality control of laboratories conducting these tests. Fourth, it will be appropriate to begin large-scale population screening in the foreseeable future, once the test detects a larger proportion of CF carriers and more information is available regarding the issues surrounding the screening process. Until that time it is considered premature to undertake population screening."

The feasibility and effectiveness of carrier screening of prospective parents in at-risk populations has been demonstrated for Tay-Sachs disease and β Thalassemia. In the population of Ashkenazi Jews (those originating in Eastern Europe), one person in 16 is a carrier of the gene for Tay-Sachs disease, compared to approximately one in 300 in the general population. In this group, marriages are now often arranged by matchmakers who alone know the carrier status of likely brides and grooms (derived from test results taken at

82 United Kingdom House of Commons Science and Technology Committee, op cit n 75, p xlii. “Even if all mutations can be detected, the ability to carry out screening in the laboratory may outstrip the resources available to provide counselling to those who are found to be carriers”: B Korf, “Molecular Diagnosis” (1995) 332 (22) NEJM 1499 at 1501.
83 Korf, ibid.
85 Ibid at 329.
86 Colten, op cit n 84, at 329.
88 See S Elias, G J Annas and J L Simpson, “Carrier Screening for Cystic Fibrosis: A Case Study in Setting Standards of Medical Practice” in G J Annas and S Elias, Gene Mapping. Using Law and Ethics as Guides (Oxford University Press, 1992), p 199. On 16 April 1997 the United States National Institutes of Health (NIH) Consensus Panel recommended that all pregnant couples, or those planning pregnancy, be offered CF testing. But the American College of Medical Genetics disapproved, stating that there were not enough educational, counselling and support services. In Australia CF carrier screening is restricted to couples, or cascade testing of an extended family, that has affected children or heterozygous babies on newborn screening. Public hospitals perform the test for $20 to $100, there being no Medicare number or rebate. No relevant National Health and Medical Research Council (NHMRC) policy statement exists: G M Turner, “Carrier Testing for Cystic Fibrosis. How Should Australia Tackle This Problem?” (1998) 168 Med J Aust 375.
school and correlated with a given number) and can thus avoid procreative pairings between carriers. The process prevents carrier youngsters being shunned in the marriage market and also heads off conflict with opposition to abortion among the Orthodox community.\textsuperscript{91}

The effectiveness of carrier-testing of prospective parents has not been established for sickle cell anaemia.\textsuperscript{92} The sickle cell anaemia carrier-screening program failed in the United States because, it is alleged, it was not adequately targeted at counselling a population considering pregnancy, because the disease itself had poorly publicised, widely varying manifestations, because there was little community acceptance and because the program appeared to discriminate against a minority group.\textsuperscript{93} Such a program might be more clinically successful in a country such as Nigeria where, probably due to malaria survival advantages, 25 per cent of the population are carriers and 1 per cent homozygous, and thus symptomatic, from sickle cell disease.\textsuperscript{94}

It has been predicted that of the 2.8 million women a year in the United States who will soon be tested to ascertain if they are carriers of genes for four major inherited disorders (cystic fibrosis, sickle cell anaemia, hemophilia and muscular dystrophy), 50,000 will probably learn they are at risk of bearing affected children.\textsuperscript{95} It is to be expected that as the Human Genome Project progresses, however, the number of genes included in the screening of potential parents for carrier status will substantially increase, with a different emphasis in each nation. In Pakistan, Egypt and other Middle-East countries, for example, alleviation of the problems associated with consanguineous unions may reportedly be the most important priority.\textsuperscript{96} It is estimated that all people are carriers of five to seven recessive genes lethal to any fetus inheriting the same mutant recessive gene from both parents.\textsuperscript{97} Given this, it is inevitable that, as a public health measure, pressure will arise for carrier screening of prospective parents to be considerably expanded, particularly as advances in diagnostic technology allow coverage of a wider range of serious debilitating diseases with greater safety. One developing alternative for women whose pregnancies have been established, by screening, to have a substantial risk of disease, may be pre-implantation genetic diagnosis of the embryo.\textsuperscript{98} Embryo disposal prior to implantation, after genetic testing, may become a significant area of covert eugenics and a source of complexity for anti-abortion legislators.

The American Medical Association has recommended that all carrier testing must be voluntary, with informed consent and maintenance of confidentiality. Patients should be informed of the potential uses of the genetic information by third parties, where explicit consent has been given for its disclosure. Third parties, including insurance

\textsuperscript{92} I M Rutkow and J M Lipton, “Mandatory Screening for Sickle Cell Anaemia” (1973) 289 NEJM 865.
\textsuperscript{93} President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, \textit{Screening and Counselling for Genetic Conditions} (US Govt Printing Office, Washington, DC, 1983), p 22.
\textsuperscript{96} Ibid.
\textsuperscript{97} F Vogel and A G Motulsky, \textit{Human Genetics: Problems and Approaches} (Springer Verlag, 1996), pp 559-569.
\textsuperscript{98} The first cases of pregnancies regularly taken to term after blastomere biopsy involved parents at risk of transmitting X-linked adrenoleukodystrophy and mental retardation (A H Handyside et al, “Pregnancies from Biopsied Human Preimplantation Embryos” (1990) 344 Nature 768), and a couple at risk of transmitting cystic fibrosis (A H Handyside et al, “Birth of a Normal Girl After In Vitro Fertilisation and Preimplantation Diagnosis Testing for Cystic Fibrosis” (1992) 327 NEJM 905). In 1995 the birth of a phenotypically normal child was reported following an IVF procedure involving epididymal sampling and intracytoplasmic injection of spermatozoid followed by blastomere biopsy for preimplantation testing for cystic fibrosis: J Liu et al, “Birth After Preimplantation Diagnosis of Cystic Fibrosis Delta F508 Mutation by Polymerase Chain Reaction in Human Embryos Resulting from Intracytoplasmic Sperm Injection With Epididymal Sperm” (1995) 272 JAMA 1858. The October 1996 newsletter of the International Working Group on Preimplantation Genetics reported that from 20 centres worldwide, more than 100 unaffected children have been born following preimplantation genetic testing performed for single gene and chromosomal disorders. About half of these were checks for aneuploidy in older women having in vitro fertilisation (IVF): J Grifo et al, “Update in Preimplantation Genetic Diagnosis: Successes, Advances and Problems” (1996) 8 Curr Opinions Obstet Gynecol 135.
companies or employers, should not be permitted to discriminate against carriers of genetic disorders, through policies which have the ultimate effect of influencing decisions about testing and reproduction. Such fetal cells in maternal blood, then screens them for a small proportion of birth defects. Ultrasound after approximately 18 weeks gestation screens for genetic abnormalities that have manifested as physical conditions. Flinders Technologies and the Boehringer Mannheim Corporation are currently running a trial of the PreScreen test which isolates fetal cells in maternal blood, then screens them for genetic disease. If successful, this could lead to a massive increase in genetic screening during pregnancy. Patients with a family or personal history of genetic abnormality constituting an increased risk to the fetus, a history of multiple miscarriages creating an increased risk of chromosomally abnormal children and advanced maternal age (that is, over 35 or some other semi-arbitrary figure), may go on to seek prenatal genetic testing, as may, in some centres, those without an obviously elevated risk, provided they understand the additional risks involved and have conformed to appropriate guidelines.

The Australian Referral Laboratory currently charges $A876 for prenatal molecular diagnosis using DNA extracted from chorionic villus tissue or amniotic cells; $A720 to $A1,784 for direct enzyme or other analysis of chorionic villus tissue; and $A1,127 to $A2,495 for enzyme or other analysis in cultured cells (chorionic villus or amniocytes). This gives some idea of the community expenditure likely to be required as a consequence of increased intrauterine genetic screening. Alongside this, however, should be balanced the reduced cost to the public purse of lifetime care for a child with a severe genetic abnormality.

Prenatal embryonic screening

In Australia, the so-called triple screening test, performed between 15 and 20 weeks gestation, checks for three hormones in maternal blood – β HCG, alpha fetoprotein and unconjugated estriol. Levels indicating a high risk for disorders such as Down’s syndrome and neural tube defects lead to diagnostic tests such as amniocentesis or chorionic villus sampling (CVS) being offered. Amniocentesis has a 1 in 200-300 miscarriage rate, whereas CVS has a significantly higher miscarriage rate and a 1 per cent chance of a mosaic result which leads to a recommendation for amniocentesis. This “triple” screening only detects a small proportion of birth defects. ultrasound after approximately 18 weeks gestation screens for genetic abnormalities that have manifested as physical conditions. Flinders Technologies and the Boehringer Mannheim Corporation are currently running a trial of the PreScreen test which isolates fetal cells in maternal blood, then screens them for genetic disease. If successful, this could lead to a massive increase in genetic screening during pregnancy. Patients with a family or personal history of genetic abnormality constituting an increased risk to the fetus, a history of multiple miscarriages creating an increased risk of chromosomally abnormal children and advanced maternal age (that is, over 35 or some other semi-arbitrary figure), may go on to seek prenatal genetic testing, as may, in some centres, those without an obviously elevated risk, provided they understand the additional risks involved and have conformed to appropriate guidelines.

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Prenatal embryonic screening has been criticised, in the absence of gene therapy, as tacitly encouraging abortion and discriminating against the handicapped. It has been viewed as a means of employing the public purse of lifetime care for a child with a severe genetic abnormality.

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100 Ibid, p 22.
101 President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Screening and Counselling for Genetic Conditions: A Report on the Ethical, Social and Legal Implications of Genetic Screening, Counselling and Education Programs (1983).
102 United Kingdom House of Commons, Science and Technology Committee, op cit n 75.
103 Council of Europe, Genetic Testing and Screening for Health Purposes (1993).
reducing public funding for the handicapped and of branding parents who carry a genetically “abnormal” child to term as irresponsible. Until recently many believed that the goal of medical genetics was to reduce the birth prevalence of babies with, or destined to develop, genetic disease. But such thinking had the tendency to lead the state to count selective abortions for genetic disease as a benefit to public health, when clearly any such procedure is a terrible setback for the parents in question. Screening is often presented as “routine” and for “reassurance”. The possibility that it may lead to consideration of further risky investigations and abortions based on probability information is frequently not raised at the time of performance. There is a grave risk of eugenics where such screening is denied particular racial or cultural groups. If illnesses such as Huntington’s disease are added to the other “routine” screening tests, there may be pressure that this only be done on the understanding that abortion will be performed if the test is positive. To do otherwise, it is sometimes argued, would be to burden a child with knowledge of its early death in disrespect of its alleged right not to know.

**Homozygote neonatal screening**

Phenylketonuria (PKU) is a genetic disease creating in homozygote neonates, an absence of phenylalanine hydroxylase, the enzyme which catalyses the synthesis of tyrosine from phenylalanine. In the late 1950s it was found that if affected babies were commenced on diets low in phenylalanine before 20 weeks of age, the usual symptoms of severe mental retardation failed to develop. Initially PKU was screened for by a urine test with low sensitivity and specificity. It was not until Guthrie reported an assay for blood phenylalanine that was cheap, easy to administer and sensitive that mass screening became feasible. Trials were commenced and data collated. Within a year the National Association for Retarded Children (NARC) was lobbying in the United States for mandatory screening. In Illinois, lobbying was commenced by the mother of a PKU child writing to the Governor. In Florida, the mother of a PKU child missed by screening was involved. Dr Guthrie was an advocate for the legislation in New York. Beginning with Massachusetts in 1963, States in America began to pass screening legislation for PKU without any attempt at co-ordination. Religious objection of parents was the most common permitted exception. Physician conduct, rather than that of parents, was controlled by the laws, six of which imposed a penalty for violation. The legislation was divided over whether the State had an obligation to follow up and treat a positive result. In at least 23 States statutes could be construed as authorising a battery of genetic screening investigations. In Maryland a Commission on Hereditary Disorders was established to oversee the operation of the legislation and public participation and education encouraged, in what has been regarded as a model screening program. PKU was the first genetic condition for which widespread newborn screening was instituted. Since it has begun, admission of

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110 Ibid, p xl.
111 “The long term aim of genetic counselling is to see that as few children as possible are born with serious genetically determined or part genetically determined handicaps”: C O Carter, “Recent Advances in Genetic Counselling” (1979) 75 Nursing Times 1795.
113 Ibid.
114 Ibid.
115 Ibid at xli.

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**Phenylketonuria with Diets Low in Phenylalanine** (1960) 26 Paediatrics 1.
118 R Guthrie, “Blood Screening for Phenylketonuria” (1961) 178 JAMA 863. In the Guthrie test a newborn’s heelprick blood is added to discs containing controls and bacteria in a nutrient medium that are inhibited unless phenylalanine is present in the blood.
119 Committee for the Study of Inborn Errors of Metabolism, National Academy of Sciences, Genetic Screening, Programs, Principles, and Research (National Academy of Sciences, 1975), p 27.
120 Ibid, pp 288-293.
121 Ibid, pp 56-69.
122 Ibid, p 50.
125 Ibid, pp 51 and 291.
children with PKU to United States institutions for the mentally disabled has virtually ceased.126

Throughout Australia, newborn heel prick blood testing is performed at day three to four of life, for PKU (risk 1:10,000, 9 cases detected each year in New South Wales), congenital hypothyroidism (risk 1:4,000, 24 cases per year in New South Wales), cystic fibrosis (via immunoreactive trypsin and the AF508 mutation) (risk 1:2,500, 38 cases per year in New South Wales) and galactosaemia (risk 1:40,000, 2 cases per year in New South Wales). New South Wales is also screening newborns, as a pilot program, for congenital adrenal hyperplasia. The tests involved are inexpensive and safe and the diseases are susceptible to treatments which lead to either complete resolution or significant reductions in morbidity.127 Such considerations appear to have outweighed the lack of informed consent regularly involved. Full informed consent for such screening has been recognised as idealistic, but nonetheless recommended by a committee report from the United States Institute of Medicine.128

The New South Wales Newborn Screening Program is organised through one central laboratory at the New Children's Hospital, Westmead, Sydney. It screens all babies born in the Australian Capital Territory and New South Wales, approximately 95,000 annually. Genetic samples from all these tests are presently stored by the state and this may come in time to create a considerable ethical dilemma.

The British Medical Association has considered a proposal for neonatal screening for muscular dystrophy, the alleged advantages being warning parents about subsequent children, informing other potential carriers in the family as well as avoiding a delay in diagnosis and the social changes that necessitates. The chief disadvantage is that parents are told their son will develop a fatal condition (usually towards the end of the teenage years) for which there is no cure, years before the first symptoms appear.129 Further, the age of onset and severity of illness is only partly predicted by this large and variably mutated gene which arises by spontaneous mutation in a substantial proportion of cases.130 In 1970 Shwachman et al recommended neonatal homozygous screening for cystic fibrosis, on the basis that delayed diagnosis could lead to many patients already having developed malnutrition, chronic lung disease, hypoproteinemia, hypochloremia and dehydration.131 The proposal was restricted by the lack of efficacy of existing tests for the disease.132 However, DNA testing for the AF508 mutant allele greatly improves the sensitivity and specificity of investigations.133 This has led to increased calls for neonatal homozygous cystic fibrosis screening, when coupled with information that parent-child bonding is not disturbed by earlier diagnosis, that suffering in parents and child and costs of subsequent healthcare are both reduced and the number of further uninvestigated, and thus possibly affected, pregnancies decreased.134

Peri-gravid genetic screening, abortion law and medical conscientious non-compliance

A variety of conceptual premises lie behind the “marketing” of peri-gravid genetic screening in all three of its major manifestations to patients and the

126 Ibid, p 56.
127 Committee on Genetics, “New Issues in Newborn Screening for Phenylketonuria and Congenital Hypothyroidism” (1982) 69 Pediatrics 1. As a result of genetic screening and resultant dietary changes, women homozygous for PKU are now living normal lives and reproducing, a situation which causes problems for their babies. See J Seymour, Fetal Welfare and the Law (Australian Medical Association, 1995), p 25. Numerous other conditions have been considered for neonatal screening including maple syrup urine disease (branched-chain ketoaciduria), biotinidase deficiency, Hartnup disease and histidinemia.
129 United Kingdom House of Commons, Science and Technology Committee, op cit n 75, p xli.
130 Ibid.
medical profession. The first is that the process facilitates choice. It is argued that couples should have the right to whatever genetic information they choose in order to make reproductive decisions, but that the state should have no power of forcing them to act upon it, for example by forgoing marriage, forgoing children or requiring their abortion or therapeutic alteration. Yet many States in the United States already mandate newborn screening programs that detect untreatable conditions with the obvious inference that they are eugenically seeking to influence parents’ reproductive decision-making. What should the attitude of doctors be to such laws?

It is difficult for doctors to object to genetic screening which offers a useful treatment once a condition is found. However, they must look beyond the language and related narratives of control, choice and reassurance to the reality. Real choice, as the law of disclosure of material medical risk (informed consent) increasingly asserts, is predicated, at least from the Western philisophic perspective, on the existence of accurate, relevant information, as well as its non-directive communication to an agent capable of understanding that routinely leads to rational and autonomous action. It is also premised on the existence of services (that is, equitable access to legalised, safe, inexpensive abortion or state financial and infrastructure assistance to the genetically impaired and their carers) that give effect to that choice. Without such legal and social supports, a public health interest in peri-gravid genetic screening may easily shade off into a pseudo-eugenics, a means of separating fetuses which society’s dominators plan to develop from those they wish to discontinue.

The Human Genome Project will lead, through increased screening information, to enhanced worldwide pressures for abortion and, consequently, for medical conscientious non-compliance. This will be exacerbated by laws on abortion which, as I will now show, are far from uniform or straightforward internationally.

The Supreme Court of the United States, for instance, in the 1970s recognised that a pregnant woman had a constitutional privacy interest, arising from the 14th Amendment’s protection of “personal liberty and restrictions upon State action”, in being permitted to have an abortion prior to viability without undue interference from the state. Subsequently, the Supreme Court nonetheless upheld a State statute prohibiting the use of public funds for performing, encouraging or counselling (possibly including genetic counselling) with respect to abortion not necessary to save maternal life. It has also upheld State legislation designed to encourage birth over abortion, by mandating waiting periods and forcing doctors to communicate information about fetal development, unless a “medical emergency” arises. The crucial demarcation between the liberty of the pregnant woman and the interest of the State in protecting the lives of its citizens was held to be viability, a line drawn at the discretion of the medical profession and the technology it commands.

A pregnant Irish girl had to appeal to the Court of Justice of the European Communities when, like thousands of her countrywomen, she decided that the fetus she was carrying should be aborted, contrary to the prohibition in s 58 of the Offences Against the Persons Act 1861, an English statute that remained in effect after Irish independence. Since 1973 in Denmark legislation has permitted abortion upon request up to the end of the 12th week of pregnancy. After this time a local social

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138 See Rogers v Whitaker (1992) 175 CLR 479.
140 Webster v Reproductive Health Services 492 US 490; 106 L Ed 2d 410; 109 S Ct 3040 (1989).
141 Planned Parenthood of Southeastern Pennsylvania v Casey 120 L Ed 2d 674; 112 S Ct 2791 (1992). An interesting feature of this case was the way in which the Supreme Court struck down the State spousal notification principle after receiving much evidence on the widespread nature of domestic violence.
council has the discretion to permit abortion for several reasons among which are severe fetal abnormality. 143 This is similar to the position in France and Belgium under laws adopted in 1975 and 1990 respectively. The abortion debate in France was dominated by the controversy over the abortion-inducing drug RU486, which was portrayed as removing physicians and risk from the process. The Abortion Act 1974 (Singapore) allows medically assisted abortion upon demand until 24 weeks. 144

In the former German Republic (East Germany) the Law on the Termination of Pregnancy 1972 and its accompanying regulations permitted abortion on demand in a medical facility until 12 weeks after conception. Subsequently in the pregnancy, abortion was under the control of a medical commission. The Federal Republic of Germany (West Germany) permitted abortion under para 218A of the Penal Code 1871. Abortion was a crime but not punishable when performed by a doctor upon a consenting woman to avoid danger to her life or serious risk to her physical or mental health, taking into account current and future living conditions. Abortion was also permitted during the first 22 weeks of pregnancy where the fetus was suffering from some hereditary disease or pre-natal injury so serious that the woman could not be expected to continue with the pregnancy. After unification, a new abortion law based on the Eastern (GDR) model was rejected as unconstitutional by the Federal Constitutional Court as being in conflict with the state’s constitutional obligation to protect life, born and unborn. Abortion was again a crime, not punishable if discretionary medical conditions were met. 145

In Canada the Criminal Code 1970 (Can), s 251(4)(c), permits termination only when continuation would endanger the life or health of the mother, which has been held to include mental health. 146

Abortion remains a crime in many developing countries and illegal abortions there account for a large percentage share of maternal mortality and morbidity. It is a story of great suffering, silenced by illiteracy, poverty, censorship, age, social taboo, poor statistical records and state apathy and corruption. Hundreds of thousands of women die or are maimed each year after illegal abortions, violently pumping blood onto the dirt floor of a hut or bottom of a bus or bullock cart or stretcher, as family and friends search in vain for help. 147

In Australia the desire of a woman to be relieved of her pregnancy is not, of itself, a justification for performing an abortion. 148 In the States of New South Wales and Victoria, it is a statutory criminal offence for a doctor to unlawfully procure an abortion for a patient. 149 Common law decisions in each of these jurisdictions, however, held that such an abortion will not be unlawful if it is necessary to preserve the woman from a serious danger to her life or her physical or mental health, not being merely the normal dangers of pregnancy or childbirth. 150 As a strict matter of law, this means that abortions are illegal if performed in those Australian States because of the mother’s difficult economic circumstances, because the conception was due to rape, because the mother is single or unmarried, because the birth would lead to the break up of the parents’ relationship or marriage, would deleteriously affect existing children or because the fetus is known to have severe genetic abnormalities.

Table 1 shows the disproportionate number of abortions performed in South Australia allegedly owing to problems with the “mental health” of the mother, taking into account her “actual or

148 R v Bayliss; R v Cullen (1986) 9 Qld Lawyer Reps 8 at 10.
149 Crimes Act 1900 (NSW), ss 20, 82-84; Crimes Act 1958 (Vic), ss 10, 65, 66.
reasonably foreseeable environment”. Many of these were probably not medical diagnoses, but acts of conscientious non-compliance by the medical profession in that State.\(^{151}\) Evidence for this conclusion is provided by a New South Wales study of 2,249 women seeking abortion, which showed that 60 per cent listed financial concerns as a primary factor in the decision.\(^{152}\) This situation has led the editor of a major Australian paper to state that “[t]he availability of abortion in some States has rested on a foundation of little more than nudges and winks”.\(^{153}\) Such comments fail to highlight the suffering produced in other countries with less advanced healthcare systems, where abortion remains illegal.

Section 82a(1)(a)(ii) of the Criminal Law Consolidation Act 1935 (SA) gives the medical profession a discretion to term an abortion “lawful” where there is a substantial risk that the child, if born, would be seriously physically or mentally handicapped. The Criminal Code Act 1983 (NT) has similar provisions. A “fetal” ground does not currently exist under the maternal health exceptions of the Criminal Code 1899 (Qld) and the Criminal Code 1924 (Tas). The Australian Capital Territory is covered by the common law exceptions developed in \(^{154}\) Wald and Davidson.\(^{155}\) Two doctors (Victor Chan and Hoh Peng Lee) were recently arrested in Western Australia for attempting to procure an abortion for reasons not related to preserving the life of the mother. This sparked legislative amendments to the Criminal Code 1913 (WA) allowing, in effect, abortion on demand up to 20 weeks gestation and beyond if two doctors agree that either mother or child has a severe medical condition. Legislators refused to debate which such respect was a matter of “subjective interpretation by the doctor” which should involve consideration of genetic conditions justified termination, on the basis that to do so was to enter into eugenics.\(^{156}\)

![Table 1. Indications for Abortion, South Australia, 1975-1979 and 1980-1984*](image)

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>1975-1979</th>
<th>1980-1984</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental disorder</td>
<td>16,795</td>
<td>19,159</td>
</tr>
<tr>
<td>Obstetric conditions</td>
<td>14</td>
<td>11</td>
</tr>
<tr>
<td>Anencephaly</td>
<td>4</td>
<td>34</td>
</tr>
<tr>
<td>Other brain/spinal anomalies</td>
<td>3</td>
<td>28</td>
</tr>
<tr>
<td>Other congenital anomalies</td>
<td>231</td>
<td>147</td>
</tr>
<tr>
<td>Rubella exposure</td>
<td>68</td>
<td>28</td>
</tr>
<tr>
<td>Other perinatal conditions</td>
<td>41</td>
<td>10</td>
</tr>
<tr>
<td>Other conditions</td>
<td>162</td>
<td>920</td>
</tr>
</tbody>
</table>


In \(^{157}\) CES v Superclinics (Australia) Pty Ltd\(^{157}\) Priestley JA held that “concern and worry” had, in a doctor’s opinion, to be sufficient to present a serious threat to the pregnant woman’s physical and mental health to make abortion lawful at common law.\(^{158}\) Kirby ACJ pointed out that the “honest belief” that Wald\(^{159}\) and Davidson\(^{160}\) required in this respect was a matter of “subjective interpretation by the doctor” which should involve consideration of serious economic and social pressures.\(^{161}\) If an abortion is attempted and the fetus is born alive the full panoply of human rights crystallise, at common law, upon it, and homicide proceedings are possible.

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\(^{151}\) Under the Criminal Law Consolidation Act 1935 (SA), ss 81, 82, 82a.  
\(^{154}\) (1971) 3 DCR (NSW) 25.  
\(^{155}\) (1969) VR 667.  
\(^{157}\) (1995) 38 NSWLR 44.  
\(^{158}\) Ibid at 82.  
\(^{159}\) (1971) 3 DCR (NSW) 25.  
\(^{161}\) CES v Superclinics (Australia) Pty Ltd (1995) 38 NSWLR 44 at 63.
If the fetus was capable of being born alive, in some jurisdictions, child destruction laws operate.\textsuperscript{162}

The doctor whose patient is considering abortion after genetic testing may thus be faced with a variety of legal obligations conflicting with medical loyalty and triggering considerations of conscientious non-compliance. He or she is an informed confidant of peri-gravid patients, with a delicate, legally mandated discretion to determine the validity of abortions (that is, is it an emergency, is the fetus viable, is there a substantial risk of severe handicap?) and an occasionally contradictory statutory responsibility (that is, in certain States in the United States) to provide clinical information designed to discourage the procedure. Doctors carrying out genetic carrier screening tests of prospective parents and mindful of medical loyalty, should only do so if the patient has fully considered the consequences of both a negative and positive result. These include, with respect to the latter, remaining childless, having an abortion, undergoing artificial fertility techniques such as pre-implantation genetic testing, discrimination, disturbance of marital relations and the consequences for any resultant child.

Two interesting recent studies cast significant light on the complex problems and chaotic considerations peri-gravid genetic screening will create for doctors sensitive to protecting the good of their patients against eugenic pressures, if need be by conscientious non-compliance.

Michie et al have recently reported a study of 149 patients attending routine genetic consultations at a single regional genetics centre in the United Kingdom. Eighteen declined to participate. There were 108 men and 23 women in the remainder (131) with a mean age of 32 years. Counselling sessions were taped, transcribed, then analysed for directiveness using a modification of the Hill counsellor verbal response category system.\textsuperscript{163} Counsellees and counsellors were also asked to rate directiveness. It was found that all consultations contained at least two directive statements, with advice ("I think it would be better not to bother your parents") and evaluation ("that is what we would consider quite a high risk") being more frequent than reinforcement ("I understand: that's really very sensible"). There was wide variability among counsellors as to directiveness, increasing among those who had not received counselling training. Counsellors communicated more directly to patients they rated as more concerned and also to those of a lower socio-economic group. Of the one-third of patients (46) who felt they had to make a decision about genetic risk, 36 felt their counsellor had a view about the decision they should take and 23 felt they were being steered toward that decision.\textsuperscript{164}

True genetic choice is allegedly axiomatically compatible only with non-directive counselling.\textsuperscript{165} The study by Michie et al shows that medical education is important in this regard, both because well-trained doctors are less directive and because there is such a wide variability between doctors with regard to directiveness. As the number of genetic tests increases, it is reasonable to view general practitioners increasingly being called upon to fulfill a genetic counselling role. This will not be easy as in many centres it is a task fulfilled by a specialist team.\textsuperscript{166} There is some evidence that many doctors currently regard opinion-seeking from patients as a sign of trust and that not to be directive in such circumstances is both disloyal and irresponsible.\textsuperscript{167} There is actually very little hard evidence that non-directiveness is perceived by patients, either at the time of visiting their doctor for genetic counselling, or subsequently, as benefiting them.\textsuperscript{168} Many patients actually report a greater

\textsuperscript{162} See, eg, Crimes Act 1958 (Vic), s 10 and Criminal Law Consolidation Act 1935 (SA), s 82a(7)-(8); Rance v Mid-Downs Health Authority [1990] NLJ 325.


perceived risk associated with more neutral counselling.\textsuperscript{169} In such a context civil liability will be an ever-present problem.\textsuperscript{170} The major threat, however, is that with inappropriate legislation and without a viable concept of medical conscientious non-compliance, directive genetic counselling could become a form of eugenics.

Some of the factors behind such a development may be seen in Eng et al's recent study of 2,824 Ashkenazi Jewish prospective parents who had enrolled as couples for Tay Sachs disease carrier screening at a genetics centre.\textsuperscript{171} Couples were offered simultaneous counselling, education and, if chosen, testing for not only Tay Sachs disease (TSD),\textsuperscript{172} but for cystic fibrosis (CF)\textsuperscript{173} and type 1 Gaucher disease (GD).\textsuperscript{174} These have carrier frequencies of 1 in 25, 1 in 25 and 1 in 18 respectively; making 1 in 8 individuals in this population a carrier for one of the diseases.

Almost all subjects who had not received prior genetic testing opted to undergo all three tests. Both prospective parents were found to be carriers 8 times for TSD, 6 times for CF and 7 for GD. All 20 of the couples where both were carriers and had a current pregnancy, opted for prenatal diagnosis by amniocentesis. Termination of pregnancy was decided for each positive test for TSD and CF, but not for the mild forms of GD. Questionnaires revealed that patients had a strong desire for knowledge about other genetic disorders, especially if recommended by their doctor, or if the disease were severe. Patients were likely to share the genetic information with their doctor and family but not with their friends. They gave much more thought as to whether to be tested for GD where the clinical manifestations may be mild and treatable. They were less likely to rely on genetic tests lacking a high sensitivity and specificity. Where a partner was found to be a carrier for one of the diseases, the spouse had a lower opinion of them if they had planned only a small number of children. This indicates that though educated patients are capable of independent decision over complex genetic information, it creates intense personal choices which may be easily influenced by a state's restriction of support services.

\section*{Conclusion}

If doctors are to remain loyal to conscience and the good of their patients undergoing peri-gravid genetic screening, they should not be shy about advocating political and legal change against eugenics. A government that reduces funding for support services for the genetically disabled, which takes the fiscal razor to genetic counselling services (especially for the poor, or for Aboriginal populations in remote areas) may be engaging in a form of eugenics contrary to international agreements.\textsuperscript{175} Doctors should lobby to ensure that mandatory genetic screening is never justified on the basis of producing a uniformity in genetic constitution that is not related to the prevention of specific diseases. They should encourage the government to subscribe to international conventions to this effect.

Similarly, doctors should vigorously advocate reform of genetically antiquated domestic laws that may compromise the good of patients and place doctors in the position of having to regularly consider conscientious non-compliance. For example, related public health legislation, medical commercial inducements or malpractice fears may encourage increased prenatal screening for which the only extant therapeutic option is termination of pregnancy. Given this focus on fetal diagnosis and health, it will become increasingly irrational for the

\begin{thebibliography}{99}

\bibitem{shiloh} S Shiloh and L Saxe, "Perception of Risk in Genetic Counselling" (1989) 3 Psychol Health 45.
\bibitem{crowley} See L Crowley-Smith, "Therapeutic Abortions and the Emergence of Wrongful Birth Actions in Australia: A Serious Danger to Mental Health?" (1996) 3 JLM 359.
\bibitem{eng} C M Eng et al, "Prenatal Genetic Carrier Testing Using Triple Disease Screening" (1997) 278 (15) JAMA 1268.
\bibitem{tay} Carrier testing for Tay Sachs disease (TSD) used enzymatic analysis of β hexosaminidase A activity in serum and leukocytes from men and non-pregnant women, and leukocytes from pregnant women. Specificity approaches 100%. Carriers so identified were confirmed by polymerase chain reaction amplification and mutation specific restriction enzyme analysis of the three common mutations (1278insSTATC, IVS12+1, G2695S) present in 97% of Ashkenazi Jewish carriers with TSD.
\bibitem{cystic} Carrier testing for cystic fibrosis (CF) was performed by analysis of five mutations (del F508, W1282X, G542X, N1303K, 3849+10kbC→T) that detected approximately 96% of Jewish carriers.
\bibitem{gaucher} Carrier testing for Gaucher disease (GD) included four mutations (N370S, 84GG, L444P, IVS2+1) that detected 95% of Jewish carriers.
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common law, as it does in certain jurisdictions in Australia, to permit abortion prior to an ever-diminishing age of viability, only in circumstances which take no account of the genetic status or characteristics of the fetus, except indirectly by their influence on maternal health. It will be even more irrational if, as in some jurisdictions in the United States, the tide of commercially motivated genetic screening remains unchecked, while State laws place increasing obstacles in the path of women seeking abortions prior to viability.

Some have seen public health law as presently involved in a detrimental slide toward privatisation and litigation-supervised self-regulation. The lack of correspondence between peri-gravid genetic screening and abortion law is an important public health issue that will not be resolved by legal desuetude.

Given the pressures likely to arise from increased peri-gravid genetic screening, what legal protections from financial or religiously motivated withdrawal of abortion services exist? If, as many fear, legislation is passed, or courts take it upon themselves to prohibit abortion on demand, it is unlikely that there will be a concomitant restriction on peri-gravid genetic screening. Doctors will have, for some time, to sail on a sea of legal and ethical uncertainty, strapped like Ulysses or Bloom to the mast, between the spectre of peri-gravid screening eugenics and concern for the good of increasingly litigious patients. It may be wise for their professional bodies to consider how best to develop the underlying virtue of medical loyalty and its correlate, conscientious non-compliance, as promoted by the Nuremberg and Geneva Declarations. If such changes are not attempted, then the negative impacts of the Human Genome Project will probably fall disproportionately on women, particularly those who are poor or otherwise vulnerable to state reproductive coercion.

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Table 2. Principles of Population-based Genetic Screening

1. The disorder screened for should create a significant burden to all affected individuals.
2. The inheritance and pathogenesis of the disorder should be scientifically understood.
3. The disorder should be preventable or practical therapy available, including before and after, non-directive genetic counselling, reproductive alternatives and social support services. Where medically controlled abortion is the primary contemplated therapy, there should be a guarantee of ready and equitable access to it.
4. The patient’s right to informed consent, voluntary participation, refusal without compromising ongoing medical care or other social services or benefits and confidentiality should be respected. Undergoing such screening should not be a precondition for insurance, health service provision, marriage, or employment, without due cause related to the health and safety of the persons concerned.
5. The cost-benefit ratio to the patient (public) should be greater than one.
6. Laboratory screening methods should minimise false positive and exclude all false negative results. They should only be performed under the supervision of a qualified physician at a licensed laboratory.
7. A practical and safe diagnostic test should be available (in addition to a screening test).
8. Both screening and diagnostic tests should be available to all who require them, regardless of financial considerations or preconditions about eventual personal choices.
9. The introduction of genetic screening should not lead to discrimination against the handicapped, or cultural or ethnic groups, particularly with regard to the provision of social services.
10. Data from such screening should be stored separately from other medical records and with prior full explanation as to access, duration and place of storage and destruction of both it and the original sample.

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