of how society perceives a particular trait also poses concern. For example the gene(s) for 'shortness' or 'fatness' (if they exist) may, based upon society's demands, be considered undesirable traits. Once labelled as 'undesirable' it may become as much a medical condition as more severe genetic conditions. Such misnomers may even cause individuals to select against these traits during prenatal screening. Alternatively individuals may seek to 'remedy' these perceived medical conditions through gene therapy.

The Australian Privacy Commissioner notes a distinction must be made 'between genetic makeup of the individual and the way that makeup manifests itself',[43] How one describes such genetic traits should neither unfairly label nor stigmatise. The Privacy Commissioner, therefore, uses 'characteristics' and 'condition' which 'should not be taken as implying anything about whether a particular characteristic of condition is commonly regarded as desirable or otherwise'.[44] While such semantics can only aid in the understanding of genetic information, it is likely to be extremely difficult to maintain.

3.5 Using Genetic Information

A broad overview suggests that there are two main uses of genetic information: these being first for medical, therapeuticor healthcare purposes, and second, for non-medical or non-therapeutic purposes. In later chapters I deal with both of these uses.

The medical uses include diagnosis, reproductive planning, disease prevention, treatment and research. These applications raise numerous legal and ethical issues, including informed consent, privacy, confidentiality, duty to warn, public health screening, and medical malpractice.[45] Of particular importance is the dissemination of the information to the individual tested. The desire, or conversely lack of desire, to know one's genetic makeup is not limited to the patient, but may extend to all those who may have inherited similar genetic material.

However, many argue that the risks involved with foresight into one's future health prospects are yet to be realised. As yet, there are few cures available for genetic conditions, and consequently genetic knowledge will often be unlikely to save lives. Instead genetic testing, and subsequent revelation of genetic disorders, may cause people to refrain from having normal relationships, bearing children, or suffering ongoing depression, advancing arguments that its use should be restricted. Others, however, argue that genetic information can free individuals of the burden of thinking they have inherited a particular genetic trait, and provide some form of relief.

Genetic information may also be of interest to public health authorities (for statistical purposes), insurers, employers, schools, child welfare agencies, adoption agencies, law enforcement officials, and the armed services. Such application has caused worldwide concern about the ability of existing law and policy to regulate non-clinical uses of genetic data, in particular the underwriting of insurers, and the hiring practices of employers.[46]

In both contexts, the broad range of use makes it extremely difficult to formulate any universally applicable principles. However, certain themes do reoccur, notably conflicts between individuals and third parties over control of genetic information, balancing the potential benefits against the cost and consequences of obtaining it, and placing into perspective the evolutionary, psychological, and social power of genetic information.[47]

Such issues are tackled on three fronts in this thesis: first the innately private relationship that exists between doctor and patient and the pressures upon it when identifiable others may be at risk; second the privacy of information in the public realm when society, institutions, or third parties may benefit; and finally, the potential for genetic discrimination of individuals, groups, or races.

The references for this article and copies of Hamish's thesis are held in the Bioethics Research Centre and the Sir Robert Stout Law Library at the University of Otago. Hamish can be contacted at the office of the Health and Disability Commissioner, PO Box 12 299, Wellington.

Open Letter

15 May 1998

The use of stored body parts or bodily substances for research purposes without informed consent

It has recently come to my attention that routinely stored pathology samples may be being used for research without the consent of the consumers involved on the belief that the sample is 'abandoned'. I would, therefore, like to take this opportunity to clarify provider obligations under the Code of Health and Disability Services Consumers' Rights when conducting research on body parts or bodily substances.

While I am able to make general comments and indicate those provisions of the Code which appear to be particularly relevant, I am not able to give advance rulings on interpretation and application of the Code. The complaints jurisdiction under the Health and Disability Commissioner Act requires investigations to be undertaken impartially and with an open mind. This would be open to challenge if I had already said that the practice under investigation was or was not a breach of the Code. However, the following general comments may be useful.

Right 9 of the Code makes it clear that the rights in the Code extend to those occasions when a consumer is participating in, or it is proposed that a consumer participate in, research. In particular, for present purposes, Rights 7(9) and 7(10) set out consumers' rights in respect of decisions about body parts or substances:

(9) Every consumer has the right to make a decision about the return or disposal of any body parts or bodily substances removed or obtained in the course of a health care procedure.

(10) Any body parts or bodily substances removed or obtained in the course of a health care procedure may be stored, preserved, or utilised only with the informed consent of the consumer.

Right 7(6) requires informed consent

to a health care procedure to be in writing if the consumer is to participate in any research. A 'health care procedure' is defined in the Health and Disability Commissioner Act 1994 to include health research.

Right 6(3)(d) entitles consumers to information about the results of research, when requested. In addition to general information about research results, Right 6(1)(f) and (g) entitles consumers to information about the results of tests and procedures. This information should be given without the consumer having to ask and may occasionally raise the issue of informing consumers of research discoveries which will affect them, for example, genetic conditions.

Consequently, in cases where pathology samples are to be stored, the consumer's consent is required. Where research is to be carried out on these pathology samples, the consumer's written consent is required. The obligation on providers is to show that all reasonable actions in the circumstances were taken to give effect to these rights. What is reasonable will be assessed on a case-by-case basis. For example, if providers are unsure if the stored sample will be used for research in the future, the mere likelihood may be enough to require written informed consent. Where the obtaining of written informed consent is culturally inappropriate, it may be reasonable in the circumstances to dispense with the need for writing, but in all such cases, the general obligation to obtain verbal informed consent still remains.

Where there is a proposal to conduct research on samples collected without donor consent for the research, for example, because the samples were collected prior to the implementation of the Code, the researcher should try to trace the relevant donors in order to obtain their informed consent. The researcher should not assume that the samples have been abandoned and the consumer does not care what use they are put to. Research without the consent of the consumer may be in breach of the Code.

Where samples are unidentifiable or stored unlinked, then the obtaining of ethical approval for the research will be one of a number of factors taken into account by the Commissioner in determining whether the researcher acted reasonably and, therefore, whether he or she has complied with the Code.

I hope these comments are of assistance.

Yours sincerely

Robyn Stent

Health and Disability Commissioner

European Association of Centres of Medical Ethics

1998 Annual General Meeting

XV European Conference: Ethics & Mental Health, Rome 15-17 October 1998

Convener: Psychoanalytic Institute for Social Research. Conference Chairman: Sandro Gindro

This conference takes up the famous WHO definition of health as a positive condition of physical, mental, and social well-being. Mental health is a crucial issue in medical ethics and bioethics, because it is a crucial issue in medicine. Actually no health policy is ethically tenable without a serious concern for people's mental conditions.

Historical Background: In 1977 the World Psychiatric Association (WPA) produced the first ethical code specifically devoted to psychiatry known as 'Declaration of Hawaii', updated in Vienna (1983) and in Madrid (1996). In 1977 the Council of Europe adopted the Recommendation 818, which called for better protection of the mentally ill. In 1983, the Committee of Ministers adopted Recommendation R (83) 2 on the legal protection of person suffering mental illness. In 1988 the European Parliament passed a resolution on ending violations of the European Convention of Human Rights within the field of psychiatry. In 1993 the European Commission (EC) funded a research programme on 'Ethical aspects of coercive treatment and / or supervision in the community of psychiatric patients' within BIOMED 1. In 1995 two Euro-conferences on the ethics of psychiatry were convened (Paris, May 1995 – Berlin, September 1995). In 1996 the WHO published a document on ethical requirements of psychiatric hospitalisation. In 1994 the General Directorate XII of the European Commission promoted a conference on 'Ethical Aspects of Brain Research'. The meeting was organised for November 1994 by the Psychoanalytic Institute for Social Research and served to create a first informal network of scholars interested in the bioethics of neuroscience and of its application in the clinical field. In 1997 the European Commission has financed a research project on 'Ethical, Legal, and Social Aspects of Brain Research' (BRAIN ELSA) in the scope of the Program BIOTECH 2.

For more information contact:

Conference Organising: P.Santoro, B.Wilcox – **11, Passeggiata di Ripetta – 00186 Rome – Italy**
Tel: + 39 6 32652401 Fax: + 39 6 32501233 Email: iprs@mclink.it