

Compulsory Licensing of Patents Inquiry
Productivity Commission
LB2 Collins Street East
Melbourne VOC 8003

Dear Sir / Madam

Inquiry into the Compulsory Licensing Provision in the Patents Act 1990 Productivity Commission

Submission by Cancer Voices Australia

Cancer Voices Australia wishes to provide consumer comment on aspects of the Productivity Commission's Draft Report on Compulsory Licensing of Patents.

Cancer Voices Australia is the independent, 100% volunteer voice of people affected by cancer, working to improve the cancer experience for Australians, their families and friends. We are active in the areas around diagnosis, information, treatment, research, support, care, survivorship and policy. To achieve this we work with decision-makers, ensuring the patient perspective is heard.

Cancer Voices has led the cancer consumer movement in Australia since 2000. Cancer Voices organisations across Australia share the same objectives and work together on national issues identified as important by their members, with consumers working to help others affected by cancer.

General comment

Australian health consumers are becoming increasingly aware of the sometimes negative impact of our present patent system on the affordability of, and equity of access to, healthcare products and services. This may be seen especially in relation to treatments and diagnostic tests. It could be argued that for people affected by cancer, this is very important. Both cancer treatment and diagnosis remain areas which need and attract a great deal of innovation due to the relative uncertainties about how to successfully deal with the many forms of cancer. The growth of genomic profiling for use in more targeted treatments and diagnoses is an example of the trend we want to see facilitated as much as possible.

Cancer Voices has been active in the public discussion about pharmaceutical patents via IP Australia's current Review, and over some years, about human gene patenting. For the latter, Cancer Voices has been a party to the present legal case about the patenting of BrCa 1 gene, the findings of which are expected this month.

Support of public interest test

We are aware of and support the submission made by our peak health consumer organisation, Consumers Health Forum of Australia (CHF). We especially endorse CHF's support of the Commission's proposal to move to a public interest test, rather than the current "reasonable requirements of the public test as criteria for gaining a compulsory license. We note that public

Interest would be assessed with regard to factors such as benefits, to consumers and the licensee, from the licensee's access to the invention; and with regard to the longer term impacts on the health of the community. We believe these should be prime criteria, noting the present arrangements barely mention the benefit to health consumers.

Awareness raising measures

Cancer Voices also supports the suggestion that information about compulsory licensing provisions should be readily accessible, written in plain English, and located on a logical Australian Government website. This would ideally include a short explanation as to how the provisions are applied to health care related patents.

Adverse impacts of patents on human genes

Our members, people affected by cancer, are extremely concerned about the threats regarding access to and ownership of breast cancer genes, posed by enforcement of international and Australian gene patents. Cancer Voices is concerned that such threats are applicable to other cancers and diseases.

As an ethical and philosophical principle, we do not believe that genes, as natural parts of the human body and other forms of life, should be patentable. We have previously recommended that Australian patent law be amended so that no part of a living thing can be patented. While this has yet to come about, we see potential for the Commission's proposals to ameliorate the more negative aspects of the present situation.

We note that international case studies show that enforcement of gene patents reduces access, and drives up testing costs dramatically, for patients. Enforcement also hinders scientific research and the sharing of important medical knowledge (Luigi Palombi: Gene Cartels Biotech Patents in the Age of Free Trade, Scribe Publications 2009). And we have seen no evidence that offering patents is necessary to encourage the identification or isolation of human genes. That they are currently patented under Australian law is an anomaly which should be corrected. It has become standard practice for researchers to patent human gene simply to ensure that no-one else does so, reducing their access, and compounding the problem. The only supporters seem to be those who have a financial interest in the present situation being maintained – this we regard as not acceptable and a conflict of interest. It is certainly not in the public interest.

International (USA and UK) legal cases have found that patents have been improperly granted over human genes. Australia is currently awaiting a decision relating to Myriad Genetics and its patent over the tumour suppressor gene BrCa1

We would like to highlight the following two points:

High risk cancer families: Currently some people from **high risk cancer families** can access genetic tests for gene mutations associated with their cancer through public hospital familial cancer centres and testing facilities. Commercial monopolies of cancer gene testing, achievable through patenting, are likely to lead to increased costs, as evidenced by the costs which could be chargeable to individuals, for instance by Genetic Technologies P/L which has an international patent for the BrCa1 and BrCa2 genes. A longer term outcome is likely to be an increase in health care costs for cancer treatment, a cost that may well have been avoided.

Medical research & pharmacogenomics: Cancer Voices NSW is very aware of the need for access to genetic material by medical researchers. We see the *development of pharmacogenomics, or personalised treatment* though the use of genetic testing of our tumour tissue, to be the light on the hill for we cancer patients. Personalised cancer treatment, using the recent surge in knowledge about human genes, will improve patient outcomes and reduce wastage of ineffective drugs and the overall costs of health care. We are all hoping that researchers will make progress quickly so that we, as well as those who follow us, can benefit. To this end we successfully encouraged the Cancer Council NSW to fund a collaborative study, and have warmly welcomed the International Cancer Genome Consortium, supported by the Australian Government to the tune of over \$20m. That project aims to speed up delivery of personalised treatment. If genes and genetic material can be patented, and if those patents are enforced, this vital area of medical research will be more costly, slower and less translatable to the end beneficiaries.

In parallel, we also commend the establishment of a National Genetic Framework as proposed by the Royal College of Pathologists of Australasia, to ensure that Australia has appropriate regulations for genetic testing.

Thankyou for the opportunity to make a submission to this important Inquiry.

Yours sincerely



Sally Crossing AM

Executive Committee, Cancer Voices Australia

8 February 2013