Dear Committee secretary,

Please find attached my submission to the Senate select committee on men's

health. I have sent it as a Rich Text Format document.

Yours sincerely, Kenneth Newton

Committee Secretary
Senate Select Committee on Men's Health
PO Box 6100
Parliament House
Canberra
ACT 2600

Dear Committee members,

As I am an individual and do not represent any organisation, I do not have the resources to make a detailed submission on all the terms of reference. However, I do wish to make some comments.

## Item 1. Funding.

There are some anomalies relating to pharmaceutical benefits which impact adversely on men with prostate cancer. Drugs used to treat lower urinary tract symptoms such as 5- $\alpha$  reductase inhibitors (e.g. finasteride, dutasteride), selective  $\alpha$ -blockers (e.g. tamsulosin) and anticholinergics (e.g. tolterodine, solifencin) are not available to men with prostate cancer under the Pharmaceutical Benefits Scheme (PBS), except for former servicemen. After radiotherapy for prostate cancer, there maybe continuing urinary symptoms. Surgery following radiotherapy is likely to be more hazardous and medical treatment may be preferred. These drugs come at a considerable cost to the individual, particularly men who are taking several of these medications in combination.

Access to imaging technology is also limited by Commonwealth regulation. Although mammography is freely available to women, as far as I am aware, transrectal ultrasound (TRUS) does not attract a Medicare rebate except if it is being done for the purposes of biopsy. Digital rectal examination (DRE) has been shown to pick up only about half the prostate tumours which are detectable by TRUS. A significant number of men have prostate cancers (especially more aggressive grades) which don't produce prostate specific antigen (PSA) which is used as a marker of prostate cancer. Therefore, tumours may be missed both on the DRE and blood testing for PSA. TRUS should be available as an option, especially for men with an increased risk of prostate cancer.

Magnetic resonance imaging (MRI) of the prostate also does not attract a Medicare rebate. For men whose prostate cancer does not produce PSA, this may be the best method for assessing disease progression. The lack of a Medicare item number not only means that there is no rebate but because these examinations don't come into the system, the costs don't count towards the Medicare safety net. For a person on a Health Care Card, the cost of a single MRI scan may be near the amount at which the safety net would normally be activated. But as the cost of these investigations does not count, the safety net is more illusory than real.

I would also point out that Medicare benefit schedules are not very user-friendly. A patient maybe advised by a staff member at a Medicare office that MRI's attract a rebate on one day, only to return later with the invoice to be told by another staff

member that no rebate applies. This can create considerable difficulties for someone on a low income.

Cancer nurse coordinators are of enormous assistance to men with prostate cancer and not surprisingly are highly regarded by the men who have access to them. There are a multitude of problems which need to be faced by men with prostate cancer on diagnosis, during the investigations in the work-up phase, deciding among the treatment options, coping with treatment and managing the problems that arise after definitive treatment. These problems are both physical and psychological. There are too few funded positions for cancer nurse coordinators, so that those who are currently employed are overstretched. Those men who don't have access to a cancer nurse coordinator are being unfairly dealt with. This situation needs to be fixed.

The support services for younger men with prostate cancer need to be increased. Prostate cancer is commonly viewed as a disease of elderly men. Younger men may feel that the support services on offer don't match the problems they are facing. The support groups affiliated with the Prostate Cancer Foundation of Australia do a very good of supporting many men with prostate cancer but younger men, particularly those with more aggressive disease, who are more likely to die from their cancer may not feel their concerns are being met. Problems such as the future of their young families and concerns about sexuality and maintaining intimate relations with their wife or partner may be of much greater concern. Phosphodiesterase 5 inhibitors (e.g. sidenafil, tadalafil, vardenafil) which may be used to treat some of their problems are not covered by the PBS.

For single younger men with prostate cancer there are some additional difficulties. Repeatedly hearing the phrase that "prostate cancer is a disease affecting the whole family" may be reassuring to those men who are in a stable family situation but for single men it tends to emphasise their social isolation. Their predicament can be summed up in the black humour contained a presentation prepared by Mr John Friedsam of the Cancer Council of New South Wales. "Hello, I'm impotent and I dribble, can I buy you a drink?"

There is a very marked disparity and the ability of country people to access is health services compared to those in large cities. Too often, I've heard politicians raise "straw man" arguments such as "we can't have a cardiac surgery unit in every small hospital, you know". Country people do not expect tertiary level cardiothoracic services in their local hospital but they should be given access to health care services on an equitable basis compared to those in metropolitan areas.

If governments are unwilling or unable to provide health care for people in the country, then they should make provision for country people to travel to the city to access the necessary health care without incurring excessive costs. The various State-based patient travel subsidy schemes usually cover only a small proportion of the actual cost of travel and accommodation. I understand that people in rural areas have much lower average incomes compared to those in urban areas.

Farmers face additional problems because they own farms and are therefore largely excluded from social security benefits. They may get a Health Care Card if they are in an Exceptional Circumstances (Drought) declared area. These declarations are for

one in 20 - 25 year events and there are major difficulties in obtaining these declarations. As it appears that the Federal Government is intent on further restricting support to drought affected farmers in the future, we can expect the situation to get worse. Only a small proportion farmers in drought declared areas will qualify for social security benefits because of the exclusion criteria. However, people in cities who may have much greater assets can qualify for social security benefits because their assets are excluded from consideration. The ownership of assets is commonly structured in such away as to ensure they will qualify. Having a social security card of some sort results in higher patient travel subsidies and much lower medication costs. Many private health care providers also offer concessional rates to social security card holders, so farmers who may have very low or negative incomes are further disadvantaged.

For people living in the city, going through treatment for a major illness such as prostate cancer may mean perhaps a couple of hours away from home or work each day over a period of months. They may have an appointment with a specialist on one day, be referred for an investigation some days later and arrange a follow-up appointment with the specialist to review the results of treatment still later on. The logistics for country people are such that they have little opportunity to return home between consultations, tests and treatments. They may be away from home for months at a time.

To be alone in the city without your usual support network is difficult enough. However, for farmers it poses additional major problems. Contrary to the belief of many in urban areas, farms don't just run themselves. Livestock need food, water and veterinary care. Crops don't plant themselves or end up in silos by magic. It is difficult to find competent and reliable help to operate a farm while you are away for prolonged periods. Graziers may have to substantially de-stock and those in engaged in cropping or horticulture can also expect a major fall in income. Therefore, people in country areas suffer multiple levels of the disadvantage on top of lesser health care facilities.

Because of less frequent contact with their health care team, country patients may find that those treating them in the city may have difficulty recalling the details of their health problems and as a result, the quality of their care may be impaired.

There are other forms of disadvantage relating to the absence of health care professionals in country areas. Although Medicare rebates are available for consultations with psychologists and exercise physiologists, if there are no accredited practitioners in the region, those rebates may as well not exist. I don't think most patient transport assistance schemes would approve transport to see an exercise physiologist.

The reimbursements for transport and accommodation are set for government employees at a level that is seen to be reasonably fair. I am unaware of any evidence that shows that the costs incurred by country patients travelling to the city for treatment are significantly different from the costs incurred by government employees. I can see no valid reason why the reimbursement schedules applying to government employees should not also apply to country patients.

The more hurdles and obstacles we put in place to prevent people from obtaining health care, the worse their health outcomes are likely to be. An example of this is the higher rates of cancer mortality for those in country areas of Queensland compared to those in the metropolitan area.

I believe the average age of a farmer is in the late 50's. Therefore, half of all farmers are older than this. This older age group is likely to require health care interventions more frequently. Therefore, there should be a greater provision of health care services in country areas to cater for this aged population. Instead, what we see is a much inferior level of services.

## Item 2. Education and awareness.

Depression is still a major problem in rural areas where appropriate facilities are few and the stresses encountered are great. The mental health seminars being run through the auspices of the NSW Farmers' Association with funding from the NSW Department of Health have been very welcome. They were originally envisaged as 2 day seminars but country people were generally unable to be away from their farms for so long. Many have to travel very long distances and would have had stay away overnight. However, the 3 hour abridged versions have been much more suited to the needs of country people. It is to be hoped that further funding can be provided so that people in country areas who are facing major and prolonged stress can be provided with a series of 3 hour sessions. Even though they may be spread over several months, people could get a total of 2 days of information, training and advice.

Young women during their child-bearing years are likely to have frequent contact with health care providers for reasons of fertility control, pregnancy and the health of their young families. Young men, if they can avoid motor vehicle accidents and sporting injuries, may have little contact with the health care system for decades. As a community, we could do a lot better in applying preventative health strategies to young men. It would be expected that by doing so we could both increased the life expectancy of men closer to that of women and increase their years of good health. Simple measures such as establishing a baseline PSA for young man may have considerable long-term benefits. If the PSA is below a certain value, then he would be unlikely to develop prostate cancer. But if the PSA is higher or following a rising trend then he should be followed more carefully. Recording easily measurable variables such as weight, blood pressure, etc at regular intervals is likely to lead to earlier intervention to reduce the risk of overt illness. However, with a mobile population, secure electronic storage of health data in a fairly standardised format would be required for major benefits to be realised.

I realise this submission may lack polish and be unreferenced. However, I considered it important to bring these issues to the attention of the Committee. Should the Committee require further information, I would be pleased to supply it if I can manage it.