

A New Zealand Layman's Perspective on Prostate Cancer

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Time and the world do not stand still. Change is the law of life and those who look only to the past or the present are certain to miss the future.

John F Kennedy

1.0 MY BRIEF

I have been asked to focus on “the various ethical and logistics issues surrounding the provision of consistent high level medical care and equitable outcomes across the whole prostate cancer pathway.” Those ethical and logistics issues immediately raise a number of further, inter-related issues:

- (a) The ethical obligation of primary care health professionals to be up-to-date with the best, latest information about prostate cancer – when PCa is just one of the many things a general practitioner “Jack or Jill of all trades and master of none” needs to know about. However, failure to be up-to-date can have literally fatal consequences when a man’s prostate cancer is not detected early enough or is not treated properly.
- (b) Professional medical organisations have an ongoing obligation to help keep primary care health professionals up-to-date – which may be challenging.
- (c) The issue of how Governments can offer (and fund) care equitably for all men, but especially for men in diverse ethnic and socio-economic communities, and geographically remote populations.
- (d) The tensions inherent where there may be limited local treatment options for men, resulting in some men choosing the most convenient treatment option rather than optimal treatment.

As the title of my address indicates, I am a New Zealand layman; that is, I am a medical consumer. When the PSA test first became available my then doctor added that to the range of my periodic blood tests. Following elevation of my PSA, I was diagnosed with prostate cancer at the age of 60, and elected to have a radical prostatectomy, and, since then, my PSA has been undetectable. I joined the Prostate Cancer Foundation of New Zealand a year later, and have been its President since 2010.

2.0 MY WISH LIST

Insanity – doing the same things over and over and expecting different results

(attributed to Albert Einstein)

2.1 As a New Zealand layman, my wish list is easy to express, but not so easy to implement. However, and happily, most of it is the subject of current initiatives!¹

2.2 Awareness programmes supported by Ministry of Health and primary health care professionals

(a) The objectives of the current New Zealand Ministry of Health Prostate Cancer Awareness and Quality Improvement Programme are:² “... to address current deficiencies by:

- providing all men with equitable access to information about prostate cancer
- ensuring general practitioners (GPs) have the appropriate knowledge and resources to effectively manage men presenting for assessment of prostate cancer or prostate cancer risk
- removing barriers that restrict the effective use of diagnostic and treatment services
- ensuring that all men have consistent care across the whole prostate cancer care pathway
- focusing on achieving equitable outcomes from care.”

(b) Noble objectives, but how are they to be delivered? The reality is that nothing will change unless awareness campaigns are well-resourced and are also supported by primary care professionals:

(i) ***Serious money is committed to spreading the message to those who need to get their prostate health checked.*** Depending on men seeing their GPs is not going to work for a number of reasons:

- A typical consultation is 15 minutes long, and little effective advice can be given if prostate health issues are tacked onto a consultation arranged for some other reason,
- Many men are staunch about their health, and resistant to the idea of getting their prostate health checked,

¹ As the balance of this paper indicates.

² See <http://www.health.govt.nz/system/files/documents/publications/prostate-cancer-awareness-and-quality-improvement-programme.pdf> and <http://www.health.govt.nz/our-work/diseases-and-conditions/cancer-programme/prostate-cancer-programme/prostate-cancer-awareness-and-quality-improvement-programme>.

- Some GPs are either ill-informed or misinformed about prostate cancer issues,³
- Handing out written material to men is not going to be effective – effective targeted marketing is required, and
- It would help if the women in men’s lives were motivated to encourage men to get checked.

I recently heard an experienced GP recently comment that he has never seen middle-aged male patients leave his surgery with a pamphlet, but their wives do. Printing material alone will be ineffective; innovative approaches are required to raise awareness.

(ii) *Primary health care professionals have clear guidance, are well-educated about prostate cancer, and spend adequate time informing men about prostate cancer.* At least the first two of those issues are scheduled to be addressed in New Zealand in the next few years.⁴ However, it is then up to all involved health care professionals to adopt and follow the new Guidelines and help make men and their families to become more aware of prostate health issues, and to improve the delivery of prostate health care.

3 I can give two illustrative proofs of that assertion:

- I had an email from a GP angry at my assertions that:
 - The Ministry of Health guidelines have done men and their GPs a disservice in recent years. As recommended by the Parliamentary Select Committee on Health in 2011, those guidelines must urgently be replaced.
 - Medical General Practitioners need to be made aware that PSA testing is the best available means of detecting early prostate cancer, which is often not revealed by any symptoms. For many men, by the time they are aware of prostate cancer symptoms it is too late to eliminate the cancer.

Patient and polite email correspondence established that the GP was entirely ignorant of the findings and recommendations of a 2011 New Zealand Parliamentary Select Committee Report on prostate cancer, and that his knowledge was selective, and he claimed that his professional bodies had failed to keep him adequately informed.

- The Prostate Cancer Foundation of New Zealand Chief Executive Officer had a horror story told to him. A man in his late 60’s informed the CEO that he had been asking his GP about PSA testing for some years, and that his GP had asked him if he had any symptoms which the doctor then identified. He was told that as there were no symptoms there was no need to get a PSA test. He eventually developed symptoms, but by the time he was aware of those symptoms the cancer was metastasised. He then told his son that at the age of about 40 he was twice as likely as other men to get prostate cancer so he should get himself checked. A few weeks later the son reported back that his GP had advised him that his blood test result was “normal.” His father asked him what his PSA was, but the son didn’t know, so his father told him to find out. When the father learned his son’s PSA level he discovered that it was higher than the father’s – so guess who went to see a urologist!

4 The New Zealand Ministry of Health Prostate Cancer Awareness and Quality Improvement Programme Working Group will ensure that GPs have a decision support tool and Patient Management Systems to inform and support their role (see <http://www.health.govt.nz/our-work/diseases-and-conditions/cancer-programme/prostate-cancer-programme/prostate-cancer-awareness-and-quality-improvement-programme> at pages 8 and 10), and improve care along the prostate cancer pathway (Ibid. at page11), and the AQIP work will include or be associated with the up-skilling of health professionals (Ibid.).

2.3 Elimination of inequalities and inequities (affecting Māori, Pacific Island and those in lower socio-economic groups, and those living in more remote and smaller communities)

- (a) A recent report funded by the New Zealand Law Foundation, *Fault Lines, Human Rights in New Zealand*, concludes that “inequalities in health outcomes for Māori, Pacific and socio-economically disadvantaged sectors of the community remain.”⁵

A number of initiatives have targeted reduction of inequalities in health outcomes for Māori and Pacific communities and families with disabled children including the development of Māori and Pacific Health Action Plans and the nurturing of Māori and Pacific health providers to enhance capacity. Strategies have also been developed for children with disabilities and in the mental health sector. Despite this, inequalities in health outcomes for Māori, Pacific and socio-economically disadvantaged sectors of the community remain and are consistent themes in the government reports, the NGO shadow reports and the Committee’s concluding observations. ...

This is morally, socially and legally unacceptable.

- (b) While the Law Foundation Report does not refer to prostate cancer, two recent Midlands Prostate Cancer research project Reports, *The Midlands Prostate Cancer Study: Understanding the Pathways of Care for Men with Localised Prostate Cancer in New Zealand*,⁶ and *Final Report for the Management of Metastatic Prostate Cancer Study*,⁷ clearly show that the “inequalities in health outcomes for Māori, Pacific and socio-economically disadvantaged sectors of the community” are very clearly a distressing reality in prostate cancer:

“Māori men are about twice as likely to have metastatic disease at diagnosis as non-Māori.”⁸

5 *Fault Lines, Human Rights in New Zealand*, New Zealand Law Foundation, page 94 – while this comment is not specific to prostate cancer the Report’s conclusions are applicable to prostate cancer as is evident from Lawrenson R, Brown C, Lao C, Obertova Z (2014), *Final report for the Management of Metastatic Prostate Cancer Study*, Uniservices Auckland, Waikato Clinical Campus, Hamilton.

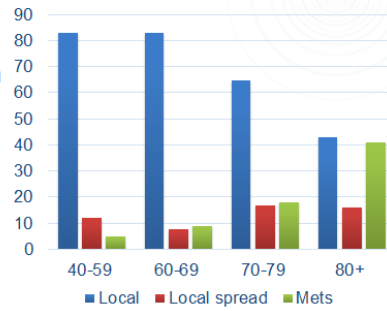
6 Health Research Council Reference, 11/082, February 2014.

7 Lawrenson R, Brown C, Lao C, Obertova Z (2014), *Final report for the Management of Metastatic Prostate Cancer Study*, Uniservices Auckland, Waikato Clinical Campus, Hamilton.

8 Lawrenson R, Brown C, Lao C, Obertova Z (2014), *Final report for the Management of Metastatic Prostate Cancer Study*, Uniservices Auckland, Waikato Clinical Campus, Hamilton, page 56, with the diagram from a PowerPoint presentation at the launch of the Report, 7 May 2015.

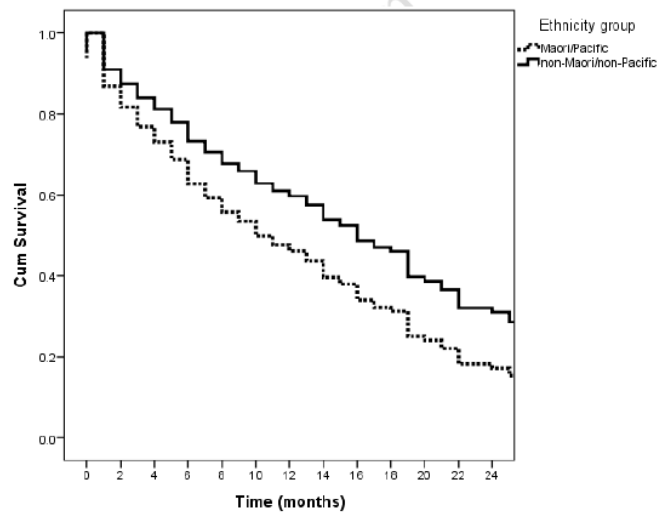
Characteristics of 535 men with prostate cancer
– 65 (12.1% with metastases)

- 19% Maori diagnosed with metastatic disease
- 10% of NZ Europeans



Māori and Pacific patients had a 49% greater risk of death following diagnosis.⁹

Figure 2 All-cause survival by ethnicity by Cox proportional hazards model.



2.4 Government funding of appropriate treatments and drugs

Treatments and drugs are inevitably costly,¹⁰ and availability of funded drugs and treatments equally inevitably depends on the weighting given to competing demands on the public purse. From May 2015 Zytiga is funded in New Zealand, but getting funding for necessary treatment modalities and drugs is a constant battle.

2.5 Acceptance of the PSA test – until something better is discovered, the best detection tool we have

In my view there are three significant things about the PSA test:

⁹ Lawrenson R, Brown C, Lao C, Obertova Z (2014), *Final report for the Management of Metastatic Prostate Cancer Study*, Uniservices Auckland, Waikato Clinical Campus, Hamilton, page 23.

¹⁰ See <http://www.stuff.co.nz/national/health/68324546/Big-Pharma-has-the-upper-hand-and-they-know-it>.

- (a) At present, the PSA test is the best means of detecting prostate cancer,¹¹ at a stage when it is likely still to be treatable.
- (b) The PSA test is not perfect. However, its accuracy is comparable to the accuracy of breast cancer screening.¹² We do not hear of a campaign to discredit breast cancer screening. Why not?
- (c) Someday there will be a better test or tests than PSA testing (but will those currently opposed to PSA testing be convinced?).

2.6 General Practitioners who know and follow best practice

- (a) Some GP’s do not believe in PSA testing, and the reasons usually relate to the (relative) unreliability of PSA testing. The same doctor probably relies on a weather report to decide what to wear or whether to go golfing or fishing, and will support mammogram testing. PSA tests will give false positives and false negatives, but if the GP waits until a man presents with symptoms of prostate cancer that man is being sentenced to a probably miserable end of life.
- (b) Some GPs are simply not well-informed.¹³
- (c) Their professional organisations must train and convince them.

2.7 General Practitioners and specialists who really understand what it’s like being diagnosed with PCa (the “human” face of care)¹⁴

11 “The PSA test remains the best single modality for detecting a risk of prostate cancer” – *Diagnosis and Management of Prostate Cancer in New Zealand Men*, para 4.1.4, <http://www.health.govt.nz/system/files/documents/publications/diagnosis-management-prostate-cancer-nz-men.pdf>. See also the New Zealand Parliamentary Health Select Committee Report, *Inquiry into early detection and treatment of prostate cancer*, July 2011 http://www.parliament.nz/resource/en-nz/49DBSCH_SCR5250_1/9af1e99ad9183fcb697b74e539e0bc3ce4b010fe.

12 The New Zealand Parliamentary Health Select Committee Report, *Inquiry into early detection and treatment of prostate cancer*, July 2011 http://www.parliament.nz/resource/en-nz/49DBSCH_SCR5250_1/9af1e99ad9183fcb697b74e539e0bc3ce4b010fe, page 20:

Table 3: Comparison of sensitivity and specificity for cancer screening tests

Screening test	PSA test	Mammography	Cervical smear	Faecal occult blood
Cancer screened	Prostate cancer ⁸	Breast cancer ⁹	Cervical DCIS ¹⁰	Bowel cancer ¹¹
Sensitivity	43–73%	63–97%	40%–81%	5.4%–83%
Specificity	56–97%	91–97%	75%–98%	65%–99%

Estimates of PSA sensitivity and specificity from the ERSPC suggest that the positive predictive value (PPV) for the PSA test which is a function of sensitivity, specificity, and disease prevalence, may be better than that for mammography...”

13 See footnote 3.

... Without clear knowledge of their current and future pathway men and their families can suffer from anxiety, causing undue stress at an already distressing time.

Patients have identified that receiving a prostate cancer diagnosis has an immediate and in some cases long-term emotional and psychological impact on themselves and their family. Men described that there is, at times, significant variability in the information they received and the pathway of care. questions and health information needs changed at times quite rapidly, with the progression of the cancer and duration of specific medications. This required ongoing support to alleviate concerns about the unknown future.

Men highlighted the need for more information, increased support, understandable future planning, and identified these needs as existing even many years after their diagnosis. Clear communication and appropriately targeted information that is adapted to health literacy level and progression of disease is an important tool in assisting patients through the cancer experience.

Those conclusions from researchers are borne out by feedback the Prostate Foundations of New Zealand and Australia receive from patients.

2.8 Impartial but empathetic advice on options relating to watchful waiting, active surveillance and treatment options¹⁵

Our qualitative research has raised a number of important issues. Firstly men and their families/whanau noted a lack of information about prognosis, treatment options, on-going monitoring and likely complications of treatment. This led to some distress which would seem to be avoidable. We also note that while men acknowledged they had reached a stage where their disease was terminal – that the support from the health services rather than intensifying left some men with a sense of abandonment.

2.9 Speedy access to treatment when required

Access to treatment varies between the public and private systems, and geographical isolation from available treatment can also cause delays. The 2013 Ministry of Health Task Force Report¹⁶ recognised that “It is essential that all men requiring assessment for possible prostate cancer and all men requiring investigation and treatment of a confirmed diagnosis of prostate cancer have timely access to high-quality health care.

14 Lawrenson R, Brown C, Lao C, Obertova Z (2014), *Final report for the Management of Metastatic Prostate Cancer Study*, Uniservices Auckland, Waikato Clinical Campus, Hamilton, pages 53-54.

15 Lawrenson R, Brown C, Lao C, Obertova Z (2014), *Final report for the Management of Metastatic Prostate Cancer Study*, Uniservices Auckland, Waikato Clinical Campus, Hamilton, page 56.

16 *Diagnosis and management of prostate cancer in New Zealand men: Recommendations from the Prostate Cancer Taskforce*, Ministry of Health, 2013, <http://www.health.govt.nz/system/files/documents/publications/diagnosis-management-prostate-cancer-nz-men.pdf>, page 52.

Achieving this level of access includes: having an acceptable wait time following general practice referral to prostate biopsy under specialist care; timely reporting on specimens by pathologists; informing men and their families and whānau of the diagnosis in a timely manner; and having acceptable wait times for treatment. These conditions apply to all of the treatment options, including active surveillance, surgery, radiation therapy and palliative care.”

The current Ministry of Health Prostate Cancer Awareness and Quality Improvement Programme proposes that¹⁷ “Men will have better access to health services, experience shorter wait times and receive consistent treatment for prostate cancer in New Zealand, with this being achieved by developing national standards and key indicators for prostate cancer, implementing monitoring of prostate cancer diagnosis and treatment times, developing and implementing guidelines on the use of active surveillance, developing and implementing guidelines for treatment of prostate cancer, and improving access to multidisciplinary advice.”

2.10 Post-treatment care – through medical professionals and effective peer-to-peer support

Lack of follow-up care and advice following treatment is a feature of several recent reports,¹⁸ and improvements should flow from the present Ministry of Health Prostate Cancer Awareness and Quality Improvement Programme.

2.11 Better palliative care

A recent Report notes ongoing concerns about palliative care.¹⁹ The Prostate Cancer Awareness and Quality Improvement Programme notes that²⁰ “There is a range of management options for men who have incurable, locally advanced or metastatic prostate cancer. Palliative care has an important role in the management of patients with metastatic prostate cancer and needs to be integrated into the patient’s care as early as possible. Providing appropriate and effective palliative care is important for the quality of life of men with metastatic prostate cancer. The Ministry is already working to improve the consistency of available palliative care services in New Zealand. This work includes implementing the Resource and Capability Framework for Integrated Adult Palliative Care Services in New Zealand (Ministry of Health 2012c).” What precisely is happening or will be done I do not at present know.

17 See <http://www.health.govt.nz/system/files/documents/publications/prostate-cancer-awareness-and-quality-improvement-programme.pdf>, page ix.

18 Lawrenson R, Brown C, Lao C, Obertova Z (2014), *Final report for the Management of Metastatic Prostate Cancer Study*, Uniservices Auckland, Waikato Clinical Campus, Hamilton, page 35.

19 Lawrenson R, Brown C, Lao C, Obertova Z (2014), *Final report for the Management of Metastatic Prostate Cancer Study*, Uniservices Auckland, Waikato Clinical Campus, Hamilton, pages 48, 49 and 55.

20 See <http://www.health.govt.nz/system/files/documents/publications/prostate-cancer-awareness-and-quality-improvement-programme.pdf>, page 13.

3.0 WHAT IS BEING DONE IN NEW ZEALAND NOW

3.1 A fellow PCFNZ Board member, who says he is “usually more of a realist rather than an idealist,” believes “there are a few things that should be happening now and some I hope will eventuate in the future:

- “at age 40 every man receives a notice, probably through electronic means, to go to his GP for a PSA blood test if there is a family history of prostate cancer,
- “then at age 50 every man receives a notice and a voucher for a free visit for a PSA test regardless of family history with a reminder from his GP to come for a check-up every year,
- “every man diagnosed with prostate cancer is referred to the Prostate Cancer Foundation and receives comprehensive information on treatments and the treatment process,
- “there will be a less invasive way of following up a PSA test if required, using high resolution ultra-sound or a scanning device. However I accept that biopsies will still be part of the process in some cases,
- “treatments will be refined so that there are less serious side-effects, and
- “there will be specialist men’s health clinics and hospitals in the main cities built and funded through the PCF and private benefactors.”

3.2 For the present, we in New Zealand can take some comfort in knowing that there is a body of work now going on which is intended to address the issues I have been asked to focus on; “the various ethical and logistics issues surrounding the provision of consistent high level medical care and equitable outcomes across the whole prostate cancer pathway.”

3.3 The Ministry of Health Working Group to which I have referred was established in late 2013 to oversee and advise on the work programmes for a Prostate Cancer Awareness and Quality Improvement Programme (AQIP) to improve awareness of prostate cancer issues, the delivery of better care to those with prostate cancer, and monitoring, evaluation and research.²¹ I am a member of the Working Group, and its work is ongoing and will continue for several more years, and a number of significant proposed outcomes are proposed to result from that work:

(a) Greater and better awareness of prostate cancer issues

- (i)** Good information about prostate cancer testing and treatment that is balanced and easy to understand is to be made available to help men have informed discussions with their GP or health professional about their prostate health, and make better decisions.

21 See <http://www.health.govt.nz/our-work/diseases-and-conditions/cancer-programme/prostate-cancer-programme/prostate-cancer-awareness-and-quality-improvement-programme> and <http://www.health.govt.nz/system/files/documents/publications/prostate-cancer-awareness-and-quality-improvement-programme.pdf>.

- (ii) A brief leaflet and more detailed booklet were produced in 2013 as the first in a range of initiatives to raise awareness of prostate cancer, to encourage men to be alert to their prostate health, and to prompt conversations with their doctor, nurse or health practitioner.
- (iii) The new resources are being based on clinical advice and recommendations from the Prostate Cancer Taskforce,²² with input from a wide range of specialists, primary health care professionals, and people representing patients.
- (iv) As general medical practitioners play an important role in helping men make decisions about prostate cancer checks and treatment, the AQIP is developing tools and support for doctors and health services so they can provide clear guidance on the possible harms and benefits of different tests and treatment options.
- (v) The AQIP is also developing guidance, training and tools to help GPs and other health professionals provide consistent, quality prostate care. These include the development of a decision support tool to facilitate discussion and shared decision-making between men and GPs (and other primary care providers), enhancements to patient management systems to help primary care services manage men with prostate cancer and track patients against agreed care plans, better integration of referral systems within DHBs, and the development of content for training and education for GPs and other health professionals.

(b) Delivery of better care along the cancer pathway

- (i) Referral guidelines and national standards are being developed so men have equal access to specialist services for assessing and treating prostate cancer. The standards will help enhance early detection while limiting the harms and complications that can be caused by unnecessary treatment.
- (ii) Guidelines are being developed for each step along the prostate cancer pathway, including guidelines to determine how far a cancer may have spread, for risk assessment of prostate cancer, for the use of active surveillance, and for the management of advanced and metastatic prostate cancer. Those guidelines will provide greater consistency in prostate cancer management.
- (iii) Tumour standards are being developed for prostate cancer which will set out best practice management of specific tumour types across a patient pathway and enable a nationally consistent and coordinated approach to care. In addition, the International Society of Urological

22 *Diagnosis and Management of Prostate Cancer in New Zealand Men*, [http://www.prostate.org.nz/documents/diagnosis-management-prostate-cancer-nz-men_\(3\).pdf](http://www.prostate.org.nz/documents/diagnosis-management-prostate-cancer-nz-men_(3).pdf).

Pathology has promulgated a tumour grading system, which is being adopted in New Zealand, to replace the Gleason scoring system.

(c) Monitoring, evaluation and research

- (i)** Collecting and analysing data is central to the function of a quality improvement programme, and evaluating and monitoring the progress of improvements, and the impact of change, are key aspects of this programme.
- (ii)** Systems are being and will be developed to improve data collection, reporting and analysis, including structured reporting for prostate cancer biopsies and prostatectomy specimens, and indicators will be implemented to enable monitoring across the prostate cancer pathway.
- (iii)** Ongoing research is intended to support continuous quality improvement and provide insights into areas such as the harms and benefits of tests and treatment, the system-wide consequences of increased referrals, the extent of metastatic disease, and the extent and cause of inequities.

3.4 My brief was to focus on “the various ethical and logistics issues surrounding the provision of consistent high level medical care and equitable outcomes across the whole prostate cancer pathway.” I will close with the following predictions:

- (a)** I believe that within the next 2-3 years we will have, in New Zealand, a sound framework to address the logistics issues surrounding the provision of consistent high level medical care and equitable outcomes across the whole prostate cancer pathway. However, providing adequate funding, and physical and human resources, to deliver on the promised improvements will be an ongoing challenge.
- (b)** The ethical issues surrounding the provision of consistent high level medical care and equitable outcomes across the whole prostate cancer pathway may, in part, be resolved when the professionals involved are provided with better information, training and resources. I suspect that, as with any profession, there will be professionals dealing with prostate cancer patients who do not undertake the necessary training, do not read the information provided, and do not use the resources provided. Worse, there are some who believe that they know better than the experts involved in developing the New Zealand Ministry of Health Prostate Cancer Awareness and Quality Improvement Programme. Those who fail to provide the most appropriate care must (and will) be held to account.

**The difficulty lies, not in the new ideas,
but in escaping from the old ones**

John Maynard Keynes