Feedback On
Draft Prostate Cancer Guidance

February 2015

Sent to:

Heather_Button@moh.govt.nz

The Contact Person for this feedback is:

Professor Jenny Carryer
Executive Director
College of Nurses Aotearoa (NZ) Inc.

j.b.carryer@massey.ac.nz

MINISTRY OF HEALTH
MANATŪ HAUORA

FEEDBACK FORM

- Prostate Cancer Management and Referral Guidance
- Prostate Cancer Active Surveillance Guidance

Introduction

You are invited to provide feedback on the following draft documents:

- *Prostate Cancer Management and Referral Guidance*
- *Prostate Cancer Active Surveillance Guidance.*

Please use this form to provide your feedback. You can provide comment on your own behalf or as a member of an organisation.

How to have your say

Please complete this form electronically and email it to Heather_Button@moh.govt.nz by 5:00 pm Friday 13 February 2015. All feedback will be acknowledged by the Ministry of Health.

When commenting on the draft documents, please be as specific as possible and where appropriate, support your comments with evidence or suggested alternatives. You can choose to answer some or all questions, or to comment one or both draft documents.

Please note that your feedback may be requested under the Official Information Act 1982. If this happens, the Ministry will release your submission to the person who requests it. If you are an individual, as opposed to an organisation, the Ministry will remove your personal details before releasing your submission if you tick the following box.

☐ I **do not** give permission for my personal details to be released to persons under the Official Information Act 1982.

Your contact information

Name of person or contact person if submission is on behalf of organisation/group:	Professor Jenny Carryer Executive Director, College of Nurses Aotearoa (NZ) Inc.
Postal address:	PO Box 1258
	Palmerston North 4440
Phone:	06 358-6000
Contact email:	j.b.carryer@massey.ac.nz

Are you submitting this as *(tick one box only in this section):*

an individual (not on behalf of an organisation)? ☐
on behalf of a group or organisation √

name of group/organisation: College of Nurses Aotearoa (NZ) Inc.

other *(please specify)*: .....

Would you like to receive a summary of feedback received?

Yes √
No ☐

Prostate Cancer Management and Referral Guidance

Review questions

Overview

1. Do you have any general comments on the Prostate Cancer Management and Referral Guidance, such as its readability, language and structure? Do you think it is easy to follow and understand?

   No, it is not that easy to follow. There is a lot of page turning in the document to get to the information needed while interpreting the flow charts. We would prefer there was more information on the flow chart such as normal PSA age related ranges so a decision could be made from the flow chart (or electronic screen) than have to flip back and forth. We understand that health professionals in Primary Health Care are becoming more familiar with this type of pathway and find them easy to navigate.

   We would prefer a user friendly electronic version which would hopefully be the outcome after the pathways are implemented into each workplace. This would make it a lot easier to navigate, it needs to be clickable to reveal the notes behind each point which would make it much more accessible. We understand this may the intention once the guideline is approved.

   It also needs to have the referral form linked into this document which should be the same format nationwide.

2. After reading this guidance, do you feel more confident managing men with symptoms suggestive of prostate cancer or who request a prostate cancer test? If not, what is needed in the guidance to improve your level of confidence?

   Yes it contains good information about appropriate testing. There are sufficient references. Although in some places, it is repetitive which we have highlighted below in the suggestions boxes. We understand people may read the pathway out of order so these sections need to be well covered which could explain this.

   There is a lot of excellent information, which we suspect will not be read by health professionals with busy workloads. Should the education/information behind this guideline be provided as an addendum, rather than included. Then the guideline could be kept short and concise rather than a 10-page document.

3. What is the best way to integrate this guidance into your work environment

   Using an electronic platform, in an existing format such as clinical pathways which have been introduced in Mid Central. National agreement on a platform with a similar system to those in PHC currently managing MOH targets.

   Would this present any challenges? If so, how could those challenges be mitigated?

The education of all health professionals and health care providers involved in this process. Educational roadshow throughout the country to all providers by the development team to address health professionals in primary health care on these new guidelines.

Flowcharts (refer to pages 2 and 3 of the Guidance)

4. Do you have any comments on the flowchart for men WITH NO SYMPTOMS? Is it easy to follow and understand?

   Flow charts are clear and the similar formatting makes them easy to follow.

   Flow Chart Page2: In regard to Haematuria and Lower Back Pain, there does need to be either back ground information for each or even better, a direct link to the "pathway" for each specific presenting problem.

5. Do you have any comments on the flowchart for men WITH SYMPTOMS? Is it easy to follow and understand?

   Links to other potential diagnosis need to be easy to access, such as LBP and haematuria.
   Normal ranges for PSA should be on the flow chart including age related guideline recommendations so a decision on referral can be made
   Presenting symptoms, does "lower back pain" not fit in with the +/- bone pain. Need to keep it simple and there is potential there to confuse or bony metastases be missed as put down to general lower back pain.
   Informed Consent – verbal sufficient
   We hope once completed the flow chart will be more eye-catching including colour.
   With the time of a consult currently 10-15mins these flow charts could be considered time consuming and we hope over time and use they will become more productive and easy to follow.
   Current MOH reporting requirements on targets do cause time constraints in PHC, our members in general practice suggest a full assessment may take several visits in this environment, organising investigations etc. This, of course, can cost money and can put off some patients who cannot afford to attend. We need to have the referral process enabling so these members of the community can attend and be referred as appropriate with adequate information for the urology department but not at the expense of scaring off our patients with cost. We need to work at improving the disparity in mortality rates in New Zealand. Having an effective management and referral system will help towards this goal.

Guidance Notes (refer to pages 4 to 8 of the Guidance)

6. Please provide any comments you have on the Guidance Notes in the tables below.

Guidance note number:	1 Preliminary Considerations
Feedback:	1.2 Family History Repetitive with note 4 on High Risk Groups and they need to be consolidated in one place. Although if it was electronic we can see the reasoning behind having it in both places.

Guidance note number:	Note 2 Informed Consent
Feedback:	We think the harms and benefits need to be documented in full here for health professionals to be able to access when discussing risks with their patients, only one example has been given which we think is not sufficient.

Guidance note number:	Note 3 DRE
Feedback:	Points 3.1 and 3.2 are repetitive and could be combined into one We appreciate having the options outlined for men refusing DRE.

Guidance note number:	Note 5 PSA Testing
Feedback:	Age related ranges should be on the flow chart. The risks/statistics quoted should be compiled under the Informed Consent section as the information men should be told. We would like clarification: for example man who is tested at 60 as concerned with his prostate cancer risk, results show his PSA was normal, DRE normal is the advice here never to get test again or only if he is worried??

Guidance note number:	Note 7 Men with symptoms
Feedback:	This is placed next to the box about UTI, but the notes do not mention UTI and addresses LUTS You should add to the flow sheet other potential causes of raised PSA such as ejaculation, DRE, biopsy etc. which you have in 5.1. So that needs to be addressed in your formatting.

Guidance note number:	8 Urgency of Referral
Feedback:	Faster Cancer treatment indicators difficult to incorporate into the care of prostate cancer, for example this document recommends rechecking an elevated PSA 2-3 months after initial test (with normal DRE) this alone would cause us to fail to meet the MOH goals for new referrals with a high suspicion of cancer. We need to have goals to meet the uniqueness of a potential prostate cancer diagnosis and accept the testing period can take longer than the current Faster Cancer Treatment recommendations. Staff resources and clinic capacity either needs to be reconsidered with these guidelines, in many DHBs, with current resources meeting the guidelines is impossible. Data collection consistency until recently has been questionable and there must be consistent and clean data collection nationwide. Immediate referral of patients with suspected spinal cord compression or renal failure should be highlighted on the flow chart in red to refer asap Prioritisation is usually done by the Urology Department and not from PHC.

Summary

7. Is there anything further you would like to provide comment on?

We think the notes that sit behind each point are useful, but often in a busy practice you do not have time to read it all. So at the start of each "note" there could be a short summation covering the "Bottom Line" which is the information that the health professional would need as a priority.

There needs to be a standardised referral to accompany this document. Preferably electronic with data fields that provide information needed to prioritise urgency of the referral in Urology Departments

Medical Practitioners are not exclusively providing the service of managing and referring patients with Prostate Cancer. Nurse Practitioners and other Advanced Practice Nurses are also involved in providing services for these men in Primary Care. So instead of singling out one profession throughout the document i.e. "Doctors and other Health Professional" we would recommend using the all-encompassing "Health Professional" as you have done in the first sentence of the document, which recognises us all without putting the focus on only one group.

Prostate Cancer Active Surveillance Guidance

Review questions

Overview

8. Do you have any general comments on the Prostate Cancer Active Surveillance Guidance, such as its readability, language and structure? Do you think it is easy to follow and understand?

   Yes, easy to follow and understand but overall the content could be condensed into a flow chart version including definitions and relevant information. Similar to the referral guidelines version.

9. After reading this guidance, do you feel more confident in having a conversation about active surveillance with men who have prostate cancer? If not, what is needed in the guidance to improve your level of confidence?

   Yes, we would be comfortable explaining this to a patient

10. What is the best way to integrate this guidance into your work environment

    In an electronic format, use in a database for prostate cancer patients. But this is often not available in all workplaces. It needs to be consistent.

    It is noted in this section (2) that these care systems and pathways are managed by DHB's and PHO – they are also managed in private practice including urologists, Radiation Oncologists and Medical Oncologists.

    Would this present any challenges? If so, how could those challenges be mitigated?

    Setting up a nationwide electronic system would be a challenge but it is needed.

    As for referral guidelines, this would also require consistent education of all health professionals involved.

    Public education required around active surveillance as a treatment option.

Content

11. Do you have any comments on the 'What is active surveillance' section of the guidance (refer to page 1 of the guidance)? For example, is the definition of active surveillance clear?

    Very clear. Terminology needs to be kept consistent, instead of mentioning "Doctors" in the text the reference should be to Health Professionals to cover other specialty groups involved in providing this service to men.

12. Do you have any comments on the 'Roles and responsibilities' section of the guidance (refer to page 1 of the guidance)? For example, is it clear who is responsible for providing active surveillance and what the roles of different health professionals are throughout the process?

    As experienced Urology Nurses we have a clear understanding of the principles of Active Surveillance. We agree the process should be led by an Urologist including putting a management plan in place. We propose the process of surveillance can be undertaken by appropriately trained Advanced Practice Nurses working in Urology Departments. We would

suggest a national programme be developed to ensure consistency and high standards are maintained by nurses working in this field.

We feel that if it is acceptable for men in remote locations in New Zealand to be cared for by Advanced Practice Nurses then it should be acceptable for all men, no matter their place of residence as the nurses either have the skills or they don't and we know they do. We also feel a Nurse Practitioner in Urology has the skills to review Active Surveillance plans.

13. Do you have any comments on the 'Rationale for active surveillance' section of the guidance (refer to page 2 of the guidance)? For example, are you clear on why active surveillance should be considered in men with localised, low risk, low volume prostate cancer?

Provide an example of an Active Surveillance Management plan. Once agreed the patient and his Health Professional would be given copes of the plan. Also specific patient education materials discussing Active Surveillance.

14. Do you have any comments on the 'Assignment of risk' section of the guidance (refer to page 2 of the guidance)? For example, do you understand what defines a prostate cancer as low, intermediate or high risk?

Present the information in a table format to make it easier to review
Reference on use of MRI would be useful. This modality not always available in smaller DHBs
Paragraph on intermediate/high risk not really needed (apart from those intermediate who meet requirements for AS) should be in later guideline for overall prostate cancer diagnosis and management, this one should be kept to AS

15. Do you have any comments on the 'Active surveillance guidance' section of the guidance (refer to page 3 of the guidance)? For example, is it clear who is eligible for active surveillance, what active surveillance involves and when someone is no longer eligible for active surveillance?

7.1 Informed Consent – provide list of up to date research on harms and benefits so men are given the best information available to make this decision.
7.2 Multidisciplinary team meetings are not a part of all urology units. Hopefully they will be in the future but this needs to be recognised, guidelines would be helpful as to which patients need to be discussed here. .
7.3 Year 2 PSA and DRE need to better defined, a lot of leeway in 3-12 months. Frequency of biopsy off-putting for some men.

Summary

16. Is there anything else you would like to comment on?

A survey of Urology Nurses in DHB outpatient departments was undertaken by Trish White in 2014 to review current participation of nurses in this Active Surveillance. The results have been presented at the specialist sub group of this project. The report is included below in full and we have listed the recommendations from this project here. They are all supported by the New Zealand Urology Nurses Society who are very interested in assisting with the development of these goals.

RECOMMENDATIONS

1. Although the numbers of nurses currently providing this service are small, we have a clear majority of the urological nursing workforce recommending this should continue and be promoted further with the establishment of national guidelines and training programmes for nurses.

2. AS to be incorporated into the advanced nursing practice roles of Urology CNS or NP in secondary services. This would be follow-up after initial diagnosis and development of a specific treatment plan by an urologist utilising the national guidelines. A collaborative team approach is recommended especially with prostate biopsy +/- MRI.

3. Once the Prostate Cancer Awareness and Quality Improvement Programme Active Surveillance guideline is completed this needs to be incorporated into all DHBs. We would suggest the potential for nursing input be included in the guideline as an option for health professionals delivering this service.

4. AS could be provided in secondary services or PHC. But the recommendation that nurses providing this service are Advanced Practice Urological Nurses, would in most instances, rule out PHC as there does not appear to be many nurses with the required qualifications working in PHC.

5. A national standardised training programme needs to be implemented for Urological Advanced Practice nurses involved in providing AS clinics to ensure high quality care.

6. As initial numbers of Advanced Practice Nurses would be small i.e. <20, for ease of training and monitoring a national programme should be implemented for this group with input in developing the training programme from NZUNS. A standard of practice would need to be developed in conjunction with the training programme which needs to be audited preferably with support from a national database. Quality initiatives for this nursing group should include peer review, development of a lead nursing role to provide training and support, regional liaison meetings and benchmarking.

SUMMARY

We believe the recommendations included in this report would benefit the care provided to men with prostate cancer undergoing AS. The potential benefits of nurse involvement in AS clinics in secondary services could include:

1. Well educated Advanced Practice Urological Nurses providing care for this group of men would allow sufficient time during appointments for ongoing education as nurse-led clinics generally have more time.
2. Allow Urologists to focus on higher acuity patients
3. Benefit elective services waiting times
4. Contribute to meeting Faster Cancer Treatment recommendations for prostate cancer patients
5. Improve job satisfaction of Urology nursing staff

Thank you for the opportunity to provide feedback and our thanks to the project teams working towards improving the care of men with prostate cancer in New Zealand.

Prostate Cancer Awareness and Quality Improvement Programme
Active surveillance and staging in localised prostate cancer

Report on Current Nursing Involvement in Active Surveillance Programmes in Secondary Services

INTRODUCTION

The Ministry of Health are currently coordinating the Prostate Cancer Awareness and Quality Improvement Programme and we are developing guidelines for men undergoing Active Surveillance (AS) for localised prostate Cancer. This multi-disciplinary team has nursing representation on both the Specialist and PHC groups.

We knew anecdotally that some nurses are involved in AS programmes nationally, but we are unaware of the extent of this practice.

As the nursing representative on the Specialist group I elected to survey the DHBs to gain a clearer perspective of nursing input into AS.

AIMS OF SURVEY

1. Identify current practice of Nurse involvement in active surveillance, e.g. how many nurses are currently seeing these patients
2. Develop recommendations for potential future practice including:
    a. Which nursing roles should provide this service?
    b. Is this service best located in PHC or secondary services?
    c. What training would be required for nurses delivering this service?
    d. How should this training be delivered?
    e. What actions would be required to ensure quality and consistency?
    f. How would we implement this service?

METHOD

A questionnaire was devised with Section One focussing on current practice in the DHB and Section Two to guide potential future development of the nursing role in AS programmes. It was sent to:

1. Urology nurses working in outpatient clinics in each of the twenty District Health Boards. Where emails addresses were not obtainable I phoned the outpatient clinics and spoke to the nurses (see *appendix one)*

2. As the leading Urological Nursing organisation, the New Zealand Urology Nurses Society committee were also surveyed for their opinion

Analysis was performed using excel spreadsheet and free comments.

SUMMARY OF RESULTS

We had a response rate of 70% from Urology Nurses working in outpatient clinics in DHBs and 100% of NZUNS committee members completed the survey. A complete transcript of results is available in appendix two. But the main results and recommendations are listed here.

1. Description of current of nurse involvement in active surveillance.

Only five DHBs currently have nurses involved in providing Active Surveillance. With three of them seeing patients in clinics. The other two are doing phone review clinics. One of these was in a rural area where Urologists do not visit often.

The nurses doing these clinics were two Nurse Practitioners, two CNS and one unknown.

The training received to run these nurse-led clinics was at postgraduate level in two cases but all had had local guidance from Urologists.

Three were performing Digital Rectal Examination (DRE).

2. What guidelines are currently in use?

No guidelines were reported. With only two DHBs saying they were under development.

3. What level of nurse should be providing this service?

Seventy-seven percent of the combined DHB and NZUNS response indicate this should be a CNS role or higher.

4. Should AS patients be seen by nurses in PHC or Secondary Services?

Combining the results from the DHBs and NZUNS committee members 60% felt AS was best provided in secondary services only. But 40% indicated either PHC or secondary services would be satisfactory.

5. Training Programmes

100% of all respondents agree that a standardised training programme should be implemented for nurses involved in AS clinics.

6. Delivery of Recommended Training Programme.

100% of NZUNS committee members recommend the training be developed at a national level and 83% of DHB's agree with this statement. NZUNS committee members were split 50/50 where it should be delivered with half preferring a national training programme and half recommending it be run regionally. With 38% DHB respondents also preferring a national training programme, 23% at a regional level and 38% at their own DHB

There was a similar response to who should deliver this training between NZUNS committee and DHB's with 50% of NZUNS committee members recommending NZUNS should be responsible for organising and running the training at a national level. With the remainder stating once a national training programme was established it could be run at a regional level. There was also support for this to potentially be considered for inclusion in a post graduate urological qualification.

RECOMMENDATIONS

1. Although the numbers of nurses currently providing this service are small, we have a clear majority of the urological nursing workforce recommending this should continue and be promoted further with the establishment of national guidelines and training programmes for nurses.

2. AS to be incorporated into the advanced nursing practice roles of Urology CNS or NP in secondary services. This would be follow-up after initial diagnosis and development of a specific treatment plan by a urologist utilising the national guidelines. A collaborative team approach is recommended especially with prostate biopsy +/- MRI.

3. Once the Prostate Cancer Awareness and Quality Improvement Programme Active Surveillance guideline is completed this needs to be incorporated into all DHBs. We would suggest the potential for nursing input be included in the guideline as an option for health professionals delivering this service.

4. AS could be provided in secondary services or PHC. But the recommendation that nurses providing this service are Advanced Practice Urological Nurses, would in most instances, rule out PHC as there does not appear to be many nurses with the required qualifications working in PHC.

5. A national standardised training programme needs to be implemented for Urological Advanced Practice nurses involved in providing AS clinics to ensure high quality care.

6. As initial numbers of Advanced Practice Nurses would be small i.e. <20, for ease of training and monitoring a national programme should be implemented for this group with input in developing the training programme from NZUNS. A standard of practice would need to be developed in conjunction with the training programme which needs to be audited preferably with support from a national database. Quality initiatives for this nursing group should include peer review, development of a lead nursing role to provide training and support, regional liaison meetings and benchmarking.

SUMMARY

We believe the recommendations included in this report would benefit the care provided to men with prostate cancer undergoing AS. The potential benefits of nurse involvement in AS clinics in secondary services could include:

1. Well educated Advanced Practice Urological Nurses providing care for this group of men would allow sufficient time during appointments for ongoing education as nurse-led clinics generally have more time.
2. Allow Urologists to focus on higher acuity patients
3. Benefit elective services waiting times
4. Contribute to meeting Faster Cancer Treatment recommendations for prostate cancer patients
5. Improve job satisfaction of Urology nursing staff

Thank you for providing feedback on the Prostate Cancer Referral and Management Guidance and Prostate Cancer Active Surveillance Guidance.

Please remember to include evidence, where possible, for the Ministry to consider other issues or recommendations.

Feedback closes: 5:00 pm on Friday 20 February 2015