

access to Clinical Nurse Specialists for men with prostate cancer

The Prostate Cancer Charity policy position August 2009

This document outlines our position on access to Clinical Nurse Specialists for men with prostate cancer and explains our reasoning behind this position.

Our Position

The Prostate Cancer Charity believes it is essential that all men with prostate cancer in the UK have access to a named Clinical Nurse Specialist (CNS) throughout all the stages of their treatment and care.

Access to a CNS will improve the patient experience of men with prostate cancer and ensure their information and support needs are met.

Clinical Nurse Specialists provide men with essential care including the provision of comprehensive information, support with making complex treatment decisions, advice on managing side effects, and emotional and psychological support.

Currently, there is under provision of Clinical Nurse Specialists for men with prostate cancer compared to some other common cancers; on average, CNS's working in urological cancer have significantly larger caseloads than those working in some other common cancers.

Men with prostate cancer report a worse experience of NHS care compared with other cancer patients in terms of level and quality of information provided and support given. We believe this is directly related to inadequate CNS provision and we want the ratio of Clinical Nurse Specialists to numbers of men diagnosed with prostate cancer to increase to match the best of provision for other common cancers.

Commissioners and providers of healthcare must recognise the importance of the CNS role in delivering improvements in the experience of care of people living with cancer, as set out in the *Cancer Reform Strategy* and *Better Cancer Care*.

In England, The Prostate Cancer Charity calls on Cancer Networks and Primary Care Trusts (PCTs) to address the under provision of CNS's for prostate cancer. Commissioners and providers must benchmark their local CNS provision and take remedial action where the CNS workforce is insufficient as recommended in the Cancer Reform Strategy. This should ensure equal access for men with prostate cancer to a CNS across all cancer networks.

We also call on the Department of Health to develop a national action plan for improving equality in access to CNS's for cancer patients.

In Scotland, The Prostate Cancer Charity calls on the Scottish Government and Health Boards to address the under provision of CNS's for prostate cancer. They must ensure that the CNS workforce is sufficient to ensure equal access to CNS's for all men with prostate cancer and take remedial action where it is not.

We also call upon the National Cancer Patient Experience Programme in England and the Better Together programme in Scotland to track patient access to Clinical Nurses Specialists for different cancers and the impact this has on patient experience.

It is essential that CNS's working in prostate cancer are provided with access to appropriate training and professional development. We call on the National Cancer Action Team and Cancer Networks in England and Managed Clinical Networks in Scotland to ensure that CNS's have the training and support necessary to enable them to meet the needs of men with prostate cancer.

The Charity is committed to campaigning for improved provision of CNS's for prostate cancer alongside improved patient experience and we will continue to monitor the situation closely.

1. Introduction

Clinical nurse specialists (CNS/specialist nurses) have been widely acknowledged as central to improving the patient experience of people diagnosed with cancer. New cancer strategies in both England¹ and Scotland² have recognised the importance of the role of CNS's in supporting patients with cancer and improving care. The importance of the CNS role within prostate cancer specifically is emphasised in the NICE *Improving Outcomes Guidance on Urological Cancers, 2002*, which recommends that all patients with urological cancers, including prostate cancer, should have access to a specialist nurse from the time of diagnosis.³

Despite this national emphasis on the importance of CNS's to cancer care, many men with prostate cancer do not have access to a specialist nurse and, in general, CNS's working in urological cancers have considerably larger case-loads than CNS's working in some of the other common cancers.^{5 8}

The Prostate Cancer Charity believes that this has a negative impact on the patient experience of men with prostate cancer and is calling on governments across the UK to address this problem and improve the provision of CNS's for men with prostate cancer.

2. The role of the Clinical Nurse Specialist in prostate cancer

Clinical Nurse Specialists exist for a number of different health conditions, e.g. multiple sclerosis, asthma and cancer. They have in depth knowledge of the physical, psychological and social effects of a specific condition and play a key role in the management of patient care.

A CNS working in cancer can carry out a wide range of tasks and there is considerable variation in the exact nature of the role across the country. The role can range from providing supportive care and information to a more clinically focussed role providing nurse-led services and clinics, or it can be a combination of both these roles.

For the purposes of this position statement, the CNS/specialist nurse role should be interpreted as referring to both of these core aspects of the CNS role.

The key tasks of the supportive care and information role include: providing support at initial diagnosis, individualised information provision, support with treatment decision making, advice on management of symptoms and side effects, support and assistance with practical issues such as finance, providing emotional and basic psychological support, signposting to specialised services and support services, and being a named and readily available contact for the patient. Nurse-led services include running diagnostic or follow-up care clinics.

Both of these roles have considerable value within the NHS and their impact is explored in more detail below (see section 4). Research²⁰⁻²⁴ has shown that the emotional and psychological support and responsive information provision provided in the supportive care element of the role has a positive impact on patient experience and quality of life. Nurse-led clinics have also been highly rated by patients due to the communication skills and availability of nurses.

Within the cancer field, concern has been expressed about the inconsistency in job-titles of roles that can be categorised as a CNS.⁴ Recent research found that almost 50 different job titles are in use for nurse specialists working in the field of urological cancers.⁵ Inconsistency in job titles has also been related to ambiguity in terms of the requirements and duties of the role.⁶ The Prostate Cancer Charter for Action, of which the Charity is a member, called in 2007 for the Cancer Action Team to lead on the development of a series of key interventions that define the CNS role⁵, working with cancer networks and professional bodies such as the British Association of Urological Nurses (BAUN) and the Royal College of Nursing (RCN). The Charity fully supports this recommendation.

It is important that men with prostate cancer have access to a CNS with the correct specialist skills and knowledge. Currently the lack of definition of the CNS role has led to many men with prostate cancer being treated by urology CNS's rather than CNS's with a uro-oncology specialism. Although a urology CNS will have skills and knowledge in a range of conditions that prostate cancer patients may experience, such as incontinence and lower urinary tract symptoms, they may not have the advanced knowledge and skills in cancer specific issues such as the effects of radiotherapy or chemotherapy. As such, it is likely to be of more benefit to men with prostate cancer to have access to a uro-oncology or prostate cancer specific CNS.

The Charity would like to see more uro-oncology CNS's in post and calls for all men with prostate cancer to have access to a uro-oncology CNS. However, due to the complex nature of prostate cancer, men may also need access to other specialist nurses. For example, a man suffering from erectile dysfunction as a side effect of treatment would get the best outcome by seeing a CNS with specialist expertise in erectile dysfunction. It is important for the named uro-oncology CNS to be able to signpost or refer men to the most appropriate specialist care or CNS to manage the specific problem they are experiencing.

3. Clinical Nurse Specialists in Uro-oncology – the current situation

3.1 Clinical Nurse Specialist provision in England and Scotland

The National Audit Office report, *Tackling Cancer: Improving the Patient Journey* (2005), found that only 50% of prostate cancer patients had access to a named nurse compared with 61% of other common cancer patients in England in 2004. A recent 2008 snapshot survey by the Charity also found that only 54% of prostate cancer patients surveyed had access to a specialist nurse.⁷ These problems with access are attributed to a lower number of CNS's working in urological cancers. The under-provision of specialist nurses for urological cancers has been acknowledged in the Cancer Reform Strategy: "*There are evident shortfalls in the number of clinical nurse specialists available to support patients with urological, lung and upper GI cancers.*"¹

Evidence has also shown that, on average, the caseloads of CNS's working in urological cancers in England are significantly higher than in other areas of cancer. For example, on average there is more than double the number of newly diagnosed patients per uro-oncology CNS as there is for a breast care CNS.⁵ The 2008 NICE publication, *Prostate Cancer: Diagnosis and Treatment*, states that the average workload of CNS's in areas excluding urology is 110 new cases per year per CNS, while in urology it is 203 new cases per year per CNS.⁸ New cases, while an indicator of case-load, are not the only part of the uro-oncology CNS role or other cancer CNS roles. There are currently 215,000 prostate cancer survivors in the UK,⁹ many of whom continue to be followed up for many years, are in active treatment for advanced cancer and have needs for many years after diagnosis, for example through side effects or late effects of treatment. Therefore a CNS will often be caring for all these men in addition to new cases. The size of the uro-oncology CNS case-load is highlighted as a major difficulty in achieving NICE recommendations on patient-centred care made in *Improving Outcomes in Urological Cancers* (2002) and *Improving Supportive and Palliative Care for Adults with Cancer* (2004). The NICE Manual on *Improving Outcomes in Urological Cancers* recognises that some CNS's "*are stretched very thinly, being solely responsible for several hundred cancer patients*".³

There are also significant geographical variations in the number of CNS's in different cancer networks across England. In 2007, all cancer networks had at least one Whole Time Equivalent (WTE) CNS working in uro-oncology. However, national research has shown a substantial disparity in the number of posts between networks. The cancer network with the highest provision of uro-oncology CNS's has 23 WTE nurses, whereas the lowest has only one. Even discarding the top and bottom 10% of the networks in terms of provision, there is a threefold variation in uro-oncology CNS provision across England.⁶ This will have a significant impact on access to a CNS in different geographical locations. The size of the CNS caseload will also impact on how easy it is for men with prostate cancer to get an appointment with a nurse and on the time the nurse has available to spend with each man.

The situation in Scotland is similar; prostate cancer accounted for 9.1% of all new cancer diagnoses in 2005, but workforce data from NHS Scotland shows that uro-oncology CNS's account for just 3.7% of all cancer CNS's. This is just seven CNS's across Scotland. This can be compared to breast and colorectal cancer which accounted for 15.2% and 12.9% respectively of new cancer diagnoses in 2005, and each has 26 CNS's (13.7% of the CNS workforce each).¹⁰

One of the contributing factors to this under provision across the UK is insufficient trained nurses. The Charity strongly supports the creation of new CNS positions; however, these must be accompanied by a commitment to, and investment in, increased training and education for nurses, enabling them to reach the level of skills and knowledge necessary to fulfil the CNS role. The Prostate Cancer Charity is contributing to this aim through an education and development programme for health professionals, but more needs to be done. We call on the National Cancer Action Team and Cancer Networks in England, and Health Boards in Scotland, to lead on the up-skilling of the nursing workforce through the introduction of a co-ordinated approach to the training and development of uro-oncology CNS's.

3.2 The effects of under-provision on care

Evidence in England suggests that the under-provision of uro-oncology specialist nurses has a negative effect on the experience of men with prostate cancer. The NAO Report, *Tackling Cancer: Improving the patient journey*, found that on a number of indicators, men with prostate cancer reported a significantly worse experience of their treatment and care than patients with other common cancers.

Patient experience of men with prostate cancer compared to patients with other cancers		
	Patients with prostate cancer	Patients with other common cancers
Side effects of treatment not discussed	11%	6%
How treatment had gone not discussed	13%	5%
Would have preferred more information	20%	13%
Fully understood how treatment had gone	70%	81%
Given information about support or self-help groups	34%	64%
Have a named nurse in charge of care	50%	61%

NAO Report: Tackling Cancer: Improving the Patient Journey

Overall, men with prostate cancer gave a less positive response than patients with other cancers for 54 out of 80 questions.¹¹ Of particular concern is the fact that higher numbers of men with prostate cancer report a lack of information and understanding about the progress of their treatment and a lack of discussion about the side effects of treatment (see table above for key survey results). These areas are of particular importance in prostate cancer, as the range of treatment options is complex and the side effects can have a significant impact on quality of life.

A UK-wide survey of the experiences of men with prostate cancer conducted by the Charity in 2005 found that specialist nurses were ranked the highest by men, in terms of healthcare professionals and help-lines, for the provision of emotional support around the time of diagnosis and treatment decision-making. However, a high proportion, 38%, of men reported that they did not have the opportunity to speak to a specialist nurse about these issues.¹²

In 2002, The Prostate Cancer Charity established its Specialist Nurse Programme, in which six prostate cancer specialist nursing posts were funded in six hospitals across England and Scotland. In order to explore worth and demonstrate impact, it was critical that the programme was subject to rigorous independent evaluation. In the autumn of 2003, King's College, London, School of Nursing and Midwifery was commissioned to undertake this work. As part of the evaluation of this programme, men who had been diagnosed with prostate cancer were surveyed and they reported significant unmet supportive care needs.¹³ For example, 30% of men reported moderate or extreme anxiety or depression, 30% reported difficulty with undertaking usual activities, 22% reported some or extreme pain, and 45% reported unmet sexuality-related needs. However men who had access to a CNS reported a range of methods through which their supportive care needs were being met.²⁵ This programme not only highlights a unacceptably high level of unmet need but also demonstrates the effectiveness of the CNS in meeting this need. The high levels of unmet need suggests an under-provision of CNS's in urological cancers that is having a significant effect on patient experience.

3.3 The financial threat

Recent pressures on the NHS have threatened to further exacerbate problems with the provision of CNS's. According to the Royal College of Nursing (RCN) in 2006, the financial deficit in the NHS in England put 15,000 nursing posts at risk, and they reported that specialist nursing posts were being specifically targeted.¹⁴ The higher cost of the CNS role compared to less specialist roles makes it particularly vulnerable to potential cuts. This risk is heightened by the problem of quantifying the value of providing information and support to patients and demonstrating the worth of the CNS role in a health system structured around tariffs, increasingly focussed on efficiency and driven by tangible, recordable outcomes.¹⁵

In 2006, there were reports in nursing journals^{14,15} of large numbers of cancer CNS's across England being asked to help out in wards and other departments to help reduce agency nursing costs. There were also reports of posts that had initially been funded by charities not being picked up by PCT's when the initial funding ran out.¹⁴ It appears that this situation has continued to be a problem. In 2008, the RCN reported that there had been a decline in the number of specialist nurses in post in England since 2006 and suggested that PCT's see specialist nurses as an 'expensive luxury'.¹⁶ It is essential that the value of CNS's to patient care is highlighted to PCT's and the role fully supported.

4. The impact of the Clinical Nurse Specialist role on patient experience

4.1 Improved patient experience

There is considerable evidence, especially in the areas of long-term conditions and palliative care, that having access to a CNS has a positive impact on patient experience and can improve satisfaction with NHS care.¹⁷

The impact of specialist nursing on patient experience has been illustrated in research evaluating the role of specialist nurses in palliative care, where a number of studies have repeatedly demonstrated a direct link between interventions by CNS's and improved patient outcomes.^{18,19} For example, a 2003 study found that positive outcomes, such as an improvement in emotional state and physical symptoms, receipt of advice or information, and improved quality of life, from specialist palliative care nursing interventions, were reported in 55% of cases.¹⁸

In terms of cancer care, there is a body of global evidence indicating that specialist nurses play a crucial role in improving the patient's experience of cancer care. For example, studies from both Australia and across Europe report significant impact on patient experience by women with breast cancer.²⁰ In particular, specialist nurses are able to bring a patient-centred approach to cancer care; providing support, advice and information to patients and being able to spend time with them when they need it.²¹⁻²⁴

The evaluation of The Prostate Cancer Charity's Specialist Nurse Programme in 2007 is one of the few projects looking specifically at the role of specialist nurses in prostate cancer. This evaluation found that patients' general impressions of Prostate Cancer Nurse Specialists (PCNSs) were overwhelmingly positive.²⁵ The evaluation found that the Specialist Nurses were well informed, open in response, positive in attitude and supportive of the patient. Patients reported the key roles of the PCNS as providing permanent access to consultation either in person or by telephone, continuity of care, and being a sympathetic and effective source of information, guidance, support and reassurance.

These findings are supported by the results from two surveys run by the Charity. The *First National Survey* in 2005 reported that specialist nurses were ranked the highest when respondents were asked "Who was most helpful in providing you with emotional support?" And a recent snapshot online survey by the Charity revealed that of those who had access to a specialist nurse, 73% found this to be 'helpful' or 'very helpful', with the majority classifying having access to CNS as 'very helpful'.⁷ These studies and other research demonstrate that, generally, men with prostate cancer who have access to a specialist nurse report a more positive experience of care.²⁶

4.2 Meeting specific patient needs

The unique characteristics of the specialist nurse role enable them to address specific patient needs that can not be met by professionals in other roles due to a lack of time or specialist training. Research has shown that the CNS role positively impacts on three main areas of patient experience: support and advice, information provision and contact with medical services.

These are discussed in detail below. The CNS role has specific importance for men with prostate cancer due to the complexity of treatment decisions facing them.

Many of the treatments for prostate cancer have significant side effects that have a long term impact on quality of life. For example the most common side effects of treatment include urinary incontinence, bowel incontinence, erectile dysfunction, loss of sex drive, fatigue, and depression. Side effects such as these have a considerable impact on quality of life and can make decisions about treatments difficult. The support of a highly qualified CNS who can talk through treatment options is of great importance to men making these choices.²⁷

Research has demonstrated a large number of specific ways in which the CNS role impacts on the patient experience:

Support and advice

- Cancer patients report a high quality supportive approach to care when they have access to a specialist nurse.^{28,29}

“I cannot put a value on how her experience, knowledge, confidence and support helped me”

- CNS’s ensure the patient has support with practical issues such as finance, or advice with obtaining benefits, or assistance at home.²⁸
- CNS’s are also able to facilitate quicker appointments with clinicians where necessary, a facet of the role highly valued by men.³⁰
- Specialist nurses provide advice on the self-management of symptoms, and help patients to understand why side effects arise and what help is available.²⁸
- Specialist nurses can provide basic psychological support and reassurance and patients report that this has a significant impact on their experience.¹³

“She was easily accessible at the end of the phone and answered all mine and families questions.”

- Cancer patients highly value the availability of specialist nurses and the unconstrained time CNS’s can have for discussing concerns.²⁶
- Follow-up care provided by CNS’s is highly valued by patients.³⁰

Information provision

- Specialist nurses play an important role in improving information provision for patients, ensuring they get the information they need.³¹
- Patients feel clearer about their diagnosis and treatment after discussing it with a specialist nurse due to the advanced communication skills of CNS’s and their availability to patients.²⁶

“It is the Nurse Practitioner [CNS] who through the subsequent reviews helps you to understand what is happening, sort out your questions and generally pick up the pieces... The starting point has to be that every man should have a nominated CNS from the day he is given his diagnosis.”

- Patients report more self-made decisions and a higher level of satisfaction with the decision making process as a result of receiving and discussing information with a specialist nurse.²⁶

Contact with medical services

- Patients report a higher level of satisfaction with services when a named specialist nurse acts as the central point of contact for care and support.³¹

I had access to a specialist nurse (Uro/Oncology) from the results clinic onwards and had her telephone number and could ring at any stage. This has provided an excellent thread of continuity through my RP [radical prostatectomy], HT [hormone therapy] and RT [radiotherapy].

- The specialist nurse acts as a liaison between the patient and the healthcare system;²⁶ translating medication information for the patient making it more accessible and acting as an intermediary between the medical treatment team and the patient.²⁸
- CNS's provide continuity of care for patients, a facet of care that is cited as a contributing factor to improved patient satisfaction.³²

The specialist nurse role is unique and incredibly valuable in terms of the service it provides. The CNS has the advanced medical knowledge and communication and support skills to provide comprehensive support to patients.

4.3 Nurse-led services

In recent years, the traditional roles and responsibilities of the CNS have begun to be extended and nurse-led services are starting to be developed as a new means to deliver care. Evaluations of these services have focused both on cost effectiveness and patient satisfaction with largely positive outcomes in both areas. A number of studies from both the UK and US have shown nurse-led clinics to be a success, having a positive impact on patient satisfaction with the level and delivery of care at all stages of the cancer patient's journey.³³

Specialist nurses are highly trained and able to deliver a range of services that have traditionally been delivered by doctors. These include delivering diagnosis, discussion of treatment options and follow-up care. There are a number of examples of successful nurse led clinics in the UK. For example, a nurse-led, 'one-stop' suspected prostate cancer clinic in Chesterfield has reported a series of practical improvements to the service such as more time per appointment for patients and better continuity of care.³⁰ Not only was the service faster and more cost effective, it also delivered a more patient-centred, supportive approach.³⁴ Similarly a nurse-led follow up service for patients undergoing pelvic radiotherapy for prostate and bladder cancer reported significantly higher satisfaction in men who had received the nurse-led service across a series of indicators. These included the amount of information provided, awareness of patient needs, worries and concerns of patients taken seriously and management of symptoms.³²

It is clear that nurse-led clinics can lead to increased satisfaction with services for patients and undoubtedly provide excellent career development opportunities for nurses. However, it is important that the promotion of this approach to care is not achieved by the diversion of resources from the role of the CNS within the Multi-Disciplinary Team.

The Charity supports the development of nurse-led services as the advanced communication skills and supportive role of specialist nurses significantly improves patient satisfaction.

5. The financial impact of the Clinical Nurse Specialist role

It is very difficult to attribute a financial value to the improved patient experiences seen through the support, advice and information provision offered by the CNS role. The problems CNS's face in proving the cost-effectiveness and financial value of their role are further exacerbated by the complexity of the cancer pathway and the lack of a clear and consistent definition of the role. This makes it difficult for Trusts in England to receive payment for CNS services under the current payment by results tariff system.¹⁴

CNS roles tend to be located in the higher nursing grades, usually grade 7 or 8, due to the level of expertise and qualifications required. As such, it is inevitable that in order to achieve the necessary target of access to a CNS for every man with prostate cancer, there will be a cost implication for the NHS. However, we believe the positive impact of the CNS role is of sufficient importance to warrant investment by the NHS.

While it is hard to measure the financial benefits of the supportive role of the Specialist Nurse within the multi-disciplinary team, the cost-effectiveness of the role of the CNS in delivery of nurse-led services is more easily demonstrated. In the UK, it has been estimated that anywhere between 30% and 70% of tasks currently undertaken by doctors could be done by nurses.³³ This has the potential to result in significant cost efficiencies for the NHS. In April 2008, the evaluation of the nurse-led diagnostic clinic in Chesterfield, detailed above, costs one session of consultant urologist time at £211 versus one session of nurse time at £80 at level 8 or £75 at level 7, and therefore the service can be a source of cost efficiency for the NHS.³⁴ Other studies have also recognised considerable cost savings, for example one study by Faithful, Corner et al in 2001 suggested a saving of 31% for a nurse-led follow up service.³²

More work needs to be done to define and quantify the impact of the supportive care aspect of the CNS role. Perhaps there is potential for the savings made by the increasing prevalence of nurse-led services to contribute to the increased funding needed by Trusts to increase the levels of CNS's in the multi-disciplinary team and provide access to a specialist nurse for all men with prostate cancer.

6. The role of Clinical Nurse Specialists in the Multi Disciplinary Team (MDT)

CNS's carry out a range of functions which make them a key member of the MDT. The Cancer Reform Strategy outlines the main functions of the specialist nurse role as being technical, information provision, emotional, and coordination.¹ As a result of their considerable experience and high level of qualification, CNS's are able to provide support to their colleagues and can be seen as experts by other members of the MDT, especially other nurses. They provide expert advice and guidance to colleagues on a range of issues including symptom control and patient communication.^{23,35} Within the team, they also deliver treatment, provide continuity of care, develop post-treatment plans and act as the central contact for patients.

Research among breast care nurse specialists has found that specialist nurses often bear responsibility for general administrative and organisational tasks within the team, such as ensuring the efficiency of internal communication, and planning and documenting team meetings.²³ CNS's are highly qualified professionals and as such, it is not a good use of their time and NHS resources to be undertaking administrative tasks. The recent Prostate Cancer Charter for Action publication, *'Because Men Matter: the case for clinical nurse specialists'*⁵, calls for the urological cancer MDT to include a team co-ordinator and a team secretary to ensure that meetings are organised, documentation is available and to provide clerical support to the MDT and facilitate communication and remove administrative responsibility from CNS's.⁵ The Charity strongly supports this. We recommend that adequate administrative support is a necessary aspect of the MDT in order to ensure that CNS's are properly supported, are released from administrative duties and have more time to carry out the clinical and supportive elements of their role.

7. Action by the Prostate Charter for Action

The Charity is a core member of the Prostate Charter for Action, which has undertaken considerable work in England into the case for CNS's. In the 2007 report, *'Because Men Matter: The case for Clinical Nurse Specialists in Prostate Cancer'*⁵, the Charter made a series of recommendations about what needs to be done to ensure that every man who is diagnosed with prostate cancer has access to an appropriately trained and experienced CNS. As a signatory of the Charter, the Charity strongly supports the recommendations of this report and is working to campaign for these recommendations to be implemented.

In particular, The Prostate Cancer Charity believes the following recommendations are vital:

- A two pronged approach is required if the NHS is to ensure that all men with prostate cancer are appropriately and effectively supported by CNS's:
 - More investment, increasing the provision of CNS's working in urological cancers
 - Greater reform, ensuring that the work of Clinical Nurse Specialists has the maximum positive impact on men with prostate cancer.⁵
- Comprehensive action is required to address the under provision of CNS's for prostate cancer, and the first step the NHS should take is to bring the provision of CNS's for urological cancers up to the same level as exists for breast cancer.
- The Department of Health should seek to bring together interested organisations to establish a consensus on what an appropriate caseload is for a CNS working in prostate cancer.
- Demonstration by service providers that every patient is able to spend sufficient time with a CNS to enable detailed discussion about issues such as treatment options, side effects and access to psychological and financial support should be a necessary condition for commissioners to contract services and a failure to demonstrate adequate provision should result in financial penalties through Payment by Results.
- The Department of Health should fund a pilot to examine the case for splitting the current functions of the CNS into a 'care tracker' or 'concierge' role focusing on ensuring co-ordination of care post diagnosis, and a new CNS role focused on providing information, supporting men making decisions about treatment and identifying, assessing and addressing areas of unmet need.

The Charity joins the Charter in calling for these recommendations to be met by the Department of Health, commissioners and providers of care. For further information please refer to the Prostate Cancer Charter for Action at: <http://www.prostatecharter.org.uk/> or read the report Because Men Matter here:

<http://www.prostatecharter.org.uk/lib/docs/because%20men%20matter%20-%20the%20case%20for%20clinical%20nurse%20specialists%20in%20prostate%20cancer.pdf>

8. Conclusion

Access to a Clinical Nurse Specialist undoubtedly improves the experience of care of men with prostate cancer. However, there is significant under-provision of CNS's within uro-oncology which results in some men having no, or poor, access to a CNS.

On average, uro-oncology CNS's have far larger case-loads than CNS's in other common cancers. The numbers of specialist nurses working in urological cancer must be increased in order to combat this problem and improve access for men with prostate cancer to individualised support, advice and information.

An increase in the overall number of CNS's working in prostate cancer does have financial implications for the NHS. However, we believe this is necessary to ensure men receive equitable treatment in relation to other patients with common cancers and to get support to make the right treatment decisions and to cope with diagnosis, managing side effects and impact of treatment.

The Prostate Cancer Charity believes that in order to ensure that men receive the highest standard of information and support, all men with prostate cancer should have access to a named Clinical Nurse Specialist throughout all the stages of their care. The Charity calls on governments across the UK and the NHS to take appropriate action to ensure that all men have access to this care wherever they live in the UK.

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