

East Lancashire Prostate Cancer Support Group Newsletter



Volume4

Issue10

Date October 2015



The gold standard prostate cancer journey: from the patient 's perspective

ROSHANI PERERA AND ROGER WOTTON

What's Inside

Patients Per- spective	P1 P2 P3 P4 P5
Prostate Prob- lem	P6
Fairweather Court Thank You Letters	P7 P8
Invitation to view Da Vinci Machine	P9

Prostate cancer is the most common cancer in men in the UK. Over 40,000 men are diagnosed with prostate cancer every year and over 250 000 are currently living with the condition.1 In 2014 a working group comprised of charities, patients and health-care professionals came together to identify what quality of care in prostate cancer really means to patients and their carers. The authors discuss the key findings from the quality standard developed by the working group and what still needs to be done to achieve a gold standard of care from the patient's perspective.

Ensuring people's views are heard at all levels and across all parts of the healthcare system is essential for creating and delivering better health and care services. This was echoed in the recent Five Year Forward View² produced by NHS England and other national NHS leadership organisations. Looking at these services through the patient lens was seen as crucial in building consensus around a clear set of quality improvements. The aim was to ensure that all men with prostate cancer are able to access the best possible care and support, regardless of where they live.

DEVELOPING QUALITY STANDARDS

Over a six-month period, the working group (Box 1) identified nine quality statements best representing the quality of care for patients with prostate cancer (Figure 1). The quality statements were further tested with a wider group of stakeholders, before being finalised and submitted to NICE to inform and help in the development of its quality standard for prostate cancer. How our quality standards compare to those developed by NICE and



published earlier this year is discussed in the accompanying piece

by Jonathan Rees (page 24).

ASSESSMENT AND DIAGNOSIS

One of the most debated elements of the pathway was the inconsistency and poor quality of care at the point of risk assessment and referral. The high death rate from prostate cancer (25–30% of those diagnosed³) is, to a large extent, due to the fact that in too many cases it is not diagnosed until it has progressed beyond the curable stage. According to members of the working group, men often present to their GP with increased urinary frequency with no other signs or symptoms unless the cancer has spread. Patients within the working group raised concern that GPs were reluctant to offer a prostate-specific antigen (PSA) test if a patient presented with no symptoms. The group also commented that a number of primary care teams (including practice nurses/nurse practitioners) were not provided with the necessary knowledge and awareness around PSA testing, leading to patients having a PSA test without being adequately informed or offered relevant counselling. In some instances a PSA test was offered to patients presenting with a urinary tract infection. Not enough men are informed about the availability of the test. Research carried out by Prostate Cancer UK shows that two thirds of men over 50 do not even know that the test exists.⁴ Awareness of PSA testing needs to be improved among men and they should be given adequate information about the PSA test itself, digital rectal examination and biopsies, with the opportunity to discuss the pros and cons of the tests with a clinician. Clinical expertise in the working group would recommend regular PSA testing for asymptomatic men from age 45 if of Black ethnicity and age 50 if otherwise. Access to local support groups should also be made available to help men improve awareness of warning signs and symptoms and when to access their GP for further investigations.

MAKING THE RIGHT DECISION

It is essential that all prostate cancer patients are provided with the most up-to-date information and the opportunity to speak to chosen members of their multidisciplinary team (MDT) in order to discuss all available treatment options. Understanding the advantages and disadvantages of each treatment option will help patients make an informed treatment choice. Often a case is discussed at MDT before the patient has been seen for their results and the MDT will suggest options to be put to the patient. The MDT must ensure that the patient has the fullest possible role in determining treatment. An important point to recognise is that patients are generally provided with a plethora of information leaflets, booklets, online references, etc., but there is often no explicit responsibility to check the patient's level of understanding or whether they know how to use the information provided. Agreeing on the 'treatment of choice' may require availability of staff trained in counselling, and access must be available and offered when appropriate. Men's views change over time with increasing awareness and meeting other patients to share experiences. The shared decision-making conversation needs both the patient and the clinician to understand the other's point of view and agree the reasons why the treatment chosen is the best one for the patient.

IMPROVING ONGOING PATIENT CARE

According to the 2014 National Cancer Patient Experience Survey (NCPES), only 20% of prostate cancer patients were offered a written care plan.⁵ The survey also highlighted that 88% of men diagnosed with prostate cancer were given the name of a CNS, compared to 93% of people diagnosed with breast cancer. Men who are living with cancer often have difficulties that go beyond their medical requirements, including financial,

emotional and practical needs, and these needs are often lifelong. Although improvements have been made since 2010, 41% of prostate cancer patients who would have liked information about how to get financial help or any benefits are still not receiving any help or advice.⁶ Providing men who are undergoing treatment for their prostate cancer with a personalised care plan offers the opportunity to discuss and be assured that the patient has appropriate treatment expectations, as well as being aware of any potential adverse consequences. These include erectile dysfunction, incontinence and reduced bone health. In addition, having the opportunity to meet with other men living with prostate cancer through support groups can offer an immense sense of support and relief to patients through being able to share experiences with fellow sufferers.

The 2014 NCPES also highlighted that 28% of prostate cancer patients mentioned that their GPs and nurses did not support them enough while being treated, and 34% did not feel that different professionals worked well together to give them the best possible care.⁵ There must be seamless integration of well co-ordinated cancer care across primary, secondary and social care. This includes clear lines of responsibility and accountability, with staff being provided with the necessary training and links to the right resources.

Furthermore, in health and social care policy, the addressing of wellbeing is becoming a growing priority. Wellbeing is a broad, dynamic and multidimensional concept, consisting of many different elements that interplay with each other, including emotional wellbeing, mental wellbeing, physical wellbeing, social wellbeing (relationships and family life) and economic wellbeing. However, despite this growing emphasis, provision of wellbeing services for men with prostate cancer appears to be highly inconsistent.

Recent research commissioned by Prostate Cancer UK in 2014 put this down to lack of resources; low awareness of the problem among clinicians; over-concentration on ‘the cancer’ relative to ‘the man’; and lack of local strategic direction.⁶ The manner and type of referral makes a difference to the take-up of support services. Integration of wellbeing into standard pathways through a holistic needs assessment is seen as important.

The group recognised that men with ‘non-curable’ prostate cancer would benefit from having access to ‘palliative’ care much earlier on in their treatment, yet the term palliative often has misleading connotations. The final inevitability requires careful management so that these men can live out the time they have left (which may be months or even years) with dignity and without unnecessary pain or false hope. For this reason, there needs to be a clear definition and understanding of what constitutes palliative care for men with prostate cancer and a clear understanding of when it should become applicable.

FINAL THOUGHTS

Through the development of this quality standard, by patients for patients, the group has tried to give patients and their partners or carers a more powerful voice and greater active involvement in setting priorities for service improvement. This includes improving access to cutting edge diagnostics, innovative treatments and clinical trials. With more men becoming long-term survivors of prostate cancer, it is essential that their needs are properly recognised, whether they be physical, emotional or social. Having the voices of prostate cancer patients uppermost in our minds is the most valuable contribution we can make to ensuring services meet the needs of patients. Moving forward, it is our expectation that commissioners, healthcare professionals, social services, patients, partners and their carers consider implementing these quality statements developed by the working group. This will improve the lives of men at risk of prostate cancer and those

living with the disease. The full report is available on the Tackle Prostate Cancer website (<http://www.tackleprostate.org/quality-standard.php>).

Declaration of interests

This work was supported by The Quality Standard Working Group for Prostate Cancer and Ipsen Limited.

REFERENCES

1. Prostate Cancer UK. What is prostate cancer?

(<http://prostatecanceruk.org/information/prostate-cancer>; accessed 7 August 2015).

2. NHS England. Five year forward view.

October 2014 (<http://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>; accessed 7 August 2015).

3. Cancer Research UK. Prostate cancer mortality statistics (<http://www.cancerresearchuk.org/cancer-info/cancerstats/types/prostate/mortality/>; accessed 7 August 2015).

4. Prostate Cancer UK. Quality care. Everywhere?

An audit of prostate cancer services in the UK

(http://prostatecanceruk.org/media/1818657/1772-day-of-action-report_for-web.pdf; accessed 7 August 2015).

5. Quality Health. Cancer patient experience

survey 2014 (<http://www.quality-health.co.uk/surveys/national-cancer-patientexperience-survey>; accessed 7 August 2015).

6. Prostate Cancer UK. Research into wellbeing services for men with prostate cancer – final report. August 2014 (<http://prostatecanceruk.org/media/2460122/Report-Wellbeingservices-for-men-with-prostate-cancer.pdf>; accessed 7 August 2015).

The nine quality statements proposed by Tackle Prostate Cancer are a hugely welcome addition to the process of defining the key elements of quality care for men with prostate cancer.

While there are overlaps with the final five statements proposed by NICE and published in June 2015¹, there are also clearly many differences, which reflect different priorities and less constraint from the methodology required by NICE when drawing up quality statements.

NICE proposes five key priorities designed to drive quality improvements in patient safety, patient experience and clinical effectiveness. The quality standard does not, unlike the Tackle statements, cover the recognition and referral of men with Complementary not competing quality standards

JONATHAN REES

The recently published NICE Prostate Cancer Quality Standard differs from the quality statements developed by Tackle Prostate Cancer and described in the previous article.

Jonathan Rees explains how the two are complementary and can sit comfortably alongside each other.

Jonathan Rees, GP, Backwell and Nailsea Medical Group, North Somerset and Special-

ist Member of the Quality Standards Advisory Committee for the NICE Prostate Cancer Quality Standard PROSTATE DISEASE

TRENDS IN UROLOGY & MEN'S HEALTH SEPTEMBER/OCTOBER 2015

www.trendsinmenshealth.com suspected prostate cancer — this will instead be covered by a separate quality standard resulting from the updated guidelines on referral for suspected cancer.

The five NICE quality statements are shown in Box 1. There are three key themes represented in the NICE statements, and those of Tackle. Firstly, men with prostate cancer need access to appropriate support, whether that is a cancer nurse specialist or specialist support when dealing with treatment side-effects. This is reflected in statements 1 and 4 of the quality standard, and elaborated upon by the Tackle quality statements, which also discuss the use of, for example, personalised care plans, support in self-management and access to high-quality end-of-life care.

Secondly, men with prostate cancer should be entitled to receive the best possible treatment, reflecting national guidelines and the current evidence base — active surveillance should be offered when appropriate, combined radiotherapy and androgen deprivation therapy should be offered when treating men with intermediate- or high-risk localised disease (rather than monotherapy with either), and men with hormone-relapsed disease should have a discussion about alternative treatments by the multidisciplinary team.

The Tackle statements ask that men have the opportunity to discuss all available treatment options and have access to the treatment of their choice, including taking part in clinical trials.

Finally, the statements in each document reflect the need for multidisciplinary management being available to men with prostate cancer — specialist nursing, urologists, oncologists, andrologists, palliative care physicians, etc.— all play a vital part in providing high-quality care.

The Tackle statements should not be seen as competing with those of NICE, but instead to comfortably sit alongside them, representing as highlighted in their introduction, what still needs to be done, from the patient's perspective, to achieve gold standard care for all men.

REFERENCE

1. NICE Quality Standard for Prostate Cancer

(QS91). June 2015 (<http://www.nice.org.uk/guidance/qs91>; accessed 20 August 2015).



From Left to Right Hazel Goulding (Treasurer) Leon D Wright (IT Admin) Stuart Marshall (Secretary) Steve Laird (Vice Chairman) Dave Riley (Chairman)

Contact Information

Tel: 07548 033930
E Mail leondwright4@gmail.com

We are a group of local people who know about prostate cancer. We are a friendly organisation dedicated to offering support to men who have had or who are experiencing the effects of this potentially life threatening disease.

The East Lanc's Prostate Cancer Support Group offers a place for free exchange of information and help for local men and their supporters (family and friends) who may be affected by this increasingly common form of male cancer.

At each meeting we strive to be a happy, supportive and upbeat group of people; encouraging open discussion on what can be a very difficult and perhaps for some an embarrassing subject. We have lively, informative, interactive, sharing and above all supportive meetings.

Prostate Problem

Charlie is sitting in the doctor's waiting room, when George, a causal acquaintance, walks in and sits next to him.

"W w what are yy you dd doing hh here?" George asks.

"I'm waiting to see the doctor," replies Charlie.

"Ww what's the mmm matter? Ww why dd do yyy you ww want to sss see him? George inquires.

"Well, I have a prostate problem," Charlie says.

"A pp prostate ppp problem, ww what's th th that?" asks George.

"If you must know, I pee like you talk!" explains

Charlie.

source: <http://www.jokebuddha.com/Prostate#ixzz3p0MYBsAw>

CM Office / Mr. Norman Hughes
Fairweather Court
Quarry Street
Padiham
BB12 8QB

04/10/15

DONATION FOR 92nd BIRTHDAY CELEBRATION OF JOE ROTHERHAM

Dear all,

On behalf of the EAST LANCASHIRE PROSTATE CANCER SUPPORT GROUP I would like to offer our belated best wishes for Joe Rotherham's 92nd birthday and **to thank you & the residents at Fairweather Court very sincerely for your kind donation of £114 to our Support Group. Please pass on our congratulations to Joe.**

Our Support Group was founded at the beginning of 2011 by people affected by Prostate Cancer in order to support local men and their families suffering from the effects of the disease. Currently 1 man in 8 will be affected by Prostate Cancer in the UK.

We have our meetings every month at the Burnley General Hospital on the 1st Thursday of every month, 2-4pm, men and their Ladies / Partners / Carers also come to our meetings, we have informative discussions and can offer information and guidance in respect of where further help can be obtained. More importantly a Support Group provides patients with the opportunity to talk to other people who know about Prostate Cancer and how they are feeling! I have enclosed our leaflet to give you a better idea of who we are and what we do.

Your generous donation will be of great help to us as the only regular income we receive is from the raffle we have at our meetings. We are all volunteers that organise and run the group and we have been fortunate so far to have been allocated the use of the Conference Room at the hospital free of charge, however we are never sure how long this may last, therefore we have always to be aware that we may have to pay for facilities at a future date. We also require funds for tea & coffee etc. at meetings, stationary and materials for promoting awareness of the group.

Once again, many, many thanks for your generous donation,

Stuart L. Marshall (Secretary)

CM Office.
Fairweather Court
Quarry Street
Padiham
BB12 8QB

16/10/15

DONATION FOR Agnes McGough's Birthday Party

Dear all,

On behalf of the EAST LANCASHIRE PROSTATE CANCER SUPPORT GROUP I would like to thank the residents of Fairweather Court once again and Agnes for the kind donation of £116 to our Support Group. **Please pass on our belated congratulations to Agnes for her birthday and our thanks for this very kind gesture.**

As I have said previously your generous donations will be of great help to us as the only regular income we receive is from the raffle we have at our meetings. We are all volunteers that organise and run the group and we have been fortunate so far to have been allocated the use of the Conference Room at Burnley General Hospital free of charge, however we are never sure how long this may last, therefore we have always to be aware that we may have to pay for facilities at a future date. We also require funds for tea & coffee etc. at meetings, stationary and materials for promoting awareness of the group.

Once again, many, many thanks for your generous donation,

Stuart L. Marshall (Secretary)

The Urology Directorate at East Lancashire Hospitals NHS Trust would like to invite you to a **'ROBOTIC OPEN EVENING'** to be held on Thursday November 19th at Royal Blackburn Hospital.

This gives the Directorate an opportunity to demonstrate its state of the art **'Da Vinci robot'** and its utility in surgery for prostate cancer. The robot has been operational in our Trust since the beginning of June 2015. All patients in the Lancashire and South Cumbria Cancer Network requiring a radical prostatectomy will be offered this cutting edge technology with all of its proven benefits.

This is a fantastic opportunity to see the Da Vinci robot in action, to meet the robotic surgery team and find out more about this exciting opportunity for our patients.

We are grateful for your support and hope to see you all at what promises to be a very exciting evening.

Kevin McGee, Chief Executive, East Lancashire Hospitals NHS Trust

Shahid Islam, Clinical Director for Urology, East Lancashire Hospitals NHS Trust

Maire Morton, Divisional Director for Surgery, East Lancashire Hospitals NHS Trust

Natalie Brockie, Divisional Manager for Surgery, East Lancashire Hospitals NHS Trust

DETAILS:

Date: Thursday 19th November 2015

Time: 4 – 8pm (please feel free to attend at any time)

Venue: Anaesthetic Seminar Room, Level 1, Royal Blackburn Hospital,

Haslingden Road, Blackburn, BB2 3HH

A buffet dinner will be available from 5pm and served in the seminar room

RSVP: By Friday 23rd October

Please email Jeanette.livings@elht.nhs.uk or call 01254 732867