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

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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. In 2014 a working group comprised of charities, patients and healthcare 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 View 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 diagnosed) 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. 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...
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reasons why the treatment chosen is the
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Men who are living with cancer often
of people diagnosed with breast cancer.
the name of a CNS, compared to 93%
diagnosed with prostate cancer were given
survey also highlighted that 88% of men
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. 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
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.3 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
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being treated, and 34% did not feel
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together to give them the best possible
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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.
Men over 50 (or black men over 45) requesting a PSA test or presenting in primary care with symptoms suggesting prostate cancer are risk assessed, counselled and offered a PSA test. If considered appropriate they should be referred to a specialist centre.

What this means to the patient:
‘Assurance that my symptoms and concerns have been taken seriously, and if I am at risk of prostate cancer it will be diagnosed sufficiently early to give me the best possible outcome.’

Men referred with suspected prostate cancer are offered the full range and access to the most up-to-date and clinically effective diagnostic technologies.

What this means to the patient:
‘Assurance that I will receive the most effective diagnostic options for my condition to be accurately graded and staged no matter where I live.’

Men with prostate cancer have the opportunity to talk through all available treatment options and are provided with comprehensive information on the risks and benefits by members of their multidisciplinary team (MDT) in order to make an informed decision.

What this means to the patient:
‘Assurance that my treatment options, whilst primarily driven by clinical expertise take into consideration my personal circumstances and lifestyle preferences. I feel comfortable with the information presented to me, such that I can make an informed decision on my treatment.’

Men with prostate cancer (regardless of stage of disease) have access to their treatment of choice, including clinical trials if deemed clinically appropriate, regardless of geographical location.

What this means to the patient:
‘Assurance that I will have access to treatments offering me the best chance of controlling my cancer and that gives me the best quality of life regardless of where I live.’

Men with prostate cancer are provided with a written personalised care plan that is regularly reviewed by their assigned clinical nurse specialist. They are signposted or referred to support groups and specialist services that are appropriate to their stage of disease to manage their physical, emotional, psychological and sexual health.

What this means to the patient:
‘Assurance that I have a personalised care plan that provides me with a “roadmap” of what lies ahead and that I have been consulted on the preparation of my care plan. I understand the process for reviewing it with my CNS.’

All men with prostate cancer (and where relevant their partner/carer) have access to specialists to support the prevention and management of their complications arising from their disease, whether physical, social, emotional or psychological, arising from the disease and its treatment.

What this means to the patient:
‘Assurance that my ongoing care will include identifying and accessing any specialist services or support that I and/or my partner will require to manage the consequences of my treatment. This should give me the best chance of returning to “normal” either after my cure or whilst living with my cancer.’

Men with prostate cancer receive guidance and a package of care to support self-management of the side effects from their treatment, if they wish to do so.

What this means to the patient:
‘Assurance that, taking account of my personal circumstances and capabilities, I have the opportunity to take control of my condition and treatment, while still being supported by appropriate medical experts.’

Men living with prostate cancer benefit from an integrated and seamless approach to their care and wellbeing appropriate to their stage of disease for the rest of their lives. This will include clear accountability and responsibility across primary and secondary care.

What this means to the patient:
‘Assurance that there is joined-up thinking in the ongoing support and advice I receive, irrespective of who I need to contact, so that I benefit from a holistic approach to all aspects of my care and will not fall between specialisations.’

All men receive and benefit from non-curative care at the appropriate stage of their disease, which is not limited to end of life care or restricted to being associated with hospice care.

What this means to the patient:
‘Assurance that I have access to all the services that will help me achieve the best quality of life at this time, enabling me to come to terms with situations that I have never had to face before. This means I don’t have to wait until I need end-of-life care to get the help that I need now.’
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.

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 2015, 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

REFERENCES

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