

Quality Standards: Prostate Cancer

DEVELOPED BY PATIENTS AND THEIR REPRESENTATIVES

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Background

The quality standard working group for prostate cancer is made up of members from Tackle (The Prostate Cancer Support Federation¹), Prostate Cancer UK, Macmillan Cancer Support, patient representatives, urologists, oncologists, clinical nurse specialists, cancer commissioners, and Ipsen Limited. They have pooled resources, in the form of a joint working initiative, to develop a quality standard that best represents the quality of care for patients with prostate cancer with a particular focus on the quality and service requirements from the perspective of a patient.

The National Institute for Health and Care Excellence (NICE) is expected to publish a quality standard for prostate cancer in June 2015 and are keen to ensure the quality statements within their quality standard are important to patients, service users and carers, and are feasible to implement. As such, we have submitted these quality statements to NICE for consideration within their quality standard for prostate cancer.

Over the last six months the working group members have identified nine quality statements that best represent the quality of care for patients with prostate cancer. As part of the development process these quality statements were also tested amongst a wider group of stakeholders to ensure they resonated with a wider audience before being finalised and submitted to NICE. Quality measures have also been developed/identified to accompany each quality statement, in order to assess the quality of care or service provision specified in the statement.

Aim

According to a report by Prostate Cancer UK (2013), there are, unfortunately, significant variations in prostate cancer incidence, patient experience, mortality and survival across the UK².

This quality standard aims to ensure all men with prostate cancer have a right to have the best possible care and support regardless of where they live.

Through this quality standard the group wish to give patients and their partner/carer a more powerful voice and active involvement in setting priorities for service improvement and in improving access to cutting edge diagnostics, innovative treatments and clinical trials.

¹ Representing 70 patient-led prostate cancer support groups and 15,000 patients

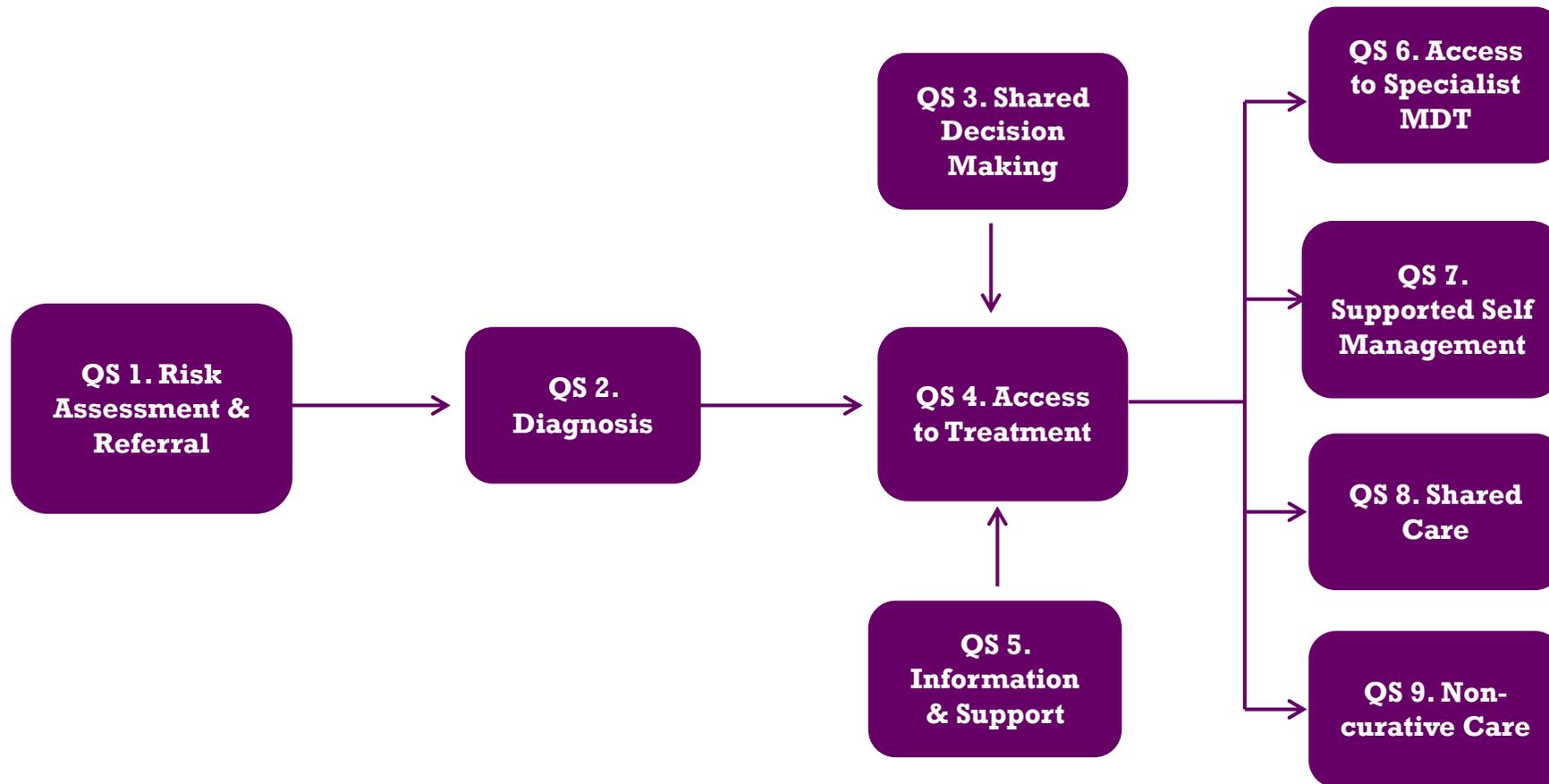
² Quality care. Everywhere? An audit of prostate cancer services in the UK. Available at: http://prostatecanceruk.org/media/1818657/1772-day-of-action-report_for-web.pdf

Working group members

1. Sandy Tyndale-Biscoe, Chair (Tackle)
2. Rowena Bartlett, Chief Executive (Tackle)
3. Roger Wotton, Chair (Vale of Aylesbury Prostate Cancer Support Group)
4. Hannah Winter, Senior Policy Officer (Prostate Cancer UK)
5. Keith Cass MBE, Founder and Researcher (Red Sock Campaign)
6. Ken Mastris, Chair (APPLE) and Chair, Europa Uomo, the European Prostate Cancer Coalition
7. Dale Rominger, service user and volunteer for Prostate Cancer UK
8. Trevor Walker, service user and volunteer for Prostate Cancer UK
9. Dany Bell, Treatment and Recovery Lead (Macmillan Cancer Support)
10. Christina Lane, Consequences of Treatment Project Manager (Macmillan Cancer Support)
11. Dr Frank Chinegwundoh MBE, Consultant Urological Surgeon (Cancer Black Care)
12. Mr Jon McFarlane, Consultant Urologist (Royal United Hospital, Somerset)
13. Sandra Dyer, Nurse Lead Prostate Cancer Project (South East Commissioning Support Unit)
14. Pauline Bagnall, Uro-oncology Nurse Specialist (British Association of Urological Nurses)
15. Barbara Gallagher, User Involvement and Patient Experience Coordinator (NHS England)
16. Sally Hodgson, Senior Product Manager (Ipsen Limited)
17. John Gilbody, Medical Adviser (Ipsen Limited)
18. Roshani Perera, Director (Wicked Minds). Acting as an advisor, rapporteur and project manager to the working group

Overview of Quality Statements in Prostate Cancer Care

The following quality statements have been developed as aspirational yet achievable markers of quality care in prostate cancer.



Glossary

Clinical Nurse Specialist (CNS): is a registered nurse with clinical expertise in nursing practice within a specialty area. Specialist nurses can work in isolation or as part of a multidisciplinary team to provide high quality, patient-centred, timely and cost-effective care. All specialist nurses provide tailored care depending on the patient's level of need. They also provide education and support for patients to manage their symptoms, particularly patients with long-term conditions and multiple morbidities.

Digital Rectal Examination (DRE): is a type of physical examination during which a doctor or nurse inserts a finger into the rectum (back passage) to feel for abnormalities.

End of Life Care: is support for people who are approaching death. It helps them to live as well as possible until they die, and to die with dignity. It also includes support for their family or carers.

High-risk groups: Examples of high-risk groups for prostate cancer are older men, men with a family history of prostate cancer and Black men are more at risk of being diagnosed with prostate cancer

Integrated care: is a term that reflects a concern to improve patient experience and achieve greater efficiency and value from health delivery systems. The aim is to address fragmentation in patient services, and enable better-coordinated and more continuous care, frequently for an ageing population, which has increasing incidence of chronic disease.

Multiparametric (mp) MRI: A new more accurate way of using MRI, called multiparametric (mp) MRI, may be able to help doctors find cancer before biopsy and help to guide the biopsy needles to where the cancer is. An mpMRI is made up of up to three different types of MRI scan which radiologists look at together to give a clearer picture of what's going on in the prostate – such as if and where there might be a tumour.

Metastatic cancer: is cancer that has spread from the place where it first started to another place in the body. A tumour formed by metastatic cancer cells is called a metastatic tumour or a metastasis.

Multidisciplinary Teams (MDTs): are composed of members from different healthcare professions with specialised skills and expertise. The members collaborate together to make treatment recommendations that facilitate quality patient care. For prostate cancer, an MDT will include, as a minimum, a urologist, a radiologist or oncologist, a CNS and a pathologist.

Palliative Care: for people living with an incurable illness, palliative care can help to make the person as comfortable as possible by relieving pain and other distressing symptoms, while providing psychological, social and spiritual support

for the person and their family or carers. This is called a holistic approach to care, as it deals with the 'whole' person rather than just one aspect of their care.

Primary Care: is the day-to-day health care given by a health care provider. Typically this provider acts as the first contact and principal point of continuing care for patients within a health care system, and coordinates other specialist care that the patient may need.

PSA Test: is a blood test that measures the amount of prostate specific antigen (PSA) in the blood. PSA is a protein produced by the prostate. It is normal for all men to have a small amount of PSA in their blood, and this amount rises as they get older. A raised PSA level may suggest a problem with the prostate.

Risk factors: A risk factor is anything that affects a person's chance of getting a disease such as cancer. Different cancers have different risk factors. Some risk factors, such as lifestyle choices, can be changed. Others, like a person's age, ethnicity, or family history, can't be changed.

Transperineal template prostate biopsy: involves the insertion of many fine needles through the skin between the scrotum and the anus in order to obtain tissue samples from the prostate for testing. The procedure is carried out with the patient under local or general anaesthesia.

Transrectal ultrasound-guided (TRUS) prostate biopsy: involves using thin needles to take around 10 to 12 small pieces of tissue from the prostate. The biopsy is done through the back passage (rectum). A local anaesthetic is injected into the back passage to ease any discomfort.

Quality statement 1: Risk assessment and referral

Men over 50 or (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.

Rationale:

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. The high death rate represents not only a personal disaster for over 10,000 men who die every year, but also a great burden on the Health Service in terms of palliative care costs (e.g. long term hormone treatment and chemotherapy).

There is often increased anxiety amongst men with risk factors, particularly those with a family history of prostate cancer. If these men present in primary care, it is important that they receive the best available information and support to assist them in the decision of whether or not to have a PSA test.

Men often present to their GP with increased urinary frequency with no other signs or symptoms unless the cancer is metastatic. Patients within our working group raised concern that GPs were reluctant to offer a PSA (prostate specific antigen) test if patient presents with no symptoms. Prostate cancer can grow slowly or very quickly. Most prostate cancer is slow-growing to start with and may never cause any symptoms or problems in a man's lifetime. However, some men will have cancer that is more aggressive or 'high risk.' This needs treatment to help prevent or delay it spreading outside the prostate gland.

Black men (irrespective of Black-African or Black-Caribbean origin) have a 3-fold higher risk of developing prostate cancer than white men [1] whilst Asian and Oriental men have the lowest incidence [2,3]. Despite the higher risk of prostate cancer, awareness of prostate cancer is low amongst Black men. Anecdotal reports also indicate low awareness amongst some GPs, with some Black men being refused a PSA test [4]. The combination of lack of cancer awareness in the Black community, and lack of cultural competence amongst health professionals, is almost certainly contributing to poorer outcomes from prostate cancer [4].

Clinical expertise in the group would recommend regular PSA testing for asymptomatic men from age 45 if Black and age 50 if White. The group also

³ <http://www.cancerresearchuk.org/cancer-info/cancerstats/keyfacts/prostate-cancer/>

commented that most Primary Care teams (including Practice Nurses /Nurse Practitioners) were not provided with the necessary education and knowledge 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 UTI). Not enough men are informed about availability of the test and research carried out by Prostate Cancer UK shows that two thirds of men over 50 do not even know that the test exists. Awareness on PSA testing needs to be improved amongst men and they should be given adequate information about the PSA blood test, the digital rectal examination (DRE) and biopsies, with the opportunity to discuss the pros and cons of the tests with a doctor or nurse. Access to local support groups should be made available to help men improve awareness on signs and symptoms and when to access their GP for further investigations.

The Prostate Cancer Risk Management Programme (PCRMP) [5] aims to help the primary care team give clear and balanced information to men who request details about testing for prostate cancer. Any man over the age of 50 who asks for a PSA test after careful consideration of the implications should be given one. However, there are growing signs that some GPs are ignoring the PCRMP, and following instead, informal “guidance” published in the BMJ [6], that recommends “Physicians can improve the health of their male patients by recommending against PSA screening for prostate cancer.” This is a dangerous trend, which will only result in more men being diagnosed late with advanced, incurable prostate cancer that is likely to kill them.

According to NICE clinical guideline 27 ‘Referral for suspected cancer’ (June 2005), in a male patient with or without lower urinary tract symptoms and in whom the prostate is normal on DRE but the age-specific PSA is raised or rising, an urgent referral should be made [7]. If there is doubt about whether to refer an asymptomatic male with a borderline level of PSA, the PSA test should be repeated after an interval of 1 to 3 months [7]. If the second test indicates that the PSA level is rising, the patient should be referred urgently.

Quality measures

Structure:

- a) Evidence of local arrangements to appropriately risk assess patients
- b) Evidence of local arrangements to adequately educate and up skill primary care providers (GPs and nurses) on PSA testing and counselling for patients receiving a test

Process:

- a) Proportion of patients offered counselling before having a PSA test
 - i. Numerator – the number of patients in the denominator who were offered counselling
 - ii. Denominator – the number of patients receiving a PSA test

Outcome:

- a) Routes to diagnosis (National Cancer Intelligence Network. Routes to diagnosis 2006-2010 workbook (Available from: <http://www.ncin.org.uk/view?rid=2645>)
 - i. Emergency
 - ii. Two-week wait
 - iii. GP referral
 - iv. Inpatient elective
- b) Stage at diagnosis of prostate cancer
- c) Evidence from patient experience surveys and feedback that patients feel their concerns were considered

Source guidance

1. Ben-Shlomo Y, Evans S, Ibrahim F, Patel B, Anson K, Chinegwundoh F, et al. The risk of prostate cancer amongst black men in the United Kingdom: the PROCESS cohort study. *Eur Urol* 2008; 53:99–105.
2. Parkin D, Whelan S, Ferlay J, Raymond LYJ. *Cancer Incidence in Five Continents*. Lyon: IARC Scientific Publications No. 143, 1997. Report No. V11.
3. Parker SL, Davis KJ, Wingo PA, Ries LA, Heath CW Jr. Cancer statistics by race and ethnicity. *CA Cancer J Clin* 1998; 48:31–48.
4. Hear me now: the uncomfortable reality of prostate cancer in black African-Caribbean men. A report by Rose Thompson, BME Cancer Communities, February 2013. <http://www.nbpa.co.uk/wp-content/uploads/2014/04/Hear-me-now.pdf>. Date accessed: December 2014.
5. NHS Cancer Screening Programmes. An easy reference to assist primary care teams in providing asymptomatic men with information on the benefits, limitations and implications of having a PSA test for prostate cancer. (2009). Available from: <http://www.cancerscreening.nhs.uk/prostate/prostate-booklet-text.pdf>. Date accessed: December 2014.
6. Wilt T.J. and Ahmed H.U. Prostate cancer screening and the management of clinically localized disease. *BMJ* 2013;346:f325. (Published 29 January 2013)
7. National Institute for Health and Care Excellence. Referral guidelines for suspected cancer. NICE clinical guideline 27(2005). Available from: <http://www.nice.org.uk/guidance/cg27/resources/guidance-referral-guidelines-for-suspected-cancer-pdf>. Date accessed: December 2014.

Quality statement 2: Diagnosis

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.

Rationale

For a patient, being informed of a suspected cancer can be a traumatic and difficult time. This is further confounded by the choice of diagnostic procedures available. Some patients in the group had experience of being offered procedures that were deemed the 'preferred option' of the healthcare professional and others spoke about requesting specific procedures based on personal information and knowledge they had gained from doing their own research. It is important for the healthcare professional to take into consideration the patient's lifestyle, personal preferences, and any co-morbidities they may have when making decisions about which diagnostic technologies are to be used.

The Trans Rectal Ultrasound prostate biopsy (TRUS) procedure can cause significant anxiety and most men describe the biopsy as an embarrassing, uncomfortable experience, and some describe it as painful. In addition, if the cancer lesions are small, biopsy may not reveal them. [1-3].

An increasing number of centres are able to offer transperineal template prostate biopsy [4]. Clinical expertise in the group highlighted that the diagnostic accuracy is double that of TRUS biopsy and the sepsis rate very much lower. They also mentioned that Transperineal biopsy was reserved for men with rising PSA and one or more negative TRUS biopsies, however it is now extended to first time biopsies, especially if the MRI pre biopsy suggests an anteriorly located cancer. In a British Association of Urological Surgeons (BAUS) session (June 2014), almost all urologists said that they would personally prefer a transperineal prostate biopsy rather than TRUS given the choice, although they recognised the current challenge of limited theatre capacity.

There is growing evidence that multiparametric (mpMRI) (using a 1.5T or 3T machine) by an experienced team of radiographers and radiologists before a prostate biopsy can provide more information by which to identify prostate cancer and thus reduce the false-negative rate [5]. An on going, large-scale trial (the PROMIS trial) is looking at mpMRI. It is has been running since 2012, and is also looking at the cost-effectiveness of using mpMRI before biopsy, which is vital information if it is to become part of standard practice in the UK. The PROMIS trial finishes in 2015.

NICE guidelines recommend that, when a patient has been diagnosed as having prostate cancer, they have access to imaging techniques such as magnetic

resonance imaging (MRI), computerised tomography (CT) scans and radioisotope bone scans to assess the extent of cancer and whether or not that has spread beyond the prostate [6].

Quality measures

Structure:

- a) Evidence of investigations used in local specialist centres
- b) Evidence of local arrangements to offer access to investigations not available locally

Process:

- a) Proportion of patients offered access to all available investigations where clinically appropriate
 - i. Numerator – the number of patients in the denominator accessing their choice of clinically appropriate investigations
 - ii. Denominator – the number of patients who were offered full range of clinically appropriate investigations

Outcome:

- a) Evidence from patient experience surveys and feedback that patients are receiving full choice and access to clinically appropriate investigations.
- b) Evidence from patient experience surveys and feedback that patients' felt their diagnosis was appropriately communicated.

Source guidance

1. Loch T, Eppelmann U, Lehmann J, Wullich B, Loch A, Stockle M. Transrectal ultrasound guided biopsy of the prostate: random sextant versus biopsies of sono-morphologically suspicious lesions. *World J Urol.* 2004;22:357–360.
2. Wefer AE, Hricak H, Vigneron DB, Coakley FV, Lu Y, Wefer J, et al. Sextant localization of prostate cancer: comparison of sextant biopsy, magnetic resonance imaging and magnetic resonance spectroscopic imaging with step section histology. *J Urol.* 2000;164:400–404.
3. Hricak H, Choyke PL, Eberhardt SC, Leibel SA, Scardino PT. Imaging prostate cancer: a multidisciplinary perspective. *Radiology.* 2007;243:28–53.
4. NICE interventional procedures guidance (IPG364). Transperineal template biopsy and mapping of the prostate. October 2010
5. Myung Sun Choi, Yong Sun Choi, Byung Il Yoon et al. The Clinical Value of Performing an MRI before Prostate Biopsy. *Korean J Urol.* Aug 2011; 52(8): 572–577.
6. Men referred for suspected prostate cancer, in accordance with NICE clinical guideline 27, recommendations 1.8.2 – 1.8.8 are offered a transrectal

ultrasound (TRUS) guided biopsy, in accordance with NICE clinical guideline 175, recommendation 1.2.4.

7. Men should be provided with comprehensive information about the biopsy procedure, in accordance with the Prostate Cancer Risk Management Programme (PCRMP) Guide No 1 (2006).
8. NICE clinical guideline 175 recommendations 1.2.6 (key priority for implementation) and 1.2.7 are followed in cases of rebiopsy.

Quality statement 3: Shared decision-making

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 multi-disciplinary 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.

Rationale

The patient and his partner, family and/or other carers should be fully informed about care and treatment options and therefore able to make appropriate decisions based upon the choices offered by their healthcare professionals. For example, the choice between radical treatment and active surveillance may be influenced by a patient's desire to retain sexual activity, physical energy and quality of life (QoL). Patients should also be informed of their nearest prostate cancer support group as well as other support mechanisms to help aid decision making.

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 MDT to discuss the pros and cons of all available treatment options in order to help aid their decision on treatment choice. The case notes, pathology reports, test results and radiology for each patient must be available to be discussed at the meeting. Often a case is discussed at MDT before the patient has been seen for the results and the MDT suggests options to be put to the patient. The MDT must ensure that the patient has the fullest possible role in determining treatment – the importance of this cannot be overstated. Therefore patient preference should be discussed within the MDT once the results and treatment options have been discussed with the patient [1]. The decisions taken about treatment options may impact upon the patient's quality of life long after treatment has finished. The National Cancer Survivorship Initiative (NCSI) suggests offering patients support in making the decisions that best reflect their individual priorities [1].

Healthcare professionals should be encouraged to use Patient Decision Aids [1], which are specially designed information resources that help men make decisions about different healthcare options. They will help patients think about why one option maybe better than another. It is important to recognise however that patients are given a plethora of information leaflets etc. but there is no explicit responsibility on the giver to check the patient's level of understanding or confusion. Agreeing on the "treatment of choice" may require staff trained in counselling, and access must be available and offered when appropriate. It is also important to bear in mind that men's views change over time depending on their experiences and who they talk to.

The shared decision-making conversation needs both the patient and professional to understand the other's point of view and agree the reasons why the treatment chosen was the best one for the patient. The reason may be that it was the best medical option or it was the best option for that patient's life. Part of the shared decision-making may also include involving the patient's partner, family members, and carer (if requested by the patient).

Quality Measures

Structure:

- a) Evidence of local arrangements to ensure that patients are supported to make informed choices using risk communication and decision support, such as patient decision aids.
- b) Evidence of local arrangements to ensure that information provided to facilitate shared decision-making is evidence-based, understandable and clearly communicated.

Process:

- a) Proportion of patients who were asked about any issues that may prevent them being actively involved in decisions about their care.
 - i. Numerator – the number of patients in the denominator who were asked about any issues that may prevent them from being actively involved in decisions about their care.
 - ii. Denominator – the number of patients accessing NHS services for prostate cancer.
- b) Proportion of patients supported to use an evidence-based patient decision aid.
 - i. Numerator – the number of patients in the denominator supported to use an evidence-based patient decision aid.
 - ii. Denominator – the number of patients accessing NHS services for whom there is a relevant evidence-based decision aid.

Outcome:

- a) Evidence from patient experience surveys and feedback that patients found that the information provided to facilitate shared decision-making was understandable and clearly communicated.
- b) Evidence from patient experience surveys and feedback that patients feel able to make decisions that reflect what is important to them.

Source guidance

1. The Right Care Shared Decision Making Programme is to embed Shared Decision Making in NHS care. This is part of the wider ambition to promote patient centred care, to increase patient choice, autonomy and involvement in clinical decision-making and make “no decision about me, without me” a reality. <http://sdm.rightcare.nhs.uk>. Date accessed: December 2014.
2. NICE clinical guideline 175 recommendations 1.1 Information and decision support for men with prostate cancer, their partners and carers.

Quality statement 4: Access to 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.

Rationale

Prostate cancer is unique in that, without solid evidence of the best treatment option, personal choice (e.g. of surgery versus radiation) becomes an important element in selecting treatment options. In the latest national cancer patient experience survey (October 2014) 73% of prostate cancer patients felt their views were taken into consideration when discussing treatment options.

The NHS Constitution sets out patients' right to treatment, right to NICE approved drugs and right to complain about their care [2]. The constitution gives the patient the right to ask their doctor and hospital for the right care. For cancer drugs that have not been approved by the National Institute for Health and Care Excellence (NICE) the Government has set up the Cancer Drugs Fund (CDF) to pay for cancer drugs that haven't been approved and aren't available within the NHS in England. There is a national list of drugs available through the Fund and if a patient meets the conditions for a drug that is on the list, he should be able to have it on the NHS regardless of geographical location within England (this is currently under review by NHS England).

Patients should also have the opportunity to speak to their specialist about whether there are any other treatments they can access such as trials of new experimental treatments going on and their eligibility to take part in one of them. Cancer Research UK publishes a clinical trials database (<http://www.cancerresearchuk.org/about-cancer/trials/>) listing trials both open and closed.

Quality Measures

Structure:

- a) Evidence of local arrangements to ensure that patients are made aware and have access to their treatment of choice, (including access to clinical trials) and clinical expertise regardless of geographical location.

Process:

- a) Proportion of patients receiving NICE approved treatments
 - i. Numerator – the number of patients in the denominator receiving NICE approved treatments

- ii. Denominator – the number of patients eligible for NICE approved treatments
- b) Proportion of patients accessing cancer treatment available through the CDF
 - i. Numerator – the number of patients in the denominator accessing treatment available through the CDF
 - ii. Denominator – the number of patients eligible for treatment available through the CDF
- c) Proportion of patients accessing cancer treatment available through clinical trials
 - iii. Numerator – the number of patients in the denominator accessing treatment available through clinical trials
 - iv. Denominator – the number of patients eligible for treatment available through clinical trials

Outcome:

- a) Evidence from patient experience surveys and feedback that patients are made aware and have access to their treatment of choice, (including access to clinical trials) and clinical expertise regardless of geographical location.

Source guidance

1. Living with & Beyond Cancer: Taking Action to Improve Outcomes (an update to the 2010 The National Cancer Survivorship Initiative Vision).
<http://www.ncsi.org.uk/wp-content/uploads/Living-with-and-beyond-2013.pdf>. Date accessed: December 2014.
2. The NHS Constitution:
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/170656/NHS_Constitution.pdf. Date accessed: December: 2014.
3. NHS England, Cancer Drugs Fund.
<http://www.england.nhs.uk/ourwork/pe/cdf/>. Date accessed: December 2014

Quality statement 5: Information and support

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.

Rationale

According to the 2014 National Cancer Patient Experience Survey (NCPES), only 20% of prostate cancer patients were offered a written care plan [1]. 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. The reason may be reflected by the 2011 CNS Census [2], which showed that urology CNS's have a caseload of 176 new patients per year compared to breast cancer CNS's with a case load of 79 per annum. In addition, men who are living with cancer often have difficulties that go beyond their medical needs to include financial, emotional, and practical needs, and these needs are often lifelong. Although improvement has been made since 2010, almost half of prostate cancer patients (41%) who would have liked information about how to get financial help or any benefits are still not receiving any [1].

Providing men undergoing treatment for their prostate cancer with a personalised care plan offers the opportunity to discuss and be assured that the patient is aware of all treatment expectations and consequences such as erectile dysfunction, incontinence, and bone health, and have access to care and wider social care support they could need as part of their care plan. 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 that they are not alone.

The NCPES demonstrates that patients with a CNS are more likely to report a positive experience of their care than patients without a CNS [1]. Therefore having a key clinical contact such as a clinical nurse specialist is vital to ensuring that the patient and their carer/family members are able to speak to a single point of contact to discuss any questions or concerns they may have during the course of their care.

The National Cancer Survivorship Initiative (NCSI)⁴ highlights a number of key interventions that could make an immediate difference, including the introduction of an integrated recovery package of:

- Structured holistic needs assessment and care planning
- Treatment summaries (linking up primary and secondary care)
- Patient education and support events (Health and Wellbeing Clinics)
- Advice about, and access to, schemes that support men to undertake physical activity and healthy weight management.

Many cancer patients and their families are dealing with a huge financial burden as a result of their illness. According to research conducted by Macmillan, 9 out of 10 cancer patients' households suffer loss of income and/or increased costs as a direct result of cancer [4]. It also highlights that far too many cancer patients are not made aware of the help that may be available to them, such as through the 'Hospital Travel Costs Scheme' or the 'NHS Low Income Scheme'. It is important therefore to also provide financial and other social care related support available to patients and their families as part of the information and support provided.

Quality Measures

Structure:

- a) Evidence of local arrangements to support coordinated care through clear and accurate information exchange (written and shared through a personalised care plan) between patient and relevant health and social care professionals.
- b) Evidence of local arrangements to ensure that patients' preferences for sharing information with partners, family members and/or carers are established, respected and reviewed throughout their care.

Process:

- a) Proportion of patients receiving a personalised care plan
 - i. Numerator – the number of patients in the denominator receiving a personalised care plan
 - ii. Denominator – the number of patients diagnosed with prostate cancer
- b) Proportion of patients who receive personalised information and support, including a written care plan and details on how to contact a named health or social care professional relevant to their wellbeing needs
 - i. Numerator – the number of people in the denominator receiving personalised information and support, including a written follow-up care plan and details on how to contact a named health or

⁴ The NCSI has now evolved into the Living With and Beyond Cancer Programme, a two-year partnership between NHS England and Macmillan Cancer Support aimed at embedding findings and recommendations into mainstream NHS commissioning and service provision.

social care professional relevant to their wellbeing needs.

- ii. Denominator – the number of people having treatment for prostate cancer.

Outcome:

- a) Evidence from patient experience surveys and feedback that patients feel that information about their care was shared clearly and accurately between relevant health and social care professionals.
- b) Evidence from patient experience surveys and feedback that patients feel that they found a written care plan was useful and helped inform them about their care
- c) Evidence from patient experience surveys and feedback that patients' preferences for sharing information with partners, family members and/or carers were established, respected and reviewed throughout their care.

Source guidance

1. Cancer Patient Experience Survey 2014. <http://www.quality-health.co.uk/surveys/national-cancer-patient-experience-survey>. Date accessed: December 2014
2. 2011 CNS Census http://www.bdnng.org.uk/documents/NCAT_Census_of_the_Cancer_Specialist_Nurse_Workforce_2011.pdf (page 10). Date accessed: December 2014
3. Living with & Beyond Cancer: Taking Action to Improve Outcomes (an update to the 2010 The National Cancer Survivorship Initiative Vision). <http://www.ncsi.org.uk/wp-content/uploads/Living-with-and-beyond-2013.pdf>. Date accessed: December 2014.
4. The hidden price of getting treatment. Macmillan Cancer Support. June 2006. <http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Costofcancer/Cancers-Hidden-Price-Tag-report-England.pdf>. Date accessed: December 2014.

Quality statement 6: Access to other specialist care

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 on going 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.

Rationale

Psychological distress, depression and anxiety are common side effects associated with prostate cancer treatment [1]. Erectile dysfunction and urinary problems are also typical, for example, 63% of patients with prostate cancer state that they are unable to maintain an erection and 38% reported urinary leakage, which is associated with lower quality of life scores [1]. Additionally the number of patients with chronic gastrointestinal (GI) symptoms after cancer therapies which have a moderate or severe impact on quality of life is similar to the number diagnosed with inflammatory bowel disease annually [2]. However, in contrast to patients with inflammatory bowel disease, most of these patients are not referred for gastroenterological assessment [2]. Bone health complication is another critically important factor for patients with advanced prostate cancer receiving hormone therapy. It is vitally important these patients are aware of the issues and treatments available as well as access to DEXA scan (a special type of X-ray that measures bone mineral density) to minimise the risk of bone health complications. It is also important to acknowledge that the significance of the side effects of treatment can be different for homosexual / bisexual men, and this must be considered by all parties at all stages of diagnosis and treatment. NICE recommends specialised support services to help patients address these side effects, especially psychological ones [3].

An estimated one in five of all prostate cancer patients do not raise, or really understand, the potential issues and associated side-effects of treatments and alternatives that may be available to them [House of Commons Committee of Public Accounts 2006]. The recent national cancer patient experience survey highlighted that before treatment, 44% of patients were not fully informed about side effects that could affect them in the future [4]. Patients who continue to survive with cancer complications may be better supported through access to an MDT at the point of diagnosis, with subsequent on-going MDT support to manage their side effects and consequences of cancer treatment.

Integration within and between MDTs is essential for patients with prostate cancer because the collaboration between prostate cancer MDT members is central to the treatment strategy, with on-going support from wider specialist to manage

pain and the adverse effects of therapy. By being familiar with the complete spectrum of management strategies, MDTs can assist patients in making treatment decisions that are specific for their individual disease state, co-morbid conditions, age and lifestyle [6].

All cancer survivors, wherever they live, can and should expect to have informed choices in relation to the services on offer to them through an established aftercare MDT [7].

Quality Measures

Structure:

- a) Evidence of local arrangements to provide patients with access to specialist MDTs to manage their side effects and main complications of treatment

Process:

- a) Proportion of patients accessing specialist MDTs to manage their side effects and main complications
 - i. Numerator – the number of patients in the denominator accessing specialist MDTs
 - ii. Denominator – the number of patients requiring specialist MDT support
- b) Proportion of patients who have a named gastroenterologist to manage their GI side effects
 - i. Numerator – the number of patients in the denominator who have a named gastroenterologist
 - ii. Denominator – the number of patients requiring a named gastroenterologist

Outcome:

- a) Evidence from patient experience surveys and feedback that patients are aware of their side effects and main complications of their treatment and know when and who to access for specialist support.
- b) Evidence from patient experience surveys and feedback that patients feel that their side effects and main complications in relation to their condition are adequately managed with access to specialist support when needed.

Source guidance

1. Prostate Cancer UK. Research into wellbeing services for men with prostate cancer –final report. August 2014. Available at: <http://prostatecanceruk.org/media/2460122/Report-Wellbeing-services-for-men-with-prostate-cancer.pdf>. Date accessed: December 2014.
2. Andreyev HJN, Davidson SE, Gillespie C, et al. Practice guidance on the management of acute and chronic gastrointestinal problems arising as a result

of treatment for cancer. *Gut* (2011).

http://www.bsg.org.uk/images/stories/docs/clinical/guidelines/rad/gi_cancer_11.pdf. Date accessed: December 2014.

3. National Institute for Health and Care Excellence. Prostate cancer: Diagnosis and treatment. NICE clinical guideline 175 (2014). Available from: <http://www.nice.org.uk/nicemedia/live/14348/66232/66232.pdf>
4. Macmillan Cancer Support. Cancer Patient Experience Survey: Insight Report and League Table 2014. October 2014. Available at: <http://www.macmillan.org.uk/Documents/AboutUs/Research/Keystats/2014-CPES-Insight-Briefing.pdf>. Date accessed: December 2014.
5. British Uro-oncology Group (BUG) and British Association of Urological Surgeons (BAUS) Section of Oncology. Interim MDT (Multi-disciplinary Team) Guidance for Managing Prostate Cancer (September 2013). Available at: <http://www.baus.org.uk/Resources/BAUS/Documents/PDF%20Documents/BAUS%20in%20general/MDT%20Prostate%20Cancer%20Guidance.pdf>. Date accessed: December 2014.
6. Living with & Beyond Cancer: Taking Action to Improve Outcomes (an update to the 2010 The National Cancer Survivorship Initiative Vision). <http://www.ncsi.org.uk/wp-content/uploads/Living-with-and-beyond-2013.pdf>. Date accessed: December 2014.
7. National Cancer Peer Review Programme. Evidence Guide for: Urology Specialist MDT. 2010.

Quality statement 7: Supported self-management

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.

Rationale

The group agreed that all men should be supported to self-manage if they wish to do so. This ideally should be in the form of a package of care that offers support to self-manage the side effects of their treatment, including hot flushes (a common side effect of hormone therapy, in a majority of patients, that could continue for the duration of treatment), fatigue, bone health and sexual issues, based on individual needs and preferences, and with the appropriate clinical assessment, support, and treatment.

All cancer survivors who are clinically safe to self-manage should be provided with comprehensive information and be involved in a remote monitoring and/or alert system that prompts screening investigations. The 'recovery package' – a combination of assessment and care planning, Treatment Summary, and a patient education and support event (Health and Wellbeing Clinic) – is potentially the most important building block for achieving good outcomes.

The implications of prostate cancer for both the patient and his partner is well-documented, with increases in men's problems relating to subsequent decreases in partner's quality of life (Kornblith et al., 2001; Eton, Lepore, and Helgeson, 2005; Ko et al., 2005). Hence, recognition of the need for self-management support designed for prostate cancer survivors as well as their partners should be considered.

Where men are assessed as lacking confidence for self-management, it is fundamental to provide access to tailored education, training, and support for the development of self-management skills and strategies, based on personalised assessment and care planning. Men should be supported to self-manage in order to:

- Feel confident and in control of their life
- Communicate effectively with professionals and be willing to share responsibility for treatment
- Manage their condition and its treatment in partnership with healthcare professionals
- Be realistic about how their condition affects them and their family
- Use their skills and knowledge to lead a full life

Quality Measures

Structure:

- a) Evidence of local arrangements to provide patients with support to self manage the side effects and consequences of their treatment in the form of a recovery package (a combination of assessment and care planning, treatment summary, and patient education and support material).

Process:

- a) Proportion of patients receiving support to self manage their treatment and the consequences of their treatment
 - i. Numerator – the number of patients in the denominator receiving support to self manage
 - ii. Denominator – the number of patients receiving, or who have received treatment for prostate cancer

Outcome:

- b) Evidence from patient experience surveys and feedback that patients receive adequate support and are confident to self manage the side effects and consequences of their treatment.

Source guidance

1. Macmillan cancer support, Self-management support for cancer survivors: guidance for developing interventions: An update of the evidence (March, 2010). Available at: http://www.trustedwriter.com/documents/guidancefordevelopinginterventions_anupdateoftheevidence.pdf. Date accessed: December 2014.
2. DH, Macmillan Cancer Support & NHS Improvement. Living with & Beyond Cancer: Taking Action to Improve Outcomes (an update to the 2010 The National Cancer Survivorship Initiative Vision). March 2013. <http://www.ncsi.org.uk/wp-content/uploads/Living-with-and-beyond-2013.pdf>. Date accessed: December 2014.

Quality statement 8: Shared care

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 on going 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.

Rationale

According to the National Cancer Patient Experience Survey (2014), 28% of prostate cancer patients mentioned that their GPs and nurses did not support them enough whilst being treated and 34% of prostate cancer patients did not feel different professionals worked well together to give them the best possible care [1].

Integrated care means all health and social care services working together across organisational and professional boundaries to ensure individual patients get the care, information, support and treatment they need, when they need it [2]. It is clear that primary care providers should play a bigger role, as it is they who inevitably care not only for prostate cancer survivors, but all those affected by prostate cancer. In order to ensure men are adequately supported to manage these needs the working group believes that there must be a seamless integration of well co-ordinated cancer care across primary (GP), secondary (hospital), and social care. This includes clear lines of responsibility and accountability with staff provided with the necessary training and links to resources.

Further more, in health and social care policy, addressing wellbeing⁵ needs is becoming a growing priority. 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 put this down to lack of resources; low awareness (of the problem and / or support services) among clinicians; over-concentration on ‘the cancer’ relative to ‘the man’; and lack of local strategic direction [3]. The manner / type of referral makes a difference to the take-up of support services – integration of wellbeing into standard pathways (through a holistic needs assessment, for example) is important. The extent of local clinical engagement in the ‘wellbeing agenda’ is therefore an important determining factor in the support men receive.

⁵ “Wellbeing” is a broad, dynamic and multi-dimensional concept consisting of many different elements interplaying with each other, including emotional wellbeing, mental wellbeing, physical wellbeing, social wellbeing (relationships and family life) and economic wellbeing.

With more men becoming long term survivors of prostate cancer it is essential follow up care to deliver timely access to treatments as and when necessary and the alleviation of suffering whilst ensuring that no one falls through the cracks.

Quality measures

Structure:

- a) Evidence of local arrangements to deliver a shared care model that allows patients to see, whenever possible, the same healthcare professional or team throughout a single episode of care.
- b) Evidence of local arrangements and written communication protocols are in place to ensure clear accountability and responsibility across the primary and secondary care interface for the management of patients with prostate cancer for the rest of their lives.

Process:

- c) Proportion of prostate cancer patients receiving care through a shared care model.
 - i. Numerator – the number of prostate cancer patients in the denominator receiving care through a shared care model.
 - ii. Denominator – the number of prostate cancer patients receiving treatment for prostate cancer.

Outcome:

- a) Evidence from patient experience surveys and feedback that, GPs and nurses within general practice did everything they could to support the patient while they were having cancer treatment.
- b) Evidence from patient experience surveys and feedback that, patients felt health and social care staff treating and caring for them (such as GP, hospital doctors, hospital nurses, specialist nurses, community nurses) work well together to give them the best possible care.

Source guidance

1. Cancer Patient Experience Survey 2014. <http://www.quality-health.co.uk/surveys/national-cancer-patient-experience-survey>. Date accessed: December 2014.
2. Patients' experience of integrated care: A report from the Cancer Campaigning Group. November 2012. Available at: <http://www.cancercampaigninggroup.org.uk/wp->

content/uploads/2012/11/Patients'-experience-of-integrated-care-A-report-from-the-Cancer-Campaigning-Group.pdf. Date accessed: December 2014.

3. Prostate Cancer UK. Research into wellbeing services for men with prostate cancer –final report. August 2014. Available at: <http://prostatecanceruk.org/media/2460122/Report-Wellbeing-services-for-men-with-prostate-cancer.pdf>. Date accessed: December 2014.

Quality statement 9: Non-curative care

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.

Rationale

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 more often than not has misleading connotations. Some of the prostate cancer patients with advanced disease that we approached felt 'the term palliative care would strike a real fear that they have entered the end game', and that 'with the loss of hope of a cure, it would be about management of the symptoms and pain management'. Others understood palliative care to mean end of life care. The inevitability of death requires careful management so that these men can live out those final 'moments' (which actually may be months or even years) with dignity and without unnecessary pain and also without false hope. For this reason there needs to be a clear statement and understanding of what constitutes palliative care for men with prostate cancer and a clear understanding of when it should become applicable. In this context the term palliative is misleading and therefore the group defined this care as non-curative care.

It is important to recognise that non-curative care can be offered following treatment or, in the earlier stages of an illness, alongside other treatments. As recommended by NICE clinical guideline (CG 175) palliative care should be made available when needed and not limited to the end of life nor should it be restricted to being associated with hospice care [1]. NICE also recommends integrating palliative interventions at any stage into coordinated care, and facilitating any transitions between care settings as smoothly as possible.

There is a full range of care phases that need to be subdivided into groups of phases that should be available to all men relative to their stage of cancer and

their quality of life issues.

- Phase 1 – care given when a man is initially diagnosed with prostate cancer, which may or may not be curable
- Phase 2 – care given when a man's prostate cancer is clinically described as being non-curable
- Phase 3 – care given in those final weeks/months
- Phase 4 – care given in those final moments (end of life care)

During all of these phases the patient, his carer, and family members should be provided with clear and relevant non-curative care information pertinent to his particular stage of diagnosis, which provides them with access to all medical and non-medical aides.

Quality measures

Structure:

- a) Evidence of local arrangements to ensure all patients are aware and have access to non-curative care and that this is not limited to end of life care or restricted to being associated with hospice care.
- b) Evidence of local arrangements and written communication protocols are in place to ensure patients, carers, and their families are aware and have access to non-curative care services whenever they may need it.

Process:

- a) Proportion of patients, carers and family members receiving non-curative care
 - i. Numerator – the number of patients, carers, and family members in the denominator accessing non-curative care services
 - iii. Denominator – the number of patients diagnosed with non-curative prostate cancer.

Outcome:

- c) Evidence from patient experience surveys and feedback that, when required, patients, carers, and their family members were aware and had access to non-curative care services.

Source guidance

1. National Institute for Health and Care Excellence. Prostate cancer: Diagnosis and treatment. NICE clinical guideline 175 (2014). Available from: <http://www.nice.org.uk/nicemedia/live/14348/66232/66232.pdf>