NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health and social care directorate

Quality standards and indicators

Briefing paper

Quality standard topic: Bladder cancer

Output: Prioritised quality improvement areas for development.

Date of Quality Standards Advisory Committee meeting: 20 May 2015

1 Contents

1 Introduction

This briefing paper presents a structured overview of potential quality improvement areas for bladder cancer. It provides the Committee with a basis for discussing and prioritising quality improvement areas for development into draft quality statements and measures for public consultation.

1.1 *Structure*

This briefing paper includes a brief description of the topic, a summary of each of the suggested quality improvement areas and supporting information.

If relevant, recommendations selected from the key development source below are included to help the Committee in considering potential statements and measures.

1.2 *Development source*

The key development source(s) referenced in this briefing paper is:

Bladder cancer: diagnosis and management. NICE guideline 2 (2015).

2 Overview

2.1 *Focus of quality standard*

This quality standard will cover the diagnosis and management of bladder cancer in adults (18 years and older) referred from primary care. It includes suspected, newly diagnosed and recurrent bladder cancers (urothelial carcinoma, adenocarcinoma, squamous cell carcinoma or small-cell carcinoma) and urethral cancers.

Definition

Bladder cancer is defined by the development of a tumour in the lining of the bladder. In the case of non-muscle-invasive bladder cancer, cancerous cells are contained inside the lining of the bladder. Muscle-invasive bladder occurs if cancerous cells spread to the surrounding muscle[1].

The main risk factor for bladder cancer is increasing age, but smoking and exposure to some industrial chemicals also increase risk.

Bladder cancer is usually identified on the basis of visible blood in the urine or blood found on urine testing, but it can commonly present for the first time as an emergency admission, which is often associated with a poor prognosis.

The involvement of the urogenital tract and the nature of the treatments give this cancer a strong psychological impact, in addition to the physical impact of the disease and its treatments, which is often profound.

Incidence and prevalence

Bladder cancer is the seventh most common cancer in the UK, with just over 10,000 cases diagnosed each year[2]. It is also the seventh most common cause of cancer death in the UK, with around 5000 deaths each year[3]. Bladder cancer is 3–4 times more common in men than in women, and the majority of cases occur in people aged over 60.

2.2 *Management*

Most bladder cancers (75–80%) do not involve the muscle wall of the bladder and are usually treated by telescopic removal of the cancer (transurethral resection of bladder tumour [TURBT]). This is often followed by instillation of chemotherapy or vaccine-based therapy into the bladder, with prolonged telescopic checking of the bladder (cystoscopy) as follow-up. Some people in this group who are at higher risk are treated with major surgery to remove the bladder (cystectomy). People with cancer in or through the bladder muscle wall may be treated with intent to cure using chemotherapy, cystectomy or radiotherapy, and those who have cancer too advanced to cure may have radiotherapy and chemotherapy.

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[1] NHS Choices (2013) Bladder cancer
[2] Cancer Research UK (2013) Bladder cancer incidence statistics
[3] Cancer Research UK (2013) Bladder cancer mortality statistics

See appendices 1 – 4 for the associated care pathway and algorithms from NICE clinical guideline NG2.

2.3 *National Outcome Frameworks*

Tables 1–2 show the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

1.1.1 Table 1 NHS Outcomes Framework 2015–16

Domain	Overarching indicators and improvement areas
1 Preventing people from dying prematurely	***Overarching indicators*** 1a Potential years of life lost (PYLL) from causes considered amenable to healthcare: i Adults 1b Life expectancy at 75 i Males ii Females ***Improvement areas*** **Reducing premature mortality from the major causes of death** 1.4 Under 75 mortality rate from cancer*(PHOF 4.5) i One- and ii Five-year survival from all cancers v One- and vi Five-year survival from cancers diagnosed at stage 1&2**(PHOF 2.19)
4 Ensuring that people have a positive experience of care	***Overarching indicator*** 4a Patient experience of primary care i GP services 4b Patient experience of hospital care 4d Patient experience characterised as poor or worse i. Primary care ii. Hospital care ***Improvement areas*** **Improving people's experience of outpatient care** 4.1 Patient experience of outpatient services **Improving hospitals' responsiveness to personal needs** 4.2 Responsiveness to in-patients' personal needs Improving people's experience of accident and emergency services 4.3 Patient experience of A&E services **Improving the experience of care for people at the end of their lives** 4.6 Bereaved carers' views on the quality of care in the last 3 months of life
Alignment across the health and social care system * Indicator is shared ** Indicator is complementary	

1.1.2 **Table 2 Public health outcomes framework for England, 2013–2016**

Domain	Objectives and indicators
2 Health improvement	***Objective*** People are helped to live healthy lifestyles, make healthy choices and reduce health inequities. ***Indicators*** 2.19 Cancer diagnosed at stage 1 and 2**(NHSOF 1.4)
4 Healthcare public health and preventing premature mortality	***Objective*** Reduced numbers of people living with preventable ill health and people dying prematurely, whilst reducing the gap between communities. ***Indicators*** 4.3 Mortality rate from cause considered preventable **(NHSOF 1a) 4.5 Under 75 mortality rate from cancer *(NHSOF 1.4)
Alignment across the health and social care system * Indicator shared with the NHS Outcomes Framework. ** Complimentary indicators in the NHS Outcomes Framework	

3 Summary of suggestions

3.1 *Responses*

In total 13 stakeholders responded to the 2-week engagement exercise 23/03/15 – 08/04/15.

Stakeholders were asked to suggest up to 5 areas for quality improvement. Specialist committee members were also invited to provide suggestions. The responses have been merged and summarised in table 3 for further consideration by the Committee.

NHS England's patient safety division did not submit any data for this topic.

Full details of all the suggestions provided are given in appendix 6 for information.

Table 3 Summary of suggested quality improvement areas

Suggested area for improvement	Stakeholders
Diagnosing and staging bladder cancer • CT or MRI staging before transurethral resection of bladder tumour (TURBT) • Imaging with TURBT • Obtaining detrusor muscle during TURBT. • Offering a single dose of intravesical mitomycin C, given at the same time as the first TURBT	• SCMx2, BAUS, NCRI/RCPH/ACP • IL • NCRI/RCPH/ACP, BAUS • SCMx3, BAUS, NCRI/RCPH/ACP
Prognostic markers and risk classification for non-muscle-invasive bladder cancer	SCMx2, RCP, NHSE
Treating non-muscle-invasive bladder cancer • Choice of intravesical BCG or radical cystectomy • Assessment by specialist urology MDT • Discharge to primary care	• NHSE • BAUS, NCRI/RCPH/ACP • SCMx2
Treating muscle-invasive bladder cancer • Review of all cases by specialist urology multidisciplinary team • Neoadjuvant chemotherapy for newly diagnosed muscle-invasive urothelial bladder cancer • Choice of radical cystectomy or radiotherapy with a radiosensitiser • Follow-up protocol after radical cystectomy	• BAUS, NCRI/RCPH/ACP • SCM, NHSE • SCMx2 • NHSE
Input from a Clinical Nurse Specialist	• ACPOPC, SCM (FBC, SCM, NHSE highlighted need for information/support)
Palliative care • Symptom management and psychosocial support • Appropriate referral to palliative care	• NHSE • APMGBI

ACP, Association of Cancer Physicians
ACPOPC, Association of Chartered Physiotherapists in Oncology and Palliative Care
APMGBI, Association for Palliative Medicine of Great Britain and Ireland
BAUS, British Association of Urological Surgeons
FBC, Fight Bladder Cancer
IL, Ipsen Limited
NCRI, National Cancer Research Institute, and the
NHSE, NHS England
RCP, Royal College of Pathologists
RCPH, Royal College of Physicians
SCM, Specialist committee member

4 Suggested improvement areas

4.1 *Diagnosing and staging bladder cancer*

4.1.1 Summary of suggestions

CT or MRI staging before transurethral resection of bladder tumour (TURBT)

Stakeholders suggested that CT or MRI staging should be considered before transurethral resection of bladder tumour (TURBT) if muscle-invasive bladder cancer is suspected at cystoscopy

Imaging with TURBT

One stakeholder commented that patients referred to a transurethral resection of bladder tumour (TURB) should be offered the best possible TURB quality, and access to the most up to date and clinically effective diagnostic and therapeutic technologies.

Obtaining detrusor muscle during TURBT

Stakeholders highlighted that failure to obtain detrusor muscle during TURBT can mean that patients have to have the procedure repeated with significant additional costs and prolongation of the pathway. It was suggested that in cases of high-risk, non-muscle-invasive bladder cancer, this is associated with a worse prognosis.

Offering a single dose of intravesical mitomycin C, given at the same time as the first TURBT

Stakeholders suggested that a single instillation of intravesical chemotherapy is effective in reducing risk of recurrence in non-muscle-invasive bladder cancer, and is a cost-effective treatment.

4.1.2 Selected recommendations from development source

Table 4 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 4 to help inform the Committee's discussion.

Table 4 Specific areas for quality improvement

Suggested quality improvement area	Suggested source guidance recommendations
CT or MRI staging before transurethral resection of bladder tumour (TURBT)	**Diagnosing and staging bladder cancer: Diagnosis** NICE NG2 Recommendation 1.2.2 (KPI)
Imaging with TURBT	**Diagnosing and staging bladder cancer: Diagnosis** NICE NG2 Recommendation 1.2.3 (KPI)
Obtaining detrusor muscle during TURBT.	**Diagnosing and staging bladder cancer: Diagnosis** NICE NG2 Recommendation 1.2.4
Offering a single dose of intravesical mitomycin C, given at the same time as the first TURBT	**Diagnosing and staging bladder cancer: Diagnosis** NICE NG2 Recommendation 1.2.7 (KPI)

Diagnosing and staging bladder cancer: Diagnosis

NICE NG2 Recommendation 1.2.2 (key priority for implementation)

Consider CT or MRI staging before transurethral resection of bladder tumour (TURBT) if muscle‑invasive bladder cancer is suspected at cystoscopy.

NICE NG2 Recommendation 1.2.3 (Key priority for implementation)

Offer white-light-guided TURBT with one of photodynamic diagnosis, narrow‑band imaging, cytology or a urinary biomarker test (such as UroVysion using fluorescence in‑situ hybridization [FISH], ImmunoCyt or a nuclear matrix protein 22 [NMP22] test) to people with suspected bladder cancer. This should be carried out or supervised by a urologist experienced in TURBT.

NICE NG2 Recommendation 1.2.4

Obtain detrusor muscle during TURBT.

NICE NG2 Recommendation 1.2.7 (key priority for implementation)

Offer people with suspected bladder cancer a single dose of intravesical mitomycin C given at the same time as the first TURBT.

4.1.3 Current UK practice

A snapshot study of TURBT procedures in the UK amongst 192 consultants [4] reported that the quality of TURBT was high. A very high percentage of cases were found to have muscle in the specimen, and zero cases were upstaged at the early re-resection. The study found that 20.8% of cases of resected specimens had no record of muscle, for which 75% were found to be low or intermediate risk tumours, and the report states that the risk of understaging in these cases is less likely to be significant. Where muscle was absent and the tumour was high-risk, all patients received appropriate further management.

The snapshot study also identified that photodynamic diagnosis (PDD)-assisted TURBT was used for only 6% of people. It found that 61% of patients received a single instillation of mitomycin C at or within 24 hours of surgery, with reasonable contraindications given in over 2/3 of cases where mitomycin C was not given. In 4 cases, respondents said it was not their local policy to give mitomycin C after TURBT.

[4] Gann C, Patel A, Fowler S, Catto J, Rosario D and O'Brien T (2013) Snapshot of transurethral resection of bladder tumours in the United Kingdom Audit (STUKA), British Association of Urological Surgeons Section of Oncology, BJUI International, Nov;112(7):881-2, PP 930-935

4.2 *Prognostic markers and risk classification for non-muscle-invasive bladder cancer*

4.2.1 Summary of suggestions

Stakeholders highlighted obtaining sufficient and accurate information for staging at TURBT can support appropriate clinical management by the multidisciplinary team, and suggested current variation in practice.

Stakeholders commented that follow-up after treatment could be better directed if risk classification is done appropriately.

4.2.2 Selected recommendations from development source

Table 5 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 5 to help inform the Committee's discussion.

Table 5 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Prognostic markers and risk classification for non-muscle-invasive bladder cancer	**Treating non-muscle-invasive bladder cancer: Prognostic markers and risk classification** NICE NG2 Recommendation 1.3.1 (KPI)

Treating non-muscle-invasive bladder cancer: Prognostic markers and risk classification

NICE NG2 Recommendation 1.3.1 (key priority for implementation)

Ensure that for people with non‑muscle‑invasive bladder cancer all of the following are recorded and used to guide discussions, both within multidisciplinary team meetings and with the person, about prognosis and treatment options:

- recurrence history
- size and number of cancers
- histological type, grade, stage and presence (or absence) of flat urothelium, detrusor muscle (muscularis propria), and carcinoma in situ
- the risk category of the person's cancer
- predicted risk of recurrence and progression, estimated using a risk prediction tool.

4.2.3 Current UK practice

A 2015 national Audit Office report[5] identified low rates of staging data for urinary bladder cancer (38%).

[5] National Audit Office (2015) Progress in improving cancer services and outcomes in England

4.3 *Treating non-muscle-invasive bladder cancer*

4.3.1 Summary of suggestions

Choice of intravesical BCG or radical cystectomy

Stakeholders suggested that people with high-risk non-muscle-invasive bladder cancer should be offered the choice of intravesical BCG (Bacille Calmette-Guérin) or radical cystectomy, and the choice be based on a full discussion with the person, the Clinical Nurse Specialist and a urologist who performs both intravesical BCG and radical cystectomy.

Assessment by specialist urology MDT

Stakeholders commented that for people in whom induction BCG has failed, the specialist urology multidisciplinary team should assess the suitability of radical cystectomy, or further intravesical therapy if radical cystectomy is unsuitable or declined by the person, or if the bladder cancer that recurs is intermediate- or low-risk. It was suggested that this would improve the quality of care, and stop people from being denied the chance of having effective treatment.

Discharge to primary care

Stakeholders highlighted that people with low risk NMIBC with no recurrence within 12 months do not require further hospital follow up. It was suggested that this could prevent people having unnecessary cystoscopies, which they can find intrusive, and make potential cost savings across the NHS.

4.3.2 Selected recommendations from development source

Table 6 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 6 to help inform the Committee's discussion.

Table 6 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Choice of intravesical BCG or radical cystectomy	**Treating non-muscle-invasive bladder cancer: High-risk non-muscle-invasive bladder cancer** NICE NG2 Recommendation 1.3.6 (KPI)
Assessment by specialist urology MDT	**Treating non-muscle-invasive bladder cancer: High-risk non-muscle-invasive bladder cancer – Intravesical BCG** NICE NG2 Recommendation 1.3.9

Discharge to primary care	**Follow-up after treatment for non-muscle-invasive bladder cancer: Low-risk non-muscle-invasive bladder cancer** NICE NG2 Recommendation 1.4.5 (KPI)

Treating non-muscle-invasive bladder cancer: High-risk non-muscle-invasive bladder cancer

NICE NG2 Recommendation 1.3.6 (key priority for implementation)

Offer the choice of intravesical BCG (Bacille Calmette Guérin) or radical cystectomy to people with high risk non muscle invasive bladder cancer, and base the choice on a full discussion with the person, the Clinical Nurse Specialist and a urologist who performs both intravesical BCG and radical cystectomy. Include in your discussion:

- the type, stage and grade of the cancer, the presence of carcinoma in situ, the presence of variant pathology, prostatic urethral or bladder neck status and the number of tumours
- risk of progression to muscle invasion, metastases and death
- risk of understaging
- benefits of both treatments, including survival rates and the likelihood of further treatment
- risks of both treatments
- factors that affect outcomes (for example, comorbidities and life expectancy)
- impact on quality of life, body image, and sexual and urinary function.

Treating non-muscle-invasive bladder cancer: High-risk non-muscle-invasive bladder cancer – Intravesical BCG

NICE NG2 Recommendation 1.3.9

For people in whom induction BCG has failed, the specialist urology multidisciplinary team should assess the suitability of radical cystectomy, or further intravesical therapy if radical cystectomy is unsuitable or declined by the person, or if the bladder cancer that recurs is intermediate- or low-risk.

Follow-up after treatment for non-muscle-invasive bladder cancer: Low-risk non-muscle-invasive bladder cancer

NICE NG2 Recommendation 1.4.5 (Key priority for implementation)

Discharge to primary care people who have had low-risk non-muscle-invasive bladder cancer and who have no recurrence of the bladder cancer within 12 months.

4.3.3 Current UK practice

A snapshot study of TURBT procedures in the UK amongst 192 consultants[6] reported that of 37 patients diagnosed with intermediate-risk tumours, only 6 (16.2%) received adjuvant treatment with intravesical chemotherapy.

[6] Gann C, Patel A, Fowler S, Catto J, Rosario D and O'Brien T (2013) Snapshot of transurethral resection of bladder tumours in the United Kingdom Audit (STUKA), British Association of Urological Surgeons Section of Oncology, BJUI International, Nov;112(7):881-2, PP 930-935

4.4 *Treating muscle-invasive bladder cancer*

4.4.1 Summary of suggestions

Review of all cases by specialist urology multidisciplinary team

Stakeholders commented that a specialist urology multidisciplinary team should review all cases of muscle‑invasive bladder cancer, including adenocarcinoma, squamous cell carcinoma and neuroendocrine carcinoma, and that the review should include histopathology, imaging and discussion of treatment options. It was suggested that this will enable people with muscle-invasive bladder cancer to be offered the full range of appropriate treatment options.

Neoadjuvant chemotherapy for newly diagnosed muscle-invasive urothelial bladder cancer

Stakeholders commented that Neoadjuvant chemotherapy using a cisplatin combination regimen before radical cystectomy or radical radiotherapy, should be offered to people with newly diagnosed muscle‑invasive urothelial bladder cancer for whom cisplatin‑based chemotherapy is suitable. It was considered that this would reduce variation and improve survival.

Choice of radical cystectomy or radiotherapy with a radiosensitiser

Stakeholders suggested that people with muscle‑invasive urothelial bladder cancer for whom radical therapy is suitable should be offered a choice of radical cystectomy or radiotherapy with a radiosensitiser. Stakeholders commented that there is no high quality evidence suggesting that surgery increases survival compared to radiotherapy for people with in this group. Stakeholders felt that people should be given a choice of either surgery or radiotherapy, as they would have strong views on the type of radical treatment that is best suited for them when presented with appropriate information.

Follow-up protocol after radical cystectomy

Stakeholders commented that after radical cystectomy the appropriate follow up protocol should be used to help detect recurrence appropriately. It was also considered that this would enable early detection of other issues, such as renal dysfunction

4.4.2 Selected recommendations from development source

Table 7 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 7 to help inform the Committee's discussion.

Table 7 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Review of all cases by specialist urology multidisciplinary team	**Treating muscle-invasive bladder cancer** NICE NG2 Recommendation 1.5.1
Neoadjuvant chemotherapy for newly diagnosed muscle-invasive urothelial bladder cancer	**Treating muscle-invasive bladder cancer: Neoadjuvant chemotherapy for newly diagnosed muscle-invasive urothelial bladder cancer** NICE NG2 Recommendation 1.5.2 (KPI)
Choice of radical cystectomy or radiotherapy with a radiosensitiser	**Treating muscle-invasive bladder cancer: Radical therapy for muscle-invasive urothelial bladder cancer** NICE NG2 Recommendation 1.5.3 (KPI)
Follow-up protocol after radical cystectomy	**Follow-up after treatment for muscle-invasive bladder cancer** NICE NG2 Recommendation 1.6.2

Treating muscle-invasive bladder cancer

NICE NG2 Recommendation 1.5.1

Ensure that a specialist urology multidisciplinary team reviews all cases of muscle-invasive bladder cancer, including adenocarcinoma, squamous cell carcinoma and neuroendocrine carcinoma, and that the review includes histopathology, imaging and discussion of treatment options.

Treating muscle-invasive bladder cancer: Neoadjuvant chemotherapy for newly diagnosed muscle-invasive urothelial bladder cancer

NICE NG2 Recommendation 1.5.2 (Key priority for implementation)

Offer neoadjuvant chemotherapy using a cisplatin combination regimen before radical cystectomy or radical radiotherapy to people with newly diagnosed muscle-invasive urothelial bladder cancer for whom cisplatin-based chemotherapy is suitable. Ensure that they have an opportunity to discuss the risks and benefits with an oncologist who treats bladder cancer.

Treating muscle-invasive bladder cancer: Radical therapy for muscle-invasive urothelial bladder cancer

NICE NG2 Recommendation 1.5.3 (Key priority for implementation)

Offer a choice of radical cystectomy or radiotherapy with a radiosensitiser to people with muscle‑invasive urothelial bladder cancer for whom radical therapy is suitable. Ensure that the choice is based on a full discussion between the person and a urologist who performs radical cystectomy, a clinical oncologist and a Clinical Nurse Specialist. Include in the discussion:

- the prognosis with or without treatment
- the limited evidence about whether surgery or radiotherapy with a radiosensitiser is the most effective cancer treatment
- the benefits and risks of surgery and radiotherapy with a radiosensitiser, including the impact on sexual and bowel function and the risk of death as a result of the treatment.

Follow-up after treatment for muscle-invasive bladder cancer

NICE NG2 Recommendation 1.6.2

After radical cystectomy consider using a follow-up protocol that consists of:

- monitoring of the upper tracts for hydronephrosis, stones and cancer using imaging and glomerular filtration rate (GFR) estimation at least annually and
- monitoring for local and distant recurrence using CT of the abdomen, pelvis and chest, carried out together with other planned CT imaging if possible, 6, 12 and 24 months after radical cystectomy and
- monitoring for metabolic acidosis and B12 and folate deficiency at least annually and
- for men with a defunctioned urethra, urethral washing for cytology and/or urethroscopy annually for 5 years to detect urethral recurrence.

4.5 *Input from a Clinical Nurse Specialist*

4.5.1 Summary of suggestions

Stakeholders commented that access to information and support makes a positive difference to the perceived quality of cancer services. It was suggested that poor access may be a reason for the comparatively low levels of patient satisfaction for urological cancer patients. Stakeholders suggested access to a Clinical Nurse Specialist is important for ensuring people with bladder cancer can receive appropriate input.

4.5.2 Selected recommendations from development source

Table 8 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 8 to help inform the Committee's discussion.

Table 8 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Input from a Clinical Nurse Specialist	**Information and support for people with bladder cancer** NICE NG2 Recommendation 1.1.2

Information and support for people with bladder cancer

NICE NG2 Recommendation 1.1.2

Offer Clinical Nurse Specialist support to people with bladder cancer and give them the Clinical Nurse Specialist's contact details.

4.5.3 Current UK practice

Data from the 2014 National Cancer Patient Experience Survey (NCPES)[7] indicated that people with urological cancers were most likely to give low scores as a reflection of their experience as a patient, which continues a trend in findings since the 2010 survey. The survey found that people with urological cancers were least likely to say that:

- they were definitely told about side effects that could affect them in future (48%)

[7] Quality Health (2014) 2014 National Cancer Patient Experience Survey National Report

- they were definitely involved in decisions about their care and treatment (68%),
- they had a discussion or were given information about the impact of cancer (63%)
- they were given information about support or self-help groups (69%)
- they were definitely given enough care and help from health or social services (51%).
- they had been given information about how to get financial help or benefits (33%).

The proportion of people saying that they had been given the name of a Clinical Nurse Specialist (79%) was also the lowest proportion according to cancer type. This is despite the fact that analysis of the 2010 survey[8], which showed the same trend, indicated that the presence of a Clinical Nurse Specialist makes a positive difference to the perceived quality of cancer services. It found pronounced differences in views between those patients with a Clinical Nurse Specialist and those without, in terms of verbal and written information, involvement, information on financial support and prescriptions, discharge information, post discharge care, and emotional support.

[8] El Turabi A. et al. (2013) Variation in reported experience of involvement in cancer treatment decision making: Evidence from the National Cancer Patient Experience Survey. British Journal of Cancer 109(3): 780-787

4.6 *Palliative care*

4.6.1 Summary of suggestions

Symptom management and psychosocial support

Stakeholders highlighted the impact of symptom management and psychosocial support on quality of life for people with incurable bladder cancer. In particular, the symptoms of bleeding and pelvic pain were identified as having a significant impact on quality of life. It was also suggested that poor pain management has a lasting impact on bereaved relatives.

Appropriate referral to palliative care

It was suggested that not all patients with incurable bladder cancer need referral to specialist palliative care services and that referral should be needs-based rather than diagnosis- or prognosis-based.

4.6.2 Selected recommendations from development source

Table 8 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 8 to help inform the Committee's discussion.

Table 8 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Symptom management and psychosocial support	**Specialist palliative care for people with incurable bladder cancer** NICE NG2 Recommendation 1.8.5
Appropriate referral to palliative care	**Specialist palliative care for people with incurable bladder cancer** NICE NG2 Recommendation 1.8.4

Specialist palliative care for people with incurable bladder cancer

NICE NG2 Recommendation 1.8.4

Discuss palliative care services with people with incurable bladder cancer and, if needed and they agree, refer them to a specialist palliative care team (for more information, see recommendation 1.1.4 on holistic needs assessment and NICE's guidelines on improving supportive and palliative care for adults with cancer and improving outcomes in urological cancers).

NICE NG2 Recommendation 1.8.5

Offer people with symptomatic incurable bladder cancer access to a urological team with the full range of options for managing symptoms.

4.6.3 Current UK practice

A study of patients with advanced or metastatic urological cancer attending a UK urology ward[9] found that 75% of out-patients would have benefitted from specialist palliative care, as they had specific problems or were generally unwell as a result of their disease, and 25% were well at the time of their visit but potential psychosocial problems arising from coping with terminal disease were not addressed.

[9] Brierly RD and O'Brien TS (2008) The importance of palliative care in urology. Urologia Internationalis. 80(1): 13-18.

4.7 *Additional areas*

4.7.1 Summary of suggestions

The improvement areas below were suggested as part of the stakeholder engagement exercise. However they were felt to be either unsuitable for development as quality statements, outside the remit of this particular quality standard referral or require further discussion by the Committee to establish potential for statement development.

There will be an opportunity for the QSAC to discuss these areas at the end of the session on 20th May.

Referral from primary care (outside the remit of the quality standard)

A stakeholder highlighted early referral from Primary Care as essential in the diagnosis of bladder cancer and improved prognosis.

Staff skills/training (unsuitable for development as quality statements)

A stakeholder suggested that **t**oo few urologists have extensive knowledge and experience with bladder cancer and the number is falling. It was suggested that cystoscopies and TURBTs are key procedures and the skills and experience of the person undertaking the procedure has a direct link with improvement of diagnosis and thus treatment and prognosis.

Consistency of Treatment (unsuitable for development as quality statements)

One stakeholder suggested that inconsistency of treatment for patients causes worry and confusion with patients and demonstrates that many patients are not getting the best standard of care.

Availability of Treatment (requires further discussion by the Committee to establish potential for statement development)

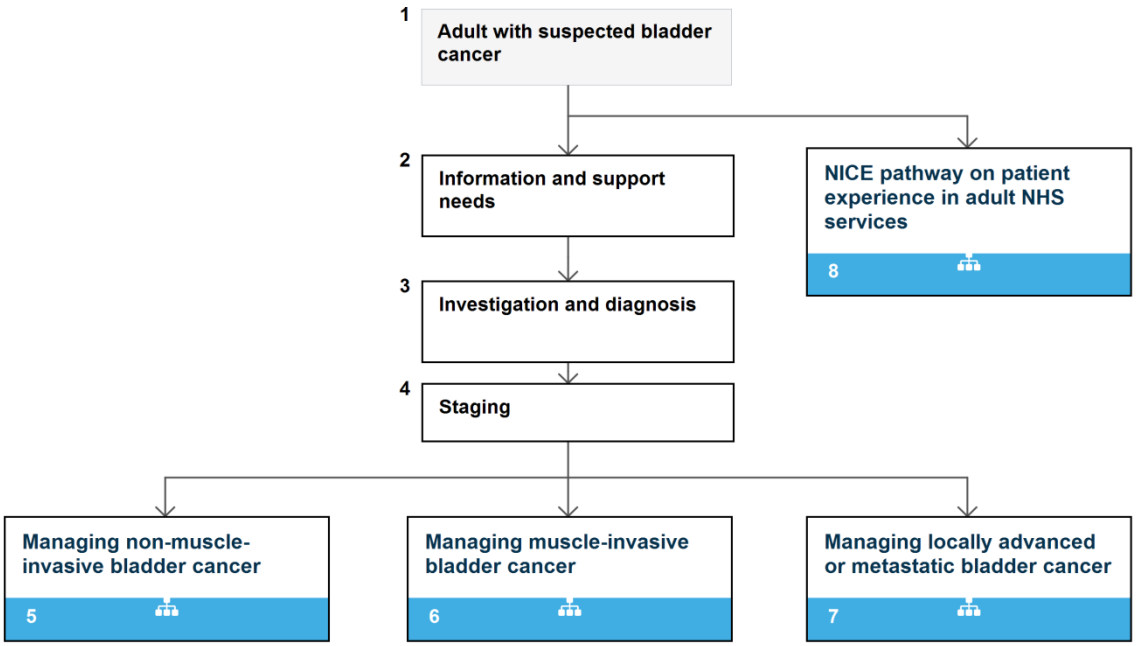
One stakeholder commented that there are few established treatments for bladder cancer patients available for all. It was suggested that more use should be made of all novel treatments where they have shown potential improvements in prognosis.

Annual satisfaction surveys (unsuitable for development as quality statements)

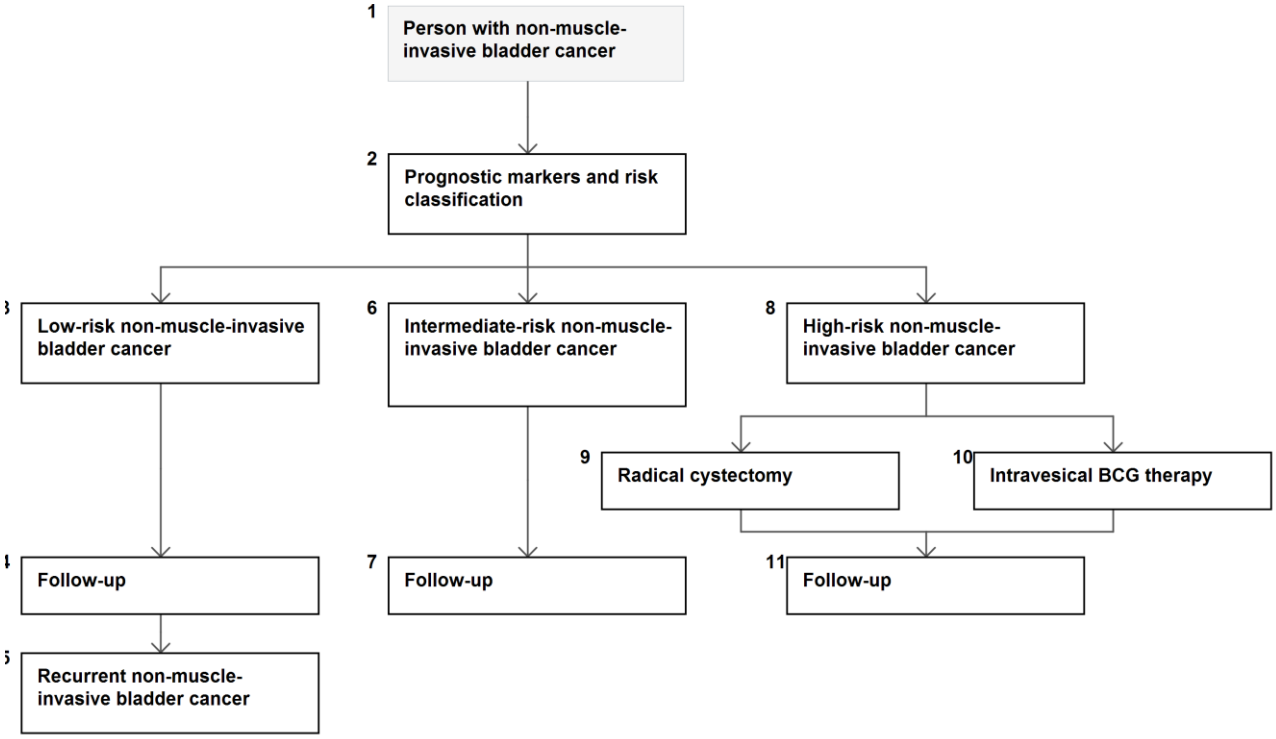
A number of stakeholders suggested that Trusts should consider conducting annual bladder cancer patient satisfaction surveys, developed by their urology multidisciplinary team and people with bladder cancer, and to use the results to guide a programme of quality improvement. Current practice data shows that compared to people with prostate cancer the experience of people with other

urological cancers, of whom the majority have bladder cancer seems to be worse. For this reason, it is important that patient experience be captured through appropriate quality measures.

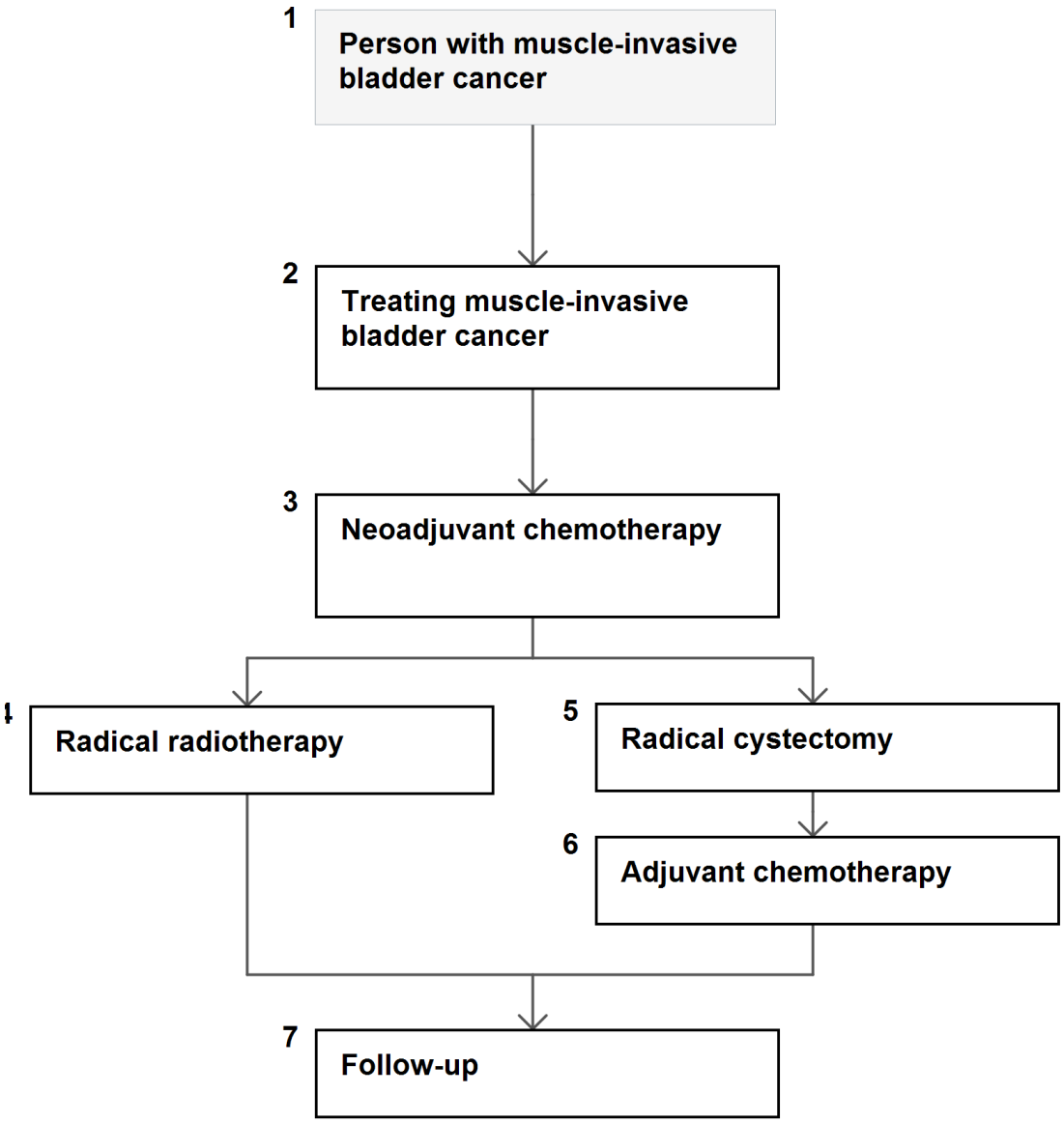
Appendix 1: Bladder cancer overview



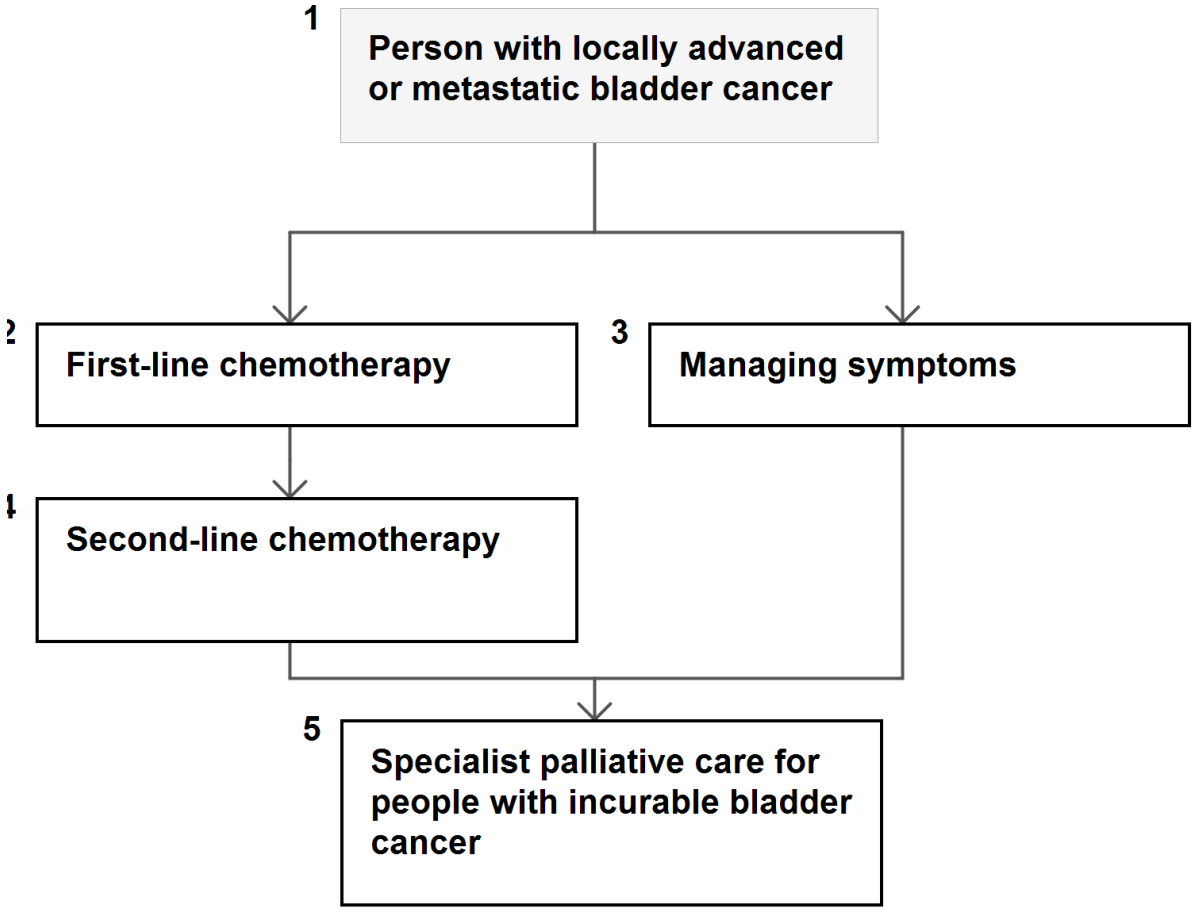
Appendix 2: Managing non-muscle-invasive bladder cancer



Appendix 3: Managing muscle-invasive bladder cancer



Appendix 4: Managing locally advanced or metastatic bladder cancer



Appendix 5: Key priorities for implementation (NG2)

Recommendations that are key priorities for implementation in the source guideline and that have been referred to in the main body of this report are highlighted in grey.

1.1.1 Information and support for people with bladder cancer

Use a holistic needs assessment to identify an individualised package of information and support for people with bladder cancer and, if they wish, their partners, families or carers, at key points in their care such as:

- when they are first diagnosed
- after they have had their first treatment
- if their bladder cancer recurs or progresses
- if their treatment is changed
- if palliative or end of life care is being discussed.

1.1.2 *Diagnosing and staging bladder cancer*

Diagnosis

Consider CT or MRI staging before transurethral resection of bladder tumour (TURBT) if muscle-invasive bladder cancer is suspected at cystoscopy.

Offer white-light-guided TURBT with one of photodynamic diagnosis, narrow-band imaging, cytology or a urinary biomarker test (such as UroVysion using fluorescence in-situ hybridization [FISH], ImmunoCyt or a nuclear matrix protein 22 [NMP22] test) to people with suspected bladder cancer. This should be carried out or supervised by a urologist experienced in TURBT.

Offer people with suspected bladder cancer a single dose of intravesical mitomycin C given at the same time as the first TURBT.

1.1.3 Treating non-muscle-invasive bladder cancer

Prognostic markers and risk classification

Ensure that for people with non-muscle-invasive bladder cancer all of the following are recorded and used to guide discussions, both within multidisciplinary team meetings and with the person, about prognosis and treatment options:

- recurrence history

- size and number of cancers
- histological type, grade, stage and presence (or absence) of flat urothelium, detrusor muscle (muscularis propria), and carcinoma in situ
- the risk category of the person's cancer
- predicted risk of recurrence and progression, estimated using a risk prediction tool.

High-risk non-muscle-invasive bladder cancer

Offer the choice of intravesical BCG (Bacille Calmette-Guérin) or radical cystectomy to people with high-risk non-muscle-invasive bladder cancer, and base the choice on a full discussion with the person, the Clinical Nurse Specialist and a urologist who performs both intravesical BCG and radical cystectomy. Include in your discussion:

- the type, stage and grade of the cancer, the presence of carcinoma in situ, the presence of variant pathology, prostatic urethral or bladder neck status and the number of tumours
- risk of progression to muscle invasion, metastases and death
- risk of understaging
- benefits of both treatments, including survival rates and the likelihood of further treatment
- risks of both treatments
- factors that affect outcomes (for example, comorbidities and life expectancy)
- impact on quality of life, body image, and sexual and urinary function.

Follow-up after treatment for non-muscle-invasive bladder cancer

Low-risk non-muscle-invasive bladder cancer

Discharge to primary care people who have had low-risk non-muscle-invasive bladder cancer and who have no recurrence of the bladder cancer within 12 months.

Intermediate-risk non-muscle-invasive bladder cancer

Offer people with intermediate-risk non-muscle-invasive bladder cancer cystoscopic follow-up at 3, 9 and 18 months, and once a year thereafter.

Treating muscle-invasive bladder cancer

Neoadjuvant chemotherapy for newly diagnosed muscle-invasive urothelial bladder cancer

Offer neoadjuvant chemotherapy using a cisplatin combination regimen before radical cystectomy or radical radiotherapy to people with newly diagnosed muscle-invasive urothelial bladder cancer for whom cisplatin-based chemotherapy is suitable. Ensure that they have an opportunity to discuss the risks and benefits with an oncologist who treats bladder cancer.

Radical therapy for muscle-invasive urothelial bladder cancer

Offer a choice of radical cystectomy or radiotherapy with a radiosensitiser to people with muscle-invasive urothelial bladder cancer for whom radical therapy is suitable. Ensure that the choice is based on a full discussion between the person and a urologist who performs radical cystectomy, a clinical oncologist and a Clinical Nurse Specialist. Include in the discussion:

- the prognosis with or without treatment
- the limited evidence about whether surgery or radiotherapy with a radiosensitiser is the most effective cancer treatment
- the benefits and risks of surgery and radiotherapy with a radiosensitiser, including the impact on sexual and bowel function and the risk of death as a result of the treatment.

Appendix 6: Suggestions from stakeholder engagement exercise – registered stakeholders

Stakeholder	Theme	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
SCM 1	Diagnosing and staging bladder cancer - Consider CT or MRI staging before transurethral resection of bladder tumour (TURBT) if muscle-invasive bladder cancer is suspected at cystoscopy	**Consider CT or MRI staging before transurethral resection of bladder tumour (TURBT) if muscle-invasive bladder cancer is suspected at cystoscopy.**	CT and MRI staging are more accurate if performed before, rather than after, TURBT.	Integration of imaging into the investigative/management pathway of patients with newly diagnosed MIBC will not only increase accuracy of staging but could also shorten the treatment pathway.	See Full NICE guideline.
British Association of Urological Surgeons	Diagnosing and staging bladder cancer - Consider CT or MRI staging before transurethral resection of bladder tumour (TURBT) if muscle-invasive bladder cancer is suspected at cystoscopy	Key area for quality improvement 1 **Consider CT or MRI staging before transurethral resection of bladder tumour (TURBT) if muscle-invasive bladder cancer is suspected at cystoscopy.**	Urologists are good at predicting muscle invasive disease at the time of initial cystoscopy (or subsequent TURBT) and therefore can request the appropriate staging tests in advance of the MDT review. This would considerably speed up the patient's pathway and definitive treatment. In addition performing the CT/MRI before TURBT would remove the risk of treatment artefacts.	Currently there is considerable delay in completeting the appropriate staging investigations in MIBC as this occurs after the diagnosis is discussed in the MDT. This leads to delays in the definitive treatment of MIBC whilst waiting for these tests to be completed. If the tests were requested at the time of initial cystoscopy or subsequent TURBT if MIBC is suspected the results would usually be available at the time of the MDT and allow better and quicker decision making.	NICE Bladder cancer guidelines NG2 recommendation 1.2.2
NCRI/RCP/ACP - joint response	Diagnosing and staging bladder	Key area for quality improvement 1	Urologists are good at predicting muscle invasive	Currently there is considerable delay in completeting the appropriate	NICE Bladder cancer guidelines

Stakeholder	Theme	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
	cancer - Consider CT or MRI staging before transurethral resection of bladder tumour (TURBT) if muscle-invasive bladder cancer is suspected at cystoscopy	**Consider CT or MRI staging before transurethral resection of bladder tumour (TURBT) if muscle-invasive bladder cancer is suspected at cystoscopy.**	disease at the time of initial cystoscopy (or subsequent TURBT) and therefore can request the appropriate staging tests in advance of the MDT review. This would considerably speed up the patient's pathway and definitive treatment	staging investigations in MIBC as this occurs after the diagnosis is discussed in the MDT. This leads to delays in the definitive treatment of MIBC whilst waiting for these tests to be completed. If the tests were requested at the time of initial cystoscopy or subsequentTURBT if MIBC is suspected the results would usually be available at the time of the MDT and allow better and quicker decision making.	NG2 recommendation 1.2.2
SCM 2	Diagnosing and staging bladder cancer - Consider CT or MRI staging before transurethral resection of bladder tumour (TURBT) if muscle-invasive bladder cancer is suspected at cystoscopy Diagnosing bladder cancer - Offer people with suspected bladder cancer a single dose of intravesical mitomycin C	Key area for quality improvement 2 Diagnosis and staging of bladder cancer	To allow rapid identification of the form of bladder cancer that is present	Imaging in muscle-invasive bladder cancer (MIBC) is not done well and is a key part of staging. Mitomycin C is not used as widely as justified by supporting evidence.	NG2

Stakeholder	Theme	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
	given at the same time as the first TURBT.				
Ipsen Limited	Diagnosing and staging bladder cancer - Imaging with TURBT	Patients referred with suspected bladder cancer are offered the full range and access to the most up to date and clinically effective diagnostic and therapeutic technologies.	There is good evidence that improved imaging beside white light cystoscopy during transurethral resection of bladder tumours improves patient outcome. New imaging technologies are recommended within NICE guidance.	In the UK, bladder cancer (BC) is the ninth most common cancer in men and the 15th in both sexes. Bladder cancer (BC) has one of the highest lifetime treatment costs per patient of all cancers. One of the reasons behind this heavy burden for the patients and economically is a high recurrence risk, associated with non-muscle invasive bladder cancer (NMIBC). Improved imaging techniques (Photodynamic diagnosis) showed the potential to reduce recurrence rates and thereby lowering the burden for the patients and treatment costs.	NICE Guidelines on Bladder Cancer 2015
Ipsen Limited	Diagnosing and staging bladder cancer - Imaging with TURBT	Patients referred to a transurethral resection of bladder tumour (TURB) should be offered the best possible TURB quality.	As a result of particularly high recurrence rates and the consequent need for further treatment as well as prolonged surveillance, bladder cancer (BC) is considered to be one of the most challenging and costliest of all solid tumours to manage. Even though most patients present with early-stage non-muscle-invasive disease, between 13-61%	In the UK, bladder cancer (BC) is the ninth most common cancer in men and the 15th in both sexes. Bladder cancer (BC) has one of the highest lifetime treatment costs per patient of all cancers. One of the reasons behind this heavy burden for the patients and economically is a high recurrence risk, associated with non-muscle invasive bladder cancer (NMIBC). Improved imaging techniques (Photodynamic diagnosis) showed the potential to reduce recurrence rates and thereby	NICE Guidelines on Bladder Cancer 2015 EAU Guidelines NMIBC 2015 http://uroweb.org/ Burger M et al. "Photodynamic Diagnosis of Non–muscle-invasive Bladder Cancer with Hexaminolevulinate Cystoscopy:

Stakeholder	Theme	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			will recur by 1 year post-transurethral resection of the bladder (TURB). Most cases of recurrence are due to incomplete visualization of the tumour at initial TURB and it is clear that the current standard of care for detection, white light cystoscopy (WLC), is inadequate and improvements are urgently needed. Standard white light guided TURB has shown poor quality concerning complete removal of all tumour tissue. It is thought that up to 50% of high-grade Ta or T1 tumors are understaged at initial TURB following WLC, necessitating a second TURB to reassess resected areas. In a comparative within-patient phase III study, 22% of patients with confirmed BC underwent a change of treatment due to improved detection after PDD guided TURB	lowering the burden for the patients and treatment costs.	A Meta-analysis of Detection and Recurrence Based on Raw Data", Eur Urol. 2013;64(5):846-54. *[Reference is attached].*

Stakeholder	Theme	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			($p<0.001$).		
NCRI/RCP/ACP - joint response	Diagnosing and staging bladder cancer - Obtain detrusor muscle during TURBT.	Key area for quality improvement 2 **Obtain detrusor muscle during TURBT.**	Making a conscious effort to obtain detrusor muscle (DM) during TURBT is an integral part of the procedure. In HR NMIBC, failure to obtain DM at the first TURBT considerably delays definitive treatment because of the need to perform a re-TURBT and is associated with a worse prognosis	Currently many TURBTs are carried out on general urology lists with little supervisions and minimal training. Studies have shown that it is relatively easy to obtain DM at the time of TURBT and conversely failure to do so can mean that patients have to have the procedure repeated with significant additional costs and a detrimental prolongation of their pathway. Making a quality standard would go a long way to improving the initial patient pathway and reduce unnecessary further operations with significant cost savings	NICE Bladder cancer guidelines NGS recommendation 1.2.4 EAU NMIBC guidelines 5.10.1
British Association of Urological Surgeons	Diagnosing and staging bladder cancer - Obtain detrusor muscle during TURBT.	Key area for quality improvement 2 **Obtain detrusor muscle during TURBT.**	Making a conscious effort to obtain detrusor muscle (DM) during TURBT is an integral part of the procedure. In HR NMIBC, failure to obtain DM at the first TURBT considerably delays definitive treatment because of the need to perform a re-TURBT and is associated with a worse prognosis	Currently many TURBTs are carried out on general urology lists with little supervisions and minimal training. Studies have shown that it is relatively easy to obtain DM at the time of TURBT and conversely failure to do so can mean that patients have to have the procedure repeated with significant additional costs and a detrimental prolongation of their pathway. Making a quality standard would go a long way to improving the initial patient pathway and reduce unnecessary further operations with significant cost savings	NICE Bladder cancer guidelines NGS recommendation 1.2.4 EAU NMIBC guidelines 5.10.1

Stakeholder	Theme	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
SCM 1	Diagnosing and staging bladder cancer - Offer people with suspected bladder cancer a single dose of intravesical mitomycin C given at the same time as the first TURBT.	**Offer people with suspected bladder cancer a single dose of intravesical mitomycin C given at the same time as the first TURBT.**	A single instillation of intravesical chemotherapy is effective in reducing risk of recurrence in NMIBC.	This is a highly effective and cost effective treatment which is not universally practiced across the UK.	See Full NICE guideline.
SCM 3	Diagnosing and staging bladder cancer - Offer people with suspected bladder cancer a single dose of intravesical mitomycin C given at the same time as the first TURBT.	Key area for quality improvement 2	There is good evidence that delivering a single dose of intravesical mitomycin C given at the same time as the first TURBT is both effective and cost-saving.	The administration of a single intravesical dose of mitomycin C at the time of first TURBT would be efficient and could be instilled while the patient is under general anaesthetic thereby minimising discomfort for the patient due to repeat procedures. It has been shown to reduce recurrence rates.	
British Association of Urological Surgeons	Diagnosing and staging bladder cancer - Offer people with suspected bladder cancer a single dose of intravesical mitomycin C	Key area for quality improvement 3 **Offer people with suspected bladder cancer a single dose of intravesical mitomycin C given at the same time as the first TURBT.**	There is level 1 evidence that this leads to a 50% reduction in subsequent recurrence rate	There is evidence of wide variations in practice in the UK. The procedure is simple and requires no additional resource and improving compliance through the standard would have a significant impact in reducing recurrence rates and cost saving through fewer re-operations	NICE Bladder cancer guidelines NG2 recommendation 1.2.7 EAU NMIBC guidelines 7.2.1.1

Stakeholder	Theme	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
	given at the same time as the first TURBT.				
NCRI/RCP/ACP - joint response	Diagnosing and staging bladder cancer - Offer people with suspected bladder cancer a single dose of intravesical mitomycin C given at the same time as the first TURBT.	Key area for quality improvement 3 **Offer people with suspected bladder cancer a single dose of intravesical mitomycin C given at the same time as the first TURBT.**	There is level 1 evidence that this leads to a 50% reduction in subsequent recurrence rate	There is evidence of wide variations in practice in the UK. The procedure is simple and requires no additional resource and improving compliance through the standard would have a significant impact in reducing recurrence rates and cost saving through fewer re-operations	NICE Bladder cancer guidelines NG2 recommendation 1.2.7 EAU NMIBC guidelines 7.2.1.1
SCM 1	Prognostic markers and risk classification for non-muscle-invasive bladder cancer	**Ensure that for people with non-muscle-invasive bladder cancer all information detailed in the NICE guideline is recorded and used to guide discussions, both within multidisciplinary team meetings and with the person, about prognosis and treatment options.**	Accurate and full recording of patient and histological factors within the MDT is important to ensure that correct management decisions are taken.	It is likely that there is variation in collection and recording of key data needed to make decisions at MDT across the UK. Implementation of this guideline will reduce variation and could lead to improvements in decision making and outcomes.	See Full NICE guideline
SCM 2	Prognostic markers and risk	Key area for quality improvement 3	Risk classification in NMIBC should allow	The GDG had a lot of feedback that risk classification is done poorly	NG2

Stakeholder	Theme	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
	classification for non-muscle-invasive bladder cancer	Treatment of non-muscle-invasive bladder cancer (NMIBC)	appropriate focus on the correct treatment and follow-up according to NG2 People with high risk NMIBC should be offered BCG or cystectomy.	across the NHS, and has made recommendations that are specific to particular risk groups, and that the choice of BCG or cystectomy is not widely offered.	
The Royal College of Pathologists	Prognostic markers and risk classification for non-muscle-invasive bladder cancer	Staging of bladder cancer at TURBT	There is variation in practice in obtaining sufficient and accurate information for staging at TURBT	Accurate staging determines the appropriate clinical management. Insufficient information required for staging may result in the procedure being repeated with delay in definitive treatment. Accurate recording of surgical and pathological information may be improved through the use of the RCPath dataset for reporting TURBT specimens.	A recent audit by the London Cancer Alliance Urology Pathway (to be published) demonstrated the variability in recording pathological information where a structured reporting proforma was not used.
SCM 2	Prognostic markers and risk classification for non-muscle-invasive bladder cancer	Key area for quality improvement 4 Follow-up after treatment of NMIBC	Follow-up seems very poorly directed, without focus on risk classification to drive the intensity of follow-up.	This risks morbidity and wastes resource on people who are at low risk and does not focus enough on those at higher risk	NG2
NHS England	Prognostic markers and risk classification for non-muscle-invasive bladder	Key area for quality improvement 3 All patients should have a full record of their cystoscopy	There is good evidence to show that this information (1.3.1) when used to ascertain the risk category can help guide the most	Standardised treatment and follow up based on risk category will reduce variation and potentially aid improvements in recurrence rates and progression.	Nice Bladder guidance 1.3.1 EAU Bladder cancer guidance

Stakeholder	Theme	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
	cancer	discussed within the MDT	appropriate treatment and follow-up (i.e using algorithms)		
NHS England	Treating non-muscle-invasive bladder cancer - Offer the choice of intravesical BCG or radical cystectomy to people with high-risk non-muscle-invasive bladder cancer	Key area for quality improvement 4 Offer the choice of intravesical BCG (Bacille Calmette-Guérin) or radical cystectomy to people with high-risk non-muscle-invasive bladder cancer, and base the choice on a full discussion with the person, the Clinical Nurse Specialist and a urologist who performs both intravesical BCG and radical cystectomy.	Bladder cancer survival has improved significantly over the years due to improved surgery and anaesthetics plus intravesical therapy. However the choice of treatment initially and upon failure of initial therapy is an art. There is evidence that shows those clinicians who have a grasp of the entire treatment pathway of bladder cancer can provide better outcomes.	We need to identify novel ways of improving outcomes further, for the complex management of high risk superficial bladder cancer patients. Bladder Cancer Specialists are likely to be a potential way forward. Evidence suggests that patients treated by such specialists can have better outcomes This will also encourage such individuals to develop larger practices, hence driving the volume outcome association.	J Urol. 2014 Sep;192(3):714-9. doi: 10.1016/j.juro.2014.02.093. Epub 2014 Mar 1
British Association of Urological Surgeons	Treating non-muscle-invasive bladder cancer - Assessment by specialist urology MDT for people in whom induction BCG has failed.	Additional developmental areas of emergent practice **For people in whom induction BCG has failed, the specialist urology multidisciplinary team should assess the suitability of radical cystectomy, or further**	Patients in whom induction BCG has failed are common but as they are considered to be NMIBC, they have up to now not been referred to the bladder sMDT. They are often therefore denied the chance of having effective treatment such as minimally invasive radical surgery or thermo-	Referring all patients with BCG failure to the bladder sMDT would not incur any additional cost but would improve the quality of care for this important group of patients. It would also strengthen the role of the bladder sMDT and lend weight to the argument that it should be an sMDT in its own right rather than as a 'bolt-on' to the prostate sMDT as is currently frequently the case	NICE Bladder cancer recommendation NG2 Recommendation 1.3.9

Stakeholder	Theme	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		intravesical therapy if radical cystectomy is unsuitable or declined by the person, or if the bladder cancer that recurs is intermediate- or low-risk.	chemotherapy		
NCRI/RCP/ACP - joint response	Treating non-muscle-invasive bladder cancer - Assessment by specialist urology MDT for people in whom induction BCG has failed.	Additional developmental areas of emergent practice **For people in whom induction BCG has failed, the specialist urology multidisciplinary team should assess the suitability of radical cystectomy, or further intravesical therapy if radical cystectomy is unsuitable or declined by the person, or if the bladder cancer that recurs is intermediate- or low-risk.**	Patients in whom induction BCG has failed are common but as they are considered to be NMIBC, they have up to now not been referred to the bladder sMDT. They are often therefore denied the chance of having effective treatment such as minimally invasive radical surgery or thermo-chemotherapy	Referring all patients with BCG failure to the bladder sMDT would not incur any additional cost but would improve the quality of care for this important group of patients. It would also strengthen the role of the bladder sMDT and lend weight to the argument that it should be an sMDT in its own right rather than as a 'bolt-on' to the prostate sMDT as if currently frequently the case	NICE Bladder cancer recommendation NG2 Recommendation 1.3.9
SCM 1	Treating non-muscle-invasive	**Discharge to primary care people**	Patients with low risk NMIBC with no recurrence	There is variability in follow up of patients with low risk NMIBC across	See Full NICE guideline.

Stakeholder	Theme	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
	bladder cancer - Discharge to primary care for people with low-risk non-muscle invasive bladder cancer and no – reoccurrence within previous 12 months	**who have had low-risk non-muscle-invasive bladder cancer and who have no recurrence of the bladder cancer within 12 months.**	within 12 months do not require further hospital follow up.	the UK. Implementation of this guideline has great potential for cost savings across the NHS.	
SCM 3	Treating non-muscle-invasive bladder cancer - Discharge to primary care for people with low-risk non-muscle invasive bladder cancer and no – reoccurrence within previous 12 months	Key area for quality improvement 3	Evidence exists that low-risk non-muscle-invasive bladder cancer patients who have had no recurrence of the bladder cancer within 12 months can be discharged to primary care.	Many patients find the check cystoscopies intrusive and unpleasant. Reducing the intensity and follow up period safely for patients with low risk non-muscle invasive disease is cost-effective and is likely to improve quality of life for patients.	
British Association of Urological Surgeons	Treating muscle-invasive bladder cancer - Review of all cases by specialist urology multidisciplinary team	Key area for quality improvement 4 **Ensure that a specialist urology multidisciplinary team reviews all cases of muscle-invasive bladder cancer, including adenocarcinoma, squamous cell**	MIBC is a complex disease that requires specialist MDT expertise and patients with MIBC need to be offered the full range of appropriate options including for example bladder reconstruction and neo-adjuvant therapy	Despite recommendations in the IOG guidance there are widespread variations in referral rates of MIBC to sMDTs. In turn many bladder sMDT are run in conjunction with e.g. the prostate sMDT. In order for all patients with MIBC to benefit from specialist bladder cancer expertise and the full range of options urologists should be encouraged to refer all patients to	NICE Bladder cancer guidelines NG2 Recommendation 1.5.1

Stakeholder	Theme	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		carcinoma and neuroendocrine carcinoma, and that the review includes histopathology, imaging and discussion of treatment options.		the local bladder sMDT. This would in in turn encourage the development of specialist bladder cancer teams (separate to prostate cancer teams)	
NCRI/RCP/ACP - joint response	Treating muscle-invasive bladder cancer - Review of all cases by specialist urology multidisciplinary team	Key area for quality improvement 4 **Ensure that a specialist urology multidisciplinary team reviews all cases of muscle-invasive bladder cancer, including adenocarcinoma, squamous cell carcinoma and neuroendocrine carcinoma, and that the review includes histopathology, imaging and discussion of treatment options.**	MIBC is a complex disease that requires specialist MDT expertise and patients with MIBC need to be offered the full range of appropriate options including for example bladder reconstruction and neo-adjuvant therapy	Despite recommendations in the IOG guidance there are widespread variations in referral rates of MIBC to sMDTs. In turn many bladder sMDT are run in conjunction with e.g. the prostate sMDT. In order for all patients with MIBC to benefit from specialist bladder cancer expertise and the full range of options urologists should be encouraged to refer all patients to the local bladder sMDT. This would in in turn encourage the development of specialist bladder cancer teams (separate to prostate cancer teams)	NICE Bladder cancer guidelines NG2 Recommendation 1.5.1
SCM 3	Treating muscle-invasive bladder cancer - Neoadjuvant chemotherapy for newly diagnosed	Key area for quality improvement 4	There is robust evidence that neoadjuvant chemotherapy using a cisplatin combination regimen before radical cystectomy or radical	Data shows that approximately 10% of bladder cancer patients receive chemotherapy. There is a concern that this is lower than to be expected especially for patients who have potentially curable disease. A full	

Stakeholder	Theme	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
	muscle-invasive urothelial bladder cancer		radiotherapy to people with newly diagnosed muscle-invasive urothelial bladder cancer for whom cisplatin-based chemotherapy improves survival.	discussion with an oncologist would allow patients to be informed about the risks and benefits of chemotherapy and potentially increase access to treatment that improves survival.	
NHS England	Treating muscle-invasive bladder cancer - Neoadjuvant chemotherapy for newly diagnosed muscle-invasive urothelial bladder cancer	Key area for quality improvement 6 Offer neoadjuvant chemotherapy using a cisplatin combination regimen before radical cystectomy or radical radiotherapy to people with newly diagnosed muscle-invasive urothelial bladder cancer for whom cisplatin-based chemotherapy is suitable. Ensure that they have an opportunity to discuss the risks and benefits with an oncologist who treats bladder cancer.	The use of NA chemotherapy is variable across the country. The percentage of patients receiving this is likely less than 1:4. NA chemo given appropriately can improve survival by up to 5%.	It will reduce variation and improve survival	NICE bladder guidance 1.5.2
SCM 3	Treating muscle-invasive bladder cancer - Choice of radical cystectomy or	Key area for quality improvement 5	Contemporary data from England suggests that approximately 10% of potentially curative muscle-invasive bladder	There is evidence to suggest that patients have strong views on the type of radical treatment that is best suited for them when presented with appropriate information. A full	

Stakeholder	Theme	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
	radiotherapy with a radiosensitiser		cancer patients are treated with bladder preserving strategies involving radical radiotherapy. There is no high quality evidence suggesting that surgery increases survival compared to radiotherapy in this group. Based on this, patients should be offered a choice of radical cystectomy or radiotherapy with a radiosensitiser to people with muscle-invasive urothelial bladder cancer for whom radical therapy is suitable.	discussion with a clinical oncologist and a surgeon specialising in radical cystectomy would allow the patient to make an informed decision and promote their individual quality of life.	
SCM 2	Treating muscle-invasive bladder cancer - Choice of radical cystectomy or radiotherapy with a radiosensitiser	Key area for quality improvement 5 The treatment of MIBC	Cure rates in MIBC are typically between 50 and 60%.	Wider use of chemotherapy will raise cure rates overall. A choice between surgery and radiotherapy should be offered. If radiotherapy is given, it should be enhanced by the use of a radiosensitiser.	NG2
NHS England	Treating muscle-invasive bladder cancer – Follow-up protocol after radical cystectomy	Key area for quality improvement 5 After radical cystectomy the appropriate follow up protocol should be used 1.6.2	Again this is variable across the country. It will help detect recurrence appropriately, although early/late treatment is debatable. More importantly renal	Cancer survivorship issues are of great importance. In bladder cancer cystectomy can result in other health issues which should be detected and acted upon before detriment.	http://www.jurology.com/article/S0022-5347(06)01937-9/abstract EAU guidelines

Stakeholder	Theme	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			dysfunction detected early can reduce potential negative health impacts . Important predisposing factors in nonobstructed cases were hypertension, recurrent urinary sepsis and a glomerular filtration rate of less than 50 ml per minute per 1.73 m2. Hypertension was an independent predictor of a decreased glomerular filtration rate in the group with worsening glomerular filtration rates. In 11% of patients deterioration was due to upper tract obstruction		bladder cancer
Association of Chartered Physiotherapists in Oncology and Palliative Care - ACPOPC	Input from a clinical Nurse Specialist	Separately list each key area for quality improvement that you would want to see covered by this quality standard. **1.1.5** **Recommendations. Information and Support for people with bladder cancer**	In many areas these are currently under resourced and over looked as a resource to facilitate support in this population group without the need for medications eg: support with diet and exercise especially in relation to incontinence. Whilst it is mentioned in the guidelines there is nothing to advice on signposting to these particular services.	There is inconsistency across the UK for support through AHPs. Some people are offered pre-habilitation and rehabilitation, some just rehabilitation however a large proportion receive no support at all as there is a lack of resource.	Please see attached the AHP cancer pathway that highlights where AHPs can help from a symptom point of view in relation to the bladder. https://www.networks.nhs.uk/nhs-networks/ahp-networks/ahp-

Stakeholder	Theme	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			Many people need support to understand how to improve their diet or levels of exercise/physical activity or need guidance on how to work their pelvic floor muscles.		qipp-toolkits/AHP_Cancer_Pathway_final%20-3.pdf
Fight Bladder Cancer	Input from a clinical Nurse Specialist	Communication and Quality of Life	The vast majority of bladder cancer patients are provided with little or no information about support groups or organisations or explanations of their treatment pathways. This causes emotional stress that can be so easily alleviated. Quality of life factors for bladder cancer patients is currently hardly considered as a concern. Investigations and treatments all come with immense quality of life issues that do not seem to have little focus by the majority of medical teams. This results is patients putting up with the treatments with all their pain and side effects as they do not believe that anything can be improved.	Bladder cancer is a complex and varied diagnosis with specific treatments that depend on a clear understanding of Stage and Grade. Treatments are almost always invasive in one form or another and come with a varied range of side effects that it is essential that the patients understands to be certain to seek medical intervention when needed. Communication and support about bladder cancer treatment side effects is poor and needs to be addressed.	Patient research by Fight Bladder Cancer 2014/2015 using their confidential support forum and http://www.ncbi.nlm.nih.gov/pubmed/17347659

Stakeholder	Theme	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
SCM 2	Input from a clinical Nurse Specialist	Key area for quality improvement 1 Information and support for people with bladder cancer	To allow shared and informed decision making by people with bladder cancer	The GDG had evidence that the experience of people with bladder cancer was less good than people with other cancers and feedback that information and support provision was not uniformly good	NG2
SCM 3	Input from a clinical Nurse Specialist	Key area for quality improvement 1 Assignment of keyworker and appropriate information giving for patients diagnosed with bladder cancer	The National Patient Experience Surveys have shown that compared to people with prostate cancer the experience of people with other urological cancers, of whom the majority have bladder cancer seems to be worse.	According to this survey, urological cancer patients were least likely to be given the contact details of their CNS. There were pronounced differences in views between those patients with a CNS and those without one in terms of verbal and written information, involvement, information on financial support and prescriptions, discharge information, post discharge care, and emotional support. This indicates that the presence of a CNS makes a positive difference to the perceived quality of cancer services and may be a reason for the comparatively low levels of patient satisfaction for urological cancer patients.	
Association of Chartered Physiotherapists in Oncology and Palliative Care - ACPOPC	Input from a clinical Nurse Specialist	Key area for quality improvement 1: Ensuring access to Specialist Allied Health Professionals 1.1.5	As above	As above	As above
Association of Chartered Physiotherapists	Input from a clinical Nurse Specialist	Key area for quality improvement 2: Managing the Side	Many side effects can be prevented and managed through Allied Health	As above	As above

Stakeholder	Theme	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
in Oncology and Palliative Care - ACPOPC		Effects of Treatments through signposting to Specialist AHPs services 1.3.13, 1.5.9	Professionals interventions such as physiotherapy services to prevent incontinence provided pre -treatment and post treatment.		
NHS England	Input from a clinical Nurse Specialist	Key area for quality improvement 2 All patients diagnosed with bladder cancer who smoke should have formal smoking cessation advice.	There is reasonable evidence to suggest smoking cessation can impact on bladder cancer recurrence and overall mortality	Smoking cessation may be seen as secondary in many clinics. The impact of utilising a cancer diagnosis to help with overall health can not be underestimated	Nice bladder guidance 1.1.6 http://www.ncsct.co.uk/usr/pub/interventions-in-secondary-care-june-10-oncology-patients-factsheet.pdf
NHS England	Palliative care - Symptom management and psychosocial support	Key area for quality improvement 1	Palliative care of patients with incurable bladder cancer, especially bleeding and pelvic pain	Symptom management and psychosocial support for people with incurable bladder cancer remain less than optimal. In particular, the symptoms of bleeding and pelvic pain have a significant impact on quality of life. Poor pain management has a lasting impact on bereaved relatives too. There are supporting recommendations in the source document about symptom management and access to specialist palliative care which would support a quality statement in this area.	http://www.ons.gov.uk/ons/rel/subnational-health1/national-survey-of-bereaved-people--voices-/2013/stb---national-survey-of-bereaved-people--voices-.html
Association for	Palliative care -	Patients with	Not all patients with	NICE guidance – bladder cancer:	http://www.nice.o

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Palliative Medicine of Great Britain and Ireland	Appropriate referral to palliative care	advanced / recurrent disease are referred to palliative care services when appropriate.	incurable bladder cancer will need referral to specialist palliative care services. Referral should be needs-based rather than diagnosis- or prognosis-based. Specialist palliative care services work with patients with complex needs when the usual medical team is struggling.	diagnosis & management NICE guideline – improving supportive & palliative care for adults with cancer House of Commons Health Committee, End of Life Care Report 2015	rg.uk/guidance/ng2/chapter/1-recommendations http://www.nice.org.uk/guidance/csgsp http://www.publications.parliament.uk/pa/cm201415/cmselect/cmhealth/805/805.pdf
British Association of Urological Surgeons	Annual satisfaction surveys	Key area for quality improvement 5 **Trusts should consider conducting annual bladder cancer patient satisfaction surveys developed by their urology multidisciplinary team and people with bladder cancer, and use the results to guide a programme of quality improvement.**	There are currently very few quality improvement programmes for bladder cancer, let alone any which use feedback from bladder cancer patients	The annual cancer patient experience survey consistently rates non prostate urology cancers (including bladder) as amongst the lowest in terms of patient satisfaction. A quality standard in this area would ensure that hospitals saw bladder cancer as a priority area for quality improvement and would allow bladder cancer patients a say in their treatment pathway which they currently don't have.	NICE Bladder cancer guidelines NG2 Recommendation 1.1.9

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NCRI/RCP/ACP - joint response	Annual satisfaction surveys	Key area for quality improvement 5 **Trusts should consider conducting annual bladder cancer patient satisfaction surveys developed by their urology multidisciplinary team and people with bladder cancer, and use the results to guide a programme of quality improvement.**	There is currently very few quality improvement programmes for bladder cancer, let alone any which use feedback from bladder cancer patients	The annual cancer patient experience survey consistently rates non prostate urology cancers (including bladder) as amongst the lowest in terms of patient satisfaction. A quality standard in this area would ensure that hospitals saw bladder cancer as a priority area for quality improvement and would allow bladder cancer patients a say in their treatment pathway which they currently don't have.	NICE Bladder cancer guidelines NG2 Recommendation 1.1.9
Fight Bladder Cancer	Early referral of suspected bladder cancer from primary care	Early Diagnosis	Early referral from Primary Care is essential in the diagnosis of bladder cancer and improves prognosis.	Late diagnosis in both men and women has seen a situation where prognosis is now getting worse for bladder cancer patients. All guidance should be focussed on improving the speed of diagnosis for all people even if they don't fit the standard age profile. Symptoms in any patient should result in the correct tests/investigations.	Delays in diagnosis and bladder cancer mortality. (2010) Hollenbeck BK1, Dunn RL, Ye Z, Hollingsworth JM, Skolarus TA, Kim SP, Montie JE, Lee CT, Wood DP Jr, Miller DC.
Fight Bladder Cancer	Staff Skills/training	Skills of medical staff	Too few urologists have extensive knowledge and experience with bladder cancer and the number is	Cystoscopies and TURBTs are key procedures and the skills and experience of the person undertaking the procedure has a	Anecdotal from talking to surgeons plus article here:

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			falling. Key procedures such as cystoscopies and TURBTs should only be carried out by or under the supervision of skilled professionals.	direct link with improvement of diagnosis and thus treatment and prognosis.	http://emjreviews.com/blog/bladder-cancer-get-turn/
Fight Bladder Cancer	Consistency of Treatment	Consistency of Treatment	The new NICE guidelines on bladder cancer highlight the inconsistency of treatment for patients. This not only causes worry and confusion with patients but is clearly a demonstration that many patients are not getting the best standard of care.	Bladder cancer prognosis is getting worse. Whilst some of this is likely be due to late diagnosis it is also likely that this is due to patients not having the optimal treatment for their specific diagnosis. It is essential that the new guidelines are followed on a consistent basis in all areas and that monitoring and assessment needs to be undertaken to ensure compliance.	NICE guidelines on bladder cancer February 2015
Fight Bladder Cancer	Availability of treatment	Availability of treatment	There are few established treatments for bladder cancer patients available for all. More use should be made of all novel treatments where they have shown potential improvements in prognosis.	Currently, procedures such as Robotic Assisted Surgery are only available in limited areas which means that those who would benefit from its use are being denied the best care. Also, the current BCG shortage provides a clear example of the lack of planning or risk management as far as the supply and availability of key essential treatments.	http://www.parliament.uk/edm/2014-15/552 http://www.fightbladdercancer.co.uk/content/advice-current-bcg-shortage
Association of Chartered Physiotherapists in Oncology and Palliative Care	Programme level	Additional developmental areas of emergent practice	It would be good to have some more Allied Health Professionals on your guidance team to help guide specific areas in		Please see AHP toolkit above.

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ACPOPC			relation to their field. One of the problems clinically is that AHPs are under-resourced and under recognised. If they are specifically mentioned within NICE guidelines (providing there was appropriate evidence for this) then there would more recognition clinically and more chance these services would be funded. As it currently stands people reading the guidance will not be aware there are number of different ways Allied Health Professionals can prevent and manage problems as a result of both the cancer and its treatments. NICE guidelines have the potential to effect this and open doors for the management of certain side effects, for example, that can be better managed through more conventional treatments rather than the traditional		

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			medical model of drugs. These in themselves produce side effects and can in some certain circumstances be avoided.		
Royal College of Nursing	NO COMMENTS	This is to inform you that the Royal College of Nursing has no comments to submit to inform on the above topic engagement at this present time. Thank you for the opportunity, we look forward to participating in the next stage of the consultation.			