Bladder Cancer Guideline

Draft Scope Stakeholder Workshop: Group Notes

Group 1

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Proposed membership of the GDG

The group seemed largely happy with the proposed GDG membership. Additional comments and clarifications as below:

Urologists x2 – the group felt it was important to try and appoint a urologist based in a specialist centre and another based in a cancer unit

Urology specialist nurse x2 – the group suggested appointing nurses with particular specialities including stoma care and intra-vesical therapy (IVT)

Radiologist – should be a radiologist specialising in urological cancers

Pathologist – should be a pathologist specialising in urological cancers

Palliative care physician – palliative care representative on the group felt it was important to try and get someone specialising in complex cancer pain

Patient/carer representative – the group considered it important to try and appoint individuals who had experienced muscle invasive bladder cancer (MIBC) and non-muscle invasive bladder cancer (NMIBC). The group also suggested appointing a representative from a bladder cancer charity.

The group agreed that additional expert advisors should be recruited to the GDG as required, for example a gynaecological oncologist –

Scope

3.1 Epidemiology

A description of carcinoma in situ should be included in 3.1 (c)

4.1 Population

It was noted that cancer of the urethra is included in the populations to be covered but is then not mentioned again throughout the rest of the scope. Staging and treatment will differ for patients with urethral cancer and are often managed by a gynaecological oncologist.

4.2 Healthcare setting

The group were happy with this section.

4.3.1 Key clinical issues that will be covered

Topic (a)
The group discussed the timing of information provision for example when cancer is suspected or at histological diagnosis. This topic was felt to be important as it might raise awareness of the cancer itself. Many information needs are relevant to this topic, including incontinence, and these should be discussed by the GDG.

The group discussed smoking cessation. It was suggested that recurrence and disease progression are less likely if you give up smoking. There is also evidence from Pfizer on their smoking cessation drug. An additional topic was proposed: 'Does smoking cessation affect the risk of recurrence and progression in patients with bladder cancer?' Smoking cessation prior to surgery was also discussed but this was felt to be a more generic issue rather than bladder cancer specific.

Topic (b)
The group felt that this topic could be of economic importance. The group suggested adding narrow band imaging to blue/white light cystoscopy in the bulleted list. They also suggested adding a bullet point about haematuria clinics, flexi-cystoscopy in haematuria clinics and the follow-up of people with negative test results but still with a high clinical suspicion of bladder cancer. Discussion about how urine tests show malignant cells for other cancers not just bladder, and that there is evidence that it only picks up high grade not low grade.

Group suggested adding a new topic – What is the most effective method of transurethral resection of bladder tumour (TURBT) for providing muscle for pathology analysis. It was noted that TURBT specimens were sometimes insufficient for proper analysis due to lack of muscle in the sample and perhaps the GDG should try to introduce a minimum standard for undertaking TURBT.

Topic (c)
Group agreed not to add PET to this topic as it is not a common staging method for bladder cancer. It was suggested that carcinoma in situ could be added here.

Topic (d)
Additional factors were suggested, including tumour subtype, tumour grade, pathological stage, multifocality, presence/absence of carcinoma in situ, tumour size, time to recurrence and necrosis. One member of the group suggested the NCC-C consider the Royal College of Pathologists 2007 bladder cancer dataset during the evidence review for this topic.

Topic (e)
The Group considered it important to stratify patients by risk for this topic. Follow up for MIBC should also be included as well the use of flexible cystoscopy and imaging during follow up. It was noted that EAU and BAUS guidelines have been published on follow-up and a study by Pickard et al on follow up after cystectomy should be published soon.

Topic (f)
The urologists on the group noted that the real issue here is that some patients who could benefit from intra-vesical chemotherapy are not receiving it. Group discussed whether this was a qualitative topic (should we look for reasons why the therapy is not being offered) but concluded that if we could demonstrate the clinical effectiveness of intra-vesical therapy then this could increase its use.

The group also considered whether to include the following topic: 'Which patients with high risk NMIBC would benefit from cystectomy? They also discussed the classification of risk (including the WHO classification) but there is also 'high grade' and 'low grade' within those levels.

Topic (g)
The group commented that there is very little evidence for this topic. They also discussed other factors for this topic such as co-morbidity and age. The group noted an issue of equity in the choice between radiotherapy and surgery. Patients would have to travel to specialist centres for surgery which may disadvantage those living far from these larger centres.

The group suggested extra topics about surgical techniques including partial cystectomy and enhanced recovery programs (which is a Department of Health initiative). It was noted than enhanced recovery often led to less bed days but more care in the community and sometimes increased re-admission rates. The guideline would need to refer to this initiative.

Cystectomy techniques were discussed further including removing lymph nodes (level and number) and therefore a possible improvement in outcomes.

Topic (h)
The group felt it important we cover both clinical effectiveness and cost effectiveness for this topic. There is currently a large variation in the number of patients receiving reconstruction across the UK, with generally fewer being offered at cancer units. Another important issue is how this is explained to patients and the difficult issue of choice.

Topic (i)
The group felt this was a sensible question and there would be good evidence available.

Topic (j)
The Group felt this was another relevant topic to include and that it was important for patients to be informed at the right time. 'Curative' to be changed to 'curable'.

Topics (k, l and m)
No comments

Topic (n)
It was suggested this topic should investigate whether earlier palliative care intervention influences later admissions and outcomes. It was also noted that palliative care was not just required at the end of life, but that some 'cured' patients experience haematuria as a side effect of treatment.

It was suggested that 'urinary diversion' should be replaced with 'treatment of urinary obstruction'. And this topic should include 'pain' rather than 'bladder pain'.

4.3.2a Clinical issues that will not be covered

The group suggested changing this to read 'indications for referral from primary care' to avoid confusion

4.4 Outcomes

The group agreed that because bladder cancer is a such a highly recurrent disease 'recurrence' should be added as an outcome. 'Field change' was another possible outcome.

The group noted the bladder cancer EORTC questionnaire was a validated QOL measure in this population.

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Group 2

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Discussion on draft scope

The group primarily focussed their discussion on section 4.3 of the scope, although section 4.1 was also briefly discussed.

4.1 Population

4.1.1 Groups that will be covered

Agreement amongst the group that the stated groups should be covered by the guideline.

Although urethral carcinoma is rare it should be included.

Some group members suggested that patients at high risk of progression were a particularly important group to cover in the guideline.

4.1.1 Groups that will not be covered

a) Agreement that bladder sarcoma should not be covered as it's a relatively small area, managed by a different group of clinicians.

b) The group agreed that children should not be considered in the guideline due to the relative rarity of the disease, and because it is managed by a different group of clinicians.

c) The group agreed that urothelial carcinoma of the ureter and renal pelvis should not be covered. Many of the group felt that this was too large an area to be covered in the guideline and would probably require a guideline on its own. However, the group did stress importance of appropriate surveillance and follow-up of bladder cancer patients to check for upper urinary tract urothelial cancer. Thus, the area was highlighted as important from a patient perspective and should be covered by the topic on patient information and support needs. The group suggested making it explicit to stakeholders at consultation that surveillance/follow-up of bladder cancer would include the upper tract surveillance.

d) The group questioned why people who are risk of bladder cancer (e.g. catheter users) are not being considered, however, it was felt that the referral for suspected cancer should cover this and that the bladder cancer guideline should concentrate from the point of diagnosis.

e) One member of the group questioned why small cell carcinoma was included but not sarcoma. However the group felt that few patients were referred back from sarcoma teams and therefore it was not considered a high priority for inclusion.

f) One member of the group stated that urothelial carcinoma of the upper tract was a big area and is sometimes missed from both kidney cancer and bladder cancer care. Suggestions were to include this term but exclude rare bladder cancers or just to include surveillance of the upper tracts in follow-up of bladder cancer. The group felt that it was too big to include and would need staging to be included if we looked at it.

g) The group agreed that secondary cancers should not be considered.

4.2 Healthcare setting

a) The group agreed on all settings where NHS funded care is provided

4.3 Clinical management

4.3.1 Key issues that will be covered

a) One member of the group mentioned that the Action on Bladder Cancer website already covers a lot of the patient information and support needs

The examples given in the draft scope came under some scrutiny from the group with many pointing out there were other areas of concern for patients. Many patients are more interested in follow-up and what will happen o them.

The group felt that there is a tendency for bladder cancer information to focus on issues that will only pertain to a minority of patients. In particular, stoma care was discussed in some detail by the group. Many of the group felt that there is often too much emphasis on patient information in this particular area. This does not reflect the experience of the average bladder cancer patient as only around 20% have muscle invasive bladder cancer.

The group want the patient information to cover the areas that are important for the other 80% of patients. Surveillance was an example of an area that would be important for the majority of patients.

The group suggested that it might be useful to separate patient information into two distinct groups; low risk and high risk, as the support needs of these two groups are very different.

Dietary options to promote health and prevent recurrence were also considered to be important areas for patients.

Smoking cessation was also considered an important area for bladder cancer patients.

b) The group mentioned that a relevant HTA has been published in this area (comparing blue light and white light cystoscopy).

One member of the group suggested that the wording of the question should be changed. The question focuses on the identification of bladder cancer but by the inclusion of cystoscopy methods, the question implicitly includes treatment.

The question essentially covers two topics in one; treatment and identification, and it may be useful to split into two separate questions.

One group member suggested that narrow band imaging should be included as an identification method.

The group also discussed haematuria tests but were told that this would be covered in the GP referral guideline. One group member stressed the importance of communication between the Bladder Cancer Guideline and the GP Referral Guideline to ensure every stage of the patient pathway is covered. The group suggested amending the wording of the question so it is clear that the guideline will not cover haematuria and that it is more about the diagnostic technologies used.

One group member suggested that the treatment aspect should include alternatives to cystoscopies. Indeed, it was suggested that a benefit of some treatments might be a reduction in the number of unnecessary cystoscopies performed.

WT suggested re-phrasing the question to ‘What is the best diagnostic method?’ or ‘How best to follow-up patients and by what means?’ This would include clinical and cost-efficacy measures. This would also apply to follow-up as it would suggest which methods have good sensitivity for recurrence of low grade bladder cancer. One group member also raised the question of which sensitivity and specificity levels are acceptable.

Urine testing in follow-up was suggested as interesting to be looked at, to reduce the need for cystoscopy, especially for low grade bladder cancer.

The group highlighted the economic importance of this topic. Indeed, the group suggested that many of the costs of these treatments are largely unknown to the clinical community.

c) The group felt that imaging was a very important topic. Also, once again, the economic aspects were considered important.

PET imaging was discussed by the group with some feeling that it should be included in the scope as some high risk patients might benefit. However, other group members felt that it was used too rarely to warrant inclusion in the question. In addition it was felt that there would not be any evidence for PET use in bladder cancer.

The group suggested the question essentially contains two aspects; staging and surveillance (possibly two separate questions).

d) The group agreed that looking at risk stratification was useful. The group discussed changing the staging groups that are commonly used. Two grading classification systems are currently used by pathologists. For example, the WHO grading system G1, G2 etc, or the new staging into low and high risk groups. Most published evidence will report on the WHO grading system. There is significant variation in which system is used and how they are applied (there is often a preference for one system over the other). Guidance could be useful in this area. If the guideline were to recommend the new staging system this would impact on the work of the RCP. A suggested question was to ask 'what specimens are required for an optimal pathological assessment of the tumour?'.

e) The group agreed that this was an important topic for inclusion in the scope

f) The group felt that this was an important topic associated with significant patient morbidity and potentially a very large aspect of the guideline. There is currently a lot of controversy and many patients affected.

The group highlighted patients at intermediate risk as an area where there is significant debate.

In high risk patients, the duration of intravesical therapy is a crucial area.

The group mentioned that newer modalities should be included and that the recent HYMN clinical trial would be a useful source of information.

g) The group stated that there is significant controversy in this particular area.

The group warned that there might be a danger of drifting into ageism in this topic as many treatments are often considered to be age-dependent.

The group felt that, as it stands, there is a gap between topic f) and g) that should be covered by a further question. This new topic should compare BCG versus cystectomy in patients with high risk non-muscle invasive bladder cancer. The new topic could possibly be stratified by patient risk group i.e. low risk/high risk NMIBC.

The group also suggested that salvage cystectomy should be covered by this topic and look at which patients are appropriate for preservation of bladder treatment, but some members of the group thought that other topics, e.g. topic g, would cover this.

h) There was quite a wide range of opinions on this particular topic.

Some members of the group suggested that the key issue here is ensuring that patients have access to the appropriate options (rather than finding the most effective method *per se*). As it stands, there is considerable variation in the methods of urinary diversion that patients are offered. This may even reflect the varying skills of the surgeons performing

the procedures and what procedures they are able to offer patients. Some group members felt it was important that the patient is able to make a decision about which procedure they have.

One group member stated that most patients are happy with whatever method of urinary diversion they end up with (based on a study conducted by this group member). Thus, the rationale for including this topic was questioned because it is already known that there is no difference in clinical outcomes between methods. As all options are not being offered in all places it was felt this was an important question.
Most of the group felt that the topic was important for patients with quality of life highlighted as a crucial outcome. Thus, some thought it should be included in the patient information and support needs topic (a).

The group suggested that the development group use a patient focus group to gather information on patient experiences with different methods.

i) The group said that there are two main radical radiotherapy regimens that are used in clinical practice. There is not believed to be any clear differences in outcomes associated with these regimens, such as response to treatment or long-term toxicity, and they have never been put head to head in a clinical trial. As it stands, the regimen used is down to the choice of the clinical centre. One group member said that outside the UK radiotherapy is used less often, so it may be useful to draw upon evidence from outside the UK.

   It is thought that there will be significant differences in cost as one regimen is given for 4 weeks and the other is given for 6 weeks. Thus, the economic implications of this topic could be crucial.

j) The group felt that this topic was very similar to the previous one so i) and j) could be combined into one topic. One group member stated that there is lots of data available for this question, and there are some trials about enhanced radiotherapy with chemotherapy, which would be relevant for the topic.

k) The group agreed that this was an important topic as there is variability in practice across the country.

l) The group felt that this topic could be combined with topic k). The group stated there is also variability in practice for this topic.

m) The question is concerned with *first line* chemotherapy but some group members felt that second line chemotherapy was also important due to the variation in practice. It was suggested that ‘first-line’ could be deleted from the question. They suggested that there is likely to be wide variation in the use of second line chemotherapy in practice. However, many of the groups felt that there was unlikely to be much evidence in this area.

Some group members felt that there was unlikely to be much variation in the chemotherapy regimens used by patients with metastatic cancer.

The GDG also felt that an additional question could be posed which considers the optimal follow-up regimen in patients who have radical treatment.

n) The group felt that there is unlikely to be much evidence in this area. However, they felt that it's an important topic for patients and should be included in the guideline. In particular, the group stressed the importance of quality of life issues in this topic. This question would be a big topic.

The group felt that additional topics should be created:

- Topic covering cystectomy, which is similar to i) The question could identify the optimal peri-operative care and surgical technique. It was felt that there would be a big gap in the guideline if it were published without looking at other cystectomy techniques.

- Follow-up for muscle invasive bladder cancer, as topic e currently only covers non-muscle invasive bladder cancer.

- BCG vs cystectomy for high risk non-muscle invasive bladder cancer

4.3.2 Key issues that will not be covered

a) The group considered haematuria to be a very important area for bladder cancer and stressed the importance of appropriately covering this in the 'Referral for suspected cancer' guideline, and ensuring that nothing fell through the gaps by not being covered in either guideline.

   One group member expressed concern that post-menopausal women with UTIs may fall between the two guidelines ('Referral for suspected cancer' and 'The diagnosis and management of bladder cancer'). It was suggested that this area is highlighted to the team developing the 'Referral for suspected cancer' guideline so that they can include it.

b) There were no issues with not covering this clinical issue.

Discussion on GDG membership

The group were happy with the composition of the GDG.

The group were happy that allied health professionals would be called on as part members of the group as and when needed rather than being a full member.

One member of the group suggested that there would be no medical oncologists who specialise in bladder cancer, but other group members said this would not be the case across all centres.