This vision does not represent government policy but provides useful insight into how urological cancer services (excluding prostate) might develop over the next 5 years

Annex L

Urological cancers[1] 2015

1. The following vision covers testicular, penile, bladder and kidney (urothelial and other renal) cancers. Cancer of the prostate is excluded from consideration as a separate vision has been produced for this cancer.

Epidemiology

2. When taken together, urological cancers (incl. prostate cancer) are the second biggest category of cancers behind skin cancers. The incidence of *testicular*, *penile*, and *kidney* cancers is expected to increase over the next 5 years. In *kidney* cancer this is mainly due to population aging and increased incidental detection. The incidence of *bladder* cancer is expected to remain broadly stable although it is likely that there will be an increase in *bladder* cancer among women due to an increase in smoking in this group. In the case of *testicular* cancer, the increase in age-specific incidence seen for many decades is likely to continue.

3. There will also be an increase in prevalence of urological cancers as people live longer with these conditions. By 2015, the NHS needs to have planned for increased services to manage urological cancers.

IOG Implementation

4. The key priority for people with urological cancers is that the improving outcomes guidance (IOG) is fully and consistently implemented across the country. By 2015 there should therefore have been many years of an IOG compliant service across the NHS and this should have been confirmed by peer review. An increase in workforce (particularly clinical nurse specialists [CNSs], histopathologists, non-surgical oncologists and allied health professionals) will be needed to support this. Commissioners should not be commissioning services from non-IOG compliant services.

Prevention

5. There are a number of lifestyle and other factors that can be associated in some part to urological cancers:
    i. smoking, obesity, long term dialysis – *kidney* cancer;
    ii. some industrial chemicals and potentially hair dyes – *urothelial* cancer;
    iii. smoking, genetic factors (that we may know more about over the next 10-15 years) and some chinese herbal medicines – *bladder* cancer;
    iv. partner with HPV associated cervical cancer – *penile* cancer; and
    v. chemical carcinogens - *testicular* cancer.

6. Efforts to support a reduction in smoking incidence and obesity are supported and should, in the long term, have an impact on the incidence of some urological cancers but this impact will not be apparent by 2015.

[1] Excluding prostate cancer

This vision does not represent government policy but provides useful insight into how urological cancer services (excluding prostate) might develop over the next 5 years

7. By 2015:
    i. there should have been the introduction of health warnings and/or regulation of specific herbal medicines;
    ii. the HSE should continue to support action to minimise exposure of workers to potentially carcinogenic chemicals;
    iii. data from the COXII inhibitor trial should be available – this may produce information of relevance to secondary prevention of superficial *bladder* cancer; and
    iv. there should be continued support for the HPV vaccination programme; in the long term this may have an impact on some urological cancers in men but this will not be known until after 2015.

Surveillance/Screening

8. There will be no evidence to support national screening for urological cancers by 2015. However, there are a number of areas where surveillance/ screening of at risk groups may be of benefit:
    i. patients on long term dialysis for kidney failure are at increased risk of *kidney* cancer. Efforts should be made to raise awareness of this in dialysis units and by 2015 all dialysis units should have a policy regarding surveillance in place;
    ii. there are 4-5 genetic disorders associated with *kidney* cancer. By 2015 either a large scale genetic study needs to have been introduced to assess the possibility of targeting screening at high risk populations or a decision needs to have been taken to introduce protocol driven screening of genetic disorders based on existing evidence via clinical genetics clinics; and
    iii. there is a familial link to *kidney* cancer with possibly more kidney cancers associated with familial links than genetic conditions. By 2015 a consensus needs to have been developed about the role of family history screening for kidney cancer screening – if such screening is introduced there may be potential savings as treatment of advanced disease is generally more costly than treating early kidney cancer.

Raising Awareness/ Improving referral

9. Known carcinogens are already proscribed so there should either be no exposure to these or those that are exposed should already be screened. However, some occupations have an increased risk of *bladder* cancer but no carcinogen has been identified. There are two key groups at risk that might benefit from targeted awareness campaigns of both employers and employees:
    i. those working in industries associated with increased incidence of urological cancers such as paint manufacturers;
    ii. those working in the hairdressing industry.

10. By 2015:
    i. all employers in industries associated with urological cancers should be raising awareness of risk among their workforce and already be arranging for them to have regular testing for micro/macro haematuria;

ii. a prospective study of urological cancer incidence and outcome in the field of hairdressing needs to have been developed and funded if robust.

11. There are a number factors associated with higher risk of *testicular* cancer: undescended testes as a baby, signs of male infertility (although the risk is very low – probably 0.5-1%), cancer in other testicle and familial link (brother and sometimes father). The dividends of screening for testicular cancer would be too small but by 2015 action should have been taken to raise awareness of risk factors amongst those at risk. For example, information should be provided for parents to enable them to inform their sons of increased risk due to testicular maldescent – the risk is 4 fold, a lifetime risk of 1 in 70.

Diagnostics

12. The gold standard for diagnosis of suspected *testicular* cancer is ultrasound and this is generally easily accessible to GPs and should become more so. However, it is important for there to be clear quality standards and protocols for ultrasound and speedy access if GPs are to make direct referrals for this test.

13. For *kidney* cancer the main indicator of potential cancer is blood in the urine (micro or macro haematuria). Patients of any age with painless visible haematuria should already be being referred urgently by their GP to a specialist in line with the NICE GP referral guidelines but clarification is needed on referral of undiagnosed recurrent urinary infections – by 2015 this clarification should have been provided. In addition the HTA has undertaken an assessment of haematuria management and findings should be supported.

14. The main presenting symptom of *bladder* cancer is haematuria. Evidence is accruing to support CT scanning as the primary imaging modality for visible haematuria. This will have cost and resource implications.

15. All patients with suspected urological cancer need a specialist assessment - it does not matter where this takes place, the key is the quality of the assessment and integration with specialist care. By 2015 it is expected that this assessment will increasingly be available more locally with the majority of urologists focusing on diagnostics and non-radical treatment aspects of the cancer pathway. Others will focus more on providing specialist radical surgery within specialist urology cancer centres.

16. It will be important to streamline diagnostics where possible in one stop clinics where most tests are performed on the same day – this is unlikely to increase workload but will require some streamlining of services eg. ensuring scanning before cystoscopy. By 2015 diagnostic services should have been redesigned to ensure that, where possible, patients are able to have the majority of diagnostic tests they may need on the same day.

This vision does not represent government policy but provides useful insight into how urological cancer services (excluding prostate) might develop over the next 5 years

17. More sensitive urinary based diagnostic tools are likely to become available over the next 5 years. For example, by 2015 there may be new tests to identify chemicals in the urine that could indicate different urological cancers and there may also be new markers that could identify those cancers which are likely to be most aggressive. These need to be kept under review and brought into standard practice when appropriate.

18. It should also be noted that some private healthcare companies are offering CT scans as part of health checks. There is no evidence that this benefits patients and can lead to unnecessary radiation exposure. It is likely that such scans will lead to an increase in the number of people identified with benign conditions or renal lesions of 2cm or less where the natural history is not known and the best form of management is uncertain. These cases are likely to be referred back into the NHS for management so there will be a clinical impact for the NHS by 2015 and, on occasion, unnecessary anxiety and intervention for patients. By 2015 an observational study of the natural history of small lesions should have been considered as this will help to decide how best to manage these cases in the future.

19. Staging should become more sophisticated over the next five years. In particular it is likely that more evidence will have built up to support increasing use of PET-CT in the management of urological cancers (excl. prostate) including metastatic disease. By 2015 there should be equal access to PET-CT for all urological cancer patients where evidence supports this.

20. By 2015 there needs to have been research to enable the development of an algorithm for risk stratification to enable more bespoke treatments to be given to patients.

Treatment

21. By 2015 it is likely that there will be more expensive targeted therapies available which will largely be additive rather than substitutive and thus an additional cost to the NHS. More evidence to support concurrent chemotherapy and radiotherapy is also likely to have built up which will have implications for NHS capacity.

22. The Cancer Drugs Fund and the introduction of Value-Based Pricing should help address the challenges urological cancer patients have sometimes experienced when trying to access drugs. This will need to be kept under close review.

23. Outcomes from managing bladder cancer are better in centres that handle large numbers of patients and have an infrastructure dedicated to managing these complex cases. The link between volume and outcome is particularly pronounced for major surgery (e.g. radical cystectomy). At present, 5 radical cystectomies per year (on a background of 50 radical pelvic procedures which could be unrelated to bladder cancer) is the minimum recommendation by centre offering the procedure. Most centres of excellence would agree that this is far too low and setting a minimum number of at least 20 per year, linked to

the total number of cases managed by the unit (e.g. to include those choosing radiotherapy) would be more appropriate.

24. Although the majority of surgery is likely to remain "open" it is expected that over the next 5 years there will be an increase in laparoscopic surgery and minimally invasive techniques as well as techniques such as radiofrequency ablation, cryotherapy and high intensity focused ultrasound (HIFU). There will be training implications for all these techniques. There are also likely to be more techniques deemed safe in NICE interventional procedures guidance that are then strongly marketed without corresponding evidence about their clinical or cost effectiveness. Resources should be made available for multi-centre studies of minimally invasive therapy, particularly in small incidental *renal* tumours to assess the true natural history and determine treatment morbidity and outcome.

25. Within the management of Non-muscle invasive bladder cancer (NMIBC) a new form of tumour resection using photodynamic diagnosis (or 'blue light' cystoscopy) is attracting attention and research. The advantage of this treatment modality is that it improves the extent of tumour resection which leads to lower recurrence rates. Multicentre prospective studies have demonstrated that the use of PDD results in more complete tumour resection, sustained reduction in tumour recurrence rates, less use of adjuvant therapy and a reduction in hospital admissions for tumour resections. Thus there is an overall cost saving per patient. Most urologists would agree that this is an improvement on standard 'white light' tumour resection however, widespread introduction is hampered by the HRG coding which at present pays the same for both 'blue light' and 'white light' cystoscopies. This means that Trusts lose money on each of the procedures due to the extra expense of the active agents. Recoding the HRG to acknowledge this extra cost would enable Trusts to introduce the technology and result in a reduced overall cost burden of the disease nationally.

26. Following transurethral resection of a NMIBC there remains a significant chance of tumour recurrence (especially if 'white light' cystoscopy is used). A single does of intravesical mitomycin within 24 hours of tumour resection can reduce recurrence rates by a third. If this 24 hour window is missed to achieve a similar reduction in recurrence would require one year of adjuvant intravesical mitomycin-C. This should be standard of care for all initial resections of suspected NMIBC.

27. By 2015 a number of actions need to have been taken in relation to treatment:
    i. NICE needs to have taken action to ensure that its interventional procedures guidance is not used to promote new procedures in a potentially misleading way;
    ii. management of T1 *renal* tumours needs to have been reconsidered – the IOG advised that district general hospitals could manage this condition but with the advent of laparoscopic nephrectomy and nephron sparing surgery this should now be managed in the specialist centre; this needs to be addressed;

iii. the British Association of Urological Surgeons (BAUS) need to provide additional clinical advice on managing complex *kidney* cancers i.e. those with IVC (inferior vena cava) and cardiac involvement and also patients with large tumours in solitary kidneys;
iv. patients need to be offered choices about how urine is diverted following cystectomy (eg. ileal conduit or reconstruction including neobladder) and bladder reconstruction post surgery;
v. there should be equitable access to neoadjuvant chemotherapy for *bladder* cancer – there are proven survival benefits with some of the older drugs but evidence suggests that they are not being offered consistently around the country; and
vi. patients need to know how their treatment choice may affect where they are treated and followed up eg. travel commitments.

28. It is also important that:
    i. all patients receive timely treatment, and the NHS should continue to deliver all cancer treatments to the 31 day target including treatment for re-occurrence and consultants should continue to be able to re-assess routine referrals and upgrade them to urgent referrals to be covered by the 62 day target when necessary; and
    ii. there should be an improved IT interface to ensure the smooth running of services.

Supportive & Palliative Care and Patient Experience

29. By 2015 it will be important that:
    i. the role that CNSs have to play in improving patient experience is recognised and supported across the NHS;
    ii. health and social care are working together to ensure that patients and their families and carers are receiving an appropriate level of support;
    iii. there is access to high quality, accurate web information in a single place about the various treatments available for urological cancers;
    iv. appropriately skilled nurses support patients by providing the necessary data and information to make informed choices about their treatment plan; and
    v. patients and carers are routinely informed about national and local support groups.

30. The patient experience, both acutely and in long-term follow-up, might be improved by increased implementation of “buddy groups” and other patient peer-support services. These have not yet become common in urological malignancies to the extent that they have in some other tumour types.

Follow up

31. Cancers (in particular *renal* cell cancers) do not obey the “5 year rule”. It would be useful if a risk stratification tool could be developed to identify the risk of relapse and likely emergence of symptoms of relapse for different treatment modalities. Although there is no strong evidence to support long term follow-up of all urological cancer patients some patients can feel cast

adrift if they are "signed-off". It is important that both they, and their GPs, have information about what to look out for, how to get additional support and how to access specialist advice if needed.

32. In addition to follow up for re-occurrence, there is the possibility of treatment induced morbidities and/or late effects due to treatment and many urological cancer patients will require continuing supportive care. For example, *bladder* patients may require stoma support. Such support will not necessarily be carried out by the same team of healthcare professionals, but nonetheless should be factored into discussions about follow-up.

33. Developing new ways of follow up, at times by different groups of professionals, can also offer opportunities for efficiency savings. For example, Clinical Nurse Specialist (CNS) led clinics for long-term follow-up of testicular cancers. Further savings may also be found by using telephone or (particularly in a predominantly youthful patient population) internet interaction rather than traditional clinic attendance. This may also have a positive impact on the patient experience for some.

34. By 2015:
    i. a risk stratification model for follow-up needs to have been developed alongside different models including community based models with clear routes back to specialist MDTs when needed. An RCT could be considered eg. intense follow-up vs. patient driven follow-up to identify possible recurrence but it might only be worth introducing this when there are appropriate treatments that can then be offered;
    ii. patients sometimes feel lost when they are "signed-off" or given the "all clear" – they need clarity about what this means in practice and how to get additional support if they need it; and
    iii. there should be better access to allied health professionals and specialist nurses to manage morbidities such as stoma care.

Underpinning programmes

Information

35. By 2015 a national urological cancers audit should have been established and it should be mandatory for MDTs managing urological cancer patients to participate in this. This should include collecting data on co-morbidity, staging and performance status and regular risk-adjusted performance and outcome data should be published to support service improvement and informed patient choice.

Research

36. By 2015 there needs to be a wider clinical trial portfolio for the full range of urological cancers and a process in place to ensure equal opportunities to access relevant trials for all patients.