Care of bladder cancer patients diagnosed in Northern Ireland 2010 & 2011 (Summary)

TIMELINES: REFERRAL TO DIAGNOSIS AND TREATMENT

Referral to First Seen by Urologist and TURB
- 59% of patients were seen by a urologist within 4 weeks of referral while 27% waited over 6 weeks.
- The overall duration from referral received to first seen by urologist was longer for patients presenting in the Belfast Trust.
- A lower proportion of patients presenting in the Belfast and Northern Trusts were seen by a urologist within 4 weeks, 45% and 47% respectively, compared to 69%, 63% and 77% in the South Eastern, Southern and Western Trusts respectively.
- Overall 28% of patients had their cancer diagnosed by TURB within 4 weeks of referral, while 61% waited 6 weeks or more.
- A significantly higher proportion of patients in the Southern Trust (44%) had a cancer diagnosis within 4 weeks of referral compared to the other 4 Trusts (24%).
- Patients who were referred to A&E (GP/self-referral) had the shortest duration from time of referral to TURB.
- For patients on a red flag pathway the median time to TURB was 63 days. 13% had TURB within 4 weeks of referral, 32% within 6 weeks, while over two thirds waited more than 6 weeks.
- Patients referred by GPs as routine, urgent/semi-urgent had the longest time from referral to TURB.

Referral to Treatment
- For patients with non-muscle invasive bladder cancer median time from first referral to secondary care to treatment (TURB) was 69 days with 41% of patients having first treatment within 62 days.
- For patients with muscle invasive disease (T2 or higher) median time from first referral to secondary care to major surgery was 118 days and median time to curative-intent oncology was 171 days.

Diagnosis to Treatment
- 42% of patients with muscle invasive disease had their major surgery within 62 days of diagnostic TURB.
- Time to major surgery from TURB was greater than 90 days in one quarter of patients.
- Median time from diagnostic TURB to treatment was 65 days for major surgery and 84 days for curative-intent oncology.

COMMUNICATION WITH PRIMARY CARE AND PATIENT INFORMATION
- Over 95% of patients had their diagnosis and management plan recorded in their GP letter.
- Two thirds of GP letters mentioned that diagnosis was discussed with the patient and a third of letters that diagnosis had been discussed with their family.
- In 31% of the letters, palliative care was mentioned.
- Discussion of diagnosis and treatment plan was recorded in the clinical notes/CaPPS in just over 80% of patients.

SURVIVAL
- Risk of death from bladder cancer was higher for women 1.5:1. However, when stage of disease was taken into account, this reduced to 1.3:1, or 30% higher in women. This however was no longer statistically significant.
- The net survival decreased with age which means that older patients are more likely to die from their bladder cancer than younger patients, even when stage is taken into account.
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- For patients aged 0 to 69 and 70 to 77, respectively.
- Large differences in net survival at 2 years were present between the 3 stage groups: non-muscle invasive (47%), and locally advanced/metastatic disease (10%).
- Those over 78 years at diagnosis had significantly poorer net survival (42%), than the younger age groups: 60% and 64% for age groups 0 to 69 and 70 to 77, respectively.

RECOMMENDATIONS
1. The public need to be educated about haematuria as an alarm symptom for cancer.
2. Reasons for late and delayed presentation of bladder cancer should be investigated.
3. Access to urology services should be assessed regionally.
4. The pathways for bladder cancer investigation and treatment should be explored to speed up this process.
5. Clinical Nurse Specialists should be available for all patients.
6. Efforts to reduce the prevalence of smoking should continue as tobacco use is a risk factor.

FURTHER INFORMATION
Further data from the N. Ireland Cancer Registry is available from the Registry website: www.qub.ac.uk/nicr, and N. Ireland Cancer Registry Centre for Public Health Mulhouse Building Grosvenor Road Belfast, BT12 6DP Phone: +44 (0)28 9063 2573 e-mail: nicr@qub.ac.uk

ACKNOWLEDGEMENTS
This audit was funded by the Guidelines and Audit Implementation Network (GAIN). NICR is funded by the Public Health Agency.

SUMMARY
Care of bladder cancer patients diagnosed in Northern Ireland 2010 & 2011

This is a summary of a report on bladder cancers diagnosed in Northern Ireland during 2010 & 2011 which can be found at www.qub.ac.uk/nicr

AIMS
1. To document care for bladder cancer patients in N. Ireland and compare with recommended guidance for investigation and treatment.
2. To explore reasons for differences in bladder cancer survival in women compared to men.
3. To serve as a benchmark for further audits.
4. To make recommendations for service improvement.

BACKGROUND
The Bladder
- Bladder cancer is the most common type of bladder cancer known as transitional cell carcinoma (TCC). There exists also Carcinoma in situ (CIS) which is a flat, high-grade lesion in the epithelium. CIS does not invade past the bladder lining, but has a high risk of progression to invasive disease.

Risk factors
- Tobacco smoking - causes 50.65% of male cases and 20.30% of female cases. Levels are associated with years of smoking and number of cigarettes smoked daily. An immediate decrease in risk occurs with cessation of smoking.
- Occupational exposure to chemicals (e.g. Dyes, paints, plastics) - second most important risk factor and accounts for 20-25% of all cases. However, because of strict regulations these chemicals contribute minimally to the current levels of bladder cancer in Western countries.
- Bladder schistosomiasis (a parasitic disease) is associated with a five-fold increased risk of urinary bladder cancer. Infections with schistosomiasis affect about 600 million people in Africa, Asia, South America, and the Caribbean, but is not a risk-factor in N. Ireland.
- Other causes of bladder cancer include previous treatment for cancer – in particular, radiotherapy to the pelvis and some forms of chemotherapy.

Common symptoms
- For early stage bladder cancer the most common symptom is blood in the urine (haematuria). Late stage symptoms include haematuria, urgency, pain on passing urine (dysuria), increased frequency and pelvic pain. In advanced disease, symptoms related to urinary tract obstruction, such as poor urine flow occur.

INCIDENCE: 2007-2011
- Transitional cell carcinoma (TCC) of the bladder:
  - 8th most common cancer in men and 16th in women.
  - Accounted for 2.6% of all cancers (excluding non-melanoma skin cancer).
  - On average 154 men and 60 women diagnosed annually, this gender difference is probably due to lifestyle and occupation risk factors that differ between the sexes.

Figure 1: Age distribution of patients diagnosed with bladder cancer in Northern Ireland 2007-2011 by sex, with age-specific rates

NATURAL MAPLE
INCIDENCE TRENDS 1993-2011

Although, the numbers of people being diagnosed has remained relatively constant from 1993 to 2011, age-standardised rates have been falling by 1.7% (p<0.01) per year in men, and 1.3% (P<0.13) in women. This fall in age-standardised rates, while total numbers remains stable, reflects the ageing of the population. The faster-falling standardised-incidence rates in men possibly reflect changes in smoking-habits between the sexes. Deaths show a similar pattern.

INTERNATIONAL COMPARISONS


Incidence rates of bladder cancer in NI (male 11.8/100,000, female 3.2/100,000 (world age-standardised rate)) during 1998-2002 were among the lowest in the Western World being significantly lower than most European countries, including the rest of the UK. By 2003-2007 rates in NI had increased to 18.3/100,000 and 5.5/100,000 for males and females respectively, both of which were similar to the rates in England although they were still lower than those in Scotland and Denmark among others. (Fig. 2)

Source: Cancer Incidence in Five Continents (IV)

Relative survival: 1995-2007

The five-year (age-standardised) relative survival for bladder cancer patients diagnosed in 1995-1999 in NI was poor in comparison to the European average and England & Wales. The rate in men (65.0%) was comparable to Scotland, Slovenia, Poland, and France, but for women NI (54.6%) had the lowest rate among the EUROCAR-4 countries.

The EUROCAR-5 data for patients diagnosed in 2000-2007 indicates that survival in NI was better than the European average for men and was similar to the average for women. However NI has a small number of female bladder cancers diagnosed each year, with the result that survival estimates fluctuate from year to year. (Fig. 3)

Source: EUROCAR-4&5

Impact of changing submitted codes

Both Cancer Incidence in Five Continents IX and EUROCAR-4 included borderline pTa, pTis tumours in their definition of bladder cancer, but NCIR submitted only invasive bladder cancer. However, for Cancer Incidence in Five Continents X and EUROCAR-5, NCIR submitted both invasive bladder cancer and borderline pTa, pTis tumours. The result of changing the codes submitted was that incidence and patient survival increased; patients diagnosed with borderline tumours generally have better prognosis.

SUMMARY OF RESULTS – DETAILS IN REPORT

PRESENTATION, DIAGNOSIS AND STAGING

- 98% of bladder cancer patients diagnosed 2010 and 2011 were included in the audit (n=362 patients).
- Half of patients were over 74 years and 73% were men.
- 72% were current or ex-smokers.
- Macroscopic haematuria was the most common presenting symptom (80%).
- 58% of patients with symptom duration recorded had haematuria for at least 1 month and 12% over 6 months.
- Women were more likely than men to present with abdominal pain, lethargy and weight loss, possibly reflecting later stage of disease at presentation.
- 57% of all patients were referred by their GPs (outpatients and A&E).
- Overall 18% of patients were referred to urologists by GPs as red flag suspect cancers and a further 14.6% were upgraded by consultants to a red flag pathway. GP referrals to A&E accounted for 10.5% while 11% were GP routine/urgent/semi-urgent/ referrals to outpatients.
- 31% of patients referred to outpatients by GPs were upgraded to ‘red flag’ by consultants.
- 21% of patients presented via A&E.
- Over a quarter of patients first presented to the Belfast Trust.
- 52% of patients first presented in outpatients clinics, with a further 16% first seen at a designated haematology clinic.
- 86% of patients were first seen by urology.
- 73% of patients had seen a urologist within 42 days of referral, 39% within 2 weeks.
- The duration from referral received to first seen by urologist was longer among patients who presented in the Belfast Trust.
- 90% of patients were discussed at MDM – Private patients were less likely to be discussed.
- 98% of patients had a cystoscopy, of these patients 98% had a TURB and 77% had a CT scan.
- 96% of patients with muscle invasive bladder cancer had a CT/MRI scan.
- 97% were histologically verified with 86% having transitional cell carcinoma.
- 98% of patients were staged, 45% Stage I and 26% Stage 4 at diagnosis.

TREATMENT

- 95% of patients had a Trans Urethral Resection of Bladder - TURB.
- A third of TURBs were carried out in the Belfast Trust.
- 83 major surgical resections were performed: cystoprostatectomy (52), cystectomy (16), and anterior exenteration of pelvis (15).
- The majority (93%) of radical cystectomies were performed in the Belfast City Hospital with 4 being performed in the Southern Trust, 1 in the Western Trust and 1 in the private sector.
- 89% of major surgical resections were performed by a uro-oncology surgeon with a case-load volume of 11 or more major procedures during the audit period.
- 11% were performed by urologists who performed 5 or fewer major procedures during the audit period.
- 83% of patients undergoing major surgery had lymph node resection performed. The median number of lymph nodes resected was 15 (range 5-28) and the median number of positive nodes was 0.
- 37% of patients were records as having been seen by a Urology Clinical Nurse Specialist. This figure may be an underestimate as this data may not have been consistently available in the clinical notes or CaPSS.
- Incidental prostate cancer was detected in 17/54 (32%) of men who had major surgical resection.

Stage I

- (Non-muscle invasive disease, n=161)
- The majority of patients with non-muscle invasive disease, or Stage I (86%, 130/161) had organ-conserving treatment with 11% (18/161) having radical cystectomy.
- Just under two thirds (62%) received courses of intravesical chemotherapy in addition to BCG therapy.

Stage 2 & 3

- (Muscle invasive disease, n=100)
- A third (36%) of patients with muscle invasive disease (Stage 2&3) had major surgical resection while 20% of patients had organ-conserving curative intent oncological therapy. A further 16% had palliative oncological treatment.
- In total 28% of patients with muscle invasive disease (Stage 2&3) had localised therapy only (TURB+.
- Just under a quarter had local tumour resection (TURB) with repeat cystoscopy to ensure disease eradication.

Stage 4

- (Advanced metastatic, n=94)
- Just under one third (n=28) of patients with locally advanced/metastatic disease (Stage 4) had radical cystectomy with 6 patients having pre-operative chemotherapy and 12 patients requiring adjunct palliative radiotherapy for residual progressive disease following cystectomy.
- One quarter (n=23) of patients were treated with palliative radiotherapy, while 26% of patients received supportive palliative care alone.
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Source: Cancer Incidence in Five Continents (CIV)

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- Incidental prostate cancer was detected in 175/4 (32%) of men who had major surgical resection.

Stage 1

(Non-muscle invasive disease, n=161)
- The majority of patients with non-muscle invasive disease, or Stage 1 (86%, 139/161) had organ-conserving treatment with 11% (18/161) having radical cystectomy.
- Just under two thirds (62%) received courses of intravesical chemotherapy and/or BCG therapy.
- Just under a quarter had local tumour resection (TURB) with repeat cystoscopy to ensure disease eradication.

Stage 2 & 3 (Muscle invasive disease, n=100)
- A third (36%) of patients with muscle invasive disease (Stage 2 & 3) had major surgical resection while 20% of patients had organ-conserving curative intent oncological therapy. A further 16% had palliative oncological treatment.
- In total 28% of patients with muscle invasive disease (Stage 2 & 3) had localised therapy only (TURB+). 16% had intravesical therapy. 14% of these 28 patients were deemed unfit due to advanced age and/or comorbidity, and a further 7 patients (25%) died within 3 months of diagnosis.

Stage 4 (Advanced metastatic, n=94)
- Just under one third (n=28) of patients were treated with palliative radiotherapy, while 67% of patients received supportive palliative care alone.

- One quarter (n=25) of patients were treated with palliative radiotherapy, while 26% of patients received supportive palliative care alone.

- Just under one third (n=28) of patients were treated with palliative radiotherapy, while 47% of patients received supportive palliative care alone.

- One quarter (n=25) of patients were treated with palliative radiotherapy, while 30% of patients received supportive palliative care alone.

- Just under one third (n=28) of patients were treated with palliative radiotherapy, while 15% of patients received supportive palliative care alone.
Northern Trusts were seen by a urologist within 4 weeks, 45% of referrals, while 61% waited 6 weeks or more. Patients who were referred to A&E (GP/self-referral) had the shortest duration from time of referral to TURB. For patients on a red flag pathway the median time to TURB was 63 days. 13% had TURB within 4 weeks of referral, 32% within 6 weeks, while over two thirds waited more than 6 weeks.

Patients referred by GPs as routine, urgent/semi-urgent had the longest time from referral to TURB.

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- 42% of patients with muscle invasive disease had their major surgery within 62 days of diagnostic TURB.
- Time to major surgery from TURB was greater than 90 days in one quarter of patients.
- Median time from diagnostic TURB to treatment was 65 days for major surgery and 84 days for curative-intent oncology.

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- Over 95% of patients had their diagnosis and management plan recorded in their GP letter.
- Two thirds of GP letters mentioned that diagnosis was discussed with the patient and a third of letters that diagnosis had been discussed with their family.
- In 31% of the letters, palliative care was mentioned.
- Discussion of diagnosis and treatment plan was recorded in the clinical notes/CaPPS in just over 80% of patients.

**SURVIVAL**
- Risk of death from bladder cancer was higher for women 1.5:1. However, when stage of disease was taken into account, this reduced to 1.3:1, or 30% reduction with age which means that older patients are more likely to die from their bladder cancer than younger patients, even when stage is taken into account.
- The net survival decreased with age which means that older patients are more likely to die from their bladder cancer than younger patients, even when stage is taken into account.
- 2 years after diagnosis, men had 57% net survival while women had 47%.
- Large differences in net survival at 2 years were present between the 3 stage groups: non-muscle invasive (88%), muscle invasive (47%), and locally advanced/metastatic disease (19%).
- Those over 78 years at diagnosis had significantly poorer net survival (42%), than the younger age groups: 60% and 64% for age groups 0 to 69 and 70 to 77, respectively.

**RECOMMENDATIONS**
1. The public need to be educated about haematuria as an alarm symptom for cancer.
2. Reasons for late and delayed presentation of bladder cancer should be investigated.
3. Access to urology service should be assessed regionally.
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**FURTHER INFORMATION**
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**BACKGROUND**

**The Bladder**
The bladder is the organ that stores urine excreted by the kidneys before disposal by urination. It is a hollow muscular, elastic organ that sits on the pelvic floor. Urine enters the bladder via two ureters (from each of two kidneys) and exits via the urethra.

**Bladder cancer**
The most common type of bladder cancer is known as transitional cell carcinoma (TCC). There exists also Carcinoma in situ (CIS) which is a flat, high-grade lesion in the epithelium. CIS does not invade past the bladder lining, but has a high risk of progression to invasive disease.

**Risk factors**
- Tobacco smoking - causes 50-65% of male cases and 20-30% of female cases. Levels are associated with years of smoking and number of cigarettes smoked daily. An immediate decrease in risk occurs with cessation of smoking.
- Occupational exposure to chemicals (e.g. Dyes, paints, plastics) - second most important risk factor and accounts for 20-25% of all cases. However, because of strict regulations these chemicals contribute minimally to the current levels of bladder cancer in Western countries.
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- Other causes of bladder cancer include previous treatment for cancer – in particular, radiotherapy to the pelvis and some forms of chemotherapy.

**Common symptoms**
- For early stage bladder cancer the most common symptom is blood in the urine (haematuria). Late stage symptoms include haematuria, urgency, pain on passing urine (dysuria), increased frequency and pelvic pain. In advanced disease, symptoms related to urinary tract obstruction, such as poor urine flow occur.

**INCIDENCE: 2007-2011**

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- 8th most common cancer in men and 16th in women.
- Accounted for 2.6% of all cancers (excluding non-melanoma skin cancer).
- On average 154 men and 60 women diagnosed annually, this gender difference is probably due to lifestyle and occupation risk factors that differ between the sexes.

**Figure 1:** Age distribution of patients diagnosed with bladder cancer in Northern Ireland 2007-2011 by sex, with age-specific rates

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