

# Rare Urological Cancers

Urological Cancers SSCRG



## Introduction

Rare urological cancers are defined here as cancer of the penis, testes, ureter & renal pelvis, plus bladder cancers of the non-transitional cell type and prostate cancer of the small cell type. Reports regarding these malignancies are uncommon, possibly due to their comparative rarity when compared with other malignancies. This report attempts to address this imbalance and be a source of information for clinicians, commissioners, charitable bodies and those with an interest in this group of tumours.

To determine whether the incidence, mortality and survival rates for the rarer tumours is actually changing, and whether there is variation over the time periods studied, the NCIN Urology SSCRG has commissioned a breakdown report on these rare urological cancers in England.

The incidence of these rare tumours varies between 17 cases of small cell prostate to 1,846 cases of testicular cancer diagnosed in 2009. This compares to 34,793 cases of all types of prostate cancer diagnosed in 2009.

Improving Outcomes in Urological Cancers Guidance (IOG) was released in 2002 (National Institute for Clinical Excellence 2002), and may have had an effect on mortality as more appropriate treatment is offered, and multi-disciplinary teams (MDTs) have been formed to discuss treatment options. However, this guidance does not cover cancers of the ureter and renal pelvis, nor the less-common sub-types of prostate and bladder cancer. No subsequent guidance has been produced in relation to the rarer urological cancers.

## Method

Diagnoses of the rare urological cancers were identified from the NCIN National Cancer Data Repository. All patients diagnosed between 1990 and 2009 in England with a tumour/histology code listed below, were included in the analysis.

Mortality was identified from the Office for National Statistics. The analysis included all patients resident in England, who died between 1995 and 2009 with an underlying cause of death given as penile, testicular or renal pelvis and ureter cancer. It was not possible to calculate mortality statistics for small cell prostate and non-transitional cell bladder cancer as information on histology, which is necessary to identify these tumours, is not included in the death database.

Age-specific counts of incidence and mortality are used to generate age-standardised incidence and mortality rates. This technique takes into account the age-structure of the populations being studied, and calculates what the rate would be in a fixed (standard) population. As the rates are calculated in the same population, it allows different areas or time periods to be compared with statistical validity even though their resident population may change. All rates are standardised to the European Standard Population. When data for all ages is presented it is per 100,000 of the standard population for all ages, similarly when age-specific data is presented (e.g. 60-69) it is per 100,000 of the standard population at those specific ages.

Period survival is used for survival calculations. Period survival utilises the fact that the component years of follow-up have separate risks of death, and these are multiplied together to get an overall survival. So for the data period 2005-09, the risk of death in year 1 is taken from 2009, the risk of death in year 2 is taken from 2008 and so on. Any changes in treatment which have increased survival in year 1 will increase the survival in subsequent years. Using period survival a predication of the survival at five years can be given even when less than five years have elapsed since diagnosis, and any more recent changes in clinical practice which have affected survival in the shorter term will be reflected. In the older time periods (e.g. 2000-2004) where there has been more than five years since diagnosis for all cases, the period survival method produces the same results as a cohort approach.

## ICD10 Codes and Morphology Codes used in this Report

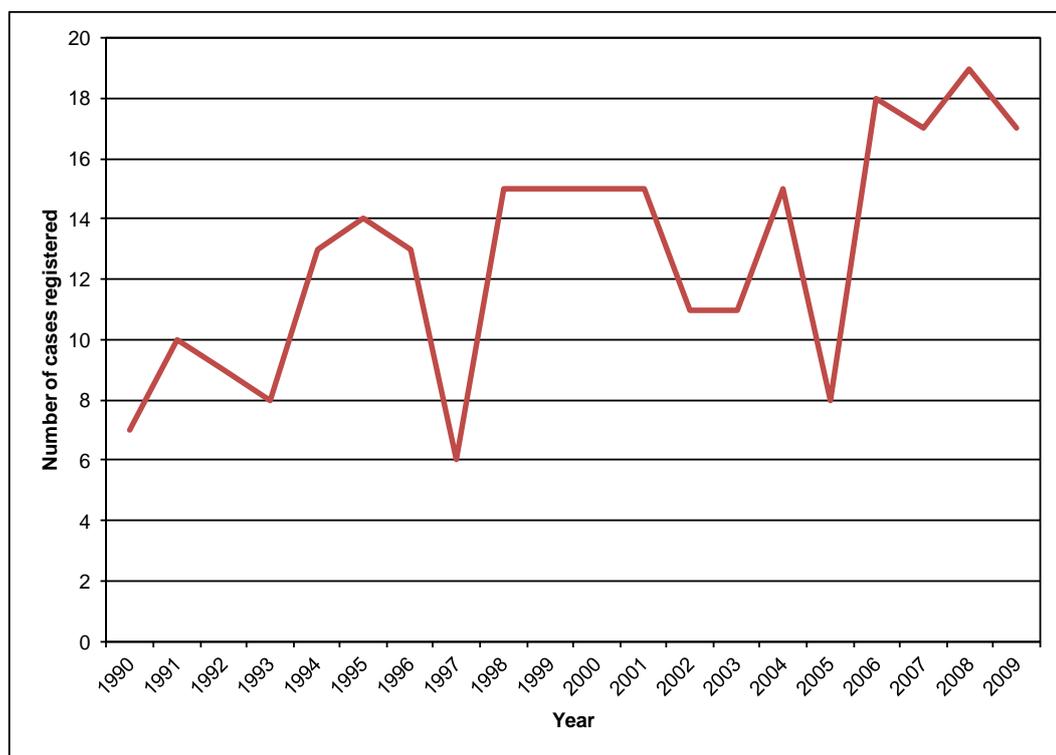
ICD 10 Code	Site	Morphology
C60	Penile	All
C61	Small Cell Prostate	8041, 8043, 8803
C62	Testicular	All
C65-C66	Ureter & Renal Pelvis	All
C67	Non-Transitional Cell Bladder	All excepting those described as "transitional"

## Results

### Small Cell Prostate Cancer – Incidence

- A very small number of small cell prostate cancers are diagnosed each year in England. Numbers range from 6 cases in 1997 to 19 cases in 2008.
- The graph shows the inherent instability of small numbers. Despite this there appears to be a slight increase in numbers of diagnoses between 1990 and 2009.
- Care must be taken when interpreting the figures for small cell prostate cancers as the percentage of cases they comprise is less than the number of cases with an unknown morphology. Although the ‘unknown’ percentage in NCDR is low (between 0.1% and 0.6%) it does fluctuate which could possibly have a large effect on the small cell incidence rate.

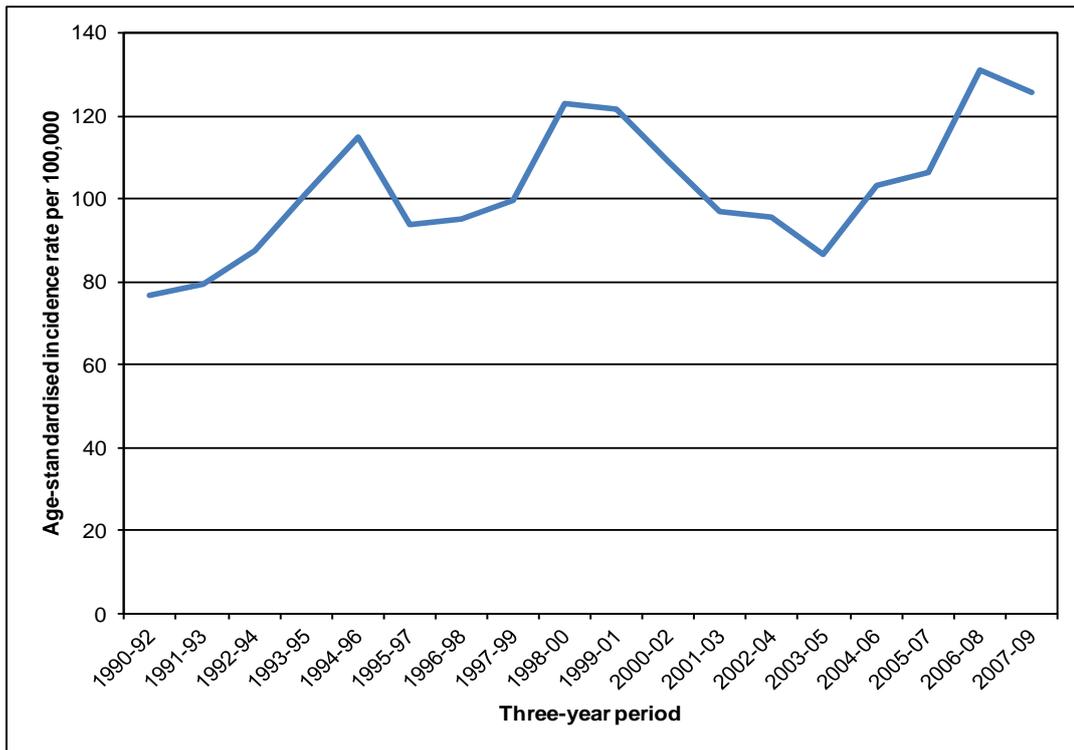
Figure 1: Incidence of small cell prostate cancer in England, 1990-2009



Source: National Cancer Data Repository; Office for National Statistics

- Standardised incidence ratios (SIRs) show the ratio of expected cases, based on a reference rate, with the observed cases. SIRs have been used as the small numbers of cases involved mean age-standardised rates would not yield valid or meaningful results.
- Standardised incidence ratios of small cell prostate cancer have also been variable over the period 1990-2009 reflecting the small number of diagnoses and the inherent instability of these numbers.
- No SIR is significantly higher compared to the reference population (England)

**Figure 2: Incidence of small cell prostate cancer, standardised incidence ratios, in England, 1990 - 2009**

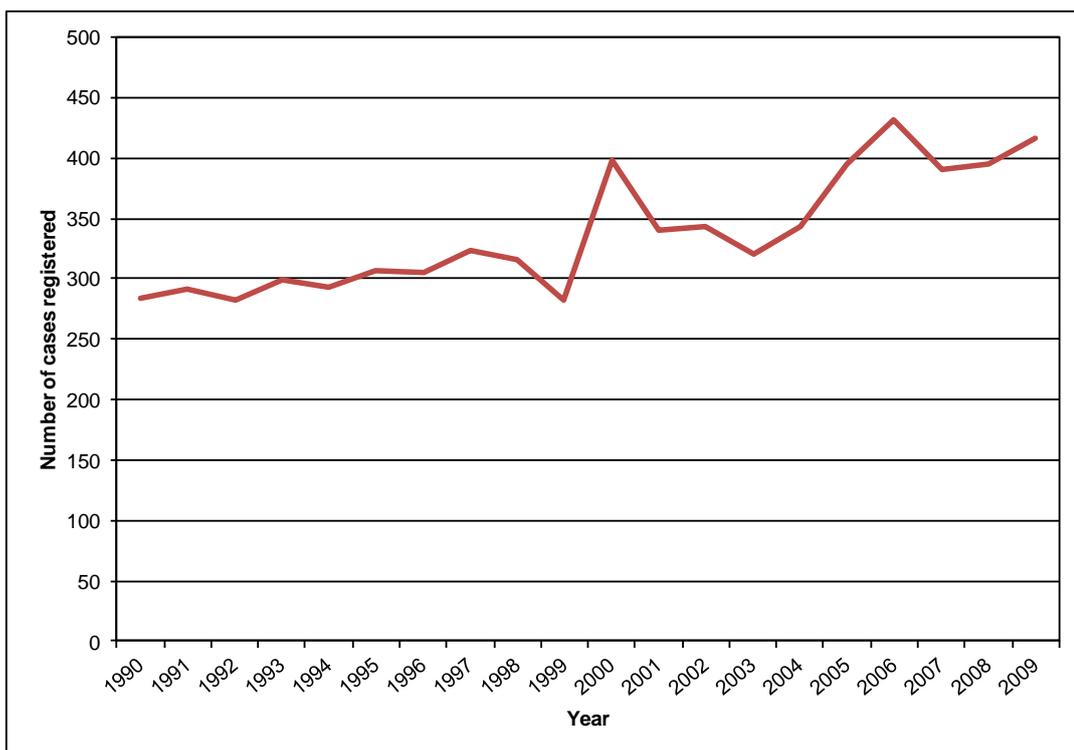


Source: National Cancer Data Repository; Office for National Statistics

### Penile cancer - Incidence

- There has been an increase in the number of diagnoses of penile cancer over the study period. In the period 1990-1992 859 cases of penile cancer were diagnosed (an average of 286 cases per year). This rises to 1,203 (an average of 401 cases per year) diagnosed between 2007 and 2009.

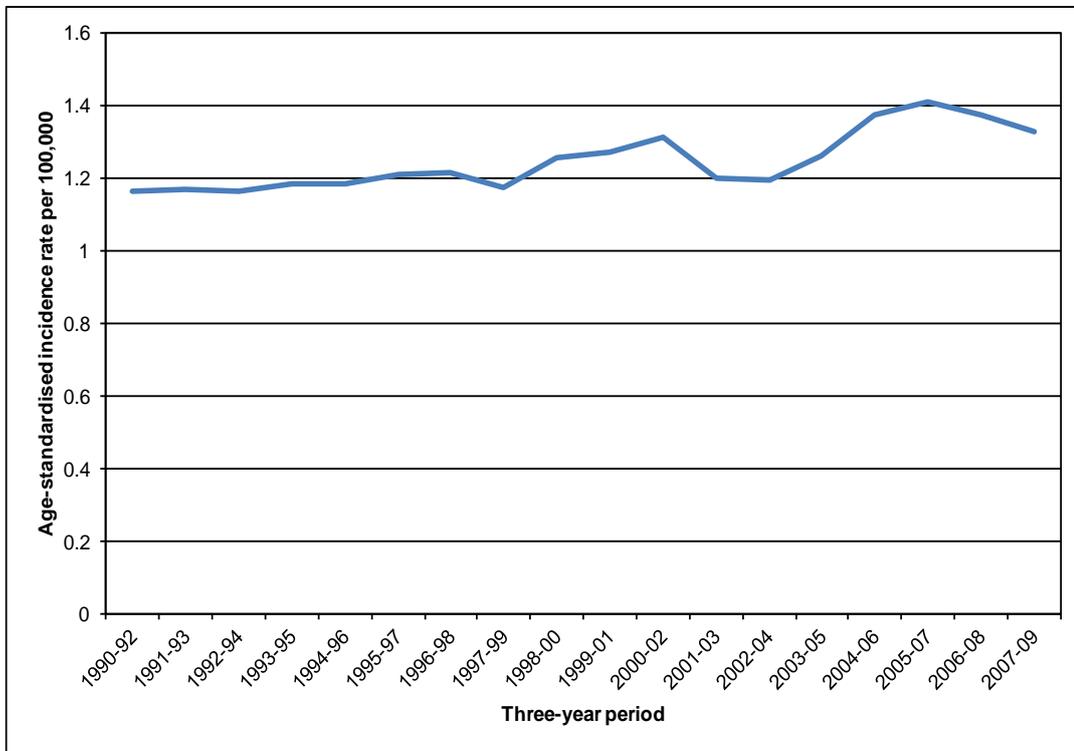
**Figure 3: Incidence of penile cancer in England, 1990-2009**



Source: National Cancer Data Repository; Office for National Statistics

- Age standardised rates of penile cancer have increased over the last four three-year periods.
- 2004-06, 2005-07 and 2006-08 have significantly higher age standardised rates than their preceding non-overlapping three-year periods; 2001-03, 2002-04 and 2003-05 respectively ( $p < 0.05$ ). The rate in the most recent three-year period of data, 2007-2009, (1.3 per 100,000) is not significantly higher than the preceding non-overlapping three-year 2004-2006.

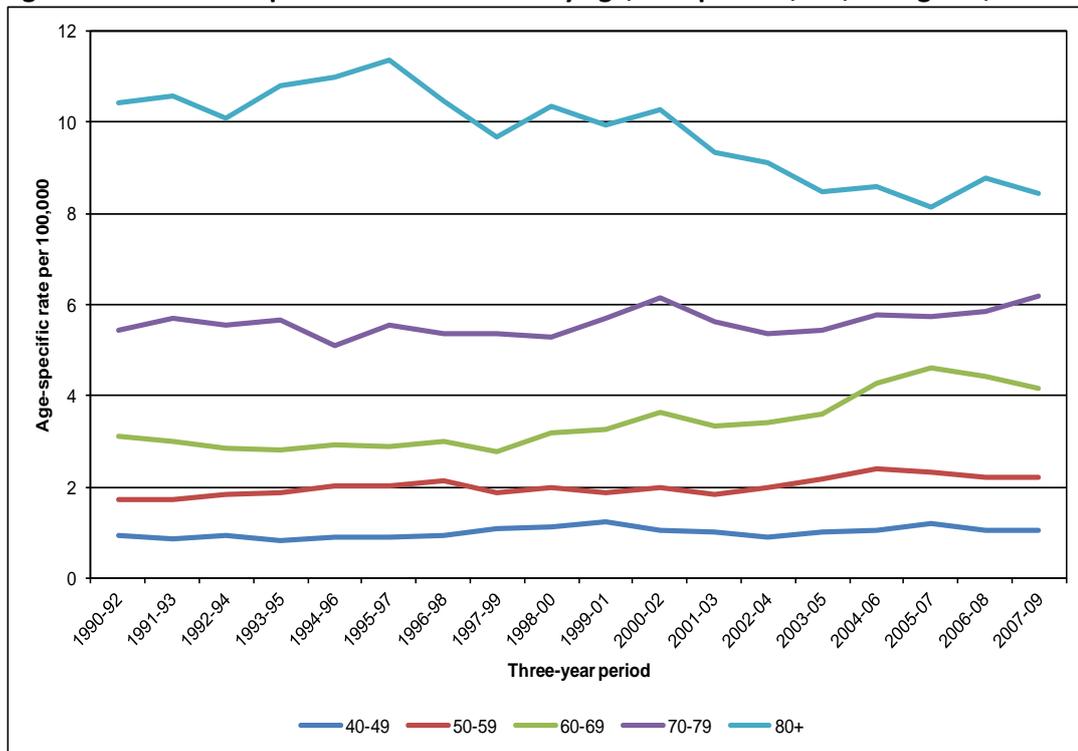
**Figure 4: Incidence of penile cancer, age-standardised rate per 100,000, in England, 1990 – 2009**



Source: National Cancer Data Repository; Office for National Statistics

- Penile cancer is relatively rare in the younger age groups. There is an age specific rate of around 1 per 100,000 in the 40-49 age group and around 2 per 100,000 in the 50-59 age group. This rises to between 8 and 11 per 100,000 in the 80+ age group.

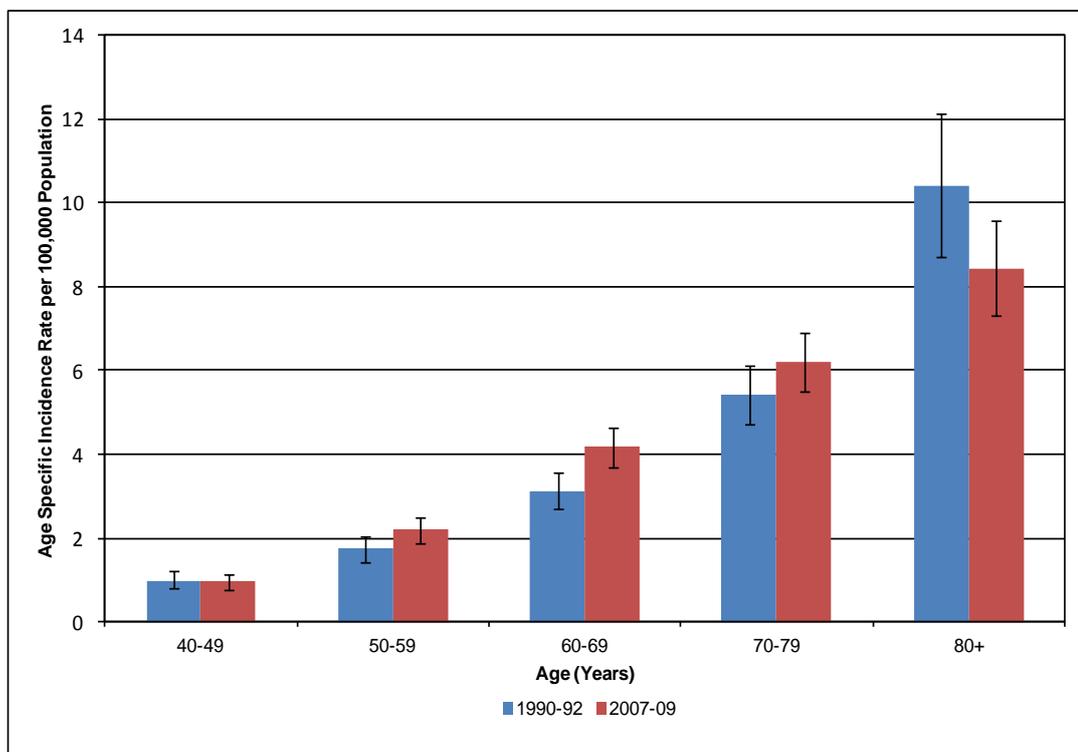
**Figure 5: Incidence of penile cancer in males by age, rate per 100,000, in England, 1990-2009**



Source: National Cancer Data Repository; Office for National Statistics

- Comparing age specific rates from the first three years (1990-92) to the last three years of the study (2007-09), the rates seen in the 50-59 and 60-69 age groups have increased significantly during this period (26% (p=0.03) and 33% (p=0.001) increase respectively).
- No statistically significant differences can be seen within the other age groups. This is more clearly seen in Figure 6.

**Figure 6: Age-specific incidence rates of penile cancer in males, rate per 100,000, in England, 1990-2009**

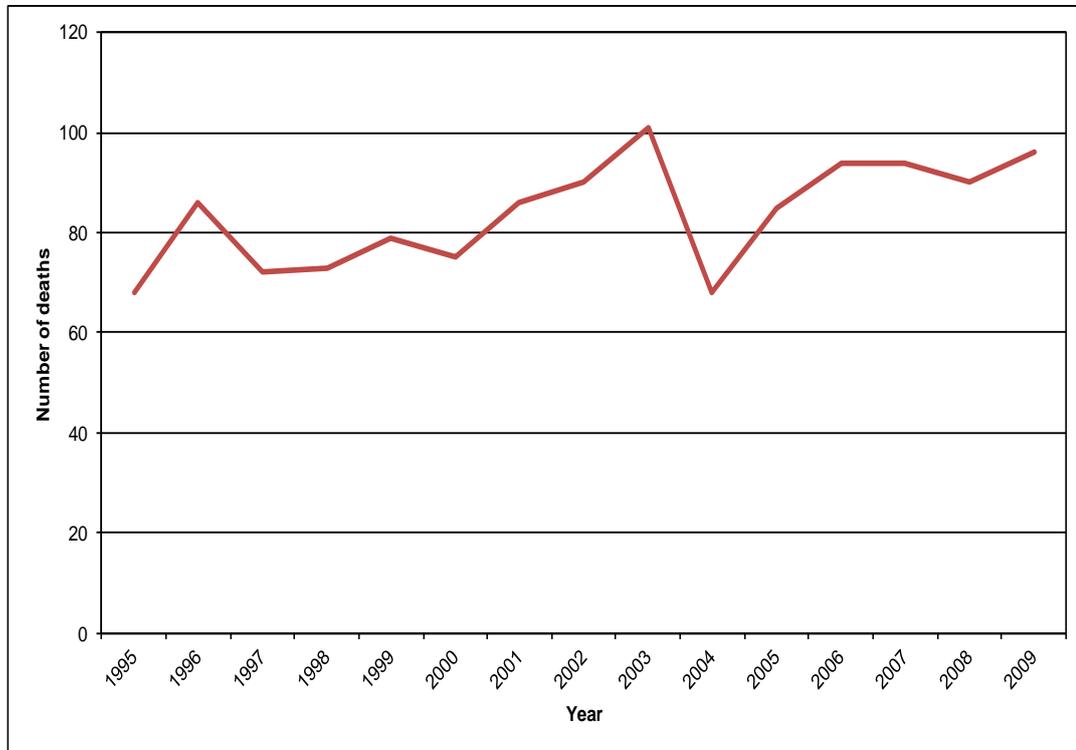


Source: National Cancer Data Repository; Office for National Statistics

## Penile Cancer – Mortality

- Presentation of penile cancer is often delayed due to patient embarrassment, but treatment is effective if the lymph nodes are not involved and so mortality rates are low.
- In all years except 2003, the number of people dying due to penile cancer is under 100.

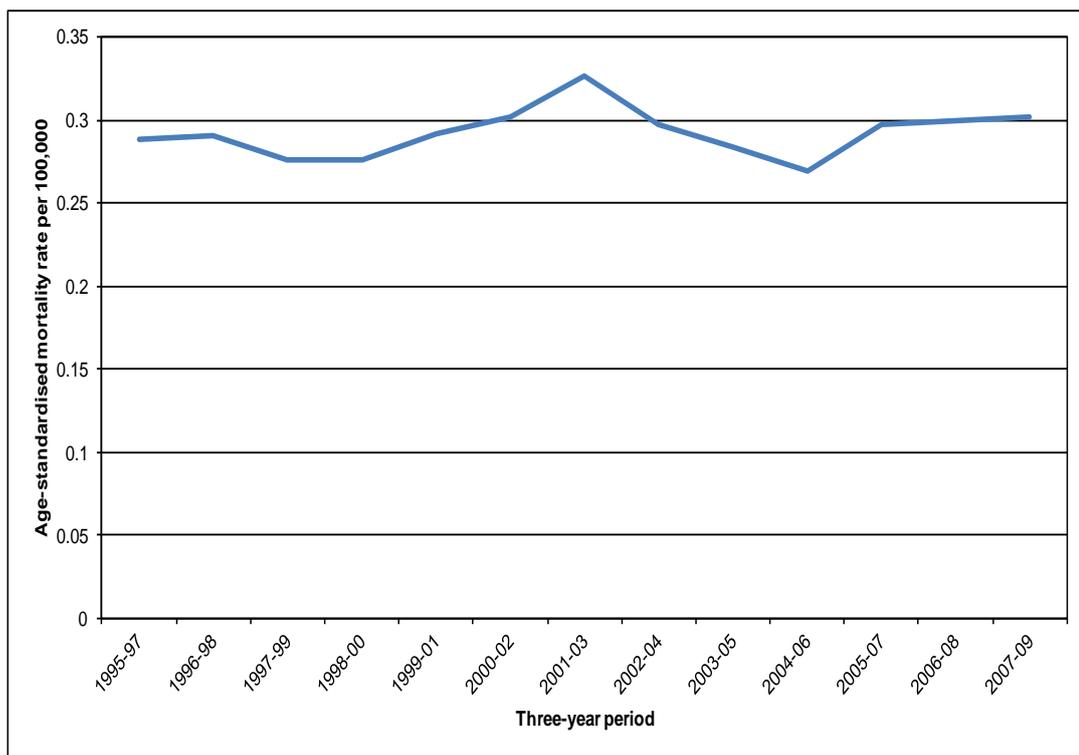
Figure 7: Mortality from penile cancer in England, 1995-2009



Source: Office for National Statistics

- Age standardised mortality rates of penile cancer have remained relatively constant over the study period at 0.3-0.4 per 100,000.
- The age standardised mortality rate in 2004-06 (0.27 per 100,000) is significantly lower than that seen in the previous non-overlapping three year period 2001-03 (0.33 per 100,000) ( $p < 0.05$ ).
- No significant differences can be seen between any of the other non-overlapping three year periods.

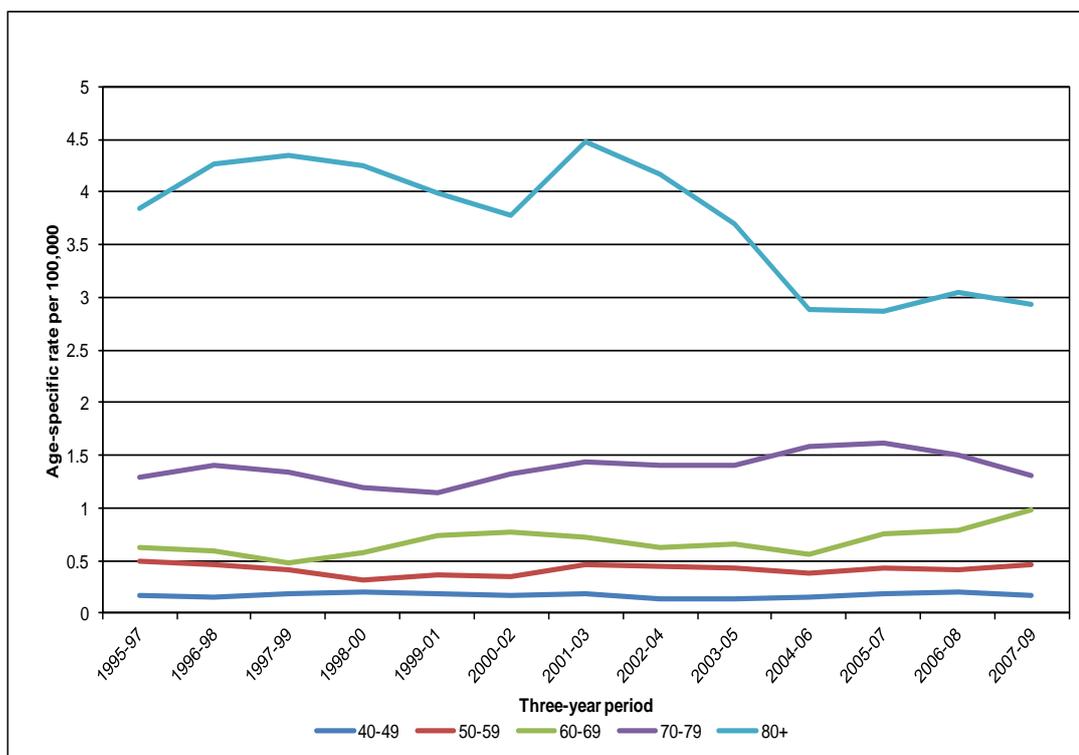
**Figure 8: Mortality from penile cancer, age-standardised rate per 100,000, in England, 1995 - 2009**



Source: Office for National Statistics

- As with penile cancer incidence, mortality in the younger age groups is low, and has remained relatively constant in the 40-79 age groups. The age specific rate seen in the 80+ age group is higher than the other age groups but is more variable during the time period studied.

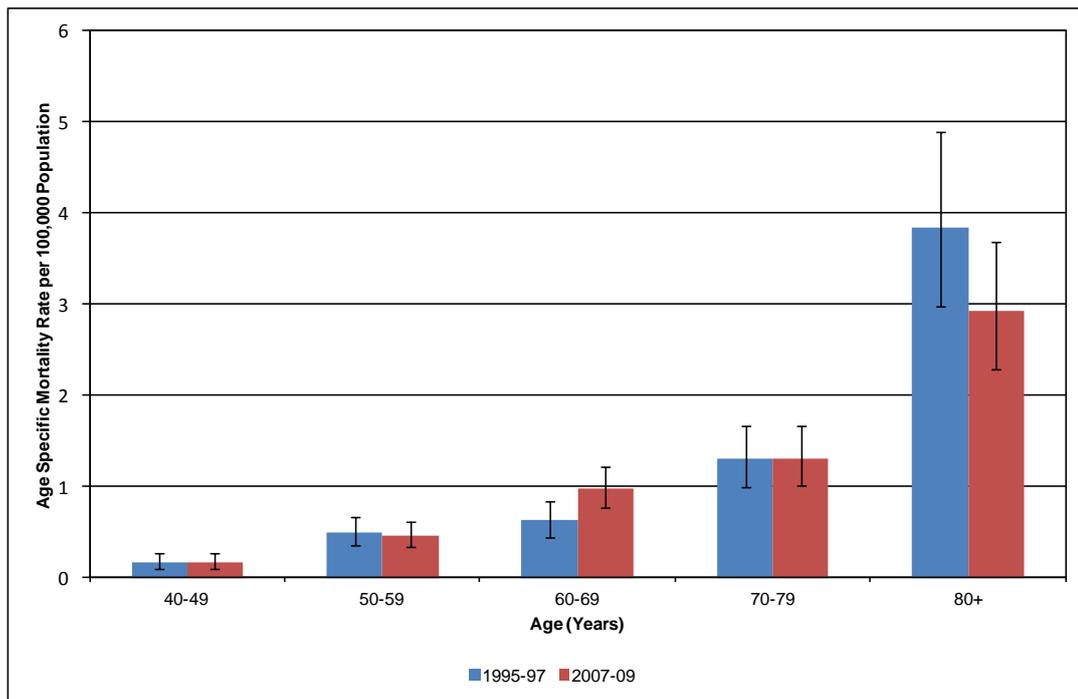
**Figure 9: Mortality from penile cancer in males by age, rate per 100,000, in England, 1995-2009**



Source: Office for National Statistics

- The age specific mortality rate of penile cancer in men aged 60-69 increased between 1995-97 and 2007-09 by 56% ( $p= 0.018$ )

Figure 10: Age-specific mortality rates of penile cancer in males, rate per 100,000, in England, 1995-2009

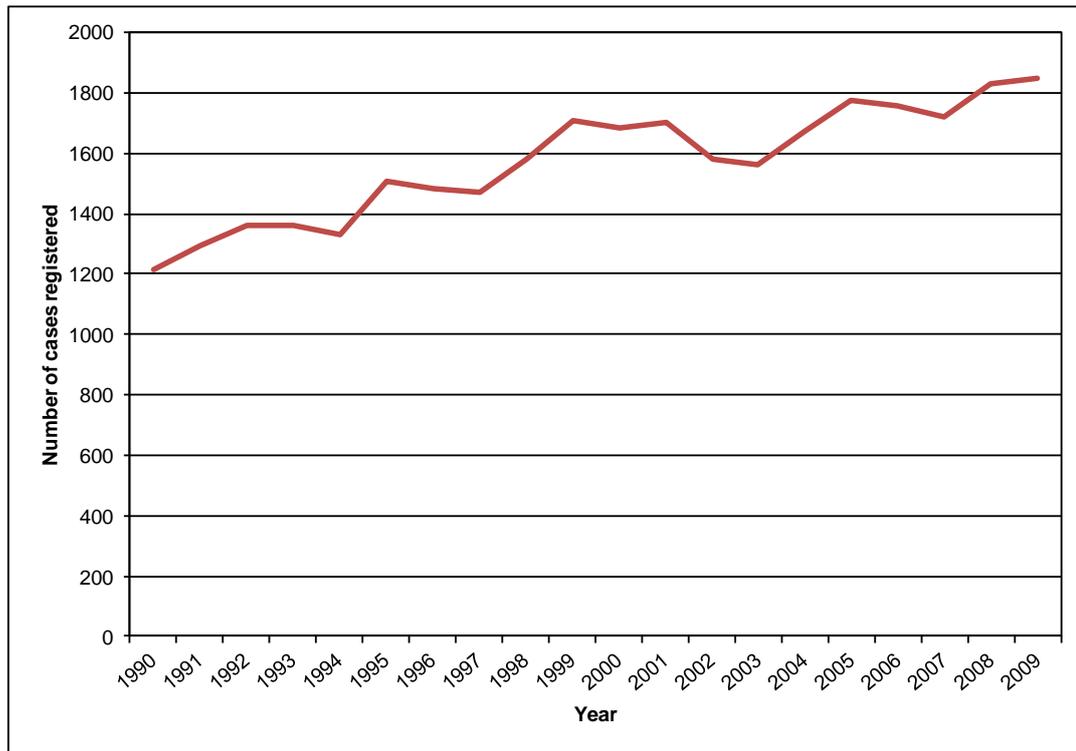


Source: Office for National Statistics

## Testicular cancer - Incidence

- Incidence of testicular cancer has risen from 1,214 cases per year in 1990 to 1,846 cases per year in 2009.

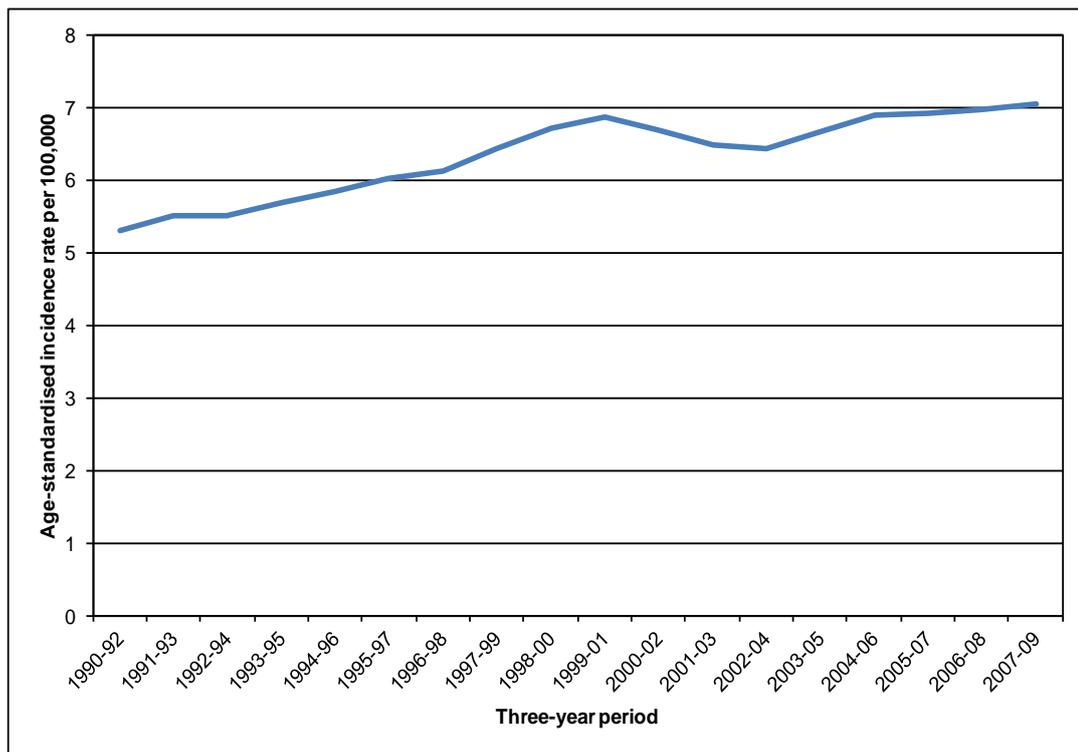
Figure 11: Incidence of testicular cancer in England, 1990-2009



Source: National Cancer Data Repository; Office for National Statistics

- The age standardised incidence rate of testicular cancer has risen from 5.3 per 100,000 in 1990-92 to 7.0 per 100,000 in 2007-09 ( $p < 0.05$ ).
- Nine out of the fourteen time periods, when compared to the previous non-overlapping three year time period are significantly higher.
- The most recent three year time period, 2007-2009, is not significantly higher than the previous non-overlapping three year time period. This could suggest a levelling off in rates of testicular cancer.

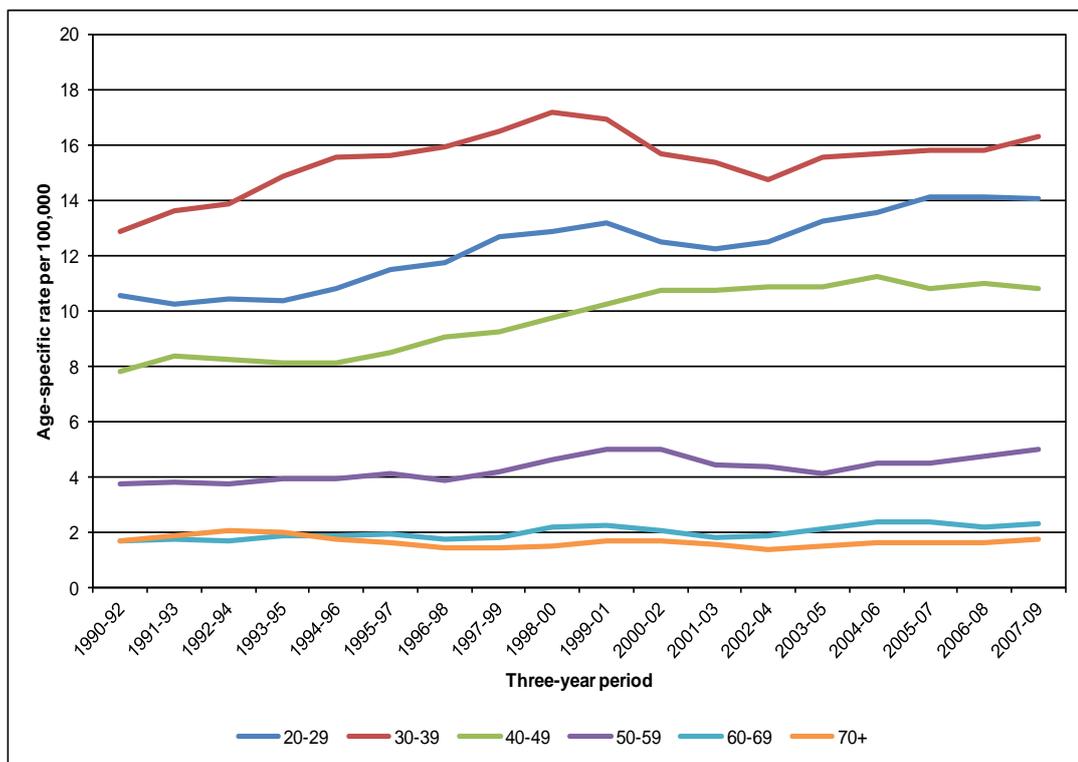
**Figure 12: Incidence of testicular cancer, age standardised rate per 100,000 in England, 1990-2009**



Source: National Cancer Data Repository; Office for National Statistics

- Testicular cancer has a pattern of age specific rates considerably different to most other cancers. The three oldest age groups have the lowest age specific rates, around 2 per 100,000, and also remain relatively stable throughout the study period. The 30-39 age group has the highest age specific rate, which has increased during the study period from 12.8 per 100,000 in 1990-92 to 16.4 per 100,000 in 2007-09 ( $p < 0.05$ ).

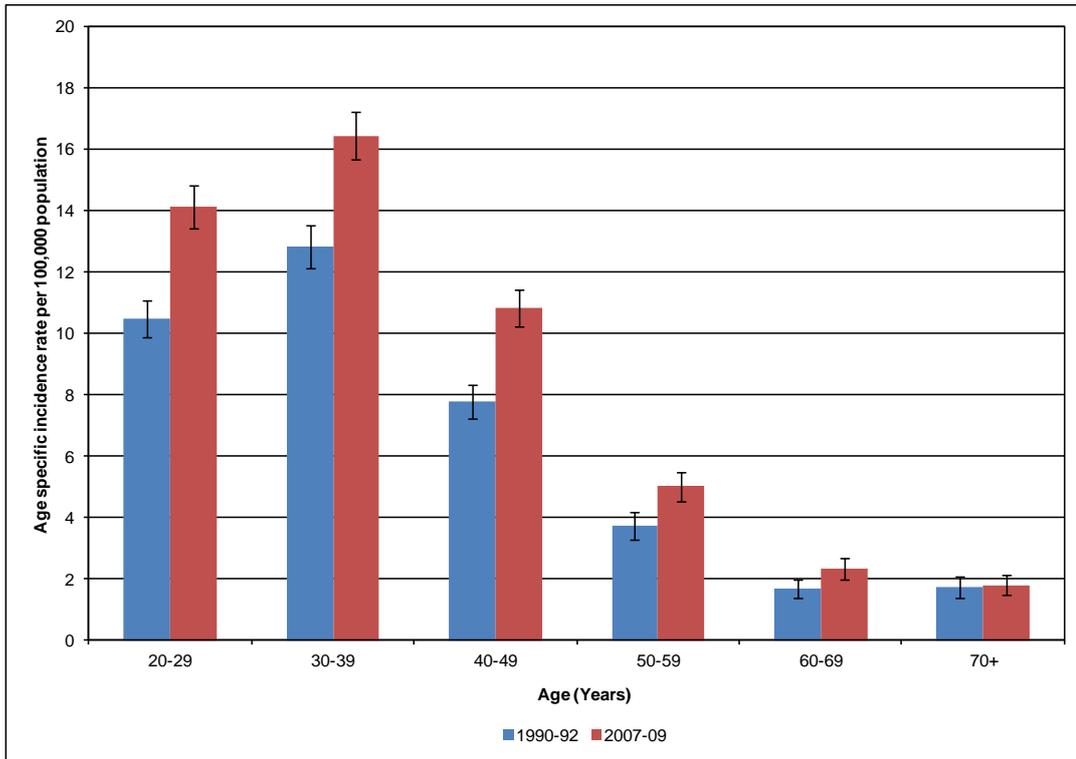
**Figure 13: Incidence of testicular cancer in males by age, rate per 100,000, in England, 1990-2009**



Source: National Cancer Data Repository; Office for National Statistics

- Comparing age specific rates from the first three years (1990-1992) to the last three years of the study 2007-2009, the rates seen in all age groups, apart from those aged 70+, have increased significantly during this period ( $p < 0.05$ ).

**Figure 14: Age-specific incidence rates of testicular cancer in males, rate per 100,000, in England, 1990-2009**

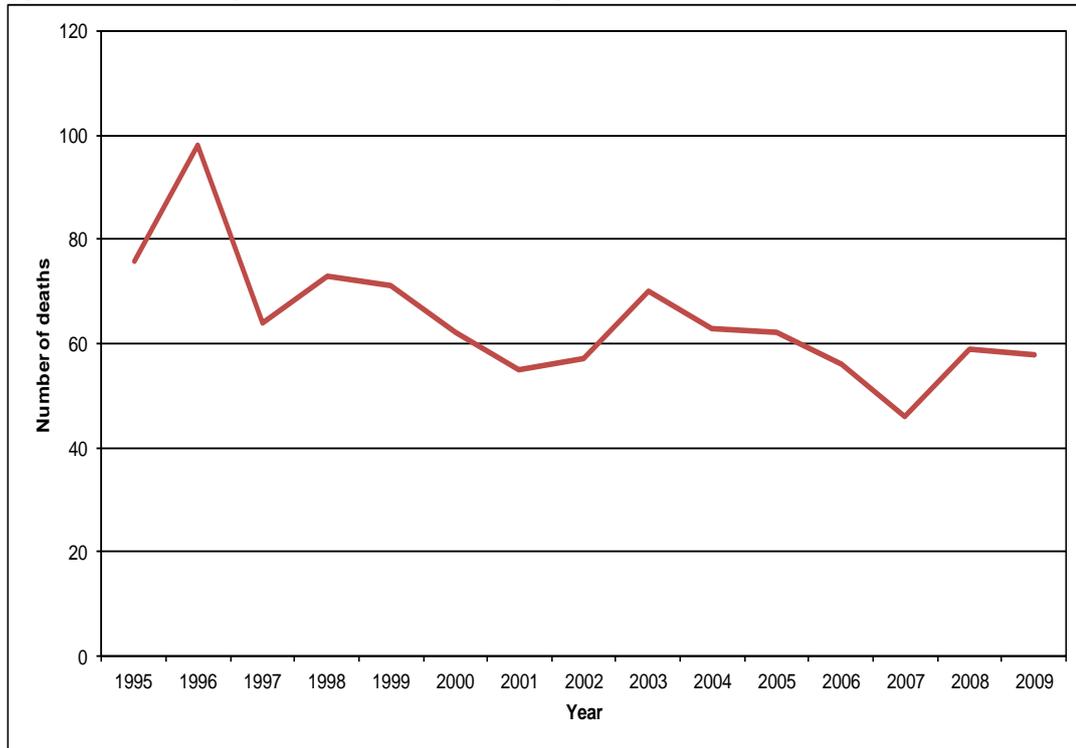


Source: National Cancer Data Repository; Office for National Statistics

## Testicular cancer – Mortality

- Mortality rates for testicular cancer have dropped during the study period from 76 deaths in 1995 to 59 in 2009.

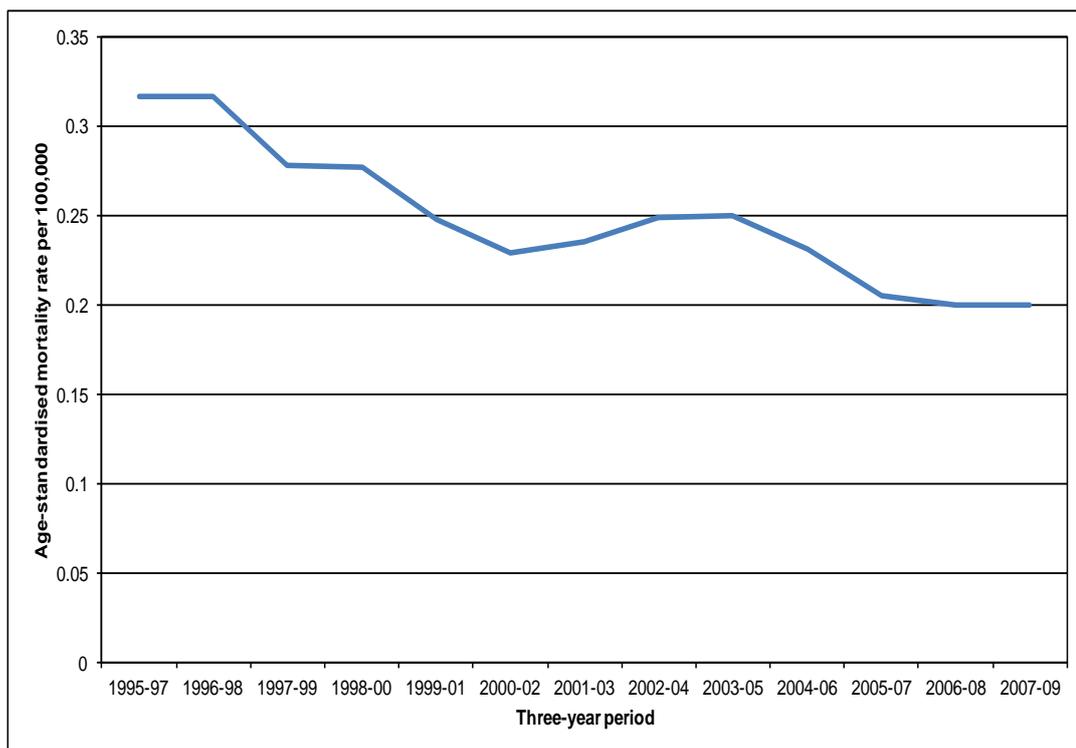
**Figure 15: Mortality of testicular cancer in England, 1990-2009**



Source: National Cancer Data Repository; Office for National Statistics

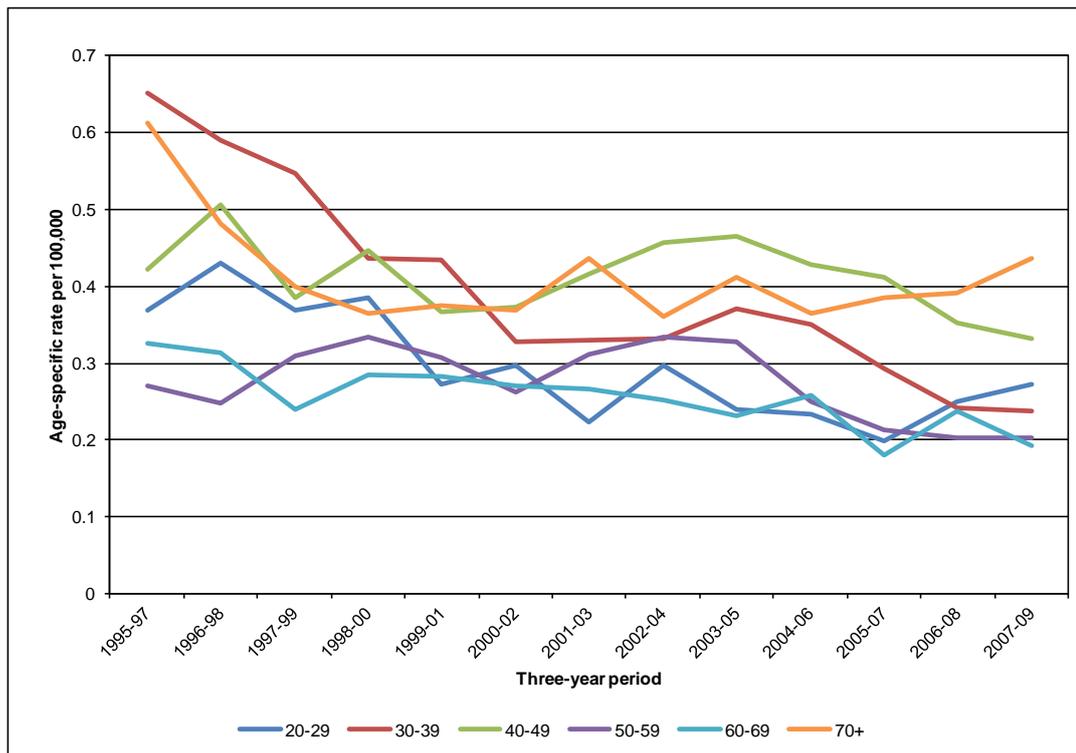
- The age standardised mortality rates of testicular cancer have fallen from 0.32 per 100,000 in 1995-97 to 0.20 per 100,000 in 2007-09 ( $p < 0.05$ ).

**Figure 16: Mortality of testicular cancer, age-standardised rate per 100,000, in England, 1995 - 2009**



Source: National Cancer Data Repository; Office for National Statistics

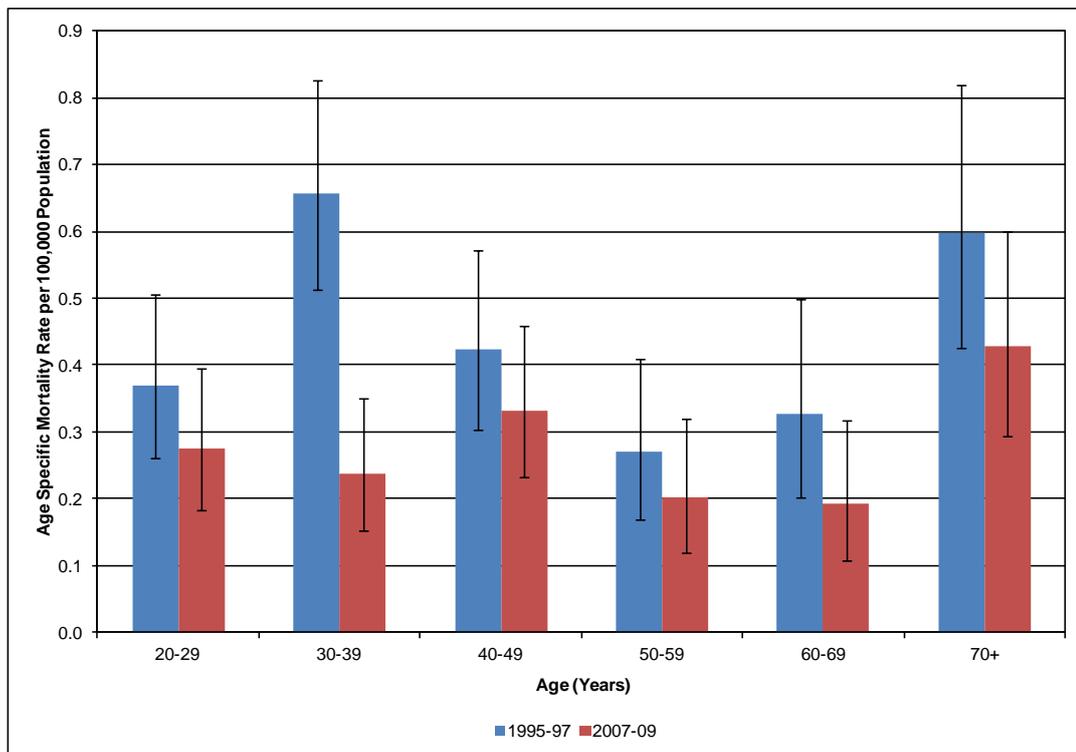
**Figure 17: Mortality of testicular cancer by age, rate per 100,000, in England, 1990-2009**



Source: National Cancer Data Repository; Office for National Statistics

- Because of small numbers of deaths, the only statistically significant difference in mortality rates (between the first three years of the study period compared with the last three years) for each age group was for men aged 30-39 at death. In this group the rate decreased from 0.66 per 100,000 to 0.24 per 100,000.

**Figure 18: Age-specific mortality rates of testicular cancer, rate per 100,000, in England, 1990-2009**

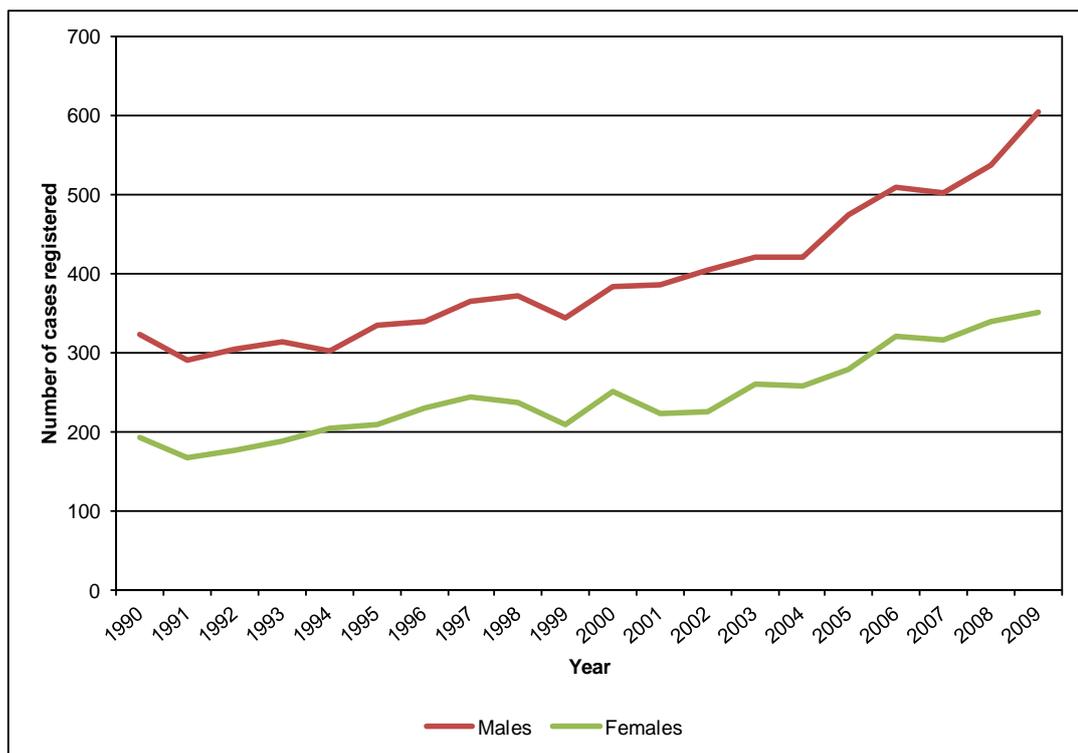


Source: National Cancer Data Repository; Office for National Statistics

## Ureter and Renal Pelvis Cancer – Incidence

- Incidence of cancer of the ureter and renal pelvis has risen in both males and females and by a similar proportion.
- In males an increase in cases of 87% has been seen between 1990 (323 cases) to 2009 where 605 cases were diagnosed.
- In females an increase in cases of 82% has been seen between 1990 (192 cases) to 2009 where 350 cases were diagnosed.

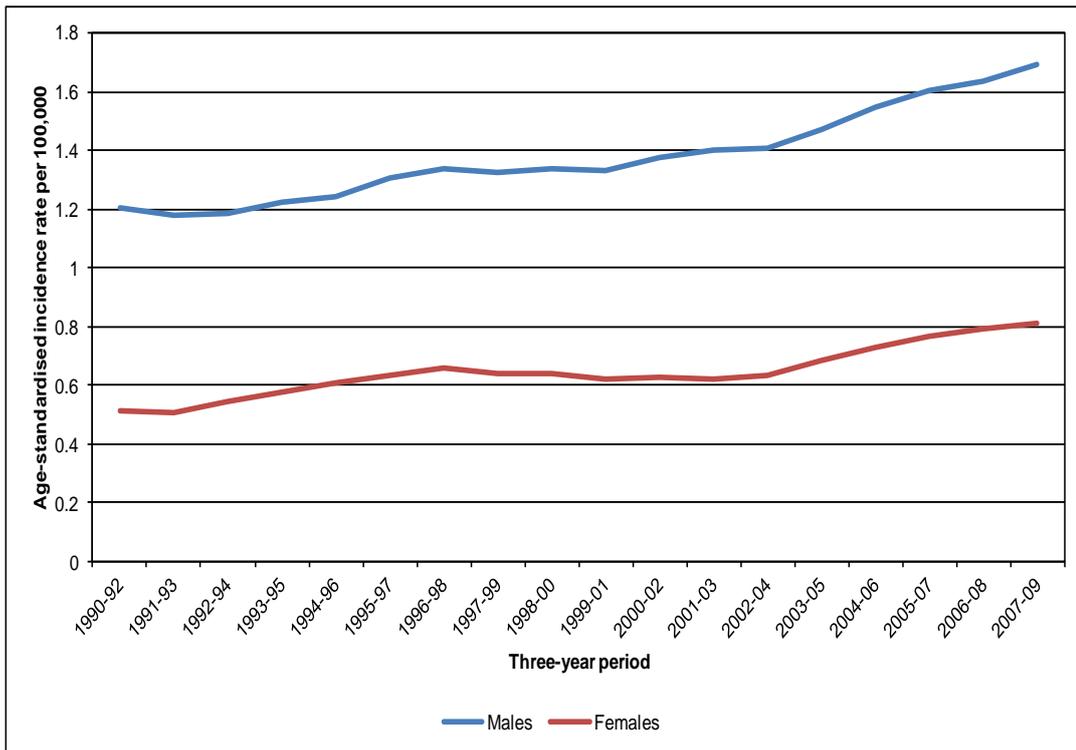
**Figure 19: Incidence of cancer of the ureter & renal pelvis in England, 1990-2009**



Source: National Cancer Data Repository; Office for National Statistics

- A similar pattern to incidence counts is seen in the age standardised rates, which show rises in both males and females, although the percentage increase in rate in females is bigger.
- In males an increase in rate of 40% was seen between 1990-92 (1.2 per 100,000) and 2007-09 (1.7 per 100,000) ( $p < 0.001$ ).
- In females an increase in rate of 57% has been seen between 1990-92 (0.5 per 100,000) and 2007-09 (0.8 per 100,000) ( $p < 0.001$ ).
- In both males and females the three most recent three year period are significantly higher ( $p < 0.05$ ) than the respective previous non-overlapping three year period.

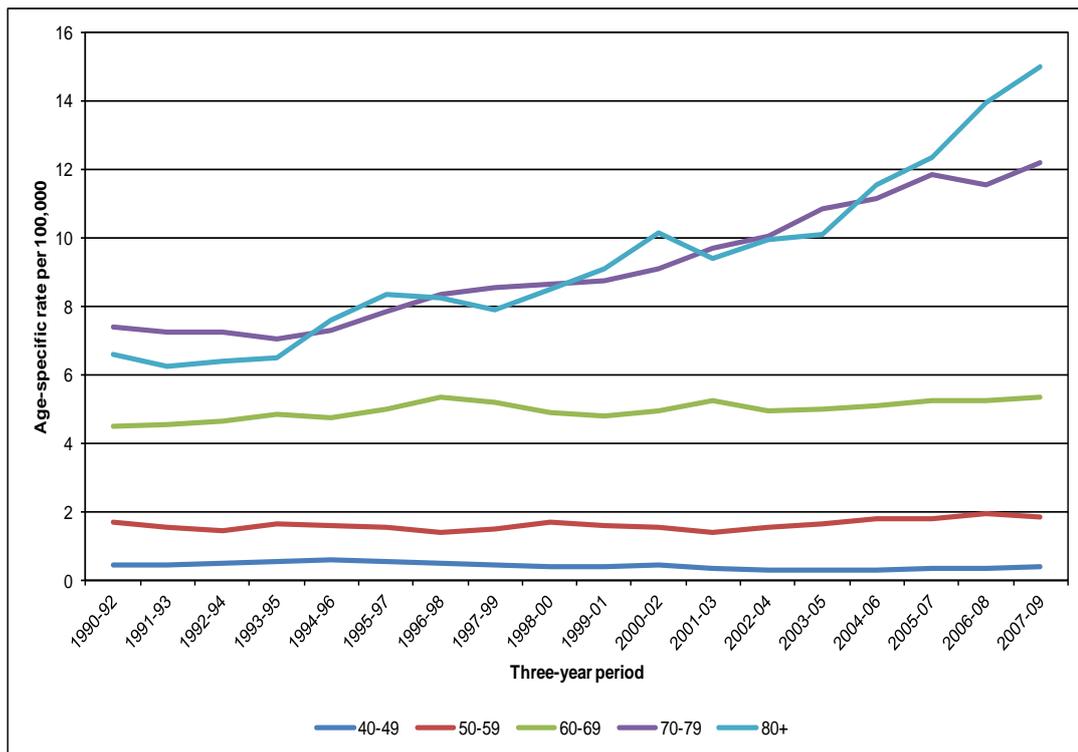
**Figure 20: Incidence of cancer of the ureter & renal pelvis, age-standardised rate per 100,000, in England, 1990 - 2009**



Source: National Cancer Data Repository; Office for National Statistics

- In males, during the study period, the 40-49, 50-59 and 60-69 age specific rates have remained at a consistent level.
- In males the age specific rates in the 70-79 and 80+ age groups have steadily risen since 1993-1995.
- The 80+ age specific rate has more than doubled from 6.6 per 100,000 in 1990-92 to 13.9 per 100,000 in 2006-08 ( $p < 0.05$ ).

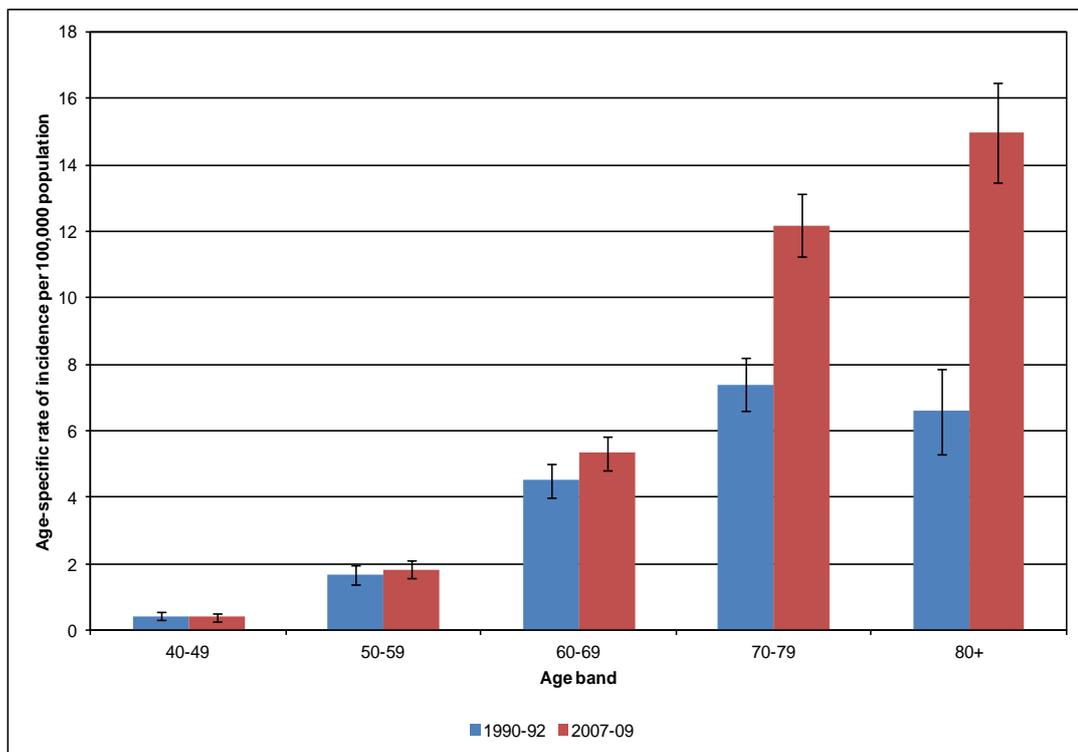
**Figure 21: Incidence of cancer of the ureter and renal pelvis in males, by age, rate per 100,000, in England, 1990-2009**



Source: National Cancer Data Repository; Office for National Statistics

- Comparing the age specific rates seen in the first three years of the study period, 1990-92, to the last three year period, 2007-09, shows that the age specific rates of the oldest two age groups have increased significantly ( $p < 0.05$ ) while the age specific rates in other age groups have not changed.

**Figure 22: Age-specific mortality rates of cancer of the ureter & renal pelvis in males, rate per 100,000, in England, 1990-2009**

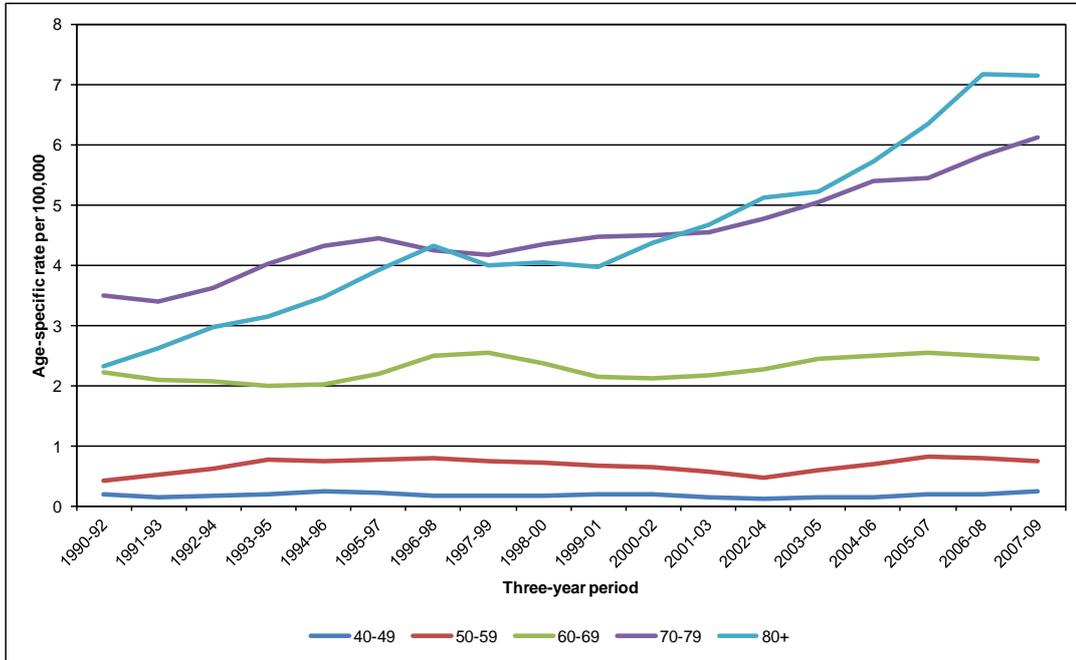


Source: National Cancer Data Repository; Office for National Statistics

- A similar pattern to that seen in males is also seen in females where during the study period, the 40-49, 50-59 and 60-69 age specific rates have remained at a consistent level.

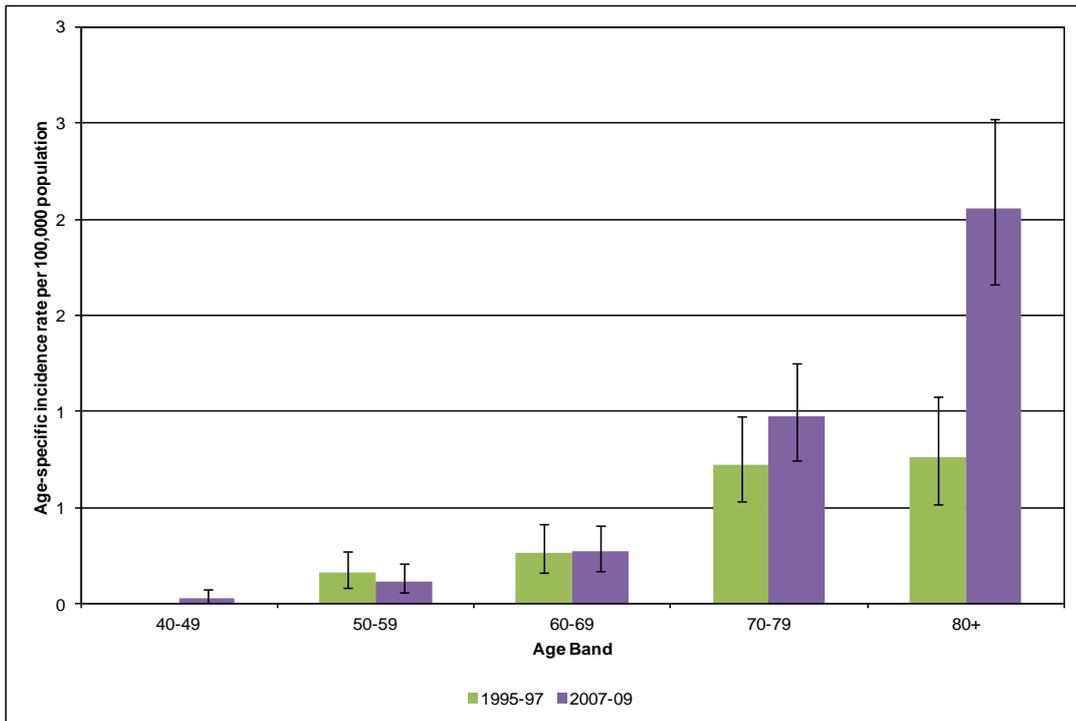
- In females the age specific rates in the older, 70-79 and 80+, age groups have consistently risen since 1993-1995.
- The 80+ age specific rate has more than trebled from 2.2 per 100,000 in 1990-92 to 7.1 per 100,000 in 2007-09 ( $p < 0.05$ ).

**Figure 23: Incidence of cancer of the ureter and renal pelvis in females, by age, rate per 100,000, in England, 1990-2009**



Source: National Cancer Data Repository; Office for National Statistics

**Figure 24: Age-specific mortality rates of cancer of the ureter & renal pelvis in females, rate per 100,000, in England, 1990-2009**



Source: National Cancer Data Repository; Office for National Statistics

- For females, as in males, comparing the age specific rates seen in the first three years of the study period, 1990-92, to the last three year period, 2007-09, shows that the age specific rates of the eldest two age groups have increased significantly ( $p < 0.05$ ), while the age specific rates in other age groups have not changed.

## Ureter and Renal Pelvis Cancer – Mortality

- The number of deaths in both males and females has increased over the period 1995-2009.
- Deaths in males have increased from 55 in 1995 to 77 deaths in 2008, a rise of 40%
- Deaths in females have increased from 33 in 1995 to 70 deaths, a rise of 112%

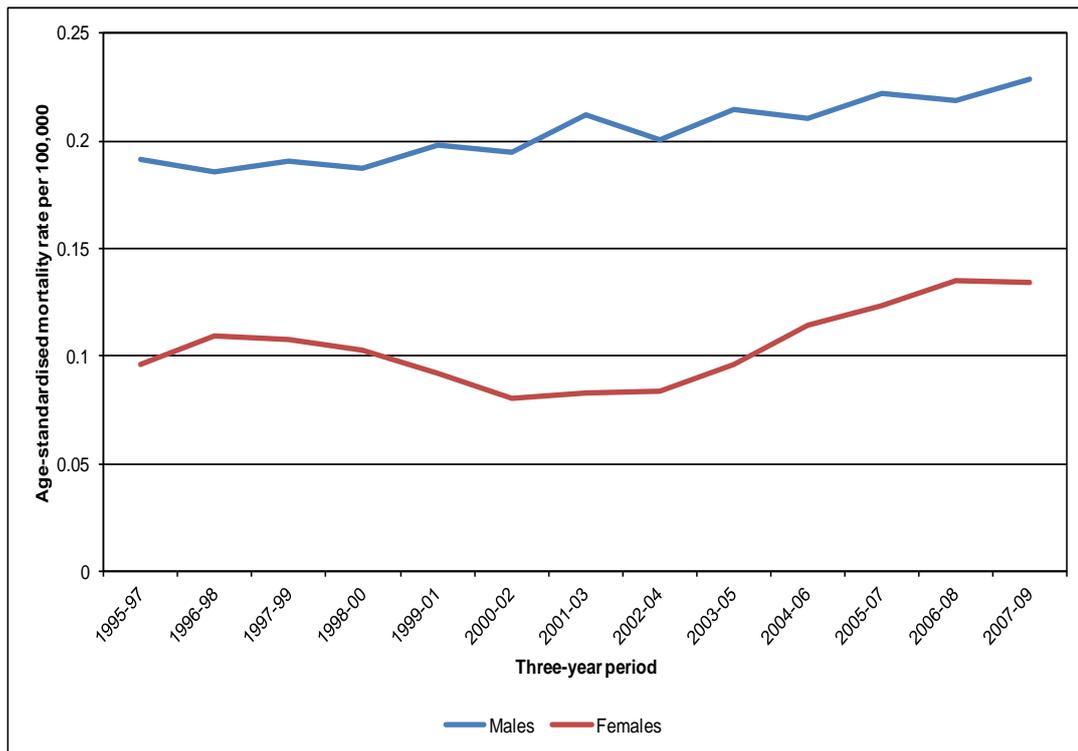
Figure 25: Mortality of cancer of the ureter & renal pelvis in England, 1990-2009



Source: National Cancer Data Repository; Office for National Statistics

- The age standardised mortality rate of cancer of the ureter and renal pelvis in males has increased from 0.19 per 100,000 in 1995-1997 to 0.23 per 100,000 in 2007-09 ( $p < 0.05$ ).
- Comparison of all the non-overlapping three year periods shows no statistically significant rises in males from one three year period to the next. This indicates that the overall rise has been very gradual.
- In females, prior to the most recent three year period, the last three non-overlapping three-year time periods, showed a significant increase in mortality ( $p < 0.05$ ).

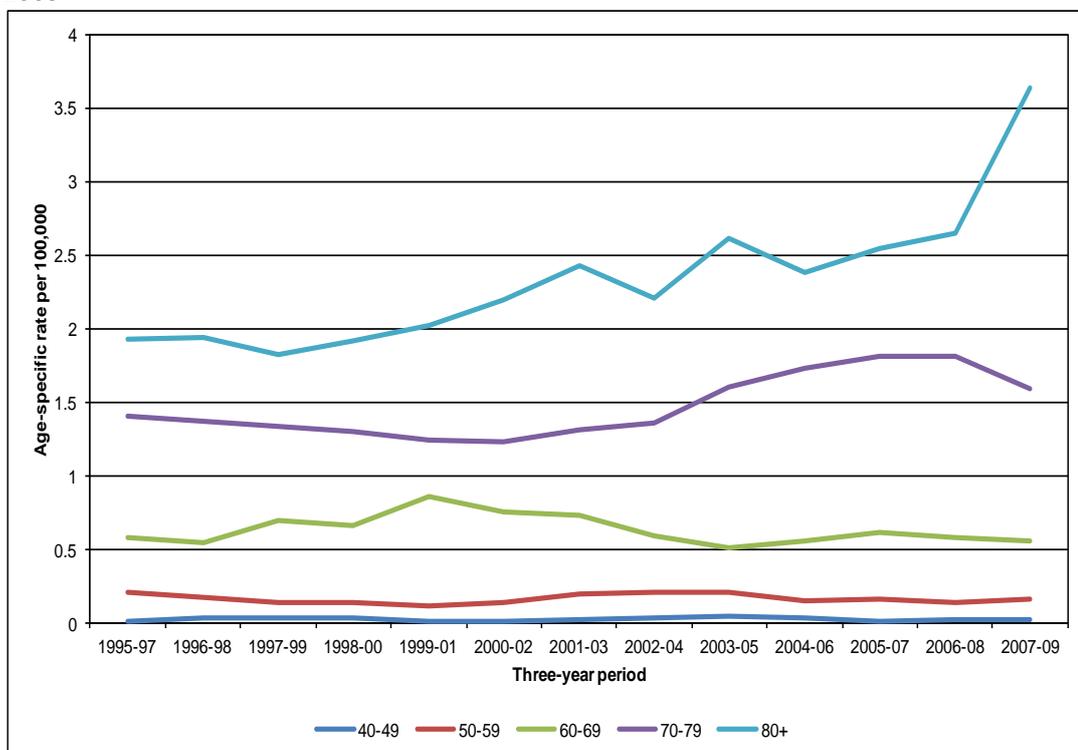
**Figure 26: Mortality from cancer of the ureter & renal pelvis, age-standardised rate per 100,000, in England, 1995 – 2009**



Source: National Cancer Data Repository; Office for National Statistics

- In no age group has there been any statistically significant change in age specific mortality rates, however, numbers are very small which makes it difficult to access variation.

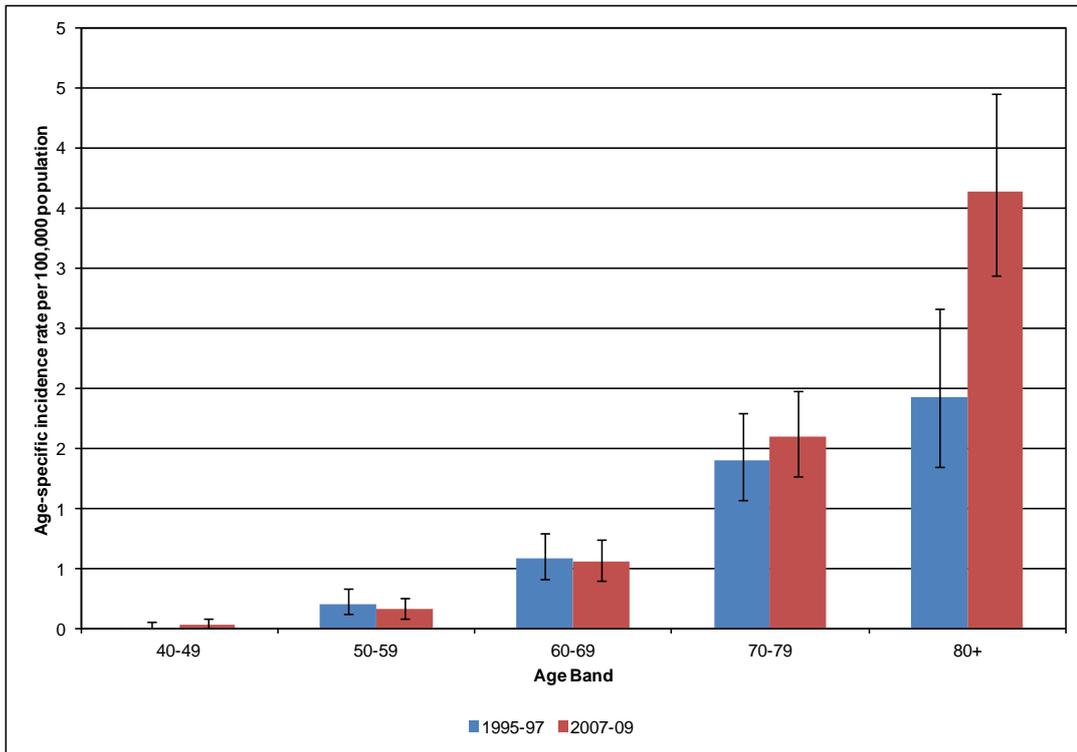
**Figure 27: Mortality from cancer of the ureter and renal pelvis in males by age, rate per 100,000, in England, 1995-2009**



Source: National Cancer Data Repository; Office for National Statistics

- In males, comparing the age-specific rates seen in the first three years of the study period, 1995-97, to the last three year period, 2007-09, shows that there was a statistically significant change only in the 80+ age groups. The age-specific rate in over 80s increased from 1.9 per 100,000 to 3.6 per 100,000 ( $p < 0.001$ )

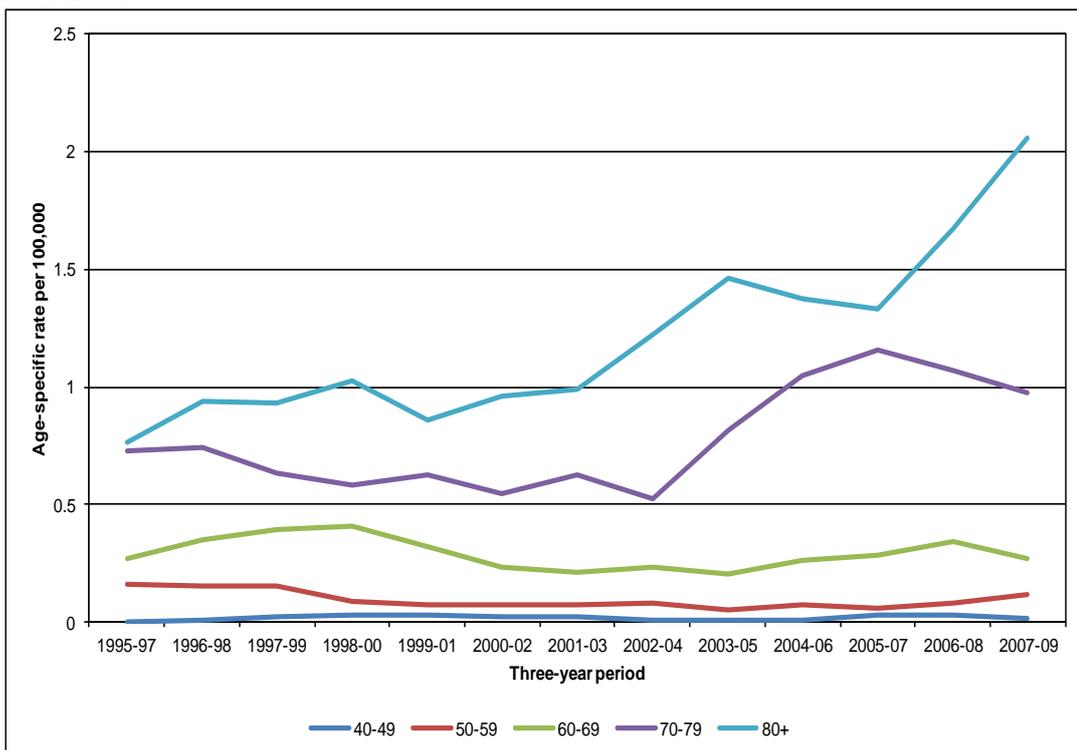
**Figure 28: Age-specific mortality rates of the ureter & renal pelvis in males, rate per 100,000, in England, 1990-2009**



Source: National Cancer Data Repository; Office for National Statistics

- A similar pattern to that seen in males is also seen in females where the mortality rates in the 40-49, 50-59, 60-69 and 70-79 age groups have remained similar over the study period. The rates have increased in the 70-79 and 80+ age groups.

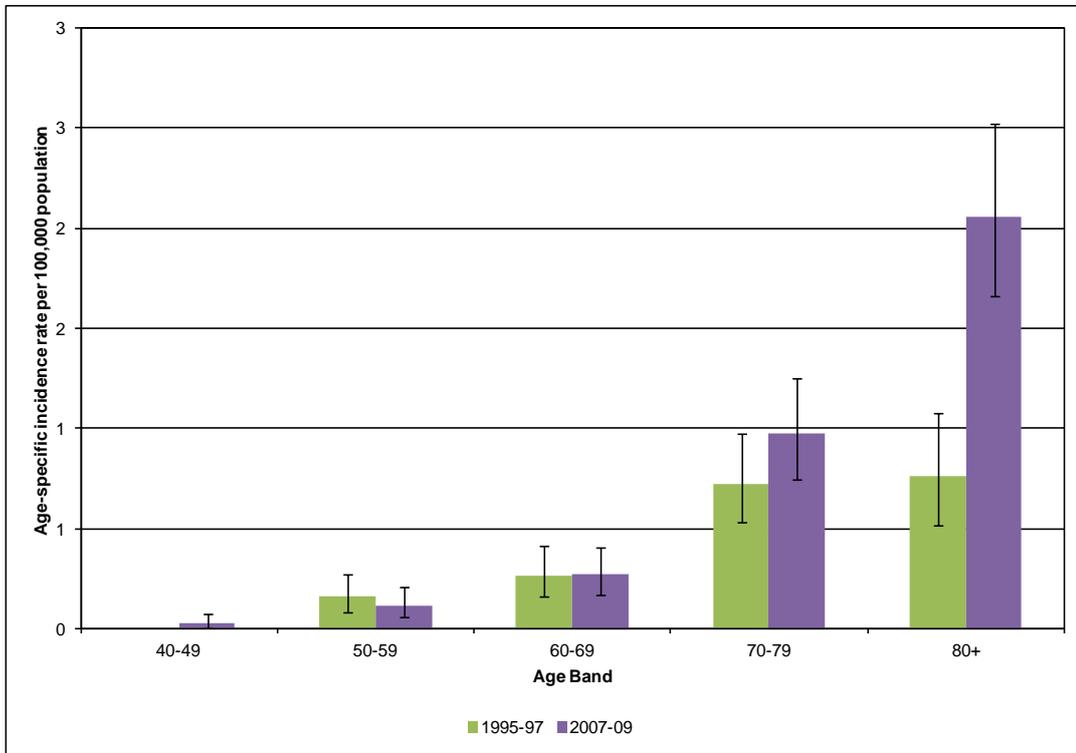
**Figure 29: Mortality from cancer of the ureter and renal pelvis in females by age, rate per 100,000, in England, 1990-2009**



Source: National Cancer Data Repository; Office for National Statistics

- The age-specific rates have significantly increased between 1995-97 and 2007-09 in the 80+ age group, from 0.76 to 2.1 per 100,000 females ( $p < 0.05$ ).

**Figure 30: Age-specific mortality rates of cancer of the ureter & renal pelvis in females, rate per 100,000, in England, 1990-2009**

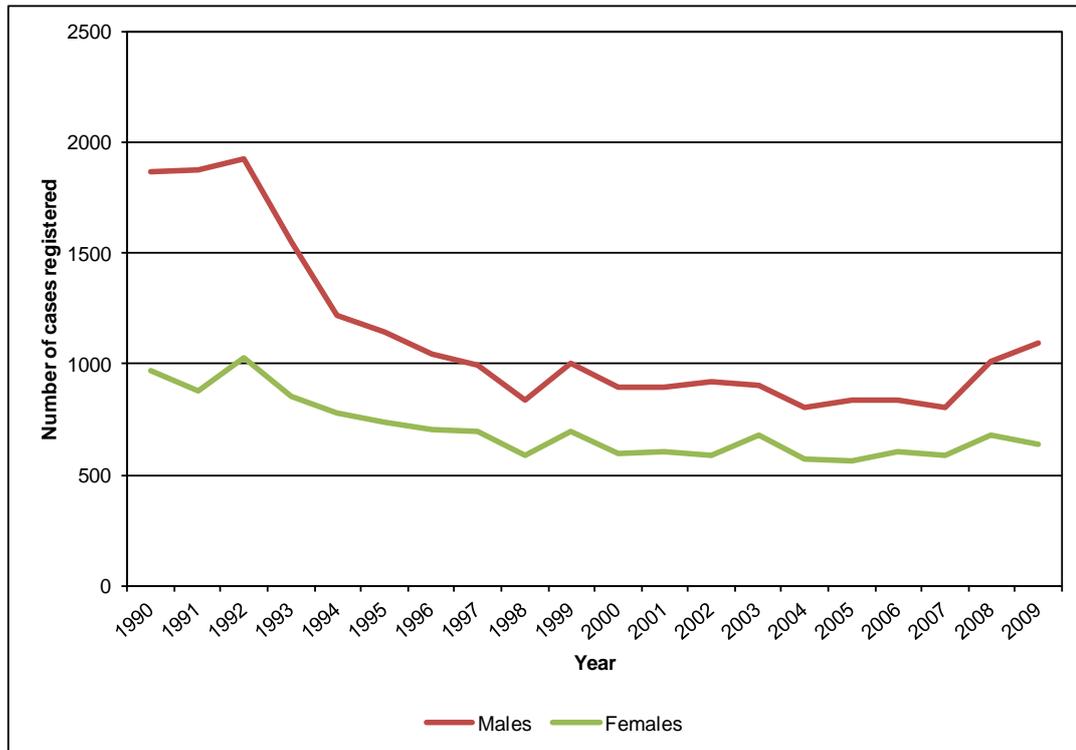


Source: National Cancer Data Repository; Office for National Statistics

## Non-Transitional Cell Bladder Cancer – Cancer

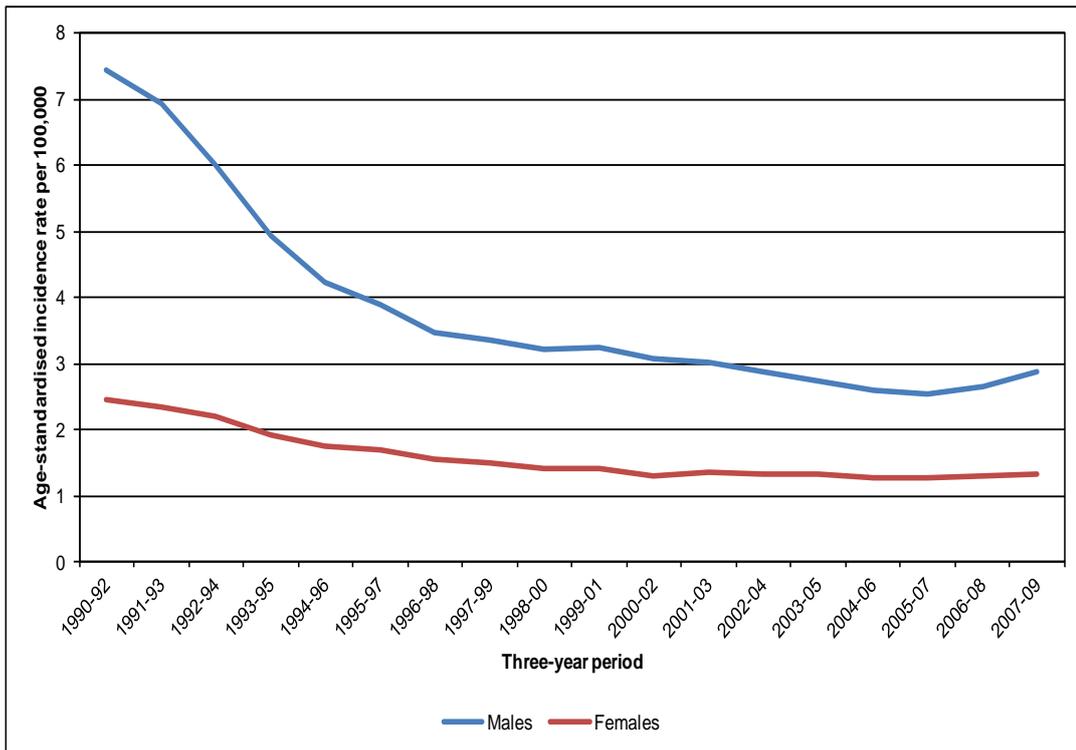
- In both males and females a decrease in incidence of non-TCC bladder cancer can be seen during the study period.
- This decrease is more pronounced in men with an average of 1,870 cases diagnosed per year between 1990 - 92 dropping to an average of 1,094 cases per year between 2007-09. This represents a decrease of 41%.
- In females an average of 969 cases were diagnosed per year between 1990-92 dropping to an average of 639 cases per year between 2007-09. This represents a decrease of 34%.

**Figure 31: Incidence of non-transitional cell carcinoma of the bladder, in England, 1990 – 2009**



Source: National Cancer Data Repository; Office for National Statistics

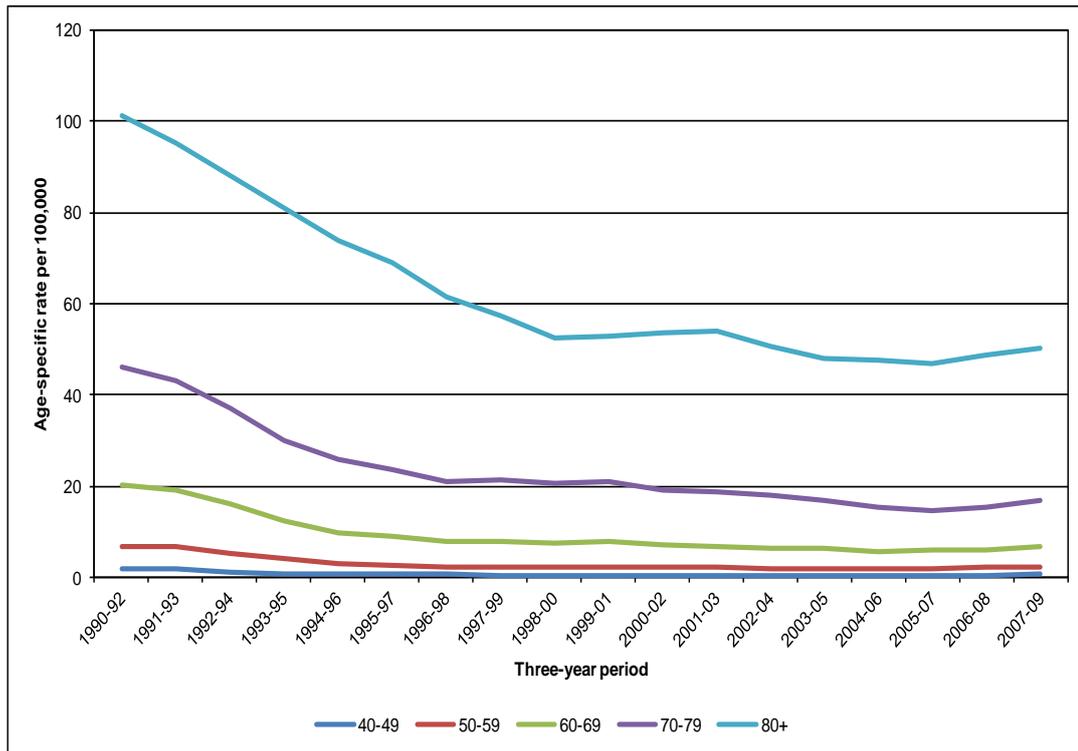
**Figure 32: Incidence of non-transitional cell carcinoma of the bladder, age-standardised rate per 100,000, in England, 1990 – 2009**



Source: National Cancer Data Repository; Office for National Statistics

- Incidence rates from non-TCC bladder cancer have dropped in both males and females. The sharp decrease in incidence which is observed for all bladder cancers around the year 2000 due to a coding change, is not apparent in non-TCC tumours.
- In males, age-specific rates have decreased in all age groups between 1990-92 and 2007-09. This drop begins to become more gradual around 1998-2000.

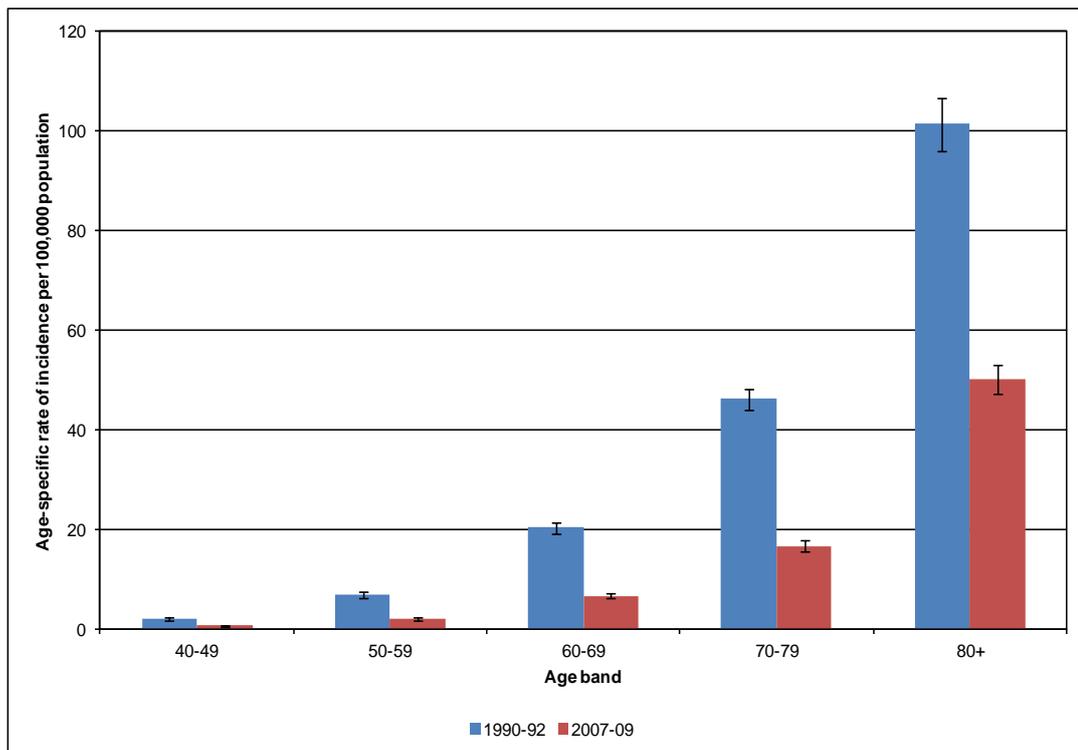
**Figure 33: Incidence of non-transitional cell carcinoma of the bladder in males by age, rate per 100,000, in England, 1990-2009**



Source: National Cancer Data Repository; Office for National Statistics

- In males, age-specific incidence rates have significantly decreased in all age groups between 1990-92 and 2007-09 ( $p < 0.001$ ).

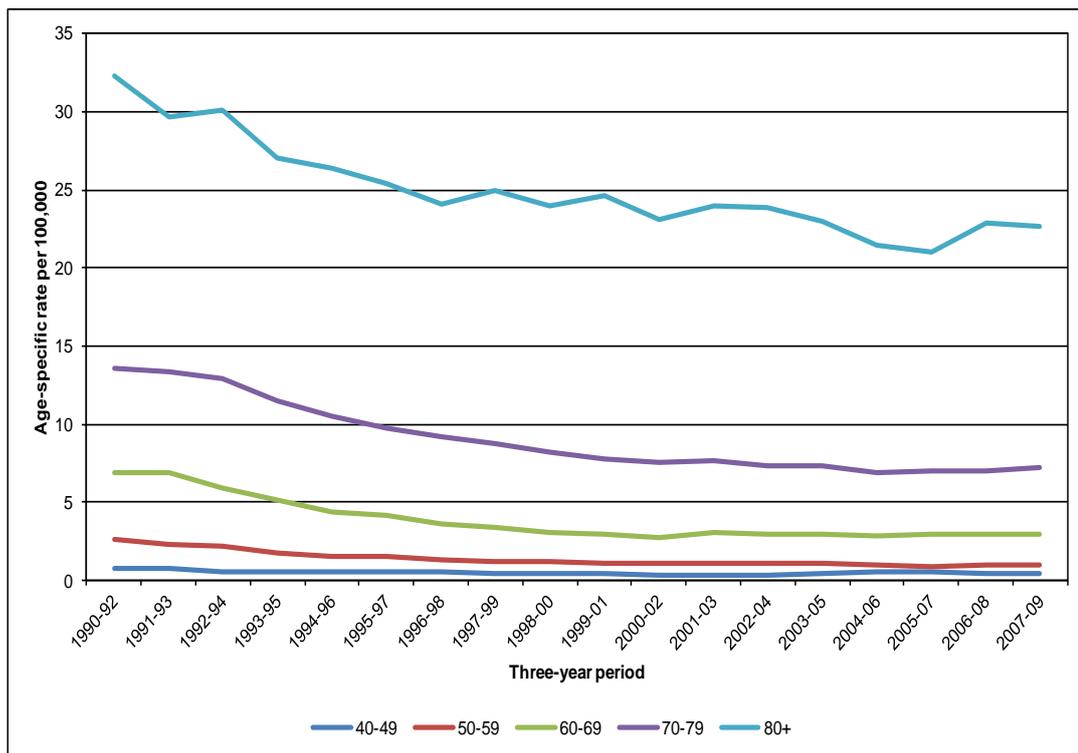
**Figure 34: Age-specific incidence rates of non-transitional cell carcinoma of the bladder in males, rate per 100,000, in England, 1990-2009**



Source: National Cancer Data Repository; Office for National Statistics

- In females, as in males, age specific incidence rates in all age groups have decreased during the study period

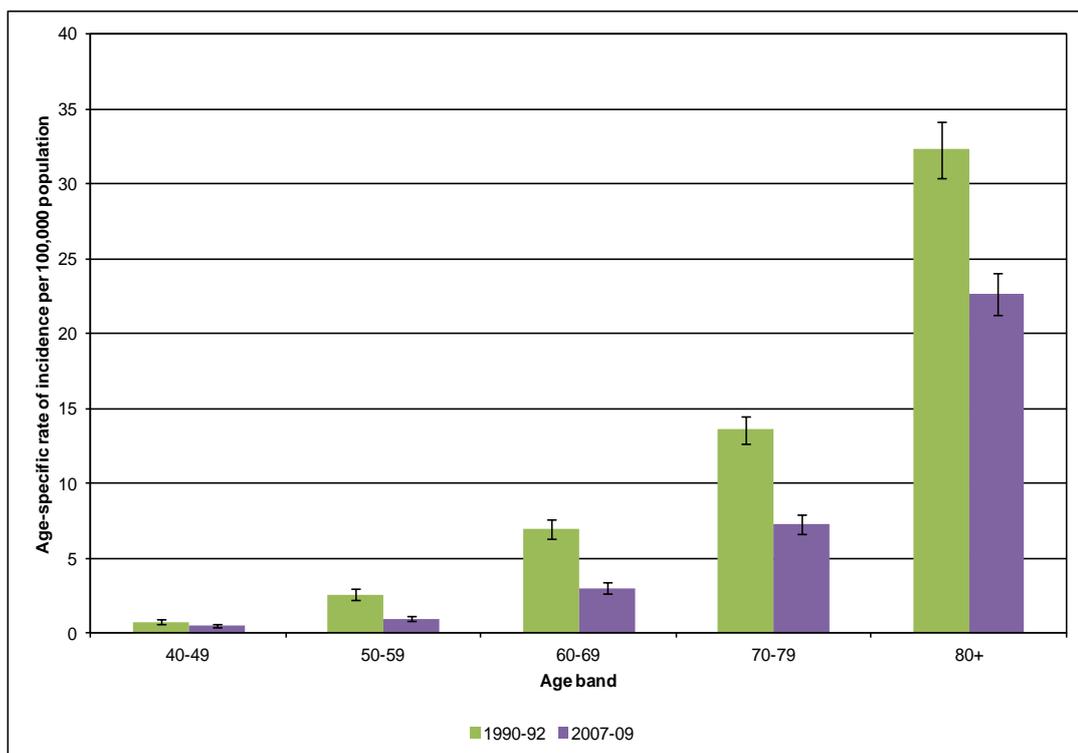
**Figure 35: Incidence of non-transitional cell carcinoma of the bladder in females by age, rate per 100,000, in England, 1990-2009**



Source: National Cancer Data Repository; Office for National Statistics

- As In males, females' age-specific incidence rates have significantly decreased in all age groups between 1990-92 and 2007-09 ( $p > 0.05$ ).

**Figure 36: Age-specific mortality rates of non-transitional cell carcinoma of the bladder in females, rate per 100,000, in England, 1990-2009**



Source: National Cancer Data Repository; Office for National Statistics

# Treatment

## Introduction

To better understand outcome measures, it is necessary to analyse what treatment pathway a patient has followed after diagnosis. Until recently it was difficult to attempt this due to the poor recording of several key data items, particularly radiotherapy. With the release of the National Radiotherapy Dataset (RTDS), recording completeness of radiotherapy data has increased. This means we are now able to take a meaningful look at the treatment pathways of each patient. Equally importantly, we can also identify the cohort of patients who have no treatments recorded, which can potentially give information on active surveillance programmes.

The NICE guidance Improving Outcomes in Urological Cancers (2002) is a comprehensive guide to urological cancers and their diagnosis and treatment. It deals with the most common urological tumours, prostate, bladder and kidney, as well as the rarer penile and testicular tumours. These malignancies have well established diagnosis and treatment regimens. The guidance does not deal fully with the other rare tumours in this report which means that often no standard treatment regimen exists. These rarer malignancies often require different and possibly more aggressive interventions. For example the practice of “active monitoring” or “watchful waiting” is often applied to men with slower growing, localised, less aggressive prostate cancers, but small cell prostate cancer is considerably more aggressive so this may not be a suitable treatment option. Also, diagnosis at an early stage is complicated by the fact that the carcinoma invades the surrounding visceral organs without the expected increase in PSA values.

**Table 1: Numbers of tumours by site and treatment received, England, 2007-09**

Treatment	Site						
	Penis	Small Cell prostate	All Prostate	Testicular	Renal Pelvis & Ureter	Non-TCC bladder	All Bladder
Surgery	965	15	33,124	4,799	1,858	2,269	21,641
Radiotherapy	66	12	14,639	303	148	375	3,341
Chemotherapy	60	26	2,062	2,741	374	598	7,567
Hormone Therapy	3	11	34,622	19	4	10	194
Any Treatment	1,001	44	65,464	5,106	2,022	2,509	22,408
<b>Total Tumours</b>	<b>1,203</b>	<b>53</b>	<b>98,902</b>	<b>5,402</b>	<b>2,649</b>	<b>4,812</b>	<b>26,526</b>

Source: National Cancer Data Repository; Office for National Statistics

- Percentages by tumour do not add up to 100% as each tumour can receive more than one type of treatment.
- “Any treatment” refers to total cases receiving any sort of treatment. This will not be the sum of individual treatments as a person may receive more than one.

**Table 2: Percentage of tumours by site and treatment received, England, 2007-09**

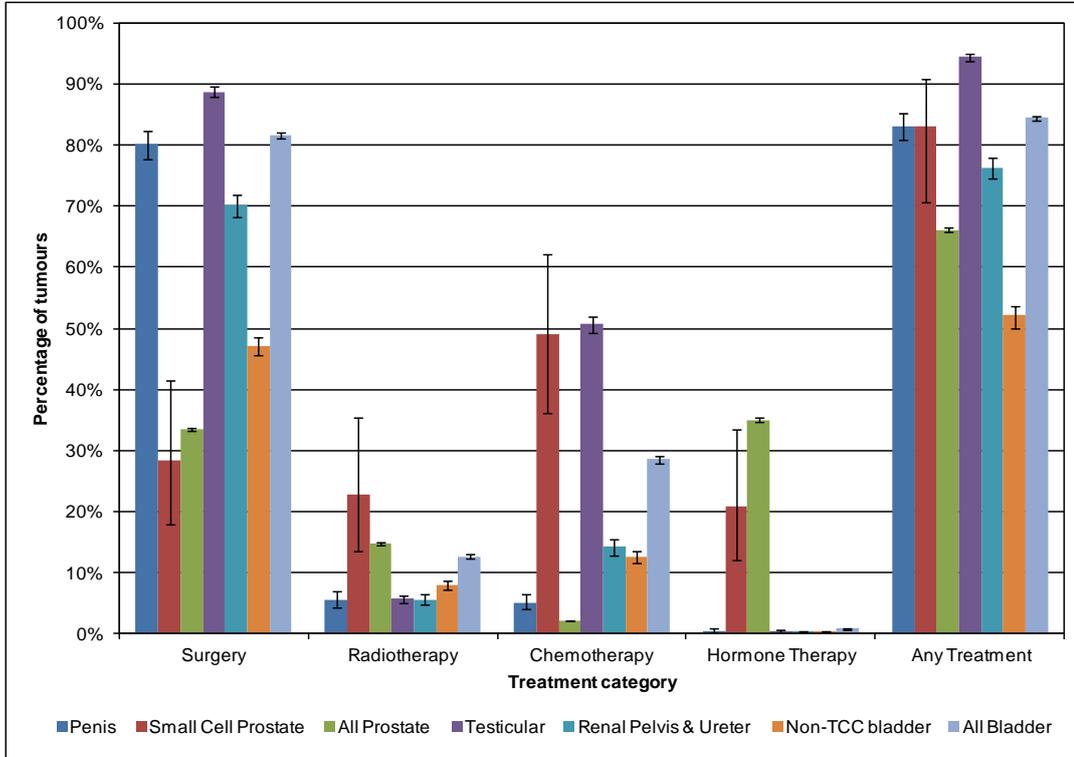
Treatment	Site						
	Penis	Small Cell prostate	All Prostate	Testicular	Renal Pelvis & Ureter	Non-TCC bladder	All Bladder
Surgery	80%	28%	33%	89%	70%	47%	82%
Radiotherapy	5%	23%	15%	6%	6%	8%	13%
Chemotherapy	5%	49%	2%	51%	14%	12%	29%
Hormone Therapy	0%	21%	35%	0%	0%	0%	1%
Any Treatment	83%	83%	66%	95%	76%	52%	84%
<b>Total Tumours</b>	<b>1,203</b>	<b>53</b>	<b>98,902</b>	<b>5,402</b>	<b>2,649</b>	<b>4,812</b>	<b>26,526</b>

Source: National Cancer Data Repository; Office for National Statistics

- Compared to prostate cancers as a whole, those men with small cell prostate cancer have higher usage of chemotherapy ( $p < 0.001$ ), and lower use of hormone therapy ( $p = 0.01$ ). More men with small cell prostate cancer have a recorded treatment of any kind ( $p = 0.001$ ). There appears to be higher radiotherapy use and lower surgery use in men with small cell prostate cancer, but the differences do not reach statistical significance.

- A lower proportion of men with non-transitional-cell bladder cancer have any recorded treatment when compared to all bladder cancers ( $p < 0.001$ ). The overall lower proportion is reflected in all treatment groups analysed ( $p < 0.001$  for all).

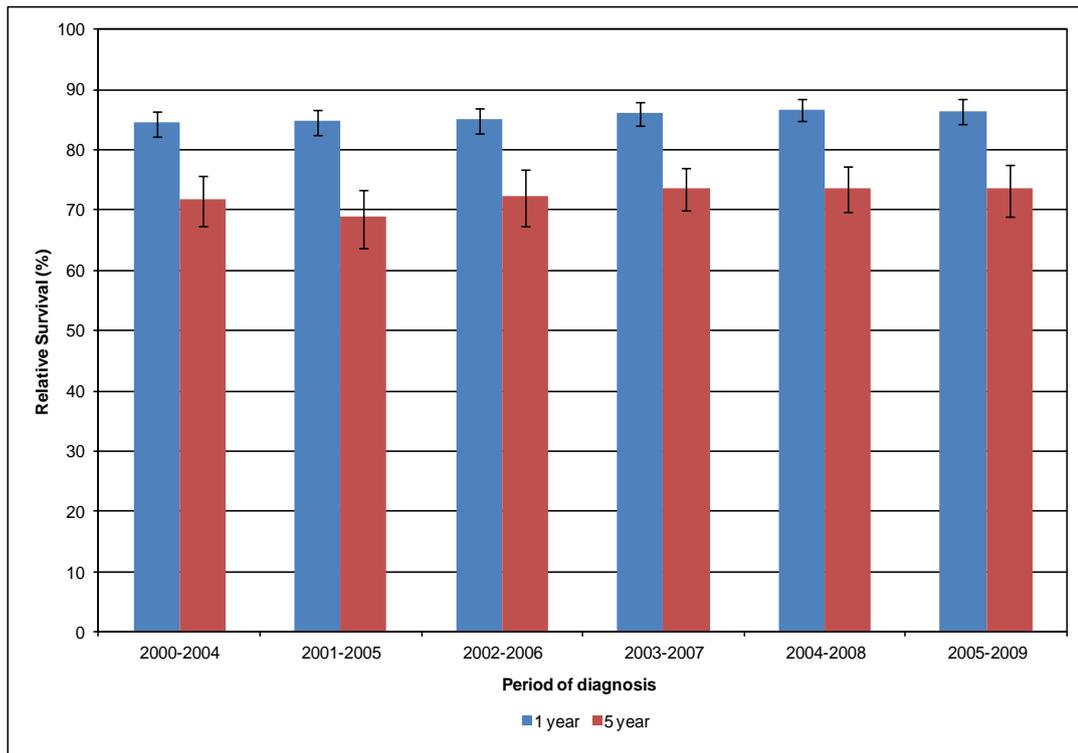
**Figure 37: Percentage of tumours by site and treatment received, England, 2007-09**



Source: National Cancer Data Repository; Office for National Statistics

## Survival

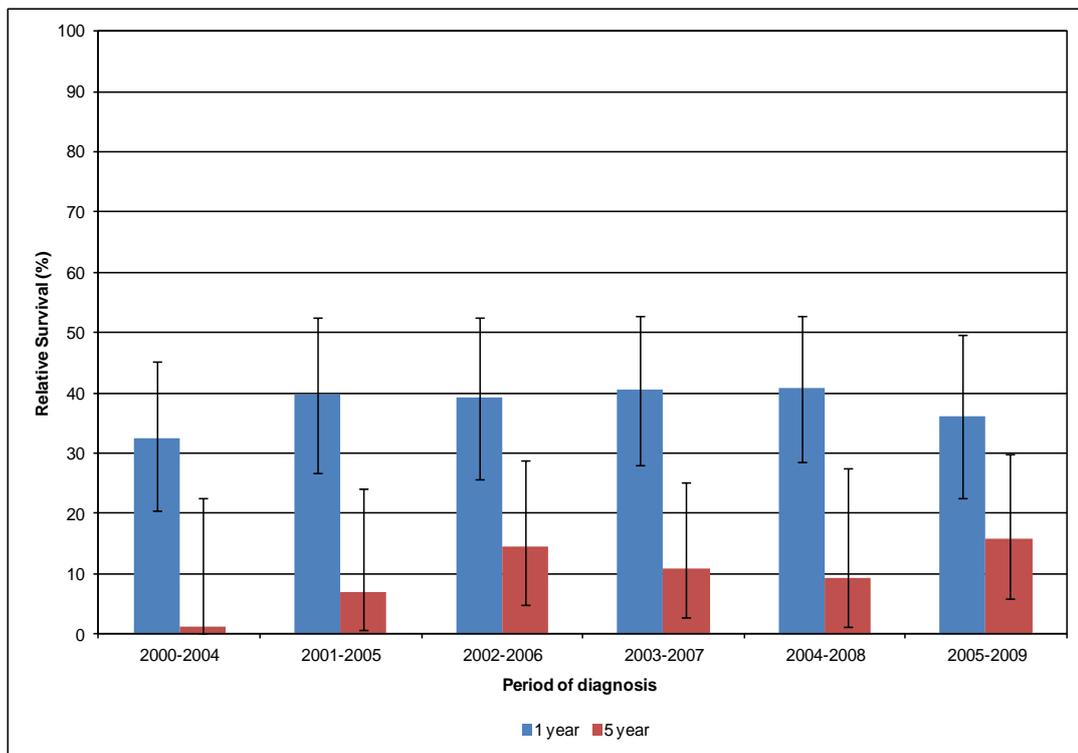
**Figure 37: Relative period survival for penile cancer in England in patients followed-up 2005-2009**



Source: National Cancer Data Repository; Office for National Statistics

- Survival from penile cancer has remained steady at around 85% one-year and 70% five-year relative survival.

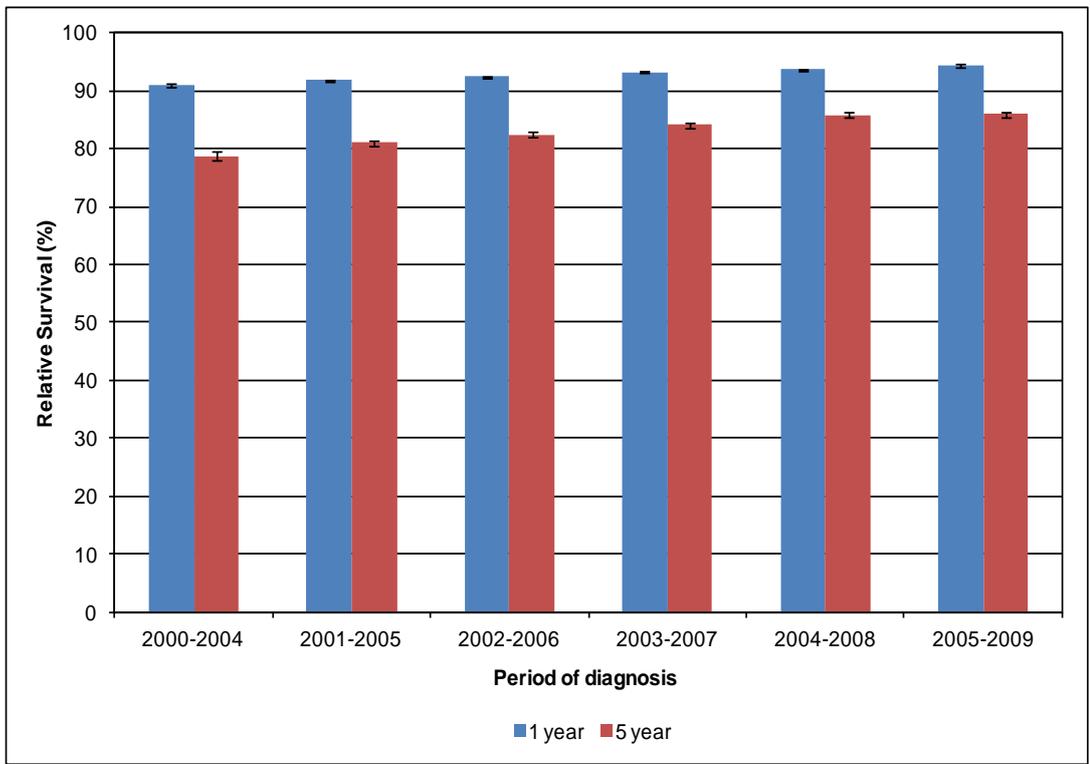
**Figure 38: Relative period survival for small cell carcinoma prostate cancer in England in patients followed-up 2005-2009**



Source: National Cancer Data Repository; Office for National Statistics

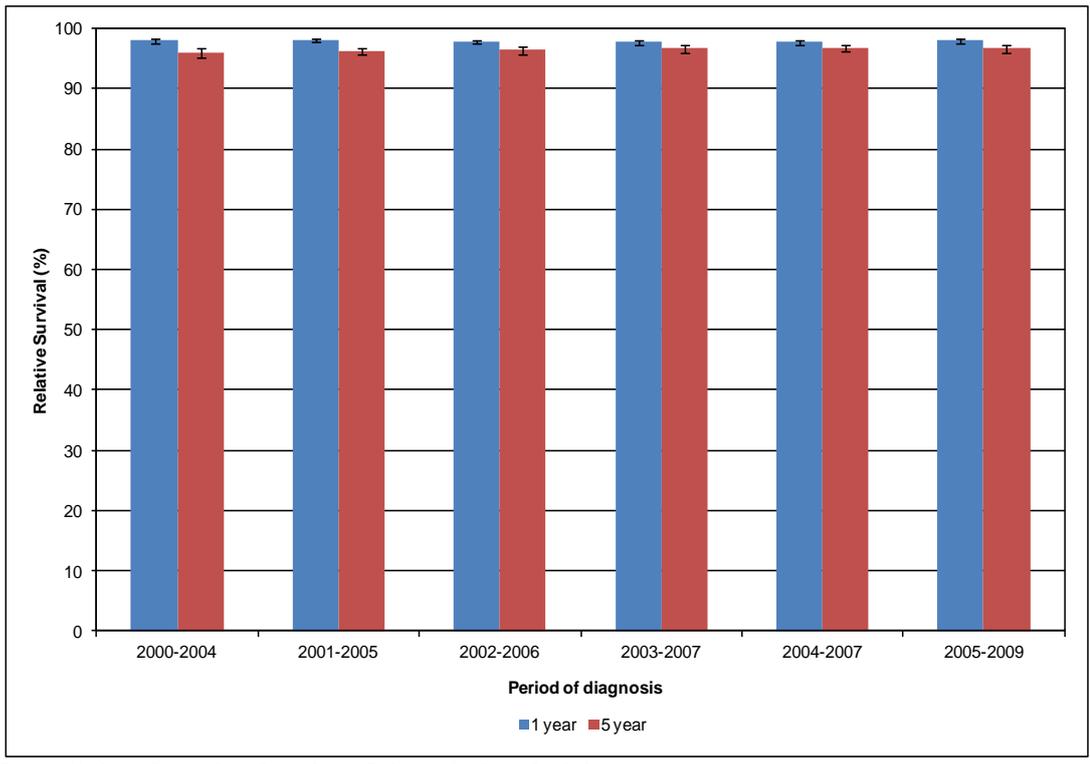
- The fluctuations seen in the small cell carcinoma of the prostate survival graph reflect the inherent instability of the very small numbers of diagnosis of this disease.
- Compared to the relative survival for all prostate cancers, survival from small cell prostate cancer is poor. One-year survival fluctuates between 30% and 40%, compared to over 90% for all prostate cancers. Five-year survival is about 10%, compared to over 80% for all prostate cancers.

**Figure 39: Relative period survival for all prostate cancers in England in patients followed-up 2005-2009**



Source: National Cancer Data Repository; Office for National Statistics

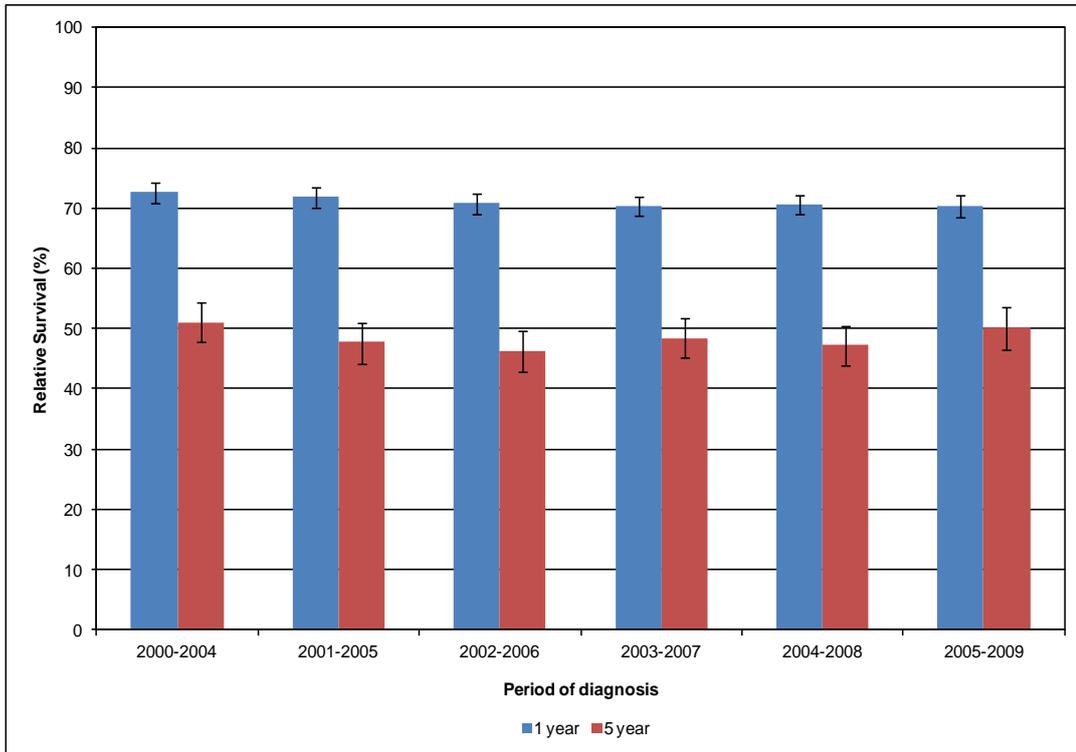
**Figure 40: Relative period survival for testicular cancer in England in patients followed-up 2005-2009**



Source: National Cancer Data Repository; Office for National Statistics

- Survival from testicular cancer is amongst the highest survival of all cancers, with over 95% five-year relative survival.

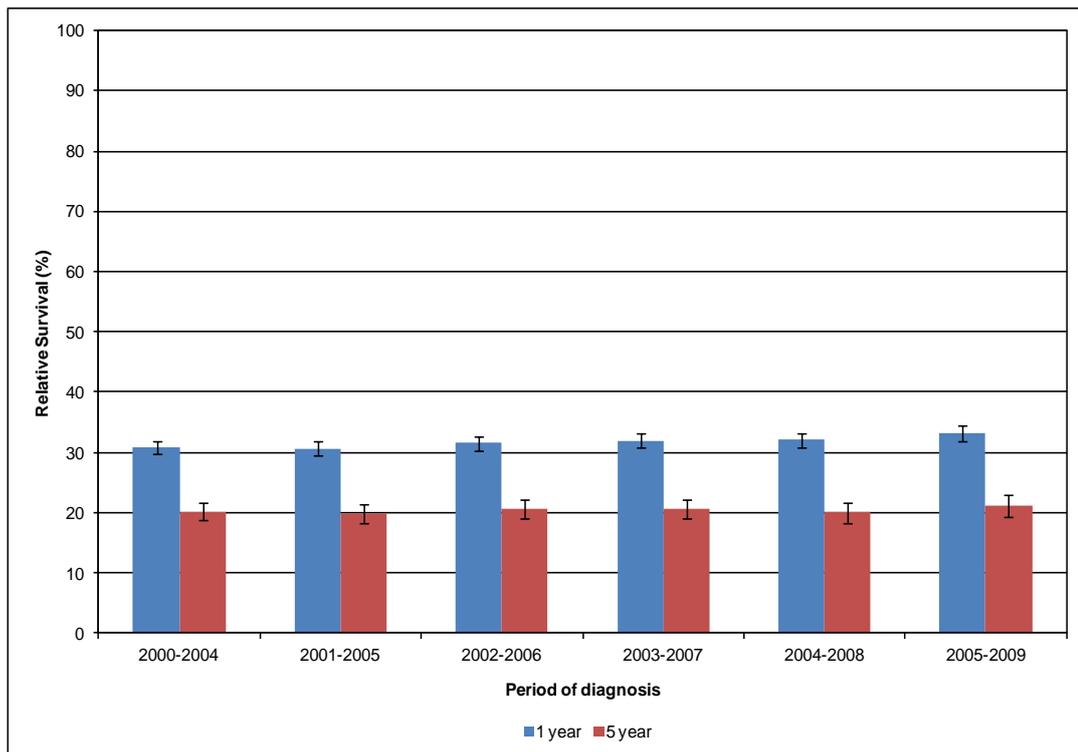
**Figure 41: Relative period survival for cancer of the ureter & renal pelvis in England in patients followed-up 2005-2009**



Source: National Cancer Data Repository; Office for National Statistics

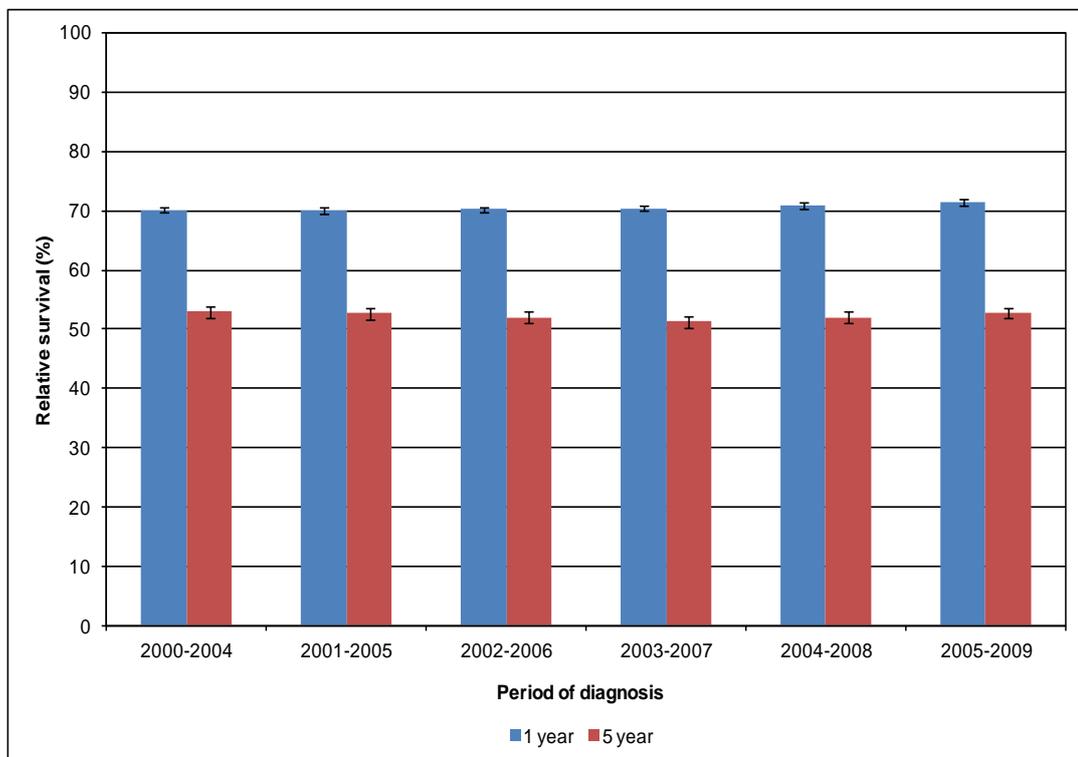
- One-year relative survival from cancers of the ureter and renal pelvis is stable at about 70%. Five-year survival appears to have fallen slightly and then risen again, to around 50%. This is similar to bladder cancer: which is usually of the same type and aetiology.
- Survival from non-transitional cell carcinomas of the bladder is lower than overall bladder cancer survival. One-year relative survival is around 30%, compared to 70%, with five-year survival around 20%, compared to just over 50%.

**Figure 42: Relative period survival for non-transitional cell carcinoma of the bladder in England in patients followed-up 2005-2009**



Source: National Cancer Data Repository; Office for National Statistics

**Figure 43: Relative period survival for all bladder cancers in England in patients followed-up 2005-2009**



Source: National Cancer Data Repository; Office for National Statistics

- It can be seen from the above graphs that both 1 and 5 years survival for each of the rare cancer types are not significantly different during any of the five-year cohorts. This could suggest that the lack of well established diagnosis treatment regimen and targeted interventions for these tumours have meant treatments have altered little over time and therefore survival has remained at a stable rate.

## Summary and Conclusions

- The number of incident cases and deaths for the rare urological cancers is varied. In 2009 incident cases ranged from 17 (small cell prostate) to 1,846 (testicular) and deaths from 58 (testicular) to 96 (penile).
- Small cell prostate cancers are so rare that it is not possible to draw firm conclusions on changes in incidence.
- Penile cancer incidence is rising, particularly in those aged 50-69. Deaths from penile cancer have not changed significantly.
- Incidence of testicular cancer is increasing in all age groups, but mortality is decreasing in all age groups. It is likely that this is due to a combination of effective therapies and increased awareness. The separate two week wait targets for testicular tumours are also likely to have contributed.
- Cancers of the renal pelvis and ureter are becoming more common. Incidence rates have steadily increased, particularly in those aged 80 and over. There has been a more gradual, but statistically significant, increase in mortality rates, and again this has been most noticeable in the elderly. This requires some explanation, as the incidence of bladder cancer (which has similar risk factors and type of disease) is steadily falling.
- Incidence of non-transitional cell bladder cancers is decreasing at all ages, in line with the overall decrease in bladder cancer incidence caused by reductions in smoking prevalence.
- There are differences in treatments given for those rare urological cancers which are subsets of a larger group (small cell prostate and non-transitional cell bladder).
- Small cell prostate cancer is more likely to be treated at all, and more likely to get chemotherapy, which is not widely used overall for prostate cancer.
- Non-transitional cell bladder cancer is less likely to be treated than bladder cancers overall, and this is true for all treatment types. This could be due to differences in presentation, but stage data are too weak to test this.
- Survival in the last decade has not changed significantly, but smaller numbers do impart a larger uncertainty on calculations.
- Survival for small cell prostate cancer and non-transitional cell bladder cancer is lower than the overall survival for these groups. It is difficult to say whether this is an inherent factor of those cancer types, whether they present later or are managed differently.

Those cancers (testicular and penile) which were given scope for specialist centres in the urological cancer Improving Outcomes Guidance (National Institute for Clinical Excellence, 2002) have better outcomes than the other rare urological cancers. It can be assumed that clinical staff working in these centres will see many more cases of such cancers, and hence build up knowledge of effective treatments and support. In contrast, small cell prostate cancer, non-transitional cell bladder cancers and cancers of the renal pelvis and ureter will be dealt with at many different trusts by many clinicians who will see only a few cases each year. These cancers were not mentioned in the original Improving Outcomes Guidance, non in any subsequent guidance, and a clear picture of appropriate treatment is missing.

An effective pooling of knowledge and skills, and subsequent dissemination, is required to ensure best practice is applied to these (and all) rare cancers. Cancer networks (which are due to be incorporated into clinical networks), cancer registries, and national bodies such as NICE can all play a part in this.

## Bibliography

National Institute for Clinical Excellence. (2002). *Improving Outcomes in Urological Cancers*. London.

## About us

The NCIN is a UK-wide initiative, working to drive improvements in standards of cancer care and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research.

Sitting within the National Cancer Research Institute (NCRI), the NCIN works closely with cancer services in England, Scotland, Wales and Northern Ireland. In England, the NCIN is part of the National Cancer Programme.

Our aims and objectives cover five core areas to improve the quality and availability of cancer data from its collection to use:

- Promoting efficient and effective data collection throughout the cancer journey
- Providing a common national repository for cancer datasets
- Producing expert analyses, to monitor patterns of cancer care
- Exploiting information to drive improvements in cancer care and clinical outcomes
- Enabling use of cancer information to support audit and research programmes

### Further information

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### About the South West Public Health Observatory

The South West Public Health Observatory (SWPHO) is part of a network of regional public health observatories in the UK (funded by the Department of Health) and Ireland. These were established in 2000 as outlined in the Government White Paper *Saving lives: our healthier nation*. Key tasks include: monitoring health and disease trends; identifying gaps in health information; advising on methods for health and health impact assessment; drawing together information from different sources; and carrying out projects on particular health issues.

The SWPHO incorporates the National Drug Treatment Monitoring System South West (NDTMS-SW), and in April 2005 merged with the South West Cancer Intelligence Service (SWCIS). The SWPHO works in partnership with a wide range of agencies, networks and organisations regionally and nationally to provide 'a seamless public health intelligence service' for the South West.

For more information about the SWPHO and its partner organisations, please visit [www.swpho.nhs.uk](http://www.swpho.nhs.uk)