

THE BRITISH ASSOCIATION OF UROLOGICAL SURGEONS

SECTION of ONCOLOGY

Analyses of Minimum data set for Urological cancers January $1^{st} - 31^{st}$ December 2000

October 2001

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BAUS Section of Oncology 2000 Minimum Dataset for Newly presenting Urological Cancers

Introduction

We are pleased to introduce our extended analyses of the 2000 data collected by members of the Section of Oncology. Considerable time has been spent in checking and refining details on all tumours registered during 2000. We have advanced our preliminary analyses of the first six months of the year to include all tumours registered between 1st January and 31st December 2000. We have incorporated comparison with National Cancer Statistics from 1997/8 and have included some preliminary work on material deprivation scores. Finally, we have included some data on outcome for patients with muscle invasive bladder cancer. We are grateful to Peter Whelan for his involvement with these follow up data.

On this occasion, we have invited commentaries from experts in the field of cancer and epidemiology and commend their varied comments to your attention.

Our comparison with the national data, pooled from the cancer registries, has revealed some interesting differences and discrepancies. Overall, we find the comparison means that our data are representative of the UK as a whole, despite the minor differences pointed out in the commentary by Dr. Michael Quinn. When comparing our data with that of the national data we should bear in mind the following:

- 1. Our data are only being collected by urologists. We have no way of estimating the number of urological cancers that are not being seen or diagnosed by urologists.
- 2. These data are being presented within nine months of the completion of the year of data collection and being compared to national data from 1997/8, which are the latest to be published. With more time and resources we have no doubt that a higher proportion of cases would be collected.
- 3. A more comprehensive set of data is being collected including staging and treatment information.
- 4. For the majority of us, there is no specific funding for the collection of these data and the analysis and presentation is entirely funded by the Section of Oncology.
- 5. Involvement of clinicians is, we believe, of crucial importance to the collection of a dataset that includes staging and treatment information. This experience is going to be of great importance when it comes to introducing national minimum datasets for cancer.

A number of other differences with the national data are worth commenting on. It emerges for example, that different cancer registries have different inclusion criteria for 'bladder cancer'. In some parts of the UK, only invasive tumours are recorded. In our dataset, 34.4% of bladder cancers are Ta tumours and any differences in the recording of these tumours, is likely to have a significant effect on the total numbers and any survival data. To enable meaningful comparison, it seems that we need an urgent agreement on which tumours should be included. Our bias, is that all transitional cell carcinoma should be included - not least because of the workload implications of the diagnosis.

Chart 38 gives the numbers of urological cancers diagnosed without histology. For prostate cancer the accounts for 7.4% of cases and for carcinoma of the kidney 16.8% although some of these were recorded as having been treated surgically so pathology must have been available. Nevertheless, these are significant numbers and we must question how these cases get recorded in the cancer registries, which rely on pathology reports and not on clinical reporting. A more detailed audit of these cases is required to make sure that they are not being missed from the national cancer registries.

Although the number of tumours being reported has shown a steady increase since we started this voluntary registry, we are still not reporting all tumours. This of course reflects who manages the patient. In the case of kidney cancer, it seems that a substantial number are never seen by a urologist. There are also interesting regional variations which should allow us to target geographical areas, which are under represented in our national database.

In this dataset we have attempted to collect data on private patients resident in the UK as well as NHS patients. The percentage of private patients recorded has increased this year to 4.4% of the whole dataset. This is still well below the expected number. Nationally 12.7% of the population has insurance with the highest insurance rates for males and females in the age band 45-54 being 15.4% and 15.6% and dropping to 9.6% and 9.5% respectively for those ages over 65 years. Extrapolating from BMI and BUPA figures 500 – 600 radical prostatectomies were performed in 2000. In our database we have 1195 radical prostatectomies, which suggests that excluding private patients would give a very skewed picture of the treatment of prostate cancer in the UK.

We have included some preliminary analyses of material deprivation scores, as described by Professor P. Townsend and mapped to post codes. The results show interesting trends, for prostate cancer, towards higher stage tumours and higher PSA with increasing deprivation. Such trends require more detailed study with other methods of assessment for material deprivation.

The National Cancer dataset is now developed and undergoing field tests. We have been involved with a mapping exercise between our own dataset and the national dataset. We are keen to hear from members who are willing and able to collect this much larger dataset. Further details can be obtained from the Department of Health website (www.cancer.nhsia.nhs.uk/dataset) or from Margaret Baldock at the NHS Information Authority (margaret.baldock@nhsia.nhs.uk).

As in any dataset there are some recurring problems with the interpretation of the terms. The word 'surveillance' appears to have different meanings for different members. We intended that surveillance be used to indicate patients having 'No active anti-cancer therapy' and suggest that this phrase be substituted for the word 'surveillance' in the 2002 version of the dataset.

We have responded to feed back from members and their nursing colleagues that the delays in the patient journey were unnecessarily elongated by use of total days rather than 'working days'. The analyses of time from referral to consultation and consultation to treatment are now based on working days.

We have heard of reference to the 'Bloody BAUS Data' from an irate nurse specialist, forced to spend part of a bank holiday in the act of data collection and transmission. We very much appreciate the effort of everyone involved in collecting and submitting the data. There seems to be a clear case for extra resource to help with the process but we are keen to maintain senior input to check the validity of data especially that relating to staging.

Once again, we are indebted to Sarah Fowler for her industry and patience in the preparation of this booklet. We consider the contents to be the best available UK data on urological cancer at the turn of the century.

Alastair Ritchie Mike Wallace

October 2001

Commentary from Peter Selby Professor of Cancer Medicine, St James's University Hospital, Leeds

The BAUS Data on Urological Cancers

When people involved in diagnosing and caring for patients with urological cancers discuss the issues surrounding their work, the importance of having a clinically useable dataset that is properly structured, available in a clinically useable timeframe, sufficiently detailed but not excessively burdensome and complete enough to allow meaningful conclusions, is always high on the list, frequently right at the top. We need this to understand properly what we are doing; what we are achieving for our patients; what changes need to be made; to monitor whether those changes actually happen and whether the expected benefits really do occur. Finally, we need these data to plan our research initiatives and to make the best use of the resources of the National Cancer Research Network. The value of the Cancer Registration process is fully recognised and acknowledged but its design and timescale means that there are limitations for clinical purposes. Ultimately, everyone hopes that a process of clinical data collection and Cancer Registration can come together into a single and effective tool.

Against this background, the data produced by the BAUS Section of Oncology represent a major step forward. This is a developmental process and we are looking at the first steps that are being taken so its incompleteness is a challenge for the future not a reason for being negative about the process as a whole. This is a lot of work. The amount of data collected is massive and it is being collected by individuals who have busy "day jobs". Support staff are in place in a patchy manner across the country but there is still no comprehensive support network for clinical data collection and the whole process has depended to a great extent on individuals' commitments and goodwill.

So what can we learn about the process? The index of completeness is estimated by comparison to the most recent Cancer Registration data. This will be imprecise. Cancer Registration is still sometimes incomplete and there are some secular trends which will have altered incidence a little in the last three years. Nevertheless the figure of 60% completeness is probably roughly correct. This is a problem because the absolute level is relatively low and because it is unlikely to be a random sample. Clearly there are individuals and regions whose contributions is less complete than some others but also it seems likely that some of the gaps will arise systematically as a result of the make-up of the BAUS Section of Oncology which does not include all interested parties. Nevertheless 60% is a success and not a failure because it demonstrates that this process is credible and supported by the majority of the key participants. The single most important message to take from these data is that it will be possible to achieve the database that we desperately need, given more support and some further developments. Congratulations to the high performers but we can learn from their experience. It is of interest that the best performing regions identified more cancers than the Cancer Registries in bladder and testicular cancer.

What will be the necessary contributions to lift the performance into the level of completeness (and follow up) that will allow us to answer all of our pressing questions? More resources and support and NHS Trusts and commissioners are now beginning to recognise that they have a responsibility to make processes like this work. So resources have to come to help individual commitment. Organisation. It will be clear to everybody who reads this report that the organisers have done a spectacularly good job. However, there is experience to add, perhaps particularly in Cancer Registries, that may help with the developments. Above all, an acknowledgement of the importance of the task and of the demonstration that the task can be successfully carried out must be acknowledged. Perhaps the biggest challenge will be in follow up. Collecting a baseline dataset is one kind of challenge. Maintaining follow up to have information on outcomes is another, and probably a more difficult one. The number of cases cumulatively increases and particularly in prostate cancer it will be decades before this

process reaches a steady state. The support and resources for follow up need to be identified but also, I suspect, before too long an integration of clinical data collection with Cancer Registration will be necessary in order to make sure there is no duplication.

Having talked about the process and the future, it is worth commenting on what the data tell us. They confirm the very large range and volumes of practice among consultants and centres; demonstrate the numerical dominance of prostate cancer in urological oncology; and tell us that some regions are more effective than others at collecting data. The information on tumour incidence, age groups, and a pattern of rare occurrence does not generate many new insights but do confirm the patterns of the diseases. Outcome data will give powerful new indicators of the results obtained in an unselected group of patients which will quite possibly alter our thinking about what is being achieved in urological oncology. The difficulty of obtaining complete staging data is well illustrated.

Among treatment options there are not too many surprises. Eleven patients were treated with curative immunotherapy for kidney cancer (just as one example) which means some optimism out there. Insights into patterns of practice are interesting. Patients with big aggressive bladder primaries (T4, G3) have about an even chance of being treated by radical surgery or radical radiation therapy if they are under 70 and about one-third of them will get chemotherapy. We have "equipoise" and this group is excluded from many of the current trials and perhaps there may be a trial to do. The data are interesting, instructive, need to be interpreted cautiously and can in all sorts of ways influence and clarify our thinking about current treatment and future research.

If we are to achieve the urological cancer services in the UK that we all seek then this exercise needs to be supported and developed as enthusiastically as we can.

Commentary from Dr M J Quinn Director, National Cancer Intelligence Centre

"In total, around 24,300 "urological" tumours were included in the BAUS survey (50 of which appear to be carcinoma in situ rather than invasive); histological confirmation was obtained for over 90%. Just over half the total were prostate tumours (12,900), and 30% bladder (7,500). Compared with incidence figures from the UK cancer registries, overall coverage was just under 60% - but it varied widely both by site and by country and region of England, and the variation by region was different among the sites [Charts 10, 11]:

| Site | Overall | Lowest | H | lighest |
|---------------|---------|---|--------------|------------------------|
| Prostate | 59% | 24% Scotland30% Wales35% N West44% EA & Oxford | 85% 96% | N & Yorks Trent |
| Bladder | 66% | 32% Scotland 38% N West 46% EA & Oxford | 72% 114% | N Thames N & Yorks |
| Kidney | 41% | 21% Scotland 21% N West 30% EA & Oxford | 60% 63% | Trent W Midlands |
| Testis | 56% | 24% Scotland30% Wales41% N Thames42% N West | 96% 114% | Trent N & Yorks |
| Pelvis/ureter | 65% | 17% Scotland27% N West31% N Ireland | 79% 145%? | W Midlands N Thames |
| Penis | 58% | 33%Scotland43%S West | 80% 82% | N & Yorks Trent |

The BAUS survey is therefore very under-representative of Scotland, Wales, and the North West and East Anglia and Oxford regions of England; and indicates possible under-registration in Northern & Yorkshire for bladder and testicular tumours - or inclusion in the BAUS survey by urologists in Northern & Yorkshire of bladder tumours which are not considered to be invasive by the cancer registries.

In addition to not being geographically representative, the BAUS cases have markedly different age distributions from the UK total, except for bladder cancers [Charts 14-19, 21-23]:

| Site | | Age group | BAUS | UK total | |
|----------|---|-----------------------|----------------|--------------------|--------------|
| Prostate | | Under 70 80 & over | 35.4% 22.1% | 29.6% 28.4% | BAUS younger |
| Kidney | М | Under 70 70 & over | 62.8% 37.2% | 57.7% ? 41.9% ? | BAUS younger |
| | F | Under 70 70 & over | 57.1% 42.9% | 50.1% 49.7% | BAUS younger |
| Testis | | Under 30 40 & over | 23.7% 40.0% | 32.7% 30.6% | BAUS older |

For bladder and kidney tumours, the sex ratios of the numbers of cases in the BAUS survey were markedly different from those for England: bladder 2.9 v 2.4, kidney 1.85 v 1.6, respectively [Chart 7].

Also, data items were sometimes missing for large proportions of records: for example, for the calculations of times to first consultation and to diagnosis, the relevant dates were known and valid for only around three quarters of tumours overall, and this varied by source of referral: GP 85%, urologist 45%, "other" 79% [Chart 27].

The BAUS data set, while achieving about 60% coverage of urological tumours, is therefore not a random or representative sample of all such tumours in the UK. The nonrepresentativeness will affect particularly any analyses involving stage (which varies with age) and socio-economic deprivation (which varies with geography). Results may also be biased because of the sometimes high proportions of "not knowns".

There was a very wide range in the numbers of tumours per consultant: around 40% saw fewer than one each week, and 80% fewer than two each week. Around 20 consultants saw three or more cases each week, and only a handful five or more [Chart 2].

Almost 80% of cases were referred by a GP and 6% by urologists. There were large differences in median times (in days) from referral to first consultation and to diagnosis, depending on the source of referral and tumour site [Charts 27, 33]:

| Source/site | Referral to first consultation | Consultation to diagnosis |
|-------------|--------------------------------|---------------------------|
| GP | 19 | 24 |
| Urologist | 12 | 13 |
| Other | 3 | 14 |
| Testis | 5 | 8 |
| Kidney | 8 | 22 |
| Bladder | 17 | 21 |
| Prostate | 19 | 25 |

In addition, in 6 of the regions/countries the 95th centile of the distribution of time to first consultation exceeded 80 days, and in (a different) 6 that of the distribution of time to diagnosis exceeded 200 days [Chart 32].

Comparisons of clinical and pathological staging for bladder and kidney tumours (although based on only about half of the total cases) showed around 90% agreement for stages Oa and I, respectively. But for bladder tumours, around 30% of clinical stage I were pathological

stage Oa; and for kidney tumours around 20% of both clinical stages II and IV were pathological stage III [Charts 48, 51].

The stage of prostate tumours at diagnosis varied markedly with age: in men under 60, almost 70% were stage II, and equal proportions stages III and IV. The proportions of stage II declined with age, to around 40% in men 85 and over; and tumours of stage III and IV both increased with age to around 30% of the total [Chart 54]. It would be valuable if comparisons of the stage distributions could be made with data from the cancer registries.

The stage of prostate tumours was correlated with PSA levels. Almost 50% of cases with stage I tumours had PSA levels of 0-5 [? units], whereas over 70% of cases with stage IV tumours had PSA levels over 50 [Chart 56].

Very high proportions of cases were treated with curative intent for cancers of the bladder (84%), kidney (75%), testis (97%), pelvis/ureter (83%) and penis (87%). In contrast, less than one third (32%) of prostate cancers were so treated; and for over 50% the intention was palliative treatment only [Chart 60].

For cases of prostate cancer treated with curative intent or placed under surveillance, PSA levels rose markedly with increasing age. For those treated with palliative intent only, very much higher proportions had PSA levels over 20.

A large amount of information is presented on type of treatment by intention of treatment but it is difficult to interpret because tumours may be treated in more than one way [Charts 62-71].

Commentary from Dr David Dearnaley, Bob Champion Reader in Prostate Cancer Studies, Institute of Cancer Research and Consultant Clinical Oncologist, Royal Marsden Hospital, Sutton, Surrey.

From a standing start, the BAUS Section of Oncology Database has achieved about 60% coverage and registration of urological cancers within a period of 3 years. This is a notable achievement and the urological cancer surgeons and other clinicians who have contributed to this success are to be applauded. Near 'real time' snapshots of urological practice are now possible which over the coming years will build into a very significant contribution to the development of urological cancer management and give a good indication of how urological practice in the UK is changing. This much has been achieved on very limited resource and further progress depends, in part, on more adequate funding. How might this be achieved? Opportunities may arise from the funding which should flow from implementation of the National COG guidelines to be published in the very near future. These will demand not only adequate registration of cases but also, and very importantly, follow-up data for the audit of performance. If near complete urological cancer registration could be achieved - giving a true 'denominator' - the database would complement Cancer Registry information and possible links will need to be explored. A second opportunity is from use of the database to fuel and support patients' recruitment into research studies - administrative costs being in-built into research proposals. Two such programmes in prostate cancer have already been established. In the first, a group of researchers from the University of Nottingham and the Institute of Cancer Research, supported by a grant from the Prostate Cancer Charitable Trust, are investigating the interactions of diet, environment and genetic predisposition in men who develop prostate cancer at a young age (less than 60 years). These younger men are identified from the BAUS database and then, with the permission of their consultant urologist, contacted by the researchers and asked to complete dietary and environmental questionnaires as well as supplying blood samples for subsequent genetic analysis as well as toenail clippings for selenium measurement. Case identification is critical and the project dependent on the BAUS dataset which complements the British Prostate Group/Cancer Research Campaign Familial Cancer cohort. Secondly, in the Thames area, a Cancer Research Campaign supported trial run by the Institute of Cancer Research Team is evaluating the issues - feasibility, effectiveness and acceptability - surrounding PSA "screening" of a high risk population, defined as first degree relatives aged 45 - 69 years of men (the index cases) diagnosed with prostate cancer under the age of 65. The Thames Cancer Registry, as well as the BAUS dataset, will be used for index case identification - again, these men will only be contacted following the approval of their treating urologist. The timeliness of information entry into the BAUS dataset is an important advantage for these studies. These research groups have established joint scientific management groups with the BAUS Oncology Group to oversee and guide the studies and further initiatives are currently being explored.

It is encouraging to be able to comment on successful initiatives and the BAUS Oncology Section's work deserves wide support from the Dept of Health and Research Funding Bodies in order to fully exploit its future potential.

Commentary from Professor Barry Hancock Department of Oncology, Weston Park Hospital, Sheffield

Urological cancer accounts for about one sixth of all cancers. Commissioner guidance for managing these cancers will be available later this year and this is likely to reaffirm the need for rapid referral, diagnosis and treatment (via the specialist multidisciplinary uro-oncology team). Of paramount importance in achieving this will be the availability of credible clinical data. This audit of the minimum dataset for urological cancers provides an excellent model on which other oncology specialities can develop their own datasets and I've no doubt that the soon-to-be-announced National Cancer Datasets will reflect this. The audit comprises well over one half of all UK urological tumours and as such can be regarded as truly nationally representative. Prostate and especially bladder cancer are proportionately better represented than other tumours, particularly kidney.

Another major bonus of such an evaluation is that we can estimate which, and how many, patients can be offered the benefits of informed participation in clinical trials. As just one example, from the data provided we could roughly estimate that of the 2,000 or so new cases of kidney carcinoma (Chart 8) comprising 40% of the UK total (Chart 10), about one fifth (Charts 47, 48) would be potentially eligible for the EORTC/CRC randomised controlled trial of adjuvant IL-2, interferon α and fluorouracil versus interferon α for patients with high risk of relapse after radical nephrectomy. The ethos of such a finding is very much in line with the establishment by the Department of Health of the National Cancer Research Institute and National Cancer Research Network.

The availability of audit data, such as provided in this report, also strengthens clinical advice on the priorities, in urological oncology, for new NHS Cancer Plan funding.

Commentary from Mr Peter Whelan Pyrah Department of Urology, St James' University Hospital, Leeds

BAUS Section of Oncology Audit Results, January to December 2000: How this data base may help in further research and clinical trials.

When the Section of Oncology was set up the aim was to enable Urologists to have contemporary data of registration and eventually clinical outcome of therapies rather than having to rely on national statistics for tumour registration or sporadic retrospective studies from a variety of institutions to assess the efficacy of our treatments. It was further hoped by some of us that the basis for well planned prospective clinical trials would be apparent, both by being able to utilise the numbers of cases being registered and for anomalies in practice to be identified, analysed, and suitable trials instituted to confirm or refute that practice.

The advent of the further elaboration of the Calman system to include the administrative mechanism to enable clinical trials to take place countrywide, which professor Peter Selby will talk about at the autumn meeting in Edinburgh, gives us a further chance to develop in all of these areas.

Based on the analysis of the number of cases of renal pelvic or ureteric tumour, Tim O'Brien has set up a simple study to look at the efficacy of Mitomycin C intravesically. From the 2000 data 361 patients were registered and yet Tim has found this trial extremely difficult to recruit to. It is essential that we all try and demonstrate that it is possible to gain useful information from the data that we are now collecting even at its most prosaic. More important questions are shown in the data that we need to address in order to be able to demonstrate good clinical practice.

If we examine charts 61, 68 and 69 looking at the type of treatment given to patients and its distribution related to age and PSA we can see a large number of individual patients with PSA's significantly elevated both in the range 21-50 and greater than 50 that apparently have been treated with curative intent. We need to know what protocol these patients have been treated on and if we are getting good results despite the apparently advanced nature of the disease of these patients especially the ones under 70 then this protocol needs to be part of a prospective trial to validate the treatment options and if the methods of therapy utilised are invalid then these types of therapies should not be offered to patients.

The whole importance of a range of prospective clinical trials is that difficult clinical problems can be tested openly and not in some serendipitous way in which sensible and indeed significant breakthroughs in therapy can be lost because they are perceived as merely anecdotes.

I hope that the analysis of invasive bladder cancers will reassure all of us that we are providing a more than respectable service countywide in the treatment of this particular condition. I believe that 18 months disease free data almost certainly will equate to cures and that the surgery across the country compares very well with the selective data that we see from single institutional reports from elsewhere.

I believe that the goal that we set ourselves in setting up this section of Oncology, of having contemporary data of the numbers of cancers that we are seeing, nearly contemporary analysis as the outcomes of therapy that they are having across the country, and the prospect of being able to put difficult clinical scenarios into sensible prospective clinical trials will enable us to both improve therapy and to get data that almost certainly is inaccessible anywhere else world wide.

AUDIT RESULTS SUMMARY January 1st – 31st December 2000

Who took part?

356 consultant urologists from 154 hospital centres, (86%, 154/179 of Urology departments recorded in the BAUS handbook), in England, Wales, Scotland and Northern Ireland provided data for this study submitting data on 24,343 newly presenting urological tumours from 1st January to 31st December 2000. Of the 356 consultants, 237 (66%) are members of the BAUS section of Oncology. These figures represent approximately 60% of the total UK tumours registered in 1997 (the most recent year available).

How were the data analysed?

Information obtained from consultants was entered into the computer database using unique identifying numbers for individual consultants or, if they preferred, a centre number. Five centres returned data under a centre number only (16 consultants in total) and data from one other centre was returned under a centre number only for 4 out of 5 consultants.

Data could be returned either by completion of a pro forma for each patient (38.3% of returns) or in electronic format using either an Access (Microsoft) database or "in-house" database (59% of returns) or a Psion database (Urocas) (2.7% of returns) designed for the purpose. The pro formas were entered directly into an Access database, at which time validation comprising mainly of checks for duplicate entries, (ensuring that synchronous bilateral tumours were included), and on dates and sex of patient could be carried out. Approximately 500 duplicate sets of data had to be removed. 41 tumours were registered twice as a tertiary referral from another centre or another consultant in the same centre. They were only included once in all the analyses using the data from the tertiary site for all analyses except those relating to delays when the primary site data was used.

The data presented here are a summary of the data received up to 17th September 2001 and relate to diagnoses made during the whole of 2000. The following data was included:

- a. Patients for who the date of diagnosis fell within the time period. (01/01/2000 to 31/12/2000). 23,877 registrations (98.1%).
- b. Patients for whom the date of diagnosis was not included, but the referral date fell within the study period. (01/01/2000 to 31/12/2000) 422 registrations (1.7%).
- c. Patients for whom the diagnosis and referral dates were not included, but the date of first consultation fell within the study period. (01/01/2000 to 31/12/2000). 44 (0.2%).

For the ranked charts (2,3,5 & 6) the individual consultant or centre identification numbers were removed and replaced with rank numbers starting at 1. A unique, confidential "Ranking Sheet" was prepared for each surgeon to enable them to identify their rank in every chart. For those charts where overall figures for the entire database are shown the ranking sheet displays the consultant's individual figures. No one else can identify the results of an individual consultant. The ranked charts are presented using similar conventions with totals, and the interquartile range. They comprise single bars, with in addition the 25, 50, and 75 percentiles and are ranked from left to right in the ascending order of the data item being measured. Where percentages are included figures have been rounded up to one decimal point.

A personal ranking sheet for each consultant was issued individually with this chartbook.

Sarah Fowler BSO Tumour Registry Manager October 2001

A. Who took part & Overall figures Chart 1

BAUS - Register of Newly Presenting Urological Tumours January 1st - December 31st 2000 Who took part

- 356 Consultants from 154 Centres provided data on 24,343 newly presenting urological tumours.
- 66% (237/356) Consultants are members of the Section of Oncology. These Consultants returned 61% of the data
- 4.4% (1067/24343) were from the private patients of 126 Consultants
- Range of Consultants per Centre = 1 10, (Median 2)
- Median number of tumours per Consultant =58, Range 1 254
- Median number of tumours per Centre = 135, Range 1 591
- 62% (15023/24343) of the data were returned electronically

Chart 2

Total Number of Newly Presenting Tumours Reported per Consultant Median: 58 (Interquartile Range 27 - 95)



Total Number of Newly Presenting Tumours Reported per Centre Median: 135 (Interquartile Range 73 - 203)



Chart 4

Number of Newly presenting Tumours by Organ per Consultant 356 Consultants reported 24,343 Tumours

| Organ | Total Number | Modian nor | Dongo |
|----------------------|----------------|-------------|---------|
| Organ | Total Nulliber | Wieulan per | Kange |
| | Reported | Consultant | |
| Prostate | 12892 | 29 | 0 – 153 |
| Bladder | 7549 | 17 | 0 – 84 |
| Kidney | 2037 | 4 | 0 – 46 |
| Testis | 980 | 2 | 0 – 84 |
| Pelvis/Ureter | 371 | 0 | 0 - 9 |
| Penis | 221 | 0 | 0 – 6 |
| Urethra | 33 | 0 | 0-2 |
| Prostatic Urethra | 34 | 0 | 0 – 2 |



Total Number of Newly Presenting Tumours Reported per Consultant by Organ where $n \ge -58$ (i.e. the median reported per consultant)

Chart 6

Total Number of Newly Presenting Tumours Reported per Consultant by Organ where n >=58 (i.e. the median reported per consultant) Ranked by Prostate proportion



| Organ | Number Recorded | Percentage of Total (24,343) | Mean Age at Diagnosis & Range | Males | Females |
|-------------------|--------------------|---------------------------------|----------------------------------|-------|---------|
| Prostate | 12892 | 53.0% | 72.6; 18 – 103 | 12892 | - |
| Bladder | 7549 | 31.0% | 71.6; 17 – 100 | 5574 | 1948 |
| Kidney | 2037 | 8.4% | 64.8; 7 – 100 | 1317 | 714 |
| Testis | 980 | 4.0% | 39.3; 15 – 92 | 980 | - |
| Pelvis/Ureter | 371 | 1.5% | 70.4; 22 – 94 | 235 | 134 |
| Penis | 221 | 0.9% | 65.3; 28 - 100 | 221 | - |
| Urethra | 33 | 0.14% | 72.8; 52 – 88 | 24 | 8 |
| Prostatic Urethra | 34 | 0.14% | 70.9; 53 – 88 | 34 | - |
| Other | 90 | 0.37% | 60.5; 24 – 90 | 60 | 29 |
| Not recorded | 136 | 0.6% | 71.3; 19 – 95 | 111 | 23 |

Overall Data by Organ

Chart 8

"Other" Organ Tumours

The 90 "Others" included:

12 Spermatic cord / Scrotum / Paratesticular
11 Adrenal tumours
7 Vaginal / Cervix / Ovarian / Endometrial
5 Retroperitoneum
5 Bones
4 Colon
3 Liver

| Region | | | |
|---------------------|----------------------|-----------|----------|
| | Total Registrations* | National | BAUS % |
| | BAUS | figures** | National |
| England: | | | |
| EA & Oxford | 1604 | 3700 | 43.4% |
| Northern & Yorks*** | 3613 | 3946 | 91.6% |
| North Thames | 2600 | 4222 | 61.6% |
| North Western | 1620 | 4670 | 34.7% |
| South Thames | 2855 | 4722 | 60.5% |
| South Western | 3472 | 5829 | 59.6% |
| Trent | 2827 | 3603 | 78.5% |
| West Midlands | 2798 | 3990 | 70.1% |
| Total England | 21389 | 34682 | 61.7% |
| Scotland | 997 | 3894 | 25.6% |
| Wales | 1288 | 2526 | 51.0% |
| Northern Ireland | 370 | 834 | 44.4% |
| Total UK | 24044 | 41936 | 57.3% |

Total Registrations per Region - 1 Prostate, Bladder, Kidney, Testis, Pelvis/Ureter & Penile Tumours*

**England : cancer statistics - registrations 1995 - 1997, England. Series MBI no. 28 - London TSO, 2001 Wales: Welsh Cancer Intelligence & Surveillance Unit - 1998

Scotland:Scotlish Cancer Registry, Scotlish Cancer Intelligence Unit,Information & Statistics Division,The National Health Service in Scotland - 1997 Northern Ireland:Northern Ireland Cancer Registry - 1997 - www.qub.ac.uk/nicr *** Known under registrations from former Northern Region

Chart 10

| | _ | | | | | 8 | | | |
|------------------|----------|----------|----------|---------|----------|----------|--------|----------|----------|
| Region | Prostate | | | Bladder | | | Kidney | | |
| | BAUS | National | BAUS % | BAUS | National | BAUS % | BAUS | National | BAUS % |
| | | figures* | National | | figures* | National | | figures* | National |
| England: | | | | | | | | | |
| EA & Oxford | 910 | 2081 | 43.7% | 464 | 1003 | 46.3% | 117 | 390 | 30.0% |
| Northern & Yorks | 1745 | ***2044 | 85.4% | 1250 | ***1093 | 114.4% | 304 | 582 | 52.2% |
| North Thames | 1442 | 2324 | 62.0% | 840 | 1174 | 71.6% | 174 | 468 | 37.2% |
| North Western | 858 | 2443 | 35.1% | 530 | 1371 | 38.7% | 122 | 571 | 21.4% |
| South Thames | 1688 | 2742 | 61.6% | 779 | 1144 | 68.1% | 214 | 540 | 39.6% |
| South Western | 1946 | 2989 | 65.1% | 1032 | 1908 | 54.1% | 278 | 592 | 47.0% |
| Trent | 1529 | 1600 | 95.6% | 869 | 1359 | 64.0% | 265 | 441 | 60.0% |
| West Midlands | 1497 | 1978 | 75.7% | 869 | 1335 | 65.1% | 268 | 426 | 62.9% |
| Total England | 11615 | 18201 | 63.8% | 6633 | 10387 | 64.0% | 1742 | 4010 | 43.4% |
| Scotland | 417 | 1813 | 23.0% | 392 | 1224 | 32.0% | 116 | 542 | 21.4% |
| | | | | | | | | | |
| Wales | 704 | 1248 | 56.4% | 406 | 842 | 48.2% | 121 | 300 | 40.3% |
| | | | | | | | | | |
| Northern Ireland | 154 | 445 | 34.6% | 115 | **174 | 66.1% | 58 | 144 | 40.3% |
| | | | | | | | | | 101070 |
| Total UK | 12890 | 21707 | 59.4% | 7546 | 11403 | 66.2% | 2037 | 4996 | 41.0% |
| | | | | | | | | | |
| | | | | | | | | | |

Total Registrations per Region - 2

*England : cancer statistics - registrations 1995 - 1997, England. Series MBI no. 28 - London TSO, 2001

Wales: Welsh Cancer Intelligence & Surveillance Unit - 1998
 Scotland:Scottish Cancer Registry, Scottish Cancer Intelligence Unit, Information & Statistics Division, The National Health Service in Scotland - 1997
 Northern Ireland:Northern Ireland Cancer Registry - 1997 - www.qub.ac.uk/nicr
 *** Known under registrations from former Northern Region

| Region | Testis | | | Pelvis/ | | | Penis | | |
|------------------|--------|----------|----------|---------|----------|----------|-------|----------|----------|
| U | BAUS | National | BAUS % | Ureter | National | BAUS % | BAUS | National | BAUS % |
| | | figures* | National | BAUS | figures* | National | | figures* | National |
| | | 0 | | | 0 | | | 0 | |
| England: | | | | | | | | | |
| EA & Oxford | 63 | 117 | 53.8% | 30 | 73 | 41.1% | 20 | 36 | 55.6% |
| Northern & Yorks | ***209 | 182 | 114.8% | 69 | ***0 | | 36 | 45 | 80.0% |
| North Thames | 78 | 189 | 41.3% | 48 | 33 | 145.5% | 18 | 34 | 52.9% |
| North Western | 69 | 164 | 42.1% | 22 | 82 | 26.8% | 19 | 39 | 48.7% |
| South Thames | 123 | 205 | 60.0% | 28 | 58 | 48.3% | 23 | 33 | 69.7% |
| South Western | 137 | 212 | 64.6% | 57 | 77 | 74.0% | 22 | 51 | 43.1% |
| Trent | 112 | 117 | 95.7% | 25 | 53 | 47.2% | 27 | 33 | 81.8% |
| West Midlands | 86 | 145 | 59.3% | 52 | 66 | 78.8% | 26 | 40 | 65.0% |
| Total England | 877 | 1411 | 62.2% | 331 | 442 | 74.9% | 191 | 311 | 61.4% |
| Scotland | 45 | 190 | 23.7% | 15 | 89 | 16.9% | 12 | 36 | 33.3% |
| | | | | | | | | | |
| Wales | 26 | 86 | 30.2% | 20 | 27 | 74.1% | 11 | 23 | 47.8% |
| | | | | | | | | | |
| Northern Ireland | 31 | 47 | 65.9% | 5 | 16 | 31.3% | 7 | 8 | 87.5% |
| | | | | | | | | | |
| Total UK | 979 | 1734 | 56.5% | 371 | 574 | 64.6% | 221 | 378 | 58.5% |
| | | | | | | | | | |

Total Registrations per Region - 3

* England : cancer statistics - registrations 1995 - 1997, England. Series MBI no. 28 - London TSO, 2001 Wales: Welsh Cancer Intelligence & Surveillance Unit - 1998 Scotland:Scottish Cancer Registry,Scottish Cancer Intelligence Unit,Information & Statistics Division,The National Health Service in Scotland - 1997 Northern Ireland:Northern Ireland Cancer Registry - 1997 - www.qub.ac.uk/nicr *** Known under registrations from former Northern Region

Chart 12

Laterality by Organ

| Organ | Total Number Recorded | Laterality recorded & % of total | Left Side * | Right Side * |
|---------------|--------------------------|--|--------------|--------------|
| Kidney | 2037 | 1874 92.0% | 912 48.7% | 962 |
| Testis | 980 | 880 89.8% | 426 48.4% | 454 |
| Pelvis/Ureter | 371 | 309 83.3% | 151 48.9% | 158 |

 * Number and percentage of those where laterality was recorded

- Total number of synchronous bilateral tumours = 8
 5 Kidney
 3 Testicular
- Total number of Tumours registered twice = 41 (Tertiary referral from another centre or another consultant in the same centre). Only included once in all analyses
- Total number of patients where there were tumours in different organs in the same year = 254 (including 4 patients with 3 separate tumours)

Chart 14



Percentage Age Distribution - Prostate Tumours BAUS 2000 median: 73 Years; Range 18 -103 (n= 12,596*)

* Age could be calculated when both date of birth and diagnosis date were recorded = 12,596/12,892 = 97.7% ** National figures are for 1997 (England, Scotland, Northern Ireland) and 1998 (Wales)



Percentage Age Distribution - Bladder Tumours - Males BAUS 2000 median Males: 72 Years; Range 18 -100 (n= 5,449*)

* Sex was recorded in 7522/7549 (99.6%) bladder tumours (5574 males & 1948 females)

Age could be calculated when both date of birth and diagnosis date were recorded = 5449/5574 (98%) & 1897/1948 (97.4%)

** National figures are for 1997 (England, Scotland, Northern Ireland) and 1998 (Wales)

Chart 16





* Sex was recorded in 7522/7549 (99.6%) bladder tumours (5574 males & 1948 females)

Age could be calculated when both date of birth and diagnosis date were recorded = 5449/5574 (98%) & 1897/1948 (97.4%) ** National figures are for 1997 (England, Scotland, Northern Ireland) and 1998 (Wales)

Percentage Age Distribution - Kidney Tumours- Males BAUS 2000 median Males : 65 Years; Range 7 -100 (n= 1,260*)



* Sex was recorded in 2031/2037 (99.7%) kidney tumours (1317 males & 714 females)

Age could be calculated when both date of birth and diagnosis date were recorded = 1260/1317 (95.7%) & 695/714 (97.3%)

** National figures are for 1997 (England, Scotland, Northern Ireland) and 1998 (Wales)







* Sex was recorded in 2031/2037 (99.7%) kidney tumours (1317 males & 714 females)

Age could be calculated when both date of birth and diagnosis date were recorded = 1260/1317 (95.7%) & 695/714 (97.3%) ** National figures are for 1997 (England, Scotland, Northern Ireland) and 1998 (Wales)



Percentage Age Distribution - Testicular Tumours BAUS 2000 median: 37 Years; Range 15 -92 (n= 943*)

* Age could be calculated when both date of birth and diagnosis date were recorded = 943/980 (96%).
 ** National figures are for 1997 (England, Scotland, Northern Ireland) and 1998 (Wales)

Chart 20

Percentage Age Distribution - Testicular Tumours

Seminoma median age : 39 years; Range 18 -87; Mean 40.6 years (n = 510*) Teratoma median age : 30 years; Range 15 - 74; Mean 32.3 years (n = 200*) Combined seminoma/teratoma median age : 32 years; Range 17 -65; Mean 33.2 years (n = 90*)



* Age could be calculated when both date of birth and diagnosis date were recorded = 943/980 (96%). Histology was reported in 928 of these tumours. (928/943 = 98.4%), 128 of these were histologies other than the above groups

Percentage Age Distribution - Pelvis/Ureteric Tumours - Males BAUS 2000 median Males : 71 Years; Range 22 -93 (n= 230*)



* Sex was recorded in 369/371 (99.5%) pelvis/ureteric tumours (235 males & 134 females)

Age could be calculated when both date of birth and diagnosis date were recorded = 230/235 (97.8%) & 132/134 (98.5%)

** National figures are for 1997 (England, Scotland, Northern Ireland) and 1998 (Wales)

Chart 22

Percentage Age Distribution - Pelvis/Ureteric Tumours - Females BAUS 2000 median Females : 75 Years; Range 38 -94 (n=132*)



* Sex was recorded in 369/371 (99.5%) pelvis/ureteric tumours (235 males & 134 females)

Age could be calculated when both date of birth and diagnosis date were recorded = 230/235 (97.8%) & 132/134 (98.5%) ** National figures are for 1997 (England, Scotland, Northern Ireland) and 1998 (Wales)



Percentage Age Distribution - Penile Tumours BAUS 200 median: 67 Years; Range 28 -100 (n= 217*)

* Age could be calculated when both date of birth and diagnosis date were recorded = 217/221 = 98.2% ** National figures are for 1997 (England, Scotland, Northern Ireland) and 1998 (Wales)

B. Referral Source & Time between Referral, First Consultation & Diagnosis Chart 24

| Organ | GP | | Urologist | | Other | | Not | |
|--------------------------|-------|------|-----------|------|-------|------|----------|------|
| | | | | | | | Recorded | |
| | N | % | N | % | N | % | N | % |
| Prostate | 9727 | 75.5 | 701 | 5.4 | 1420 | 11.0 | 1044 | 8.1 |
| Bladder | 5636 | 74.6 | 337 | 4.5 | 915 | 2.1 | 661 | 8.8 |
| Kidney | 977 | 47.9 | 156 | 7.7 | 748 | 36.7 | 156 | 7.7 |
| Testis | 670 | 68.4 | 118 | 12.0 | 129 | 13.2 | 63 | 6.4 |
| Pelvis/Ureter | 241 | 65.0 | 33 | 8.9 | 65 | 17.5 | 32 | 8.6 |
| Penis | 135 | 61.1 | 20 | 9.1 | 50 | 22.6 | 16 | 7.2 |
| Urethra | 20 | 60.6 | 3 | 9.0 | 5 | 15.2 | 5 | 15.2 |
| Prostatic Urethra | 19 | 55.9 | 3 | 8.8 | 4 | 11.8 | 8 | 23.5 |
| Other or Not Recorded | 105 | 46.5 | 7 | 3.1 | 41 | 8.1 | 73 | 14.3 |
| Totals | 17530 | 72.0 | 1378 | 5.7 | 3377 | 13.9 | 2058 | 8.4 |

Source of Referral by Organ

Chart 25

"Other" Sources of Referral by Organ included:

| | Prostate | Bladder | Kidney | Testis | Pelvis/ Ureter | Penis | Urethra | Prostatic Urethra |
|---|----------|---------|--------|--------|-------------------|-------|---------|----------------------|
| Consultant Physicians | 434 | 230 | 294 | 18 | 18 | 24 | - | - |
| Consultant Surgeons | 360 | 157 | 196 | 34 | 15 | 8 | 1 | 2 |
| A & E | 263 | 224 | 76 | 31 | 12 | 9 | 1 | 2 |
| Gynaecology | - | 130 | 24 | - | 6 | - | 3 | - |
| Care of Elderly | 75 | 28 | 17 | - | - | 1 | - | - |
| Haematology | 15 | 16 | 26 | 1 | 3 | - | - | - |
| Oncologists | 19 | 7 | 29 | 15 | 1 | 3 | - | - |
| Discovered during Urological Follow-up | 59 | 26 | 3 | 1 | 5 | 1 | - | - |
| Radiology | 4 | 4 | 15 | 9 | 1 | 1 | - | - |
| Incidental Finding | 9 | 10 | 8 | - | - | - | - | - |

| Region | GP | | Urologist | | Other | | Not | |
|------------------|-------|------|-----------|------|-------|------|----------|------|
| | | | | | | | Recorded | |
| | N | % | Ν | % | Ν | % | N | % |
| England: | | | | | | | | |
| EA & Oxford | 1321 | 81.6 | 54 | 3.3 | 97 | 6.0 | 147 | 9.1 |
| Northern & Yorks | 2252 | 61.8 | 474 | 13.0 | 461 | 12.7 | 456 | 12.5 |
| North Thames | 1683 | 64.1 | 87 | 3.3 | 416 | 15.9 | 438 | 16.7 |
| North Western | 1112 | 68.2 | 223 | 13.7 | 269 | 16.5 | 27 | 1.7 |
| South Thames | 2053 | 71.2 | 77 | 2.7 | 389 | 13.5 | 365 | 12.6 |
| South Western | 2871 | 81.0 | 113 | 3.2 | 352 | 9.9 | 208 | 5.9 |
| Trent | 2227 | 77.9 | 80 | 2.8 | 448 | 15.7 | 102 | 3.6 |
| West Midlands | 2080 | 72.9 | 180 | 6.3 | 475 | 16.6 | 117 | 4.1 |
| Total England | 15599 | 72.0 | 1288 | 6.0 | 2907 | 13.4 | 1860 | 8.6 |
| Scotland | 748 | 74.4 | 43 | 4.3 | 178 | 17.7 | 36 | 3.6 |
| Wales | 945 | 72.4 | 38 | 2.9 | 199 | 15.2 | 124 | 9.5 |
| Northern Ireland | 235 | 63.2 | 9 | 2.4 | 90 | 24.2 | 38 | 10.2 |
| Total UK | 17527 | 72.0 | 1378 | 5.7 | 3374 | 13.9 | 2058 | 8.4 |

Source of Referral by Region Region could be identified in 24337/24343 tumours (99.9%)

N.B. In the following charts "Time to consultation" means the time between referral and first consultation and "Time to diagnosis" means the time between first consultation and diagnosis date. All times have been calculated excluding weekends but it was not possible to exclude any public / NHS holidays.

Chart 27





* Times were calculated when dates of referral, consultation and diagnosis were known and diagnosis date was not before referral date (N = 18,552/24,343 = 76.2% tumours Referral Source was recorded in 18,097/18,552 cases:

GP - 14837/17530 =84.6%; Urologist 626/1378 = 45.4%; Other 2634/3336 = 79.0%).

| Times to First Consultation and Diagnosis in Days |
|---|
| when referred by GP (14,837 tumours) |
| Excluding those diagnosed before Referral |

| Days to Diagnosis | Time to first | Time from first |
|-------------------|---------------|-----------------|
| | Consultation | consultation to |
| | | Diagnosis |
| 0 * | 347 – 2.3% | 238 - 1.6% |
| 1 – 14 | 5554 - 37.4% | 4949 - 33.4% |
| 15 – 28 | 4117 – 27.7% | 3174 – 21.4% |
| 29 - 60 | 3402 - 22.9% | 3432 – 23.1% |
| More than 60 days | 1417 – 9.6% | 3044 - 20.5% |

* = the number seen either on the day

of referral or diagnosed at first consultation

Chart 29

Times to First Consultation and Diagnosis in Days when referred by a Urologist (626 tumours) Excluding those diagnosed before Referral

| Days to Diagnosis | Time to first Consultation | Time from first consultation to Diagnosis |
|-------------------|-------------------------------|---|
| 0 * | 38 - 6.1% | 19 – 3.0% |
| 1 – 14 | 307 – 49.0% | 308 - 49.2% |
| 15 – 28 | 138 - 22.0% | 114 – 18.2% |
| 29 - 60 | 96 - 15.3% | 94 – 15.0% |
| More than 60 days | 47 – 7.5% | 91 – 14.5% |

* = the number seen either on the day

of referral or diagnosed at first consultation

Times to First Consultation and Diagnosis in Days when referred by "Other"source (2634 tumours) Excluding those diagnosed before Referral

| Days to Diagnosis | Time to first | Time from first |
|-------------------|---------------|-----------------|
| | Consultation | consultation to |
| | | Diagnosis |
| 0 * | 262 - 9.9% | 62 – 2.4% |
| 1 – 14 | 1606 - 61.0% | 1266 - 48.1% |
| 15 – 28 | 364 - 13.8% | 462 – 17.5% |
| 29 - 60 | 282 - 10.7% | 450 – 17.1% |
| More than 60 days | 120 – 4.6% | 394 – 14.9% |

* = the number seen either on the day of referral or diagnosed at first consultation

Chart 31

Median Time to First Consultation and Diagnosis in Days by Region for tumours referred by GP Excluding tumours diagnosed before Referral*



* Times were calculated when region (n = 24,337), dates of referral, consultation and diagnosis were known and diagnosis date was not before referral date (N = 18,552/24,343 = 76.2% tumours)

| Times to First Consultation and Diagnosis in Days by Region for tumours |
|---|
| referred by GP |
| Excluding tumours diagnosed before Referral |

| Excluding | tumours | ulagiloseu | Deloie | Kelell |
|-----------|---------|------------|--------|--------|
| Time to | | | т | ima ta |

| | Consultation | Consultation | | | Diagnosis | | |
|------------------------------------|--------------|--------------|---------------|--------|-----------|---------------|--|
| Region | Median | Mean | Range (0-95%) | Median | Mean | Range (0-95%) | |
| EA & Oxford (965 tumours) | 18 | 27.4 | 0 – 68 days | 21 | 42.0 | 0 – 163 days | |
| Northern & Yorks (1962 tumours) | 17 | 26.4 | 0 – 81 days | 22 | 48.9 | 0 – 159 days | |
| North Thames (1435 tumours) | 23 | 32.9 | 0 – 96 days | 29 | 79.5 | 0 – 302 days | |
| North Western (943 tumours) | 17 | 25.9 | 0 – 79 days | 24 | 60.0 | 0 – 235 days | |
| South Thames (1654 tumours) | 21 | 31.5 | 0 – 85 days | 25 | 66.9 | 0 – 261 days | |
| South Western (2324 tumours) | 17 | 25.6 | 0 – 68 days | 24 | 55.1 | 0 – 187 days | |
| Trent (2051 tumours) | 18 | 27.1 | 0 – 88 days | 24 | 55.2 | 0 – 178 days | |
| West Midlands (1822 tumours) | 19 | 26.8 | 0 - 71 days | 25 | 59.8 | 0 – 209 days | |
| Total England (13156 tumours) | 19 | 27.8 | 0 – 80 days | 24 | 58.4 | 0 – 205 days | |
| Scotland (655 tumours) | 24 | 32.4 | 0 – 87 days | 24 | 50.9 | 0 – 156 days | |
| Wales (818 tumours) | 19 | 31.8 | 0 – 108 days | 24 | 75.6 | 0 – 293 days | |
| Northern Ireland (205 tumours) | 15 | 24.3 | 0 – 77 days | 16 | 78.4 | 1 – 391 days | |

Chart 33





* Times were calculated when dates of referral, consultation and diagnosis were known and diagnosis date was not before referral date (N = 18,552/24,343 = 76.2% tumours -Bladder = 5900/7549 = 78.2%; Kidney = 1449/2037 = 71.1%; Testis = 710/980 = 72.4%; Pelvis/Ureter = 285/371 = 76.8%; Penis = 168/221 = 76.0%. Prostate tumours were only included if they > T1b = 8443/10757 = 78.5%

Times to First Consultation and Diagnosis in Days by Prostate (8443 tumours) Excluding tumours diagnosed before Referral and those with T1a or T1b

| Days to Diagnosis | Time to first Consultation | Time from first consultation to Diagnosis |
|-------------------|-------------------------------|---|
| 0 * | 248 - 2.9% | 166 – 2.0% |
| 1 – 14 | 3087 - 36.6% | 2922 - 34.6% |
| 15 – 28 | 2264 - 26.8% | 1620 – 19.2% |
| 29 - 60 | 1971 – 23.3% | 1841–21.8% |
| More than 60 days | 873 - 10.3% | 1894 – 22.4% |

* = the number seen either on the day of referral or diagnosed at first consultation

Chart 35

Times to First Consultation and Diagnosis in Days by Bladder (5900 tumours) Excluding those diagnosed before Referral

| Days to Diagnosis | Time to first Consultation | Time from first consultation to Diagnosis |
|-------------------|-------------------------------|---|
| 0 * | 206 - 3.5% | 109 – 1.8% |
| 1 – 14 | 2336 - 39.6% | 2191 –37.1% |
| 15 – 28 | 1665 - 28.2% | 1360 - 23.1% |
| 29 - 60 | 1225 - 20.8% | 1389 – 23.5% |
| More than 60 days | 468 – 7.9% | 851 – 14.4% |

* = the number seen on the day

of referral or diagnosed at first consultation

Times to First Consultation and Diagnosis in Days by Kidney (1449 tumours) Excluding those diagnosed before Referral

| Days to Diagnosis | Time to first | Time from first |
|-------------------|---------------|-----------------|
| | Consultation | consultation to |
| | | Diagnosis |
| 0 * | 78 – 5.4% | 27 – 1.9% |
| 1 – 14 | 871 – 60.1% | 485 – 33.5% |
| 15 – 28 | 293 - 20.2% | 381 - 26.3% |
| 29 - 60 | 142 – 9.8% | 356 - 24.6% |
| More than 60 days | 65 – 4.5% | 200 - 13.8% |

* = the number seen on the day

of referral or diagnosed at first consultation

Chart 37

Times to First Consultation and Diagnosis in Days by Testis (710 tumours) Excluding those diagnosed before Referral

| Days to Diagnosis | Time to first Consultation | Time from first consultation to |
|-------------------|-------------------------------|------------------------------------|
| | | Diagnosis |
| 0 * | 37 – 5.2% | 10 – 1.4% |
| 1 – 14 | 533 - 75.1% | 525 - 73.9% |
| 15 – 28 | 69 – 9.7% | 92 - 13.0% |
| 29 - 60 | 54 – 7.6% | 49 – 6.9% |
| More than 60 days | 17 – 2.4% | 34 – 4.8% |

* = the number of seen on the day

of referral or diagnosed at first consultation

C. Histology Chart 38

| Organ | Confirmation Obtained | | Confirmation Not Obtained | | Not Recorded | |
|--------------------------------|--------------------------|------|------------------------------|------|-----------------|------|
| | N | % | Ν | % | Ν | % |
| Prostate (12892) | 11937 | 92.6 | 754 | 5.8 | 201 | 1.6 |
| Bladder (7549) | 7300 | 96.7 | 121 | 1.6 | 128 | 1.7 |
| Kidney (2037) | 1694 | 83.2 | 297 | 14.6 | 46 | 2.3 |
| Testis (980) | 954 | 97.3 | 7 | 0.7 | 19 | 1.9 |
| Pelvis/Ureter (371) | 334 | 90.0 | 34 | 9.2 | 3 | 0.8 |
| Penis (221) | 217 | 98.2 | 4 | 1.8 | 0 | 0 |
| Urethra (33) | 32 | 97.0 | 1 | 3.0 | 0 | 0 |
| Prostatic Urethra (34) | 33 | 97.1 | 1 | 2.9 | 0 | 23.5 |
| Other or Not Recorded (226) | 126 | 55.7 | 14 | 6.2 | 86 | 38.1 |
| Totals (24343) | 22627 | 93.0 | 1233 | 5.1 | 483 | 1.9 |

Histological Confirmation of Diagnosis by Organ

Chart 39

Tumours for which Histological confirmation was not obtained Prostate tumours only Total tumours = 754 / 12892 = 5.8 %* Median age:80 years, Range 52 - 99

| Known Treatment Intention | Total number and percentage | Mean PSA at Diagnosis |
|------------------------------|-----------------------------|-----------------------|
| Curative | 30 - 4.3% | 274.5 |
| Palliative | 587 - 84.3% | 828 |
| Surveillance | 79 – 11.4% | 183 |

 \ast The treatment intention was recorded in 696 / 754 (92.3%) tumours where histological confirmation was not obtained

Known Treatment Intention and Type Prostate Tumours for which Histological confirmation was not obtained - Total Numbers Reported with those as only Treatment in ()

| | a | D 111 (1 | a |
|--|----------|-------------------|--------------|
| Treatment | Curative | Palliative | Surveillance |
| | | | |
| Surgery: | | | |
| Endoscopic Resection | 3 (1) | 14 (1) | 2 (2) |
| Endoscopic Resection + 1 shot intravesical | | | |
| chemotherapy | - | - | 1 (1) |
| Radical Ablative Surgery | 2 (2) | 2 (1) | - |
| | | | |
| Organ Conserving Surgery | - | 2 (2) | 1 (1) |
| | | | |
| Other Surgery | - | 6 (2) | - |
| | | | |
| Radiation Therapy | 11 (6) | 36 (9) | - |
| | | | |
| Systemic Chemotherapy | - | 2 (2) | - |
| TI TI | 22 (15) | <i>550 (511</i>) | E (E) |
| normone Therapy | 25 (15) | (511) | 5 (5) |
| Other Treatment | | 4 | 4 (4) |
| Other I reathent | - | - | 4 (4) |
| | 1 | | |

Chart 41

Tumours for which Histological confirmation was not obtained Kidney tumours only Total tumours = 297 / 2037 = 14.6 %* Median age Males :73 years, Range 19 - 94 Median age Females :75 years, Range 41 - 94

| Known Treatment Intention | Male | Female |
|------------------------------|------------|------------|
| Curative | 33 - 19.1% | 13 - 13.0% |
| Palliative | 90 - 52.0% | 52 - 52.0% |
| Surveillance | 50 - 28.9% | 35 - 35.0% |

* Sex was recorded in 296/297 tumours and the treatment intention was recorded in 173 /189 males (91.5%) and 100/107 females (93.5%) where histological confirmation was not obtained

Known Treatment Intention and Type Kidney Tumours for which Histological confirmation was not obtained - Total Numbers Reported with those as only Treatment in ()

| Treatment | Curative | Palliative | Surveillance |
|--------------------------|----------|------------|--------------|
| Surgery: | | | |
| Endoscopic Resection | 1 (1) | - | - |
| Radical Ablative Surgery | 37 (31) | 1 | - |
| Organ Conserving Surgery | 2 (2) | - | - |
| Other Surgery | 2 (1) | 6 (2) | 1 (1) |
| Radiation Therapy | 1 (1) | 15 (9) | - |
| Systemic Chemotherapy | 2 (1) | 6 (6) | - |
| Hormone Therapy | - | 22 (18) | 2 (2) |
| Immunotherapy | 2 | 21 (15) | - |
| Other Treatment | 3 | 36 (29) | 8 (8) |

Chart 43

Known Histology by Organ

| | Prostate | Bladder | Kidney | Testis | Pelvis/ Ureter | Penis | Urethra | Prostatic Urethra |
|------------------------------|----------------|---------------|----------------|--------------|-------------------|--------------|-------------|----------------------|
| Adenocarcinoma | 11678 99.0% | 107 1.5% | 1395 *84.0% | 8 0.9% | 8 2.4% | 4 1.9% | 10 31.3% | 6 18.8% |
| тсс | 68 0.6% | 6791 94.0% | 127 7.7% | 4 0.4% | 312 95.4% | 1 0.5% | 15 46.9% | 24 75.0% |
| SCC | 8 0.1% | 126 1.7% | 1 0.1% | 2 0.2% | 1 0.3% | 173 81.2% | 2 6.3% | - |
| Mixed TCC / SCC | - | 60 0.8% | 1 0.1% | 15 1.6% | 2 0.6% | - | - | 1 3.1% |
| Seminoma | - | - | - | 520 55.2% | - | 1 0.5% | - | - |
| Teratoma | - | - | - | 205 21.8% | - | - | - | - |
| Mixed Seminoma / Teratoma | - | - | - | 86 9.1% | - | - | - | - |
| Other | 51 0.4% | 141 2.0% | 133 8.0% | 99 10.5% | 3 0.9% | 34 16.0% | 5 15.6% | 1 3.1% |

*N.B. Includes 1050 renal cell carcinomas

| | Prostate | Bladder | Kidney | Testis | Penis |
|--|----------|---------|--------|--------|-------|
| Carcinoma in situ | 16 | 26 | - | - | 8 |
| Oncocytoma | 1 | - | 19 | - | - |
| Sarcoma/Liposarcoma /Leiomyosarcoma | 4 | 19 | 13 | 1 | 1 |
| Haematological cancers | 3 | 6 | 13 | 18 | - |
| Leydig cell | - | - | - | 26 | - |
| Adenocarcinoma & TCC | - | 3 | - | - | - |
| Sertoli | - | - | - | 7 | - |
| Intratubular germ cell | - | - | - | 5 | - |
| Melanoma | - | - | - | 1 | 3 |
| Small cell ca/papillary renal cell / spindle cell | 4 | 11 | 55 | - | 1 |

"Other" Histologies reported included:

Chart 45

| Organ | Radiology | Cytology | Tumour Marker | Clinical | Other |
|----------------------------------|-----------|----------|------------------|----------|-------|
| Prostate (754 tumours) | 147 | 36 | 542 | 50 | 48 |
| Bladder (121 tumours) | 28 | 19 | 1 | 72 | 21 |
| Kidney (297 tumours) | 263 | 6 | - | 79 | 14 |
| Pelvis/Ureter (34 tumours) | 22 | 9 | 2 | 6 | 3 |
| Testis (7 tumours) | 5 | - | 2 | 3 | - |
| Penis (4 tumours) | 1 | 2 | - | 2 | - |
| Urethra (1 patient) | - | - | 1 | - | - |
| Prostatic Urethra (1 patient) | - | - | - | 1 | - |

Basis of Diagnosis when Histological Confirmation Not Obtained (1233 tumours - 5.1% of total)

N.B. More than one method might be used for each tumour

| 1 01 0 | entage (| × 100 | | 10 11 | Direr | cintiat | |
|---------------------------|----------|-------|----------|-------|-------|---------|-----------------------|
| Organ | Well | | Moderate | | Poor | | % of Total Tumours |
| (Number Known) | Ν | % | N | % | Ν | % | Reported |
| Prostate (11134) | 1923 | 17.3 | 6140 | 55.1 | 3071 | 27.6 | 86.4 |
| Bladder (6791) | 1966 | 29.0 | 2403 | 35.4 | 2422 | 35.7 | 90.0 |
| Kidney (1309) | 381 | 29.1 | 608 | 46.4 | 320 | 24.4 | 64.3 |
| Testis (492) | 237 | 48.2 | 135 | 27.4 | 20 | 24.4 | 50.2 |
| Pelvis/Ureter (321) | 59 | 18.4 | 136 | 42.4 | 126 | 39.2 | 86.5 |
| Penis (174) | 62 | 35.6 | 75 | 43.1 | 37 | 21.3 | 78.7 |
| Urethra (27) | 4 | 14.8 | 13 | 48.1 | 10 | 37.0 | 81.8 |
| Prostatic Urethra (32) | 8 | 25.0 | 10 | 31.3 | 14 | 43.8 | 94.1 |

Known Differentiation by Organ Percentage & Total of Known Differentiation

D. Staging

Participants were asked to return both clinical and pathological TNM categories using the 1997 version of the TNM classification for Urological tumours which were included in the data dictionary sent to all participants.

In order to make interpretation of the resultant information easier each patient was staged, wherever possible, using the classifications as shown in the following charts. If the pathological TNM categories were given and appropriate then these were used for the staging, failing this the clinical TNM categories were used.

Unfortunately less than 50% of the returns had either the full pathological TNM or clinical TNM categories and an estimate had to be made from what information was provided. (Many forms did not include any N and M categories.)

The data on the following charts should therefore be regarded with caution.

Chart 47

| Known Staging | Total Known | |
|---------------------------------------|----------------------------------|------|
| | Ν | % |
| Stage I (T1 N0 M0) | 614 | 33.8 |
| Stage II (T2 N0 M0) | 427 | 23.5 |
| Stage III (T1, T2, T3 N0,N1 M0) | 449 | 24.7 |
| Stage IV (T4 N0 N1 M0 | 328 | 18.0 |
| Any T N2 M0 Any T any N M1) | including 215 with metastases | 11.8 |

Staging of Kidney Tumours A total of 2037 Kidney Tumours were reported Staging could be estimated in 1818 (89.2%)

N.B. A pathological staging for Kidney tumours was only included for those where radical or organ conserving surgery was performed (n =1574)

Staging of Kidney Tumours Comparison of clinical & pathological staging Staging could be compared in 53.5% (1090/2037) of the total reported



Chart 49

Staging of Pelvis / Ureteric Tumours A total of 371 Tumours were reported Staging could be estimated in 318 (85.7%)

| Known Staging | Total Known | |
|--|---------------------------------|------|
| | Ν | % |
| Stage 0a (Ta N0 M0) | 62 | 19.5 |
| Stage 0is (Tis N0 M0) | 2 | 6.3 |
| Stage I (T1 N0 M0) | 95 | 29.9 |
| Stage II (T2 N0 M0) | 62 | 19.5 |
| Stage III (T3 N0 M0) | 52 | 16.4 |
| Stage IV (T4 N0 M0 | 45 | 14.2 |
| Any T N1, N2, N3 M0 Any T any N M1) | including 11 with metastases | 3.5 |

N.B. A pathological staging for Pelvis / Ureteric tumours was only included for those where radical or organ conserving surgery was performed (n =301)

Staging of Bladder Tumours A total of 7549 BladderTumours were reported Staging could be estimated in 5839 (77.3%)

| Known Staging | Total Known | |
|--|----------------------------------|------|
| | Ν | % |
| Stage 0a (Ta N0 M0) | 2011 | 34.4 |
| Stage 0is (Tis N0 M0) | 90 | 1.5 |
| Stage I (T1 N0 M0) | 1879 | 32.2 |
| Stage II (T2a, 2b N0 M0) | 893 | 15.3 |
| Stage III (T3a, 3b, 4a N0 M0) | 668 | 11.4 |
| Stage IV (T4b N0 M0 | 298 | 5.1 |
| Any T N1, N2, N3 M0 Any T any N M1) | including 108 with metastases | 1.8 |

N.B. A pathological staging for Stage II, III or IV Bladder tumours was only included for tumours where radical surgery was performed (n =375)

Chart 51

Staging of Bladder Tumours Comparison of clinical & pathological staging Staging could be compared in 47.5% (3585/7549) of the total reported



Staging of Prostate Tumours A total of 12892 Prostate Tumours were reported Staging could be estimated in 10402 (80.7%)

| Known Staging | Total Known | |
|--|-----------------|------|
| | Ν | % |
| Stage I | 141 | 1.4 |
| (T1a N0 M0 | | |
| Well Differentiated) | | |
| Stage II | t1 - 553 | 5.3 |
| (T1a N0 M0 Mod or Poor differentiation | t1a - 209 | 2.0 |
| T1b, 1c, 1, 2, N0 M0 Any | t1b - 329 | 3.2 |
| differentiation) | t1c - 1636 | 15.7 |
| | t2 - 3080 | 29.6 |
| Stage III | 2505 | 24.1 |
| (T3 N0 M0 Any differentiation) | | |
| Stage IV | 1949 | 18.7 |
| (T4 N0 M0 Any differentiation | | |
| Any T N1 M0 Any differentiation | including 1267 | 12.2 |
| Any T Any N M1 Any differentiation) | with metastases | |

N.B. A pathological staging for Prostate tumours was only included for those where radical or organ conserving surgery was performed (n =1267)

Chart 53

Staging of Prostate Tumours Comparison of clinical & pathological staging







* Age could be calculated when both date of birth and diagnosis date were recorded

Chart 55

| Prostate | Cancers | reported | 1998 - | 2000 |
|----------|---------|----------|--------|------|
|----------|---------|----------|--------|------|

| | 1998 (6 months only) | 1999 | 2000 |
|-------------------------------------|--------------------------|--------------|------------------------|
| Total number reported | 2909 | 9781 | 12892 |
| Median age at diagnosis | 74 | 73 | 73 |
| Number having T1c | 250 - 8.6% | 1366 - 14.0% | 1636 - 12.7% |
| Number having Metastases (M +ve) | 43 – 14.9% | 1214 – 12.4% | 1267 / 10329* 12.6% |

* Number where staging could be estimated

Staging of Prostate Tumours by PSA

Numbers falling in each category* PSA was recorded in 89.4% tumours (11531/12892) Gleason scores were recorded in 80.6% tumours (10397/12892)

| Known Clinical Staging | Total Patients | PSA 0-5 N % | PSA 6-10 N % | PSA 11-20 N % | PSA 21-50 N % | PSA > 50 N % |
|---|-------------------|-------------------|----------------------|---------------------|---------------------|---------------------|
| Stage I (T1a N0 M0 Well Differentiated) | 96 | 47 49.0% | 23 24.0% | 16 16.7% | 8 8.3% | 2 2.1% |
| Stage II (T1a N0 M0 Mod or Poor differentiation T1b, 1c, 1, 2, N0 M0 Any differentiation) | 5167 | 426 8.2% | 1615 <i>31.3%</i> | 1453 28.1% | 1077 20.8% | 596 11.5% |
| Stage III (T3 N0 M0 Any differentiation) | 2064 | 66 3.2% | 212 10.3% | 375 18.2% | 674 32.7% | 737 35.7% |
| Stage IV (T4 N0 M0 Any differentiation Any T N1 M0 Any differentiation Any T Any N M1 Any differentiation) | 1481 | 23 1.6% | 66 4.5% | 95 6.4% | 244 16.5% | 1048 70.8% |
| Totals | 8808 * | 562 6.4% | 1916 21.8% | 1939 22.0% | 2008 22.8% | 2383 27.1% |

N.B. Excluding pathologies other than Adenocarcinoma.

* Tumours where staging could be estimated, PSA was recorded and Histology = adenocarcinoma

Chart 57

Staging of TesticularTumours A total of 980 Testicular Tumours were reported Staging could be estimated in 877 (89.5%)

| Known Staging Total numbers where | Seminoma | | Teratoma | | Combined Seminoma/ Teratoma | | Other Histology | |
|--|----------|------|----------|------|-----------------------------------|------|--------------------|------|
| staging & histology known: | | 492 | | 191 | | 79 | | 112 |
| | Ν | % | Ν | % | Ν | % | Ν | % |
| Stage 0 (Tis N0 M0 S0,SX) | 4 | 0.8 | 0 | 0 | 1 | 1.3 | 4 | 3.6 |
| Stage I (T1,2,3,4 N0 M0 SX) | 126 | 25.6 | 40 | 20.9 | 20 | 25.3 | 40 | 35.7 |
| Stage IA (T1, N0 M0 S0) | 173 | 35.2 | 26 | 13.6 | 13 | 16.5 | 21 | 18.8 |
| Stage IB (T2, 3, 4, N0 M0 S0) | 43 | 8.7 | 14 | 7.3 | 6 | 7.6 | 5 | 4.5 |
| Stage IS (Any T N0 M0 S1, 2, 3) | 123 | 25.0 | 91 | 47.6 | 35 | 44.3 | 27 | 24.1 |
| Stage II (Any T, N1, 2, 3, M0, SX, 0, 1) | 18 | 3.7 | 9 | 4.7 | 0 | 0 | 9 | 8.0 |
| Stage III (Any T, Any N, M1, 1a, SX, 0, 1,2, 3 Any T, N1, 2, 3, M0, S2, 3 Any T, Any N, M1b, Any S) | 5 | 1.0 | 11 | 5.8 | 4 | 5.1 | 6 | 5.4 |

TesticularTumours by SerumTumour Marker A total of 980 Testicular Tumours were reported Tumour markers and Histology were reported in 842 (85.9%)

| Serum Tumour Marker Total numbers where tumour | Seminoma | | Teratoma | | Combined Seminoma/ Teratoma | | Other Histology | |
|---|----------|------|----------|------|-----------------------------------|------|--------------------|------|
| marker & histology known: | | 366 | | 148 | | 61 | | 67 |
| | Ν | % | Ν | % | Ν | % | Ν | % |
| S0 (Serum marker study levels within normal limits | 238 | 65.0 | 47 | 31.8 | 22 | 36.1 | 37 | 55.2 |
| S1 (LDH <1.5*N and HCG (ml/U/ml) <5,000 and AFP (ng/ml) <1,000) | 107 | 29.2 | 72 | 48.6 | 30 | 49.2 | 20 | 29.9 |
| S2 (LDH 1.5 – 10 *N or HCG (ml/U/ml) 5,000 - 50,000 or AFP (ng/ml) 1,000 – 10,000) | 15 | 4.1 | 22 | 14.9 | 5 | 8.2 | 5 | 7.5 |
| S3 (LDH >10*N or HCG (ml/U/ml) > 50,000 or AFP (ng/ml) >10,000) | 6 | 1.6 | 7 | 4.7 | 4 | 6.6 | 5 | 7.5 |

N.B. N indicates the upper limit or normal for the LDH assay

Chart 59

Staging of Penile Tumours A total of 221 Penile Tumours were reported Staging could be estimated in 186 (84.2%)

| Known Staging | Total Known | |
|---------------------|-----------------|------|
| | Ν | % |
| Stage 0 | 35 | 18.8 |
| (Tis, a, N0 M0) | | |
| Stage I | 60 | 32.3 |
| (T1 N0 M0 | | |
| Stage II | 60 | 32.3 |
| (T2 N0, N1 M0) | | |
| Stage III | 22 | 11.8 |
| (T1, 2, N2 M0 | | |
| T3, N0, N1, N2, M0) | | |
| Stage IV | 9 | 4.8 |
| (T4 Any N M0 | | |
| Any T N3 M0 | including 4 | 2.2 |
| Any T Any N M1) | with metastases | |

E. Initial Treatment Intention and Type Chart 60

| Organ | Curative | | Palliative | | Surveillance | | % of Total |
|---------------------------|----------|------|------------|------|--------------|------|--------------|
| (Number Known) | Ν | % | N | % | Ν | % | Reported |
| Prostate (10919) | 3510 | 32.1 | 5697 | 52.2 | 1712 | 15.7 | 85.0 |
| Bladder (6853) | 5774 | 84.3 | 962 | 14.0 | 117 | 1.7 | 90.8 |
| Kidney (1882) | 1415 | 75.2 | 356 | 18.9 | 111 | 5.9 | 92.4 |
| Testis (919) | 891 | 97.0 | 18 | 2.0 | 10 | 1 | 93. 8 |
| Pelvis/Ureter (336) | 280 | 83.3 | 47 | 14.0 | 9 | 2.7 | 90.6 |
| Penis (196) | 172 | 87.8 | 19 | 9.7 | 5 | 2.6 | 88.7 |
| Urethra (32) | 22 | 68.8 | 10 | 31.2 | 0 | 0 | 97.0 |
| Prostatic Urethra (24) | 12 | 50.0 | 10 | 41.7 | 2 | 8.3 | 70.6 |

Initial Treatment Intention by Organ Percentage & Total of Known Intent

Chart 61





Known Treatment Management - Kidney Tumours Total Numbers Reported with those as only Treatment in () (N.B. Excluding TCC's)

| Treatment | Curative | Palliative | Surveillance |
|----------------------------|-------------|------------|--------------|
| | | | |
| Surgery: | | | |
| Endoscopic Resection | 11 (3) | 3 (1) | 2 (2) |
| Radical Ablative Surgery | 1173 (1122) | 121 (68) | 4 (3) |
| Organ Conserving Surgery * | 60 (56) | 1 (1) | - |
| Other Surgery | 13 (4) | 24 (11) | 5 (3) |
| Radiation Therapy | 11 (2) | 33 (9) | 1 |
| Systemic Chemotherapy | 7 (2) | 10 (4) | 2 (1) |
| Hormone Therapy | 2 (0) | 19 (13) | 2 (1) |
| Immunotherapy | 11 (1) | 62 (21) | 1 |
| Other Treatment | 14 (1) | 23 (8) | 2 (2) |

* Performed by 32 centres, median per centre = 1, Range 1 - 8 122 centres performed no organ conserving surgery

Chart 63

| | 1 | - | |
|---|-----------|------------|--------------|
| Treatment | Curative | Palliative | Surveillance |
| | | | |
| Surgery: | | | |
| Endoscopic Resection | 25 (10) | 5 (4) | - |
| Endoscopic Resection + 1 shot intravesical chemotherapy | 3 (1) | - | - |
| Radical Ablative Surgery | 220 (194) | 16 (12) | - |
| Organ Conserving Surgery | 18 (17) | 1 (1) | - |
| Other Surgery | 11 (8) | 3 (3) | - |
| Radiation Therapy | 20 (2) | 9 (6) | - |
| Systemic Chemotherapy | 4 (2) | 5 (3) | - |
| Intra-vesical Chemotherapy (course) | 2 | - | - |
| Immunotherapy | 2 | - | - |
| Other Treatment | 9 (2) | 4 (4) | 1 (1) |

Known Treatment Management - Pelvis/Ureteric Tumours Total Numbers Reported with those as only Treatment in ()

| T | | T- C1 | | T- C2 | T1 C1 | T1 C2 | T1 C2 |
|-------------------------------------|---------|---------|--------|---------|--------|--------|-----------|
| l reatment | 115 | 18 G1 | 1a G2 | 18 65 | IIGI | 11 G2 | 1165 |
| Surgery: | | | | | | | |
| Endoscopic Resection | 44 (16) | 466 | 368 | 59 (34) | 294 | 394 | 244 (135) |
| | | (420) | (322) | | (268) | (321) | |
| Endoscopic Resection + 1 shot | 13 (5) | 418 | 408 | 58 (38) | 211 | 337 | 148 (101) |
| intravesical chemotherapy | | (398) | (384) | | (201) | (305) | |
| Radical Ablative Surgery | 6 (5) | 4 (3) | 1 (1) | 2 (1) | 7 (7) | 5 (4) | 21 (14) |
| Organ Conserving Surgery | - | 1 | - | 1 | 2 (1) | 1 | 3 (3) |
| Other Surgery | 6 (3) | 28 (7) | 21 (7) | 5 (1) | 6 (1) | 11 | 5 (3) |
| Radiation Therapy | 1 | 1 | - | 6 (1) | 1 | 11 (2) | 47 (11) |
| Systemic Chemotherapy | 1 | - | - | 1 | 1 | - | 2 |
| Intra-vesical Chemotherapy (course) | 24 (3) | 26 (2) | 45 (2) | 24 (2) | 20 (2) | 47 (2) | 71 (2) |
| Hormone Therapy | - | - | 2 | 1 | 1 | 4 | 2 |
| Immunotherapy | 25 (13) | 2 | 4 | 11 | 2 (1) | 8 (1) | 31 (1) |
| Other Treatment | - | 12 (12) | 8 (8) | 1 | 3 (1) | 10 (1) | 7 (3) |
| Total Tumours Reported | 49 | 948 | 821 | 127 | 537 | 756 | 470 |

Known Management by T category and Grade - Bladder Tumours Total Numbers Reported with those as only Treatment in ()

Chart 65

Known Management by T category and Grade - Bladder Tumours where Age is less than 70 Total Numbers Reported with those as only Treatment in ()

| Treatment | T2 G1 | T2 G2 | T2 G3 | T3 G1 | T3 G2 | T3 G3 | T4 G1 | T4 G2 | T4 G3 |
|--|-------|---------|------------|-------|------------|------------|-------|-------|---------|
| Surgery: | 8 (5) | 27 (14) | 80 | 3 | 13(1) | 64 | 1 | 7 (3) | 38 (12) |
| Endoscopic Resection | ~ / | , , | (22) | | | (12) | | , , | , , |
| Endoscopic Resection + 1 shot intravesical chemotherapy | 6 (6) | 13 (7) | 9 (2) | - | 2 (1) | 2 (1) | - | - | 1 (1) |
| Radical Ablative Surgery | - | 23 (17) | 85 (58) | 1 (1) | 16 (10) | 70 (46) | 2 (1) | 2 (1) | 35 (15) |
| Organ Conserving Surgery | - | 2 (1) | 2 | - | - | - | - | - | - |
| Other Surgery | - | 3 | 6 | - | 3 | 8 (2) | - | 2 | 6 (2) |
| Radiation Therapy | 3 | 15 (4) | 48 (11) | 2 | 8 (3) | 56 (12) | - | 3 | 31 (11) |
| Systemic Chemotherapy | - | 1 | 7 | 2 | 1 | 10 (1) | - | 4 (2) | 21 (3) |
| Intra-vesical Chemotherapy (course) | 1 | 4 (1) | 4 | - | - | - | - | - | - |
| Hormone Therapy | 1 | - | - | - | - | 1 (1) | - | 1 (1) | 1 |
| Immunotherapy | - | 2 | - | - | - | 1(1) | - | - | - |
| Other Treatment | - | - | 4(1) | 1 | 1 | 4 | - | - | 3 |
| Total Tumours Reported | 18 | 74 | 183 | 6 | 30 | 151 | 2 | 13 | 93 |

| Treatment | T2 G1 | T2 G2 | T2 G3 | T3 G1 | T3 G2 | T3 G3 | T4 G1 | T4 G2 | T4 G3 |
|--|--------|---------|-------------|-------|---------|-------------|-------|--------|---------|
| Surgery: Endoscopic Resection | 11 (7) | 89 (48) | 241 (89) | 1 | 31 (12) | 199 (62) | 2 | 11 (6) | 67 (27) |
| Endoscopic Resection + 1 shot intravesical chemotherapy | 5 (4) | 27 (18) | 35 (20) | - | 6 (3) | 14 (3) | - | 5 (2) | 3 (1) |
| Radical Ablative Surgery | 3 (3) | 12 (6) | 42 (32) | - | 10 (8) | 54 (37) | 2 (1) | - | 20 (11) |
| Organ Conserving Surgery | 1 (1) | 1 (1) | - | - | 1 (1) | 1 (1) | - | - | 1 (1) |
| Other Surgery | - | 4 | 6 (2) | 1 | - | 3 (1) | - | 2 | 4 (3) |
| Radiation Therapy | 5 (1) | 42 (12) | 177 (38) | 3 (1) | 20 (4) | 180 (56) | - | 12 (2) | 56 (17) |
| Systemic Chemotherapy | - | - | 2 | - | - | 6 (1) | - | - | 12 (1) |
| Intra-vesical Chemotherapy (course) | 1 | 4 | 6 | - | 1 | 1 | - | - | - |
| Hormone Therapy | - | 1 | 2 | - | 2 | - | - | 1 (1) | 2 |
| Immunotherapy | - | - | 3 | - | - | 2 | - | - | 1 |
| Other Treatment | - | 3 | 7 (2) | - | | 12 (3) | 1 | 1 (1) | 4 (2) |
| Total Tumours Reported | 24 | 142 | 381 | 6 | 55 | 344 | 5 | 23 | 132 |

Known Management by T category and Grade - Bladder Tumours where Age > = 70 Total Numbers Reported with those as only Treatment in ()

Chart 67

Known Management Intention - Prostate Tumours Total Numbers Reported with those as only Treatment in ()

| Treatment | Curative | Palliative/ Surveillance |
|--------------------------|-------------|--------------------------|
| Surgery: | | |
| Endoscopic Resection | 362 (173) | 1404 (609) |
| Radical Ablative Surgery | 1128 (1015) | 67 (28) |
| Organ Conserving Surgery | 2 | 36 (11) |
| Other Surgery | 54 (13) | 379 (132) |
| Radiation Therapy | 1807 (956) | 407 (97) |
| Systemic Chemotherapy | 6 (1) | 12 (6) |
| Hormone Therapy | 916 (131) | 5059 (3877) |
| Immunotherapy | - | 4 (1) |
| Other Treatment | 114 (44) | 150 (62) |

| Treatment | PSA | PSA | PSA | PSA | PSA | PSA |
|----------------------------------|-----------|--------------|-----------|-------------|-----------|-----------|
| | 0-5 | 6-10 | 11-15 | 16-20 | 21-50 | >50 |
| Surgery: Endoscopic Resection | 89 (61) | 60 (33) | 37 (17) | 24 (6) | 70 (22) | 97 (11) |
| Radical Ablative Surgery | 148 (126) | 486 (400) | 180 (168) | 66 (50) | 45 (33) | 14 (4) |
| Organ Conserving Surgery | - | - | - | - | 3 | 4 (1) |
| Other Surgery | 7 (2) | 27 (7) | 20 (4) | 13 (3) | 17 (6) | 36 (7) |
| Radiation Therapy | 96 (51) | 332 (182) | 211 (114) | 157 (74) | 271 (117) | 100 (22) |
| Systemic Chemotherapy | 3 (2) | 1 | - | - | 2 | - |
| Hormone Therapy | 71 (22) | 200 (47) | 133 (41) | 111 (31) | 383 (200) | 692 (502) |
| Immunotherapy | - | - | - | - | 1 | - |
| Other Treatment | 20 (13) | 42 (21) | 20 (9) | 14 (5) | 13 (1) | 16 (4) |

Known Management by PSA - Prostate Tumours where age is less than 70 Total Numbers Reported with those as only Treatment in ()

Chart 69

Known Management by PSA - Prostate Tumours where age is >= 70 Total Numbers Reported with those as only Treatment in ()

| Treatment | PSA 0-5 | PSA 6-10 | PSA 11-15 | PSA 16-20 | PSA 21-50 | PSA >50 |
|----------------------------------|------------|--------------|--------------|--------------|--------------|----------------|
| Surgery: Endoscopic Resection | 144 (1100 | 142 (90) | 116 (58) | 96 (49) | 275 (86) | 368 (56) |
| Radical Ablative Surgery | 14 (10) | 59 (55) | 28 (25) | 15 (11) | 22 (15) | 34 (16) |
| Organ Conserving Surgery | 1 | 2 (1) | 3 (1) | | 5 (1) | 15 (4) |
| Other Surgery | 9 (2) | 28 (11) | 45 (17) | 29 (11) | 77 (21) | 91 (16) |
| Radiation Therapy | 58 (28) | 231 (123) | 215 (113) | 126 (67) | 271 (107) | 95 (20) |
| Systemic Chemotherapy | 1 (1) | 1 | | 1 (1) | 5 (1) | 2 (2) |
| Hormone Therapy | 100 (56) | 306 (170) | 343 (206) | 324 (220) | 1285 (939) | 2049 (1622) |
| Immunotherapy | | 1 | | | 1 | 1 |
| Other Treatment | 14 (4) | 32 (18) | 27 (14) | 22 (13) | 31 (17) | 20 (5) |

Known Management - Testicular Tumours Total Numbers Reported with those as only Treatment in ()

| Treatment | Curative | Palliative |
|--------------------------|----------|------------|
| Radical Ablative Surgery | 777(308) | 10 (6) |
| Organ Conserving Surgery | 2 (1) | - |
| Other Surgery | 21 (9) | 2 |
| Radiation Therapy | 271 (24) | 2 |
| Systemic Chemotherapy | 222 (28) | 8 (1) |
| Other Treatment | 74 (7) | 2 (1) |

Chart 71

Known Management - Penile Tumours Total Numbers Reported with those as only Treatment in ()

| Treatment | Curative | Palliative |
|--------------------------|----------|------------|
| Surgery: | | |
| Radical Ablative Surgery | 68 (65) | 4 (4) |
| Organ Conserving Surgery | 60 (43) | 4 (1) |
| Other Surgery | 33 (17) | 6 (2) |
| Radiation Therapy | 33 (8) | 7 (4) |
| Other Treatment | 7 (3) | - |

F. Tertiary Referrals Chart 72

Tertiary Referrals - Overall Data by Organ 6.0% (1458/24343) of all tumours were tertiary referrals (referred by a Urologist (1378) or Oncologist (80))

| Organ | Number Recorded | Mean Range | Age at Diagnosis & | Males | Females | % of Total Registrations * |
|-------------------|--------------------|---------------|--------------------|-------|---------|-------------------------------|
| Prostate | 720 | 67.4; | 40 - 94 | 720 | - | 5.6 |
| Bladder | 344 | 72.7; | 39 – 97 | 254 | 90 | 4.6 |
| Kidney | 185 | 61.6; | 7 – 93 | 129 | 56 | 9.1 |
| Testis | 133 | 40.0; | 17 – 77 | 133 | - | 13.6 |
| Pelvis/Ureter | 34 | 70.5; | 32 - 81 | 24 | 10 | 9.2 |
| Penis | 23 | 62.3; | 37 – 100 | 23 | - | 10.4 |
| Urethra | 3 | 59.3; | 52 - 66 | 1 | 2 | 9.1 |
| Prostatic Urethra | 3 | 61.5; | 53 - 70 | 3 | - | 8.8 |
| Other | 10 | 53.3; | 24 – 78 | 6 | 3 | 11.1 |
| Not recorded | 3 | | | 3 | 0 | 2.2 |

* % of the total registrations for each tumour site e.g. prostate = 720/12892 = 5.6%

Chart 73

Tertiary Referrals - Staging of Kidney Tumours A total of 185 Kidney Tumours were reported Staging could be estimated in 171 (92.4%)

| Known Staging | Total Known | |
|---------------------------------------|---------------------------------|------|
| | Ν | % |
| Stage I (T1 N0 M0) | 45 | 26.3 |
| Stage II (T2 N0 M0) | 27 | 15.8 |
| Stage III (T1, T2, T3 N0,N1 M0) | 49 | 28.7 |
| Stage IV (T4 N0 N1 M0 | 50 | 29.2 |
| Any T N2 M0 Any T any N M1 | including 40 with metastases | 23.4 |

N.B. A pathological staging for Kidney tumours was only included for those where radical or organ conserving surgery was performed

Tertiary Referrals -Staging of Bladder Tumours A total of 344 BladderTumours were reported Staging could be estimated in 284 (82.6%)

| Known Staging | Total Known | |
|--|---------------------------------|------|
| | Ν | % |
| Stage 0a (Ta N0 M0) | 72 | 25.3 |
| Stage 0is (Tis N0 M0) | 2 | 0.7 |
| Stage I (T1 N0 M0) | 44 | 15.5 |
| Stage II (T2a, 2b N0 M0) | 60 | 21.1 |
| Stage III (T3a, 3b, 4a N0 M0) | 71 | 25.0 |
| Stage IV (T4b N0 M0 | 35 | 12.3 |
| Any T N1, N2, N3 M0 Any T any N M1) | including 10 with metastases | 3.5 |

N.B. A pathological staging for Stage II, III or IV Bladder tumours was only included for tumours where radical surgery was performed

Chart 75

Tertiary Referrals - Staging of Prostate Tumours A total of 720 Prostate Tumours were reported Staging could be estimated in 614 (85.3%)

| Known Staging | Total Known | |
|--|-----------------|------|
| | Ν | % |
| Stage I | 5 | 0.8 |
| (T1a N0 M0 | | |
| Well Differentiated) | | |
| Stage II | t1 - 32 | 5.2 |
| (T1a N0 M0 Mod or Poor differentiation | t1a – 7 | 1.1 |
| T1b, 1c, 1, 2, N0 M0 Any | t1b – 13 | 2.1 |
| differentiation) | t1c – 115 | 18.7 |
| | t2 – 235 | 38.3 |
| Stage III | 142 | 23.1 |
| (T3 N0 M0 Any differentiation) | | |
| Stage IV | 65 | 10.6 |
| (T4 N0 M0 Any differentiation | | |
| Any T N1 M0 Any differentiation | including 34 | 5.5 |
| Any T Any N M1 Any differentiation) | with metastases | |

N.B. A pathological staging for Prostate tumours was only included for those where radical or organ conserving surgery was performed

G. Material Deprivation Scores

Material Deprivation was studied using the Townsend Material Deprivation Score. This was constructed by Professor P. Townsend based on 1991 Census Small Area Statistics and uses the following four variables from the census data:

- i. Unemployment unemployed residents over 16 as a percentage of all economically active residents aged over 16.
- ii. Overcrowding households with 1 person per room and over as a percentage of all households.
- iii. Non car ownership households with no car as a percentage of all households.
- iv. Non home ownership households not owning their own home as a percentage of all households.

Data is given equal weights and combined into a single indicator where negative scores indicate affluent areas and positive scores deprived areas. Postcodes are then mapped to Townsend scores. Once the score was obtained it was divided into quintiles, Group 1 being the most affluent and Group 5 the most deprived.

Townsend scores are available for England and Wales.

We are grateful to Gulnaz Begum of the CRC Trials Unit at the University of Birmingham for allocating the Townsend scores to our data.

Chart 76

| Organ | Group 1 | | Group 2 | | Group 3 | | Group 4 | | Group 5 | |
|---------------------|---------|------|---------|------|---------|------|---------|------|---------|------|
| | Ν | % | Ν | % | Ν | % | Ν | % | Ν | % |
| Prostate –NHS | 2094 | 20.9 | 2065 | 20.6 | 2005 | 20.0 | 2009 | 20.0 | 1870 | 18.6 |
| Prostate – PP | 194 | 38.0 | 125 | 24.5 | 93 | 18.2 | 68 | 13.3 | 31 | 6.1 |
| Bladder – NHS | 988 | 17.0 | 1108 | 19.1 | 1161 | 20.0 | 1220 | 21.0 | 1322 | 22.8 |
| Bladder – PP | 50 | 31.1 | 44 | 27.3 | 36 | 22.4 | 21 | 13.0 | 10 | 6.2 |
| Kidney – NHS | 296 | 18.9 | 296 | 18.9 | 285 | 18.2 | 326 | 20.8 | 361 | 3.1 |
| Kidney – PP | 24 | 46.1 | 11 | 21.2 | 11 | 21.2 | 5 | 9.6 | 1 | 1.9 |
| Testis – NHS | 126 | 17.4 | 35 | 18.7 | 156 | 21.6 | 141 | 19.5 | 166 | 22.9 |
| Testis – PP | 15 | 33.3 | 5 | 11.1 | 12 | 26.7 | 3 | 6.7 | 10 | 22.2 |
| Pelvis/Ureter – NHS | 54 | 8.7 | 54 | 18.7 | 61 | 1.1 | 55 | 19.0 | 65 | 22.5 |
| Pelvis/Ureter - PP | 5 | 31.3 | 2 | 12.5 | 3 | 18.8 | 5 | 31.3 | 1 | 6.3 |
| Penis – NHS | 26 | 14.9 | 31 | 17.8 | 43 | 24.6 | 43 | 24.6 | 32 | 18.3 |
| Penis – PP | 8 | 80.0 | 1 | 10.0 | 1 | 10.0 | 0 | | 0 | |

Townsend Groups by Organ* and whether the registration came from the NHS or Private Practice

* Townsend Groups could be allocated to 80.6 % (19629 /24343) registrations : Prostate (10554/12892) 81.9%; Bladder (5960/7549) 79.0%; Kidney (1616/2037) 79.3%; Testis (769/980) 78.5%; Pelvis / Ureter (305/371) 82.2% and Penis (185/221) 83.7%



Bladder Tumours by Townsend Group Median Time to First Consultation and Diagnosis in Days by Organ Excluding tumours diagnosed before Referral*

* Times were calculated when dates of referral, consultation and diagnosis were known

and diagnosis date was not before referral date . Total number of bladder tumours allocated a Townsend group = 5960

Chart 78

| Townsend Group | 0a | | 0is | | I | | Π | | III | | IV | |
|-------------------|-----|------|-----|------|-----|------|-----|------|-----|------|----|------|
| F | Ν | % | Ν | % | Ν | % | Ν | % | Ν | % | | % |
| Group 1 | 284 | 17.5 | 18 | 25.7 | 253 | 17.3 | 117 | 16.3 | 96 | 18.1 | 41 | 17.2 |
| Group 2 | 291 | 18.0 | 10 | 14.3 | 320 | 22.0 | 133 | 18.6 | 91 | 17.1 | 44 | 18.4 |
| Group 3 | 322 | 19.9 | 18 | 25.7 | 286 | 19.6 | 154 | 21.5 | 97 | 18.3 | 46 | 19.3 |
| Group 4 | 333 | 20.6 | 10 | 14.3 | 298 | 20.4 | 149 | 20.8 | 114 | 21.5 | 59 | 24.7 |
| Group 5 | 390 | 24.1 | 14 | 20.0 | 305 | 20.9 | 163 | 22.8 | 133 | 25.1 | 49 | 20.5 |

Townsend Groups by Stage - Bladder Tumours* Number and Percentage of each Stage by Group

* Townsend Groups could be allocated to 79.0% (5960 / 7549) of Bladder registrations and staging could be estimated in 4638 / 5960 = 77.8%



Prostate Tumours by Townsend Group Median Time to First Consultation and Diagnosis in Days by Organ Excluding tumours diagnosed before Referral*

* Times were calculated when dates of referral, consultation and diagnosis were known

and diagnosis date was not before referral date . Total number of bladder tumours allocated a Townsend group = 10554

Chart 80

| Townsend Group | I | | II | | III | | IV | |
|-------------------|----|------|------|------|-----|------|-----|------|
| - | Ν | % | Ν | % | Ν | % | | % |
| Group 1 | 23 | 19.3 | 1118 | 23.7 | 455 | 21.3 | 339 | 20.8 |
| Group 2 | 22 | 18.5 | 1025 | 21.7 | 417 | 19.6 | 326 | 20.0 |
| Group 3 | 26 | 21.9 | 935 | 19.8 | 412 | 19.3 | 320 | 19.6 |
| Group 4 | 26 | 21.9 | 890 | 18.9 | 432 | 20.3 | 334 | 20.4 |
| Group 5 | 22 | 18.5 | 746 | 15.8 | 416 | 19.5 | 315 | 19.3 |

Townsend Groups by Stage - Prostate Tumours* Number and Percentage of each Stage by Group

* Townsend Groups could be allocated to 81.9% (10554/12892) of Prostate registrations and staging could be estimated in 8599/10554 = 81.5%

Townsend Groups by Age at Diagnosis - Prostate Tumours* Number and Percentage of each Age Group by Townsend Group

| <70 years | | 70 – 79 years | | >= 80 years | |
|-----------|---|--|--|---|---|
| Ν | % | Ν | % | Ν | % |
| 823 | 24.8 | 816 | 20.5 | 417 | 20.3 |
| 733 | 22.1 | 811 | 20.4 | 419 | 20.4 |
| 635 | 19.1 | 802 | 20.2 | 399 | 19.5 |
| 599 | 18.1 | 804 | 20.2 | 424 | 20.7 |
| 527 | 15.9 | 745 | 18.7 | 391 | 19.1 |
| | <70 years N 823 733 635 599 527 | <70 years N % 823 24.8 733 22.1 635 19.1 599 18.1 527 15.9 | <70 years 70 – 79 years N % N 823 24.8 816 733 22.1 811 635 19.1 802 599 18.1 804 527 15.9 745 | <70 years 70 – 79 years N % N % 823 24.8 816 20.5 733 22.1 811 20.4 635 19.1 802 20.2 599 18.1 804 20.2 527 15.9 745 18.7 | <70 years 70 - 79 years >= 80 years N % N % N 823 24.8 816 20.5 417 733 22.1 811 20.4 419 635 19.1 802 20.2 399 599 18.1 804 20.2 424 527 15.9 745 18.7 391 |

* Townsend Groups could be allocated to 81.9% (10554/12892) of Prostate registrations and age could be calculated when both date of diagnosis and date of birth were known - 9345/10554 = 88.5%

Chart 82

Townsend Groups by PSA at Diagnosis - Prostate Tumours* Number and Percentage of each PSA Group by Townsend Group

| Townsend | PSA 0 - 10 | | PSA 11 – 20 | | PSA > 20 | |
|----------|------------|------|-------------|------|----------|------|
| Group | Ν | % | N | % | Ν | % |
| Group 1 | 594 | 23.5 | 471 | 23.3 | 991 | 20.7 |
| Group 2 | 540 | 21.4 | 445 | 22.0 | 978 | 20.4 |
| Group 3 | 503 | 19.9 | 403 | 19.9 | 930 | 19.4 |
| Group 4 | 463 | 18.4 | 381 | 18.8 | 983 | 20.5 |
| Group 5 | 423 | 16.8 | 323 | 16.0 | 917 | 19.1 |

 \ast Townsend Groups could be allocated to 81.9% (10554/12892) of Prostate registrations and PSA was recorded in 9345 of these - 88.5%

H. Completeness of Data Chart 83

Completeness of Data -1 Percentage and numbers of Total Returns unknown

| Data Item | 2000 | | 1999 | | 1998 | |
|------------------------------------|----------|---------|---------|---------|---------|---------|
| | Number | % of | Number | % of | Number | % of |
| | Unknown | Total | Unknown | Total | Unknown | Total |
| | | Returns | | Returns | | Returns |
| | | 24343 | | 19009 | | 6406 |
| Centre no or Cons no | 0 | 0% | 9 | 0.04% | 2 | 0.03% |
| Hospital number | *577 | 2.4% | 257** | 1.4% | 22 | 0.3% |
| NHS number | 8580 | 35.2% | 6946 | 36.5% | - | |
| Postcode | 1573 | 6.5% | 1319 | 6.9% | - | |
| Sex | 39 | 0.2% | 118 | 0.6% | 47 | 0.7% |
| Date of Birth | 192 | 0.8% | 217 | 1.1% | 155 | 2.4% |
| Organ | 136 | 0.6% | 83 | 0.4% | 27 | 0.4% |
| Date of Diagnosis | 466 | 1.9% | 604 | 3.2% | - | |
| Referral Source | 2058 | 8.5% | 1096 | 5.8% | - | |
| Date of Referral | 2931 | 12.0% | 1820 | 9.6% | - | |
| Date of First Consultation | 3205 | 13.2% | - | | - | |
| Histological confirmation | 483 | 2.0% | 321 | 1.7% | - | |
| Basis of diagnosis if no Histology | 111/1233 | 9.0% | 71/875 | 8.1% | - | |

* 349 who were private patients, ** includes 198 who were private patients

Chart 84

Completeness of Data -2 Percentage and numbers of Total Returns unknown

| Data Item | 2000 | | 1999 | | 1998 | |
|--------------------------|------------|------------|------------|------------|------------|---------|
| | Number | % of Total | Number | % of Total | Number | % of |
| | Unknown | Returns | Unknown | Returns | Unknown | Total |
| | | 24343 | | 19009 | | Returns |
| | | | | | | 6406 |
| Histology | 261/22627 | 1.2% | 258/17813 | 1.4% | 116 | 1.8% |
| Differentiation | 2690/22627 | 11.9% | 2200/17813 | 12.4% | 608 | 9.5% |
| Clinical T Category | 3835 | 15.8% | 3357 | 17.7% | 542 | 8.5% |
| Clinical N Category | 6244 | 25.7% | 6555 | 34.5% | 1686 | 26.3% |
| Clinical M Category | 6273 | 25.8% | 6467 | 34.0% | 1658 | 25.9% |
| Pathological T Category | 7175/22627 | 31.7% | 6223/17813 | 34.9% | - | |
| Pathological N Category | 9703/22627 | 43.0% | 9061/17813 | 50.9% | - | |
| Pathological M Category | 9793/22627 | 43.3% | 9055/17813 | 50.8% | - | |
| PSA at time of Diagnosis | 1361/12892 | 10.6% | 1071/9277 | 11.5% | - | |
| Gleason Scores | 2495/12892 | 19.4% | - | | - | |
| S Category | 338/980 | 34.5% | 307/838 | 36.6% | - | |
| Treatment Intention | 3067 | 12.6% | 1646 | 8.7% | 626 | 9.8% |
| Treatment Type | 567/19299 | 2.9% | 331/15714 | 2.1% | 351 / 4832 | 7.3% |

I. Follow up of 1998 T2 plus Bladder

The Treatment of Muscle Invasive Bladder Cancer in the United Kingdom in 1998 (the results of a 6 month audit by the BAUS section of Oncology)

Introduction:

Muscle invasive bladder cancer imposes a heavy workload on urological departments. The best methods of treating this disease are considered to be primarily surgical though good results are reported and obtained by the use of radiotherapy. The exact role of neo adjuvant or adjuvant chemotherapy is not clear and many of the patients still present late or are considered too old or to have too many co-morbid factors to make attempted definitive treatment a practical proposition.

These data, which are recorded below, are unedited and are a "snapshot" of practice in the United Kingdom in the latter 6 months of 1998, with sufficient data to show the outcomes of these treatment choices after a minimum follow up of 18 months.

Results

406 patients with T2 or greater muscle invasive bladder cancer were registered when follow up data was available. The cases have been placed in their initial diagnostic category, which relied on transurethral resection and imaging, but only patients who had a cystectomy have final definitive histology. The tables outlined below reflect attempted definitive therapy and make no comment on patients who have received only palliative treatment.

Table 1

| Status | Time from Diagnosis | Ν | % |
|-----------------------|---------------------|----|------|
| | | 63 | 100 |
| Alive and Well | 18 months | 40 | 63.5 |
| Alive with metastases | 18 months | 4 | 6.3 |
| Dead * | 6 months | 4 | 6.3 |
| Dead * | 12 months | 5 | 7.9 |
| Dead * | 18 months | 5 | 7.9 |
| Metastases | 6 months | 3 | 9.5 |
| Metastases | 12 months | 4 | 6.3 |

T2 Cystectomy – Total number of patients = 63

* Dead due to bladder cancer

Table 2

T2 Radiotherapy – Total number of patients = 75

| Status | Time from Diagnosis | Ν | % |
|-----------------------|---------------------|----|------|
| | | 75 | 100 |
| Alive and Well | 18 months | 42 | 56.0 |
| Alive with metastases | 18 months | 4 | 5.3 |
| Dead * | 6 months | 4 | 5.3 |
| Dead * | 12 months | 9 | 12.0 |
| Dead * | 18 months | 9 | 12.0 |
| Metastases | 6 months | 10 | 13.3 |
| Metastases | 12 months | 8 | 10.7 |

* Dead due to bladder cancer

Table 3

T3 Cystectomy – Total number of patients = 45

| Status | Time from Diagnosis | N | % |
|-----------------------|---------------------|----|------|
| | | 45 | 100 |
| Alive and Well | 18 months | 26 | 57.8 |
| Alive with metastases | 18 months | 1 | 2.2 |
| Dead * | 6 months | 7 | 15.6 |
| Dead * | 12 months | 5 | 11.1 |
| Dead * | 18 months | 2 | 4.4 |
| Metastases | 6 months | 3 | 6.7 |
| Metastases | 12 months | 1 | 2.2 |

* Dead due to bladder cancer

Table 4

T3 Radiotherapy – Total number of patients = 60

| Status | Time from Diagnosis | Ν | % |
|-----------------------|---------------------|----|------|
| | | 60 | 100 |
| Alive and Well | 18 months | 19 | 31.7 |
| Alive with metastases | 18 months | 5 | 8.3 |
| Dead * | 6 months | 8 | 13.3 |
| Dead * | 12 months | 9 | 15.0 |
| Dead * | 18 months | 7 | 11.7 |
| Metastases | 6 months | 9 | 15.0 |
| Metastases | 12 months | 8 | 13.3 |

* Dead due to bladder cancer

| Adjuvant Chemotherapy | 31 |
|-----------------------|----|
| First line treatment | 12 |
| New adjuvant therapy | 4 |

Discussion and Summary

243 patients out of 406 (59.9%) received definitive treatment for muscle invasive bladder cancer, 138 of these were designated T2. 63 Received primary cystectomy, 40 were alive and free of disease at 18 months (63.5%), 75 patients received radiotherapy, 42 (56%) of whom were alive and well, free of disease at 18 months. In addition, a further 8 patients, 4 from the cystectomy group and 4 from the radiotherapy group, were alive but with known metastases at 18 months.

At this stage of the disease there was no discernible benefit for either therapy except that both groups are likely to have had a significant number of patients within them that were under staged, proven by pathological staging of the cystectomy series. In the patients diagnosed by TUR and imaging as a T3 lesion prior to treatment, 45 of these patients underwent primary cystectomy and 26 were alive and well at 18 months representing 57.8%. There was one additional patient alive and well with metastases. However of the 60 patients who received primary radiotherapy only 19 (31.7%) were alive and well at 18 months and although an additional 5 patients (8.3%) were alive with metastases there was still, however, a significant difference between the outcome of the radiotherapy group T3 patients and those receiving surgery.

Interestingly, only 48 patients out of 363 had any form of chemotherapy. 31 had it in the adjuvant phase, presumably patients developing metastases, and 16 had chemotherapy as their first therapy, the rational for this was likely to be determined by the clinical findings.

A snapshot of the practice for the treatment of muscle invasive bladder cancer in the first half of 1998 shows remarkable consistency of therapeutic outcome at 18 months. Just over 61% of patients were alive and disease free whether they had a T2 or a T3 lesion and were treated by primary cystectomy. 56% of patients were alive and disease free if they had a T2 lesion at primary diagnosis treated with radiotherapy. Only the group of patients designated as T3 and presumably representing a group of patients who were probably under-staged had a poorer outcome. These results certainly fall within the range usually reported by single institutions except for very highly selected patients. It does show that there seems to be lack of an integrated role for chemotherapy with barely 11% of patients receiving any systemic chemotherapy for muscle invasive bladder cancer.

The latest analysis of the EORTC/MRC neo-adjuvant study would seem to show a small but consistent benefit to patients receiving neo-adjuvant therapy which, given the consistency of both the radiotherapy and especially surgery for T2 and T3 disease, would suggest a further 6-8% survival advantage would be possible for these patients with an integrated, multi-disciplinary approach to the effective utilisation of chemotherapy. This remains an area that needs further prospective randomised clinical trials. It does, howeve, r emphasise that the goal of any national system of patient care is to produce consistent figures for a given treatment nationally rather than to have spectacular figures in one or two isolated centres with a rapid fall off for the average spread across a particular country. The former goal certainly appears to have been achieved and this has been prior to any integrated system for the management of this disease.

The consistency of surgical outcome of patients with T2 and T3 bladder cancer is encouraging and suggests that the delivery of therapy is as effective nation-wide in this country as the best units reporting their studies in Europe and the United States. What does seem to be lacking is an integrated policy for the management of disease relapse with chemotherapy, and no policy for cases having neo-adjuvant or adjuvant therapy if they are judged to be at risk. These areas need exploration by prospective randomised trials.

P Whelan