

Monitoring care of Prostate cancer patients in Northern Ireland diagnosed 2006 (with comparisons 1996 & 2001)





2006 Prostate



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Edited by: Finian Bannon and Anna Gavin

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Prostate 2006

## FOREWORD

This report describes the characteristics of patients with prostate cancer and their care in 2006. It also makes comparisons with the care received by patients with this condition in 1996 and 2001. The report introduces the third phase of a process, supported by local clinicians, where the care of cancer patients and their survival is documented in detail. In building on the information for patients diagnosed in 1996 and 2001, it demonstrates welcome changes in service organisation.

It is very reassuring to have evidence of improved services which reflects excellent, co-operative working of professionals and the investment in services. We are on a journey and there is still considerable room for improvement. This report provides valuable information which is essential in helping us to track our progress and identify those areas where change is still needed. This series of reports highlights the importance of the Cancer Registry as a valuable public health tool which has grown and developed significantly over the last few years and now plays a leading role in monitoring cancer care within Northern Ireland.

Mudrae Anghiel

Dr Michael McBride Chief Medical Officer

Prostate 2006

# ACKNOWLEDGEMENTS

This report has been compiled in collaboration with the Northern Ireland Cancer Network (NICaN) Urology Regional Cancer Group. I am grateful to the clinicians who helped with determining the data items to collect, their interpretation and final presentation.

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The quality of data in this project is the result of the work of the Registry Tumour Verification Officers, Jackie Kelly and Donna Floyd, who meticulously extracted detailed information from clinical records for analysis and presentation in this report. Data abstraction was facilitated by Colin Fox of the Registry's IT group. The analysis of data was undertaken by Dr. Finian Bannon. A special word of gratitude to the Medical Records staff of all the hospitals in N. Ireland who have facilitated the Registry in this work.

The work of the N. Ireland Cancer Registry, including the production of this report, is the result of the work of the Registry team. I wish also to record my thanks to the Steering Group and Council of the Registry who guide that work.

anna Gavin

A Gavin Director, NICR 2009



# NORTHERN IRELAND CANCER NETWORK – REGIONAL UROLOGY GROUP

The Northern Ireland Cancer Network (NICaN) is a managed clinical network working towards the continuous improvement in cancer care and cancer survival for the people of Northern Ireland. It aims to promote equitable provision of high quality, patient focused and clinically effective cancer services. The way in which this is being achieved is by supporting groups of health professionals, patients and voluntary sector representatives to work together in a coordinated way across geographical, organisational and professional boundaries.

For urological cancers (including prostate), a multi-professional, multidisciplinary group meets regularly to drive forward the agenda of improving the care and outcomes for people with urological cancer. The group's remit includes being the authoritative source of expertise and guidance to planners, commissioners and providers of service, indicating resource requirements, reviewing and agreeing regionally agreed standards of care and driving forward service improvements.

The NICaN Urology Regional Group was established in April 2008 and is chaired by Mr. Hugh Mullen (Director, Performance Management and Service Improvement, Regional Health and Social Care Board) while Mr. Patrick Keane (Consultant Surgeon, Belfast Trust) provides clinical leadership to the group.

Recent achievements for the group include the development of standards for inclusion within the cancer service framework, active contribution to the regional urology review, development of regionally agreed care pathways and the commencement of work on the patient information pathway for prostate cancer.

The work of the N. Ireland Cancer Registry in producing audit figures, such as in this report, provides valuable information to clinicians and NICaN in order to facilitate service improvement.

Network website: http://www.cancerni.net/og/urologygroup

Network contact: Bridget Tourish, Clinical Network Co-ordinator, 02890 565860 or via e-mail btourish@nican.n-i.nhs.uk.

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## **SECTION I – INTRODUCTION, BACKGROUND & METHODS**

### Introduction

This Report is the third in a series which examines in detail the pathway of care for cancer patients in N. Ireland. Prostate cancer represents a major cancer and this report assesses change in service provision over a 10 year period.

The Campbell Report resulted from the work of many clinicians, service planners and patients<sup>1</sup>. It made 14 recommendations with the aim of improving cancer services in N. Ireland (see Appendix A).

Subsequent to the publication of the Campbell Report, a Cancer Working Group produced a sub-group report on urological cancer<sup>2</sup>. This made 13 specific general recommendations in relation to prostate cancer services in N. Ireland (see Appendix B).

The most recent cancer services audit of prostate cancer patients diagnosed in N. Ireland in the years 1996 and 2001<sup>3</sup> noted the following changes to service.

- Rates of radical prostatectomy and radiotherapy increased markedly.
- Use of CT and MRI scanning to determine stage increased, however, recording of stage was poor.
- Recording of Gleason score improved considerably.
- Although more patients were referred to oncologists there was little evidence that Multidisciplinary Team Meetings had taken place.
- Observed survival improved between 1996 and 2001, some of this is due to bias introduced by the detection of asymptomatic disease in younger men.

Overall recommendations of the 1996 & 2001 report were:

- The recommendations of the Campbell sub-group on urological cancers should be further implemented.
- The delivery of Prostate Cancer Services should be reaudited for patients diagnosed in 2006.
- Further research into the impact of PSA testing on disease levels and outcomes should be supported.

This report fulfils the second recommendation.

#### Current Guidance

The *Referral guidelines for suspected cancer*<sup>4</sup> produced by the National Institute for Health and Clinical Excellence (NICE) in 2005 have among their recommendations the following:

- Patients presenting with symptoms suggesting prostate cancer should have a digital rectal examination (DRE) and prostate-specific antigen (PSA) test after counselling. Symptoms will be related to the lower urinary tract and may be inflammatory or obstructive.
- Prostate cancer is also a possibility in male patients with any of the following unexplained symptoms: haematuria, lower back pain, bone pain, erectile dysfunction, and weight loss (especially in the elderly). These patients should also be offered a DRE and a PSA test.
- Urinary infection should be excluded before PSA testing, especially in men presenting with lower tract symptoms. The PSA test should be postponed for at least 1 month after treatment of a proven urinary infection.

- If a hard, irregular prostate typical of a prostate carcinoma is felt on rectal examination, then
  the patient should be referred urgently. The PSA should be measured and the result should
  accompany the referral. Patients do not need urgent referral if the prostate is simply enlarged
  and the PSA is in the age-specific reference range. (The age-specific cut-off PSA measurements
  recommended by the Prostate Cancer Risk Management Programme are as follows: aged 50–59
  years ≥ 3.0 ng/ml; aged 60–69 years ≥ 4.0 ng/ml; aged 70 years and older ≥ 5.0 ng/ml. [Note that
  there are no age-specific reference ranges for men aged over 80 years. Nearly all men of this age
  have at least a focus of cancer in the prostate. Prostate cancer only needs to be diagnosed in this
  age group if it is likely to need palliative treatment.])
- In a male patient with or without lower urinary tract symptoms and in whom the prostate is normal on DRE but the age-specific PSA is raised or rising, an urgent referral should be made. In those patients whose clinical state is compromised by other comorbidities, a discussion with the patient or carers and/or a specialist in urological cancer may be more appropriate.
- Symptomatic patients with high PSA levels should be referred urgently.
- If there is doubt about whether to refer an asymptomatic male with a borderline level of PSA, the PSA test should be repeated after an interval of 1 to 3 months. If the second test indicates that the PSA level is rising, the patient should be referred urgently.

In 2008, NICE produced clinical guidance<sup>5</sup> on the diagnosis and treatment of prostate cancer. Although not in place at the time of this audit, it is included here for completeness. Among the recommendations were:

Communication and support

- Men with prostate cancer should be offered individualised information tailored to their own needs. This information should be given by a healthcare professional (for example, a consultant or specialist nurse) and may be supported by written and visual media (for example, slide sets or DVDs).
- Healthcare professionals caring for men with prostate cancer should ascertain the extent to which the man wishes to be involved in decision making and ensure that he has sufficient information to do so.
- A validated, up-to-date decision aid is recommended for use in all urological cancer multidisciplinary teams (MDTs). It should be offered to men with localised prostate cancer when making treatment decisions, by healthcare professionals trained in its use.

Diagnosis and staging of prostate cancer

- To help men decide whether to have a prostate biopsy, healthcare professionals should discuss with them their PSA level, DRE (digital rectal examination) findings (including an estimate of prostate size) and comorbidities, together with their risk factors (including increasing age and black African or black Caribbean ethnicity) and any history of a previous negative prostate biopsy. The serum PSA level alone should not automatically lead to a prostate biopsy.
- If the clinical suspicion of prostate cancer is high, because of a high PSA value and evidence of bone metastases (identified by a positive isotope bone scan or sclerotic metastases on plain radiographs), prostate biopsy for histological confirmation should <u>not</u> be performed, unless this is required as part of a clinical trial.
- Computerised tomography (CT) of the pelvis is <u>not</u> recommended for men with low- or intermediate-risk localised prostate cancer (see table 1).
- The results of all prostate biopsies should be reviewed by a urological cancer MDT. Men should only be re-biopsied following a negative biopsy after an MDT review of the risk characteristics including life expectancy, PSA, DRE and prostate volume.
- Isotope bone scans should be performed when hormonal therapy is being deferred through watchful waiting in asymptomatic men who are at high risk of developing bone complications.

• Men with high-risk localised (see table 1) and locally advanced prostate cancer who are being considered for radical treatment should have pelvic imaging with either magnetic resonance imaging (MRI), or CT if MRI is contraindicated.

| Table 1: Risk stratification for men with localised prostate cancer. |  |    |        |    |         |  |
|--|--|----|--------|----|---------|--|
|  | PSA Gleason score Clinical stage                     |    |        |    |         |  |
| Low risk   | <pre>&lt; 10 ng/ml and <math>\leq 6</math> and</pre> |    | T1 T2a |    |         |  |
| Intermediate risk  | 10–20 ng/ml  | or | 7      | or | T2b T2c |  |
| High risk  | > 20 ng/ml   | or | 8-10   | or | T3 T4   |  |

Localised prostate cancer

- Urological cancer MDTs should assign a risk category (see table 1 above) to all newly diagnosed men with localised prostate cancer.
- Men with localised prostate cancer who have chosen a watchful waiting regimen and who have evidence of significant disease progression (that is, rapidly rising PSA level or bone pain) should be reviewed by a member of the urological cancer MDT.
- Men with low-risk localised prostate cancer who are considered suitable for radical treatment should first be offered active surveillance.
- Active surveillance is particularly suitable for a subgroup of men with low-risk localised prostate cancer who have clinical stage T1c, a Gleason score of 3+3, a PSA density of less than 0.15 ng/ml and who have cancer in less than 50% of their total number of biopsy cores with less than 10 mm of any core involved.
- Active surveillance should be discussed as an option with men who have intermediate-risk localised prostate cancer (see table 1).
- Active surveillance is not recommended for men with high-risk localised prostate cancer.
- Men with localised prostate cancer who have chosen an active surveillance regimen and who have evidence of disease progression (that is, a rise in PSA level or adverse findings on biopsy) should be offered radical treatment.
- The decision to proceed from an active surveillance regimen to radical treatment should be made in the light of the individual man's personal preferences, comorbidities and life expectancy.

Radical treatment

- Healthcare professionals should offer radical prostatectomy or radical radiotherapy (conformal) to men with intermediate-risk localised prostate cancer.
- Healthcare professionals should offer radical prostatectomy or radical radiotherapy (conformal) to men with high-risk localised prostate cancer when there is a realistic prospect of long-term disease control.
- Brachytherapy is not recommended for men with high-risk localised prostate cancer.
- Men undergoing radical external beam radiotherapy for localised prostate cancer should receive a minimum dose of 74 Gy to the prostate at no more than 2 Gy per fraction.
- Adjuvant hormonal therapy is recommended for a minimum of 2 years in men receiving radical radiotherapy for localised prostate cancer who have a Gleason score greater than or equal to 8.

#### Follow-up

- Men with prostate cancer who have chosen a watchful waiting regimen with no curative intent should normally be followed up in primary care in accordance with protocols agreed by the local urological cancer MDT and the relevant primary care organisation(s). Their PSA should be measured at least once a year.
- PSA levels for all men with prostate cancer who are having radical treatment should be checked at the earliest 6 weeks following treatment, at least every 6 months for the first 2 years and then at least once a year thereafter.
- After at least 2 years, men with a stable PSA who have had no significant treatment complications, should be offered follow-up outside hospital (for example, in primary care) by telephone or secure electronic communications, unless they are taking part in a clinical trial that requires formal clinic-based follow-up. Direct access to the urological cancer MDT should be offered and explained.

Managing adverse effects of treatment

- Given the range of treatment modalities and their serious side effects, men with prostate cancer who are candidates for radical treatment should have the opportunity to discuss their treatment options with a specialist surgical oncologist and a specialist clinical oncologist.
- The nature and treatment of radiation-induced injury to the gastrointestinal tract should be included in the training programmes for oncologists and gastroenterologists.
- Prior to treatment, men should be warned that treatment for prostate cancer may result in the loss of sexual function.
- Men experiencing troublesome urinary symptoms before treatment should be offered a urological assessment.
- Healthcare professionals should ensure that men with troublesome urinary symptoms after treatment have access to specialist continence services for assessment, diagnosis and conservative treatment. This may include coping strategies, along with pelvic floor muscle re-education, bladder retraining and pharmacotherapy.

Managing relapse after radical treatment

- Analyse serial PSA levels after radical treatment using the same assay technique.
- Biochemical relapse (a rising PSA) alone should not necessarily prompt an immediate change in treatment.
- Biochemical relapse should trigger an estimate of PSA doubling time, based on a minimum of 3 measurements over at least a 6 month period.
- Men with biochemical relapse after radical prostatectomy, with no known metastases, should be offered radical radiotherapy to the prostatic bed.
- Men with biochemical relapse should be considered for entry to appropriate clinical trials.
- Hormonal therapy is not routinely recommended for men with prostate cancer who have a biochemical relapse unless they have:
  - Symptomatic local disease progression, or
  - Any proven metastases, or
  - A PSA doubling time of less than 3 months.

Locally advanced prostate cancer

- Neoadjuvant and concurrent luteinising hormone-releasing hormone agonist (LHRHa) therapy is recommended for 3 to 6 months in men receiving radical radiotherapy for locally advanced prostate cancer.
- Adjuvant hormonal therapy is recommended for a minimum of 2 years in men receiving radical radiotherapy for locally advanced prostate cancer who have a Gleason score of greater than or equal to 8.
- Clinical oncologists should consider pelvic radiotherapy in men with locally advanced prostate cancer who have a greater than 15% risk of pelvic lymph node involvement and who are to receive neoadjuvant hormonal therapy and radical radiotherapy.

Metastatic Prostate Cancer

- Healthcare professionals should offer bilateral orchidectomy to all men with metastatic prostate cancer as an alternative to continuous LHRHa therapy.
- For men with metastatic prostate cancer who are willing to accept the adverse impact on overall survival and gynaecomastia in the hope of retaining sexual function, anti-androgen monotherapy with bicalutamide (150 mg) should be offered.
- When men with prostate cancer develop biochemical evidence of hormone-refractory disease, their treatment options should be discussed by the urological cancer MDT with a view to seeking an oncologist and/or specialist palliative care opinion, as appropriate.
- The routine use of spinal MRI for all men with hormone-refractory prostate cancer and known bone metastases is <u>not</u> recommended.
- Bisphosphonates for pain relief may be considered for men with hormone-refractory prostate cancer when other treatments (including analgesics and palliative radiotherapy) have failed. The oral or intravenous route of administration should be chosen according to convenience, tolerability and cost.
- Strontium-89 should be considered for men with hormone-refractory prostate cancer and painful bone metastases, especially those men who are unlikely to receive myelosuppressive chemotherapy.

Palliative care

- Men with metastatic prostate cancer should be offered tailored information and access to specialist urology and palliative care teams to address the specific needs of men with metastatic prostate cancer. They should have the opportunity to discuss any significant changes in their disease status or symptoms as these occur.
- Palliative interventions at any stage should be integrated into coordinated care, and any transitions between care settings should be facilitated as smoothly as possible.
- Healthcare professionals should ensure that palliative care is available when needed and is not limited to the end of life. It should not be restricted to being associated with hospice care.



### **Project** aim

This Report aims to measure changes to care for men with prostate cancer from 1996 to 2006 and to determine whether they are in keeping with the recommended guidance on investigation and treatment.

## Background

In the years 2000-2006, in N. Ireland, prostate cancer accounted for 20.9% of male cancers (excluding non-melanoma skin cancer) an increase from 15.5% in 1993-1996. In 2006, the cumulative risk of getting the disease (from age 0 to 74) was 7.9% (or one man in every 13), an increase from 3.9% (or one man in every 25) in 1993. Prostate cancer is the only cancer where the average age of diagnosis has changed markedly, in 1993-1996 the average age at diagnosis was 74.4 years, in the years 2000-2006 it is 71.0 years. Excluding non-melanoma skin cancer, prostate cancer is the most common cancer among men in N. Ireland today. The 5-year relative survival from prostate cancer for patients diagnosed in 2000-2004 in N. Ireland was 73.1%<sup>6</sup>.



Figure 1: Incidence and mortality of prostate cancer in N. Ireland 1993-2006

In N. Ireland, from 1993-2006, the number of men diagnosed with prostate cancer increased from 470 to 819. Over the same period, there has been little change in deaths from prostate cancer with about 200 men dying from the disease every year (Fig. 1, see Appendix C for actual numbers).





Figure 2: European age standardised rates (EASR) for incidence and mortality of men diagnosed in N. Ireland from 1993 to 2006

The European age standardised incidence rate (EASIR) for N. Ireland, which allows for international comparison and takes account of changing age structures over time, has increased sharply (+45%) over the years 1999 to 2003 (Fig. 2) from a rate of 63 to 92 men per 100,000 before levelling again from 2004 to 2006 (see Appendix C for actual rates). The annual percentage change (APC) in incidence rates from 1999 to 2003 was 9.7% (P<0.05). The European age standardised mortality rate (EASMR) from 1993-2006 has not increased significantly, in fact there is some evidence that it has decreased with an APC of -0.9% (P=0.06).



Figure 3: Age specific mortality rates of prostate cancer in N. Ireland from 1993-2006

\*The truncated mortality rate for patients age 60-74 was standardised using the European Age Standard Population weights; the other age groups are age specific rates. \*\*\*  $r_{2006}$  is the expected mortality rate (per 100,000) in 2006 for each age group of patients.

Figure 3 analyses the falling prostate cancer mortality rate by various age groups. The age-specific prostate cancer mortality rate for patients aged from 80 to 84 years declined significantly (P<0.01) from 1993 to 2006 with an annual percentage change (APC) of -2.2; the APC for the rate of men dying from prostate cancer aged 75-79 years also showed a decline (although not significant) of 2.31 APC (P=0.053) (see figure above). This likely reflects improvements in treatment of locally advanced and metastalic disease in the preceding 10 years. Death rates for men aged 60-74 remained unchanged.

The rise in incidence, which is similar, but later, to rises experienced in many developed countries, is most likely due to increased detection of prostate cancer through increased testing for Prostate Specific Antigen (PSA), whose level in the blood can be raised by a malignant tumour in the prostate gland. It is not surprising then, that increased incidence rates in N. Ireland have coincided with a large increase in PSA testing since 1994 (Fig. 4).



Figure 4: Number of PSA tests in N. Ireland from 1994-2006

It might appear that PSA testing is a useful way to screen for prostate cancer, particularly if survival rates have been increasing rapidly since its introduction. However, it is worth considering that survival is calculated from the time of diagnosis which, with PSA testing, may be earlier than diagnosis based on symptoms and so observed survival will increase although actual survival may stay the same. This is called 'lead time bias'.

#### Lead Time Bias example



In the example above, both patients live to the same point in their illness. Patient (B) with the PSA test will have known about his cancer for 5 years compared with 3 if he had not had a PSA test. Lead time bias makes the use of survival statistics as a means to test the usefulness of the PSA test for prostate cancer

screening debatable, and now epidemiologists are studying mortality rates as a more appropriate method: if there is a genuine survival advantage to men through earlier PSA-detected diagnosis and treatment, then this should translate into lower mortality rates.

Also, PSA testing for prostate cancer does not meet the well-defined and internationally accepted criteria for a screening test<sup>7</sup>. Two major international randomised control trials studying PSA-screening have reported results recently<sup>8,9</sup>. The Prostate, Lung, Colorectal and Ovarian cancer trial (PLCO)<sup>8</sup> in the USA randomly assigned and offered annual PSA testing for 6 years and digital rectal examination for 4 years to half of 76,693 men, and the other half, the control group, received 'usual' care which could include screening depending on the care provider (rates of screening in this control group ranged from 40-52% over the course of the study). After 7-10 years of follow-up in the PLCO trial, the rate of death from prostate cancer was very low and did not differ between the two groups.

In the second study, the European Randomised Screening for Prostate Cancer Trial (ERSPC)<sup>9</sup>, 182,000 men were randomly assigned to either a screened group, who were offered PSA screening at an average of once every four years, or a control group who received no such screening. The results from the ERSPC trial, after a 9-year median follow-up, showed a 20% reduction in death rate from prostate cancer in the PSA-based screening group; this group, though, was associated with a high risk of over-diagnosis. In summary, there is some evidence that mortality rates from prostate cancer in men who have been screened for prostate cancer decline after 8 years in comparison to those patients who received no screening but with over diagnosis of cancers.

It will be several years before these trials are fully complete. Meanwhile many men have had a PSA test which has resulted in further investigation and treatment with questionable benefit for the patient. Studies have shown that many healthy men have small foci of prostate cancer which will cause them no symptoms, nor affect their life expectancy in any way.

#### Risk factors

Increasing age is the most important risk factor in prostate cancer. Many men will develop prostate cancer in their life, especially as they age and many will die as a result of other diseases. Family history is a strong risk factor in the development of prostate cancer, a man who has a relative with prostate cancer has twice the risk of developing the disease.<sup>10</sup> This risk increases to three times the average if the relative is a brother and increases to four times the average if a father, brother or son was diagnosed before age 60.<sup>11</sup> A strong family history of breast cancer is also an indication of an increased risk as it may indicate the presence of the faulty BRCA1 or BRCA2 gene which can increase the risk of prostate cancer.<sup>12,13</sup> Other known, but relatively weak risk factors for prostate cancer are black ethnic race<sup>14</sup> and a diet with high animal fat consumption<sup>14</sup> and low levels of selenium.<sup>15</sup>

#### The prostate gland



The prostate is a small gland in males which is found surrounding a tube called the urethra which leaves the bladder. There are several possible urinary symptoms associated with cancer of this gland including difficulty or pain in passing urine, more frequent or urgent urination or passing blood in the urine.



However, many older men have problems passing urine which are due to prostate enlargement but not cancer. Pain in the back, hips or pelvis may also be a sign of prostate cancer<sup>16</sup>, but is also common with increasing age and has many non-cancer causes.

**International 5-year survival estimates** (Note: relative survival adjusts for background mortality and is higher than observed mortality)

For prostate cancer patients diagnosed 1995-1999, N. Ireland had an age-standardised 5-year relative survival of 60.8% which lagged behind the average of EUROCARE 4 countries of 73.9%<sup>17</sup>. However, by 2001 the 5-year relative survival in N. Ireland increased to 76.8%, which is comparable to period analysis estimates of EUROCARE 4<sup>18</sup> for years 2000-2002 of 77.5%, while the same estimates for the USA were 99.3%<sup>18</sup>. Survival estimates between countries are, however, problematic to interpret as comparisons are made between different patient groups due to differences in the use of PSA tests.

### **Study methods**

#### Data collection

Registry Tumour Verification Officers (TVOs) collected data by reviewing clinical notes of patients already registered with the N. Ireland Cancer Registry with a diagnosis of prostate cancer (topography codes ICD-10<sup>19</sup> C61). For many patients, cases notes from different hospitals were reviewed to complete their audit. Data was then entered into an electronic proforma, which had been developed with the guidance of clinicians; a copy is available at www.qub.ac.uk/nicr.

#### **Exclusions & analyses**

Patients were excluded if their records lacked sufficient information, or information was available only from a death certificate (DCO) or post-mortem. The patients included in the report generally received some investigation or treatment in the hospital health system, therefore the audit report measures the performance of this sector more than any other (e.g. GP, hospice, etc.). After cleaning and validation, data analysis was carried out in Stata<sup>20</sup>. Tests for statistical significance used in the report include Chi-square and Kaplan-Meier (survival analysis).

## SECTION II – RESULTS OF PROSTATE CANCER AUDIT

## **Study patients**

Since the completion of the 1996 & 2001 audit, the incidence of prostate cancer patients in 2001 increased by 96 (+20.5%) to 565 and so the 2001 figures for the total number of patients is higher than in the previously published audit report (1996 incidence increased by 17 patients). These prostate cancer patients were most likely diagnosed and treated solely by their GP. They only became known to the Registry when they died a number of years later with a mention of prostate cancer on their death certificate or subsequent information obtained through hospital admissions.

It can be expected that the incidence of prostate cancer for 2006 will also be an underestimate; however the study patients will represent quite accurately the patients who received significant treatment in the hospital health system as these patients are flagged by multiple information sources.

#### **Study patients**

| Study patients                        | Number of patients |             |             |
|---------------------------------------|--------------------|-------------|-------------|
|                                       | 1996               | 2001        | 2006        |
| Total number of patients              | 460                | 565         | 819         |
| Exclusions – Death Certificate Only   | 13                 | 0           | 1           |
| Exclusions – Lack of information      | 67                 | 129         | 36          |
| Total exclusions                      | 80                 | 129         | 37          |
| Total Reported on (% of all patients) | 380 (82.6%)        | 436 (77.2%) | 782 (95.5%) |
| Average age at diagnosis              | 74.1               | 72.0        | 70.5        |
| Median age at diagnosis               | 74.8               | 72.1        | 70.3        |

- The number of men diagnosed with prostate cancer has increased by 78% between 1996 and 2006. The reduction in average age from 74.1 years in 1996 indicates more diagnosis of prostate cancer in younger men due to increased use of PSA testing.
- Observed survival will be influenced upwards because the patients diagnosed in 2006 are younger and have a longer life expectancy than those diagnosed in 1996 and 2001. In addition, PSA testing detects both significant and non-significant disease and results in lead time bias (see page 14).

| Deprivation Quintile Number of patients (%) |               |               | %)            |
|---|---------------|---------------|---------------|
|   | 1996 (n*=459) | 2001 (n*=564) | 2006 (n*=818) |
| Quintile 1 (Most affluent)                  | 80 (17%)      | 111 (20%)     | 152 (19%)     |
| Quintile 2                                  | 104 (23%)     | 114 (20%)     | 182 (22%)     |
| Quintile 3                                  | 102 (22%)     | 136 (24%)     | 175 (21%)     |
| Quintile 4                                  | 101 (22%)     | 106 (19%)     | 171 (21%)     |
| Quintile 5 (Least affluent)                 | 72 (16%)      | 97 (17%)      | 138 (17%)     |

#### Socio-economic residential area of all registered prostate cancer patients in N. Ireland

\*Three patients, one in each year, couldn't be assigned a postcode

• The population of N. Ireland can be divided into five equally sized quintiles ranked by socioeconomic deprivation level of area of residence. If a disease is not related to deprivation, it is expected that approximately 20% of all incidence would fall in each quintile. Although both the most and the least affluent areas had fewer than expected cases, there was little difference in the incidence of prostate cancer by socio-economic groups.

• The distribution of patients across the socio-economic quintiles did not differ (P=0.81) between the years.

## **Referral and presentation**

#### Source of referral to specialist care

| Source                    | Number of patients (%) |              |              |
|---------------------------|------------------------|--------------|--------------|
|                           | 1996 (n=380)           | 2001 (n=436) | 2006 (n=782) |
| GP (General Practitioner) | 330 (87%)              | 373 (86%)    | 585 (75%)    |
| Physician                 | 16 (4%)                | 15 (3%)      | 25 (3%)      |
| Self-presented            | 4 (1%)                 | 3 (<1%)      | 25 (3%)      |
| Under review by Urologist | 2 (<1%)                | 5 (1%)       | 65 (8%)      |
| Accident and Emergency    | 5 (1%)                 | 1 (<1%)      | 5 (<1%)      |
| Other speciality          | 4 (1%)                 | 2 (<1%)      | 2 (<1%)      |
| Surgery                   | 14 (4%)                | 15 (3%)      | 11 (1%)      |
| Other*                    | 5 (1%)                 | 10 (2%)      | 17 (2%)      |
| Not recorded              | 0                      | 12 (3%)      | 47 (6%)      |

\*other included screening, inpatient, district nurse, private patient

• In 2006, 75% of patients were referred to a specialist by their GP; this proportion is down from 2001 & 1996, reflecting slight increases in self-referral and referral from urologists review which might suggest incidental findings.

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#### Patients presenting within their own Board

| Board of residence               | Number of Patients<br>(% of all patients resident in that Board) |           |           |
|----------------------------------|--|-----------|-----------|
| Year                             | 1996*  | 2001*     | 2006*     |
| NHSSB (Northern Area Trust)      | 89 (83%)   | 54 (57%)  | 80 (43%)  |
| EHSSB Total                      | 143 (99%)  | 161 (99%) | 259 (98%) |
| EHSSB (Belfast Trust)            |  | —         | 93 (76%)  |
| EHSSB (South Eastern Area Trust) | —  | —         | 87 (62%)  |
| SHSSB (Southern Area Trust)      | 55 (89%)   | 52 (69%)  | 137 (83%) |
| WHSSB (Western Area Trust)       | 64 (97%)   | 87 (99%)  | 102 (96%) |

\*the hospital of presentation was missing for 44 patients in 2006; a patient in each of 2001 and 2006 couldn't be assigned a postcode

• In 2006, there was a decrease in the percentage of patients resident in the Northern Board that presented in a hospital in the Northern Board (43%).

- Since 2006, the majority of patients in the EHSSB, SHSSB, and WHSSB presented within their own Board of residence.
- In 2006, 51% of patients resident in the Northern Board and 16% of patients resident in the Southern Board presented in the Eastern Board Hospitals.
- In 2006, 24% of patients resident in the Belfast Area Trust presented in the South Eastern Area Trust, while 35% of patients resident in the South Eastern Area Trust presented in the Belfast Area Trust.

#### Mode of presentation

| Mode of presentation    | Nu           | mber of Patients ( | %)           |
|-------------------------|--------------|--------------------|--------------|
|                         | 1996 (n=380) | 2001 (n=436)       | 2006 (n=782) |
| Out-patient             | 228 (60%)    | 269 (62%)          | 557 (71%)    |
| Medical emergency       | 40 (10%)     | 33 (7%)            | 29 (4%)      |
| Surgical emergency      | 72 (19%)     | 29 (6%)            | 40 (5%)      |
| Consultant referral     | 34 (9%)      | 16 (4%)            | 17 (2%)      |
| Under urological review | 0            | 2 (<1%)            | 74 (10%)     |
| Other*                  | 6 (2%)       | 75 (17%)           | 39 (5%)      |
| Not recorded            | 0            | 12 (3%)            | 26 (3%)      |

\*other includes clinics that cater for men, or patients in hospital for other reasons.

- In 2006, 71% of patients presented as an outpatient, an increase from previous years translating into a doubling of patient numbers.
- In 2006, 69 patients presented as a surgical or medical emergency, a slight increase from 2001, but a significant (P<0.01) reduction from 112 patients in 1996.
- 10% of patients in 2006 were under review with a urologist when they presented at a hospital and eventually were diagnosed with prostate cancer.



### Hospital of presentation

| Hospital                            | Numb         | er of patients (% o | f total)     |
|-------------------------------------|--------------|---------------------|--------------|
|                                     | 1996 (n=380) | 2001 (n=436)        | 2006 (n=782) |
| Belfast City Hospital (BCH)*        | 58 (15%)     | 72 (17%)            | 203 (26%)    |
| Mater Infirmorum Hospital (MIH)     | 19 (5%)      | 28 (6%)             | 44 (6%)      |
| Royal Victoria Hospital (RVH)*      | 7 (2%)       | 10 (2%)             | 11 (1%)      |
| Belvoir Park Hospital (BPR) **      | 1 (<1%)      | 1 (<1%)             | 0            |
| TOTAL BELFAST TRUST                 | 85 (22%)     | 111 (25%)           | 257 (33%)    |
| Ulster Hospital (UH)*               | 54 (14%)     | 67 (15%)            | 50 (6%)      |
| Downe Hospital (DH)                 | 17 (4%)      | 21 (5%)             | 30 (4%)      |
| Ards Hospital (AR)***               | 4 (1%)       | 0                   | 28 (4%)      |
| Lagan Valley Hospital (LVH)         | 3 (<1%)      | 20 (5%)             | 16 (2%)      |
| TOTAL SOUTH-EASTERN TRUST           | 78 (20%)     | 108 (25%)           | 125 (16%)    |
| TOTAL EHSSB                         | 163 (42%)    | 219 (50%)           | 382 (49%)    |
| Causeway Hospital (CAU)             | 28 (7%)      | 27 (6%)             | 45 (6%)      |
| Antrim Hospital (ANT)*              | 38 (10%)     | 18 (4%)             | 27 (3%)      |
| Mid Ulster Hospital (MUH)           | 10 (3%)      | 7 (2%)              | 4 (<1%)      |
| Whiteabbey Hospital (WHA)           | 11 (3%)      | 2 (<1%)             | 3 (<1%)      |
| Carrickfergus Hospital (CFH)        | 0            | 0                   | 1 (<1%)      |
| Braid Valley Hospital (BVH)         | 1 (<1%)      | 0                   | 0            |
| Moyle Hospital (MLE)                | 1 (<1%)      | 0                   | 0            |
| Waveney Hospital (WAV)              | 1 (<1%)      | 1 (<1%)             | 0            |
| TOTAL NHSSB/NORTHERN TRUST          | 90 (24%)     | 55 (13%)            | 80 (10%)     |
| Craigavon Area Hospital (CAH)*      | 40 (11%)     | 39 (9%)             | 108 (14%)    |
| Daisy Hill Hospital (DHH)           | 11 (3%)      | 13 (3%)             | 40 (5%)      |
| South Tyrone Hospital (STH)         | 7 (2%)       | 0                   | 0            |
| Banbridge Hospital (BBH)            | 0            | 1 (<1%)             | 0            |
| TOTAL SHSSB/SOUTHERN TRUST          | 58 (15%)     | 53 (12%)            | 148 (19%)    |
| Altnagelvin Hospital (AH)*          | 31 (8%)      | 53 (12%)            | 93 (12%)     |
| Tyrone County Hospital (TCH)        | 19 (5%)      | 23 (5%)             | 7 (<1%)      |
| Roe Valley (RV)                     | 0            | 1 (<1%)             | 6 (<1%)      |
| Erne Hospital (ERN)                 | 18 (5%)      | 17 (4%)             | 5 (<1%)      |
| TOTAL WHSSB/WESTERN TRUST           | 68 (18%)     | 94 (22%)            | 111 (14%)    |
| Ulster Independent Clinic (UIC)     | 1 (<1%)      | 12 (3%)             | 14 (2%)      |
| North West Independent Clinic (NWC) | 0            | 3 (<1%)             | 3 (<1%)      |
| TOTAL PRIVATE HOSPITALS             | 1 (<1%)      | 15 (3%)             | 17 (2%)      |
|                                     |              |                     |              |
| Not Recorded                        | 0            | 0                   | 44 (6%)      |

\*Cancer Unit \*\* BPR provided the regional radiotherapy/oncology service until 17/3/2006 when the role was taken over by the BCH Cancer Centre. \*\*\* Changed to community health facility with no inpatient facilities by 2001

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• In 1996, 380 patients presented to 22 hospitals; in 2001, 436 patients presented to 21 hospitals, and in 2006, 782 patients presented to 20 hospitals.

By 2006,

- 26% of patients presented to Belfast City Hospital, an increase from 17% in 2001, however, due to increased number of patients with prostate cancer, this represented a 2.8 fold increase in patient numbers from 72 to 203.
- Craigavon Area Hospital also saw a 2.7 fold increase in patients presenting from 39 in 2001 to 108 in 2006.
- The number of patients presenting to Altnagelvin increased 1.75 fold between 2001 and 2006 from 53 to 93, respectively.
- Fewer patients presented to the Ulster Hospital in 2006 compared with 2001.
- The proportion of patients presenting from the private sector was small (2%).
- Around 63% of patients presented to a Cancer Unit.

**Hospital ever attended excluding the Cancer Centre** (Note: as patients can attend more than one hospital in their Health Board area, the percentage ever attending a Board will not generally equal the sum of the hospital percentages)

| Hospital                            | Numbe        | er of patients (% o | f total)     |
|-------------------------------------|--------------|---------------------|--------------|
|                                     | 1996 (n=380) | 2001 (n=436)        | 2006 (n=782) |
| Belfast City Hospital (BCH)*        | 82 (22%)     | 150 (34%)           | 279 (36%)    |
| Mater Infirmorum Hospital (MIH)     | 19 (5%)      | 28 (6%)             | 46 (6%)      |
| Royal Victoria Hospital (RVH)*      | 13 (3%)      | 18 (4%)             | 12 (2%)      |
| Musgrave Park Hospital (MPH)        | 0            | 22 (5%)             | 2 (<1%)      |
| TOTAL BELFAST TRUST                 | 108 (28%)    | 196 (45%)           | 318 (41%)    |
| Ulster Hospital (UH) *              | 56 (15%)     | 69 (16%)            | 76 (10%)     |
| Ards Hospital (AR)**                | 9 (2%)       | 1 (<1%)             | 53 (7%)      |
| Downe Hospital (DH)                 | 17 (4%)      | 22 (5%)             | 33 (4%)      |
| Lagan Valley Hospital (LVH)         | 3 (<1%)      | 37 (8%)             | 22 (3%)      |
| TOTAL SOUTH-EASTERN TRUST           | 78 (21%)     | 112 (26%)           | 135 (17%)    |
| TOTAL EHSSB                         | 179 (47%)    | 277 (64%)           | 424 (54%)    |
| Antrim Hospital (ANT)*              | 50 (13%)     | 21 (5%)             | 68 (9%)      |
| Causeway Hospital (CAU)             | 28 (7%)      | 30 (7%)             | 54 (7%)      |
| Mid Ulster Hospital (MUH)           | 10 (3%)      | 7 (2%)              | 4 (<1%)      |
| Whiteabbey Hospital (WHA)           | 11 (3%)      | 2 (<1%)             | 3 (<1%)      |
| Carrickfergus Hospital (CFH)        | 0            | 0                   | 1 (<1%)      |
| Waveney Hospital (WAV)              | 1 (<1%)      | 1 (<1%)             | 0            |
| Moyle Hospital (MLE)                | 1 (<1%)      | 0                   | 0            |
| Braid Valley Hospital (BVH)         | 1 (<1%)      | 0                   | 0            |
| TOTAL NHSSB/NORTHERN TRUST          | 91 (24%)     | 58 (13%)            | 100 (13%)    |
| Craigavon Area Hospital (CAH)*      | 44 (12%)     | 46 (11%)            | 161 (21%)    |
| Daisy Hill Hospital (DHH)           | 11 (3%)      | 15 (3%)             | 42 (5%)      |
| South Tyrone Hospital (STH)         | 7 (2%)       | 0                   | 4 (<1%)      |
| Banbridge Hospital (BBH)            | 1 (<1%)      | 2 (<1%)             | 1 (<1%)      |
| Armagh Community Hospital (ACH)     | 1 (<1%)      | 1 (<1%)             | 0            |
| TOTAL SHSSB/SOUTHERN TRUST          | 62 (16%)     | 57 (13%)            | 165 (21%)    |
| Altnagelvin Hospital (AH)*          | 31 (8%)      | 72 (17%)            | 117 (15%)    |
| Tyrone County Hospital (TCH)        | 20 (5%)      | 40 (9%)             | 8 (1%)       |
| Erne Hospital (ERN)                 | 18 (5%)      | 33 (8%)             | 6 (<1%)      |
| Roe Valley (RV)                     | 0            | 1 (<1%)             | 6 (<1%)      |
| TOTAL WHSSB/WESTERN TRUST           | 68 (18%)     | 104 (24%)           | 119 (15%)    |
| Ulster Independent Clinic (UIC)     | 1 (<1%)      | 15 (3%)             | 34 (4%)      |
| North West Independent Clinic (NWC) | 0            | 3 (<1%)             | 3 (<1%)      |
|                                     |              |                     |              |

\* Cancer Unit \*\* Changed to community health facility with no inpatient facilities by 2001

In 2006:

- 36% (n=279) of patients attended the Belfast City Hospital at some stage in their patient journey; 73% of them (n=203) as first presentation.
- 21% (n=161) of patients attended Craigavon Area Hospital; 67% of them (n=108) as first presentation.
- 5% of patients attended the private sector at some stage in their diagnosis or treatment of prostate cancer.

Hospitals attended (Note: Cancer Centre is included as a hospital)

- In 2006, 36% of patients attended one hospital, 42% two hospitals, 21% three hospitals and 1% attended four hospitals for their investigations and treatment.
- By 2006, more patients were attending two or three hospitals in the course of their diagnosis and treatment than in previous years.

#### Percentage of patients attending one, two, three or four hospitals



- One patient in 2001 attended a fifth hospital, which was the Cancer Centre.
- 64% of patients in 2006 attended more than one hospital for their investigation and treatments; this underlines the need for good communication.

| Comorbidity*            | Number of patients (% of total) |              |              |
|-------------------------|---------------------------------|--------------|--------------|
|                         | 1996 (n=380)                    | 2001 (n=436) | 2006 (n=782) |
| Cardiovascular disease  | 113 (30%)                       | 131 (30%)    | 134 (17%)    |
| Cerebrovascular disease | 26 (7%)                         | 16 (4%)      | 65 (8%)      |
| Diabetes                | 21 (6%)                         | 45 (10%)     | 96 (12%)     |
| Other malignancy        | 22 (6%)                         | 55 (13%)     | 150 (19%)    |
| Dementia                | 2 (<1%)                         | 5 (1%)       | 8 (1%)       |

#### Comorbidities at presentation (Note: patients may have had more than one comorbidity)

\*Comorbidities were recorded differently in 2006 (see table below), and were reclassified, as far as possible, for comparison with 1996 and 2001

In 2006,

- The percentage of patients with cardiovascular disease has declined, but the numbers are stable.
- There was an increase in the recorded number of patients with 'other malignancy'; this may be an effect of recording.

#### **Charlson Comorbidity score**

The Charlson score has recently<sup>21</sup> been proposed as a tool for objectively assessing a patient's comorbidities with a view to assist clinical decision making. The Charlson score<sup>21</sup> takes into account the presence of 19 diseases scored on the basis of their association with mortality. The weights for each disease are added up and added to scores depending on the patient's age (less than 40 years = 0; 41 to 50 years = 1; 51 to 60 years = 2; 60 to 70 years = 3; greater than 71 years = 4).

| Comorbidity (weights)                                  | Number of patients (%) |
|--|------------------------|
|  | (n=782)                |
| History of myocardial infarction (1)                   | 116 (15%)              |
| Congestive cardiac failure (1)                         | 28 (4%)                |
| Peripheral vascular disease (including leg ulcers) (1) | 25 (3%)                |
| Chronic obstructive pulmonary disease (1)              | 58 (7%)                |
| Diabetes mellitus (without end organ damage) (1)       | 93 (12%)               |
| Cerebrovascular disease (1)                            | 65 (8%)                |
| Dementia (1)   | 8 (1%)                 |
| Ulcers (stomach) (1)                                   | 63 (8%)                |
| Connective tissue disease (1)                          | 8 (1%)                 |
| Mild liver disease (1)                                 | 2 (<1%)                |
| Hemiplegia (2)   | 5 (<1%)                |
| Moderate to severe chronic renal failure (2)           | 27 (3%)                |
| Diabetes mellitus (with end-organ damage) (2)          | 6 (<1%)                |
| Malignancy (2)   | 90 (12%)               |
| Leukaemia (2)  | 1 (<1%)                |
| Lymphoma (2)   | 3 (<1%)                |
| Moderate to severe liver disease (3)                   | 0                      |
| Metastatic solid tumour (prostate cancer only) (6)     | 105 (13%)              |
| AIDS (6)   | 0                      |

Comorbidities in 2006 (Note: patients may have had more than one comorbidity)

• The comorbidities reflect the older age group who get prostate cancer.

- In 2006, the most common comorbidity among patients was myocardial infarction (15%); in addition, 12.6% of patients had a record of diabetes.
- In 2006, 12% of patients had another malignancy, the most frequent were the following: nonmelanoma skin cancer 5.4% (of patients), bladder 1.7%, colorectal 0.9%, malignant melanoma 0.8%, lung 0.5%, upper Gl 0.4%.
- One in eleven patients (n=67) had a metastatic prostate cancer in 2006.

#### Distribution of the Charlson score in 2006

| Charlson Score             | Number of patients (%) |
|----------------------------|------------------------|
|                            | (n=782)                |
| 1 to 3                     | 206 (26%)              |
| 4 to 6                     | 320 (41%)              |
| 7 to 9                     | 78 (10%)               |
| 10 to 14                   | 90 (12%)               |
| Comorbidities not recorded | 88 (11%)               |

• 26% of patients in 2006 had a Charlson comorbidity score of less than 4.

Symptoms/signs at presentation (Note: patients may present with more than one symptom)

| Symptoms/signs                                      | Number of patients (% of Total) |              |              |  |
|---|---------------------------------|--------------|--------------|--|
|   | 1996 (n=380)                    | 2001 (n=436) | 2006 (n=782) |  |
| Nocturia (Urinating frequently at night)            | 232 (61%)                       | 223 (51%)    | 458 (59%)    |  |
| Retention (Inability to urinate)                    | 88 (23%)                        | 81 (19%)     | 82 (10%)     |  |
| Incontinence/terminal dribbling                     | 162 (43%)                       | 141 (32%)    | 231 (30%)    |  |
| Bone pain   | 37 (10%)                        | 40 (9%)      | 37 (5%)      |  |
| Weight loss   | 36 (9%)                         | 24 (6%)      | 39 (5%)      |  |
| Lethargy  | 18 (5%)                         | 36 (8%)      | 11 (1%)      |  |
| Poor flow   | *                               | —            | 308 (39%)    |  |
| Urgency   | —                               | —            | 149 (19%)    |  |
| Dysuria (pain on urinating)/Urinary tract infection | _                               | —            | 110 (14%)    |  |
| Incomplete emptying                                 | —                               | —            | 91 (12%)     |  |
| Urinary frequency (daytime)                         |                                 |              | 324 (41%)    |  |
| Abnormal urinanalysis                               |                                 | _            | 110 (14%)    |  |
| No urinary symptoms                                 | 48 (13%)                        | 97 (22%)     | 149 (19%)    |  |

\* collected in 2006 only

• Each year approximately 40 patients present with bone pain (as more patients are diagnosed the percentage drops).

• In 2006, over a fifth of prostate cancer patients (n=173) diagnosed in N. Ireland had no urinary symptoms; the number of patients with no urinary symptoms has increased approximately 3.5 times since 1996 (n=48).

• Frequency in the need to urinate, both by day (2006 only) and by night, was the most common symptom experienced by patients, with over half of them in all years experiencing nocturia. These however are also common symptoms in men of this age group due to benign prostatic hyperplasia.

# Investigations

**Investigations recorded in notes** (Note: Patients may have had more than one type of investigation)

| Investigation                            | Number of patients (%) |              |              |  |
|--|------------------------|--------------|--------------|--|
| All Patients                             | 1996 (n=380)           | 2001 (n=436) | 2006 (n=782) |  |
| PSA test at or prior to diagnosis        | 371 (98%)              | 431 (99%)    | 774 (99%)    |  |
| Digital Rectal Examination (DRE)         | 323 (85%)              | 334 (77%)    | 714 (91%)    |  |
| Bone scan                                | 206 (54%)              | 254 (58%)    | 532 (68%)    |  |
| CT scan                                  | 45 (12%)               | 149 (34%)    | 132 (17%)    |  |
| MRI scan                                 | 5 (1%)                 | 88 (20%)     | 468 (60%)    |  |
| Prostate biopsy                          | 91 (24%)               | 378 (87%)    | 622 (80%)    |  |
|  |                        |              |              |  |
| Surgery Patients (radical prostatectomy) | 1996 (n=3)             | 2001 (n=43)  | 2006 (n=59)  |  |
| PSA test at or prior to diagnosis        | 3 (100%)               | 43 (100%)    | 58 (98%)     |  |
| Digital Rectal Examination (DRE)         | 2 (67%)                | 29 (67%)     | 53 (90%)     |  |
| Bone scan                                | 2 (67%)                | 13 (30%)     | 24 (41%)     |  |
| CT scan                                  | 2 (67%)                | 10 (23%)     | 8 (14%)      |  |
| MRI scan                                 | 0 (0%)                 | 7 (16%)      | 47 (80%)     |  |
| Prostate biopsy                          | 0 (0%)                 | 43 (100%)    | 58 (98%)     |  |

• Nearly all patients had a PSA test taken before diagnosis.

- The recording of patient's receiving a DRE increased in 2006 to 91%.
- The proportion of prostate cancer patients receiving a bone scan increased to 68% in 2006.
- In 2006, 622 patients had a prostate biopsy which is a 7 fold increase since 1996 (n=91) and a 65% increase from 2001 (n=378).
- The proportion of patients receiving an MRI scan increased markedly to 60% in 2006 up from 20% in 2001; almost four fifths of surgery patients received an MRI.
- For surgery patients, the proportion recorded as having received a DRE increased to 90%.



The proportions of patients recorded as receiving different scan combinations in 2006



#### Percentage of 2006 patients with bone, MRI, or CT scan by Board of residence

- Patients in the Southern Board were more likely to have received a bone scan or an MRI than any other Board reaching levels of 77% and 65%, respectively.
- The use of CT scanning was most common in the Eastern Board at 24% and lowest in the Western Board at 7%.



#### Percentage of 2006 patients with bone, MRI, or CT scan by age group

- Patients aged younger than 60 were more likely (84%) to receive an MRI scan than patients aged 80 years or over (10%).
- The most frequent scan for older patients (80 years of age or more) was a bone scan with 53% having one.

#### **Highest PSA level before diagnosis**

| PSA level             | Number of patients (%) |              |              |  |
|-----------------------|------------------------|--------------|--------------|--|
|                       | 1996 (n=380)           | 2001 (n=436) | 2006 (n=782) |  |
| 0 to 3.9              | 23 (6%)                | 16 (4%)      | 34 (4%)      |  |
| 4 to 9.9              | 25 (7%)                | 68 (16%)     | 216 (28%)    |  |
| 10 to 19.9            | 44 (12%)               | 101 (23%)    | 219 (28%)    |  |
| 20 to 29.9            | 41 (11%)               | 52 (12%)     | 89 (11%)     |  |
| 30+                   | 238 (63%)              | 194 (44%)    | 216 (28%)    |  |
| No record of PSA test | 9 (2%)                 | 5 (1%)       | 8 (1%)       |  |

From 1996 to 2006:

- There was no significant decrease in the number of men with a PSA over 30 ng/ml (P=0.28), and no significant change in the number with a PSA over 20 ng/ml.
- There was a five fold increase in the prostate cancer patients with a PSA <10 ng/ml (P<0.001).
- There was a 5 fold increase in prostate cancer patients with a PSA <20 ng/ml (P<0.001).

#### Highest recorded PSA level prior to diagnosis by age group in 2006

| PSA level             | Number of patients (%) |                      |                      |                 |
|-----------------------|------------------------|----------------------|----------------------|-----------------|
|                       | Age bands              |                      |                      |                 |
|                       | 0 to 59<br>(n*=91)     | 60 to 69<br>(n*=287) | 70 to 79<br>(n*=296) | 80+<br>(n*=108) |
| 0 to 3.9              | 6 (7%)                 | 14 (5%)              | 8 (3%)               | 6 (5%)          |
| 4 to 9.9              | 52 (57%)               | 110 (38%)            | 49 (16%)             | 5 (5%)          |
| 10 to 19.9            | 18 (20%)               | 81 (28%)             | 100 (34%)            | 20 (18%)        |
| 20 to 29.9            | 5 (5%)                 | 27 (9%)              | 42 (14%)             | 15 (14%)        |
| 30+                   | 9 (10%)                | 53 (19%)             | 95 (32%)             | 59 (55%)        |
| No record of PSA test | 1 (1%)                 | 2 (<1%)              | 2 (<1%)              | 3 (3%)          |

\*the total number of patients with a recorded PSA level before diagnosis in this age band is the denominator of the % in columns.

• With increasing age, prostate cancer patients were more likely to have a higher PSA level.

#### Assessed by urologist at any stage

| Patients assessed by urologist           | Number of patients assessed (% of total) |              |              |  |  |
|--|--|--------------|--------------|--|--|
| All patients                             | 1996 (n=380)                             | 2001 (n=436) | 2006 (n=782) |  |  |
| Assessed by urologist at any stage       | 183 (48%)                                | 335 (77%)    | 767 (98%)    |  |  |
|  |  |              |              |  |  |
| Surgery patients (radical prostatectomy) | 1996 (n=3)                               | 2001 (n=43)  | 2006 (n=59)  |  |  |
| Assessed by urologist at any stage       | 3 (100%)                                 | 42 (98%)*    | 59 (100%)    |  |  |

\*One patient's clinical notes were incomplete

• In 2006 nearly all patients (98%) were recorded as having seen a urologist at some stage in their treatment pathway, an increase from 77% in 2001.

• All surgery patients, except one in 2001 who had incomplete clinical notes, had a record of having been seen by an urologist.

#### Patients assessed by urologist within their own Board of residence

| Board of residence               | Number of Patients<br>(% presenting within their own Board) |           |           |
|----------------------------------|---|-----------|-----------|
|                                  | 1996  | 2006*     |           |
| NHSSB (Northern Area Trust)      | 24 (53%)  | 27 (42%)  | 77 (42%)  |
| EHSSB Total                      | 65 (97%)  | 134 (99%) | 255 (98%) |
| EHSSB (Belfast Trust)            |   | _         | 88 (75%)  |
| EHSSB (South Eastern Area Trust) | —   | —         | 86 (61%)  |
| SHSSB (Southern Area Trust)      | 39 (93%)  | 39 (71%)  | 137 (83%) |
| WHSSB (Western Area Trust)       | 27 (96%)  | 56 (98%)  | 98 (96%)  |

\*Two patients, one in each of year 2001 and 2006, couldn't be assigned a postcode

In 2006:

- Over 90% of patients resident in the Eastern and Western Boards were assessed by a urologist in hospitals in those board areas.
- 52% of patients resident in the NHSSB were assessed by a urologist in the EHSSB.
- 25% of patients resident in the Belfast Area Trust were assessed by a urologist in the South Eastern Area Trust, while 37% of patients resident in the South Eastern Area Trust were assessed by a urologist in the Belfast Area Trust.

#### Management discussed with an oncologist

| Management discussed oncologist          | Number of patients assessed (% of total) |              |              |  |  |
|--|--|--------------|--------------|--|--|
| All patients                             | 1996 (n=380)                             | 2001 (n=436) | 2006 (n=782) |  |  |
| Management discussed oncologist          | 54 (14%)                                 | 171 (39%)    | 498 (64%)    |  |  |
|  |  |              |              |  |  |
| Surgery patients (radical prostatectomy) | 1996 (n=3)                               | 2001 (n=43)  | 2006 (n=59)  |  |  |
| Management discussed oncologist          | 1 (33%)                                  | 10 (23%)     | 31 (53%)     |  |  |

- In 2006, 64% of patients were recorded as having had their management discussed with an oncologist, an increase from 39% in 2001.
- By 2006, 53% of surgery patients were recorded as having their management discussed with an oncologist.

#### Management discussed with an oncologist by age group

| Age      | Number of Patients<br>(% of patients in that age group) |              |           |
|----------|---|--------------|-----------|
|          | 1996 (n=54)   | 2006 (n=498) |           |
| 0 to 59  | 14 (58%)  | 29 (63%)     | 62 (68%)  |
| 60 to 69 | 19 (20%)  | 73 (54%)     | 223 (78%) |
| 70 to 79 | 13 (8%)   | 59 (36%)     | 188 (64%) |
| 80+      | 8 (8%)  | 10 (11%)     | 25 (23%)  |

In 2006,

- Younger people were more likely than older people to have their management discussed with an oncologist, this may reflect clinical need.
- For all ages, but especially those aged over 60 years, referral to oncology increased.
- 68% of patients under 60 years of age had their management discussed by an oncologist, an increase of 10% from 1996 (58%).

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#### Hospital first seen by urologist

| Hospital                            | Number of patients (% of total) |              |              |  |
|-------------------------------------|---------------------------------|--------------|--------------|--|
|                                     | 1996 (n=183)                    | 2001 (n=328) | 2006 (n=728) |  |
| Belfast City Hospital (BCH)*        | 64 (35%)                        | 74 (23%)     | 206 (28%)    |  |
| Mater Infirmorum Hospital (MIH)     | 19 (10%)                        | 28 (9%)      | 44 (6%)      |  |
| Royal Victoria Hospital (RVH)*      | 6 (3%)                          | 4 (1%)       | 6 (<1%)      |  |
| TOTAL BELFAST TRUST                 | 89 (48%)                        | 106 (32%)    | 256 (35%)    |  |
| TOTAL EHSSB AREA                    | 89 (48%)                        | 184 (56%)    | 379 (52%)    |  |
| Ulster Hospital (UH)*               | 0                               | 63 (19%)     | 45 (6%)      |  |
| Ards Hospital (AR)**                | 0                               | 0            | 32 (4%)      |  |
| Downe Hospital (DH)                 | 0                               | 0            | 31 (4%)      |  |
| Lagan Valley Hospital (LVH)         | 0                               | 15 (5%)      | 15 (2%)      |  |
| TOTAL SOUTH-EASTERN TRUST           | 0                               | 78 (24%)     | 123 (17%)    |  |
| Causeway Hospital (CAU)             | 22 (12%)                        | 25 (8%)      | 44 (6%)      |  |
| Antrim Hospital (ANT)*              | 2 (1%)                          | 1 (<1%)      | 28 (4%)      |  |
| Mid Ulster Hospital (MUH)           | 0                               | 1 (<1%)      | 4 (<1%)      |  |
| Carrickfergus Hospital (CFH)        | 0                               | 0            | 1 (<1%)      |  |
| TOTAL NHSSB/NORTHERN TRUST          | 24 (13%)                        | 27 (8%)      | 77 (11%)     |  |
| Craigavon Area Hospital (CAH)*      | 42 (23%)                        | 40 (12%)     | 111 (15%)    |  |
| Daisy Hill Hospital (DHH)           | 0                               | 0            | 37 (5%)      |  |
| Banbridge Hospital (BBH)            | 0                               | 1 (<1%)      | 1 (<1%)      |  |
| TOTAL SHSSB/SOUTHERN TRUST          | 42 (23%)                        | 41 (13%)     | 149 (20%)    |  |
| Altnagelvin Hospital (AH)*          | 27 (15%)                        | 58 (18%)     | 99 (14%)     |  |
| Roe Valley (RV)                     | 0                               | 1 (<1%)      | 5 (<1%)      |  |
| Erne Hospital (ERN)                 | 0                               | 1 (<1%)      | 2 (<1%)      |  |
| Tyrone County Hospital (TCH)        | 0                               | 0            | 1 (<1%)      |  |
| TOTAL WHSSB/WESTERN TRUST           | 27 (15%)                        | 60 (18%)     | 107 (15%)    |  |
| Ulster Independent Clinic (UIC)     | 1 (<1%)                         | 14 (4%)      | 13 (2%)      |  |
| North West Independent Clinic (NWC) | 0                               | 2 (<1%)      | 3 (<1%)      |  |
| TOTAL PRIVATE HOSPITALS             | 1 (<1%)                         | 16 (5%)      | 16 (2%)      |  |

\* Cancer Unit \*\* Changed to community health facility with no inpatient facilities by 2001

- In 2006, Belfast City Hospital, Craigavon Area Hospital, and Altnagelvin Hospital handled between them 57% of all urological assessment of prostate cancer patients.
- Patients saw urologists in 7 hospitals in 1996, 15 in 2001, and 20 in 2006.
#### Method of Diagnosis

In agreement with national and international guidelines, NICR uses a hierarchy when deciding the certainty of a cancer diagnosis. Microscopic verification (MV) (histology/cytology) is generally most reliable. However, if this is not possible, results of imaging procedures such as CT scan or chest X-ray, which for some patients is the only way of confirming a diagnosis, is accepted. In the absence of any microscopic or visual confirmation of the prostate cancer, the Registry accepts the opinion of a clinician (CO) that the patient has cancer.

| Method of diagnosis | Number of patients (%) |                 |                 |                  |                |                |
|---------------------|------------------------|-----------------|-----------------|------------------|----------------|----------------|
| wethou of ulagnosis | All patients           |                 |                 | Surgery Patients |                |                |
|                     | 1996<br>(n=380)        | 2001<br>(n=436) | 2006<br>(n=782) | 1996<br>(n=3)    | 2001<br>(n=43) | 2006<br>(n=59) |
| Histopathology      | 304 (80%)              | 388 (89%)       | 725 (92%)       | 3 (100%)         | 42 (98%)       | 59 (100%)      |
| Scan*               | 25 (6%)                | 13 (3%)         | 18 (2%)         | 0                | 0              | 0              |
| Clinical opinion    | 45 (12%)               | 23 (5%)         | 38 (5%)         | 0                | 0              | 0              |
| Other**             | 6 (2%)                 | 12 (3%)         | 1 (<1%)         | 0                | 1 (2%)         | 0              |

\*Scan includes bone scan, US, CT, MRI \*\* 'Other' cytology, PSA.

- In 2006, 92% of patients had a histologically confirmed diagnosis of prostate cancer, and 100% for surgery patients.
- The proportion of patients diagnosed by clinical opinion alone declined from 12% in 1996 to 5% in 2001 & 2006, however the number varied around 40 in 1996 and 2006.
- Only 5 patients had a PSA test recorded as a method of diagnosis (2 patients in each of 1996 and 2001, and 1 patient 2006).

### **Histopathology and Staging**

#### **Histopathological Type**

| Sub type                    | Number of patients |              |              |  |  |
|-----------------------------|--------------------|--------------|--------------|--|--|
|                             | 1996 (n=380)       | 2001 (n=436) | 2006 (n=782) |  |  |
| Adenocarcinoma              | 287 (76%)          | 377 (86%)    | 723 (92%)    |  |  |
| Carcinoma                   | 4 (1%)             | 8 (2%)       | 1 (<1%)      |  |  |
| Other malignancies          | 15 (4%)            | 7 (2%)       | 1 (<1%)      |  |  |
| Not histologically verified | 74 (19%)           | 44 (10%)     | 57 (7%)      |  |  |

• There was better histopathological subtyping in 2001 & 2006 compared with 1996, with a smaller proportion (7%) not histologically verified in 2006.

• Adenocarcinoma was the most common histological type, and the proportion of patients with this type has been increasing since 1996 at 76% to 92% in 2006.



#### Histological classification of prostate cancer

\* 'Non MV'= Non-microscopically verified

#### Histopathological type of 'other malignancies' (Note: see above table)

| Sub type (morphology code*)          | Number of patients |            |            |  |
|--------------------------------------|--------------------|------------|------------|--|
|                                      | 1996 (n=15)        | 2001 (n=7) | 2006 (n=1) |  |
| Acinar cell carcinoma (M85503)       | 3                  | 3          | 1          |  |
| Small cell carcinoma, NOS** (M80413) | 1                  | 0          | 0          |  |
| Mucinous carcinoma (M84803)          | 1                  | 0          | 0          |  |
| Unspecified (M80003)                 | 10                 | 4          | 0          |  |

\*For an explanation of morphology codes see reference 19, \*\* NOS, not otherwise specified

• In 2006, there were no histologically-verified cancers that were coded as unspecified.

#### Staging (see also Appendix D)

Recording of stage in the clinical notes had improved by 2006, with 72% (n=562) of patients having stage recorded compared to only 29% (n=111) in 1996. By 2006, 54% of patients undergoing radical prostatectomy (n=32) had a stage recorded in their notes, down from 86% (n=37) in 2001.

When stage was not recorded and there was sufficient information available in the clinical notes, Registry Tumour Verification Oficers (TVOs) were able to assign a stage group (Registry-assigned stage) (see Appendix D: Staging of prostate cancer).

| TNIM stage |  | atients)        |                 |               |                |                |
|------------|--|-----------------|-----------------|---------------|----------------|----------------|
| TNM stage  |  | All patients    |                 | S             | urgery patient | ts             |
|            | 1996<br>(n=111)                                    | 2001<br>(n=266) | 2006<br>(n=562) | 1996<br>(n=0) | 2001<br>(n=37) | 2006<br>(n=32) |
| 1          | 2 (2%)   | 10 (4%)         | 2 (<1%)         | 0             | 0              | 0              |
| Ш          | 9 (8%)   | 116 (43%)       | 303 (53%)       | 0             | 15 (41%)       | 21 (66%)       |
| Ш          | 11 (10%)   | 74 (28%)        | 134 (24%)       | 0             | 20 (54%)       | 11 (34%)       |
| IV         | 89 (80%)   | 66 (25%)        | 123 (22%)       | 0             | 2 (5%)         | 0              |
|            | Insufficient data* for staging (% of all patients) |                 |                 |               |                |                |
|            | 1996<br>n=(380)                                    | 2001<br>(n=436) | 2006<br>(n=782) | 1996<br>(n=3) | 2001<br>(n=43) | 2006<br>(n=59) |
|            | 269 (71%)  | 170 (39%)       | 220 (28%)       | 3 (100%)      | 6 (14%)        | 27 (46%)       |

### TNM Stage (recorded in notes or Registry-assigned)

\*Staging for these patients was not possible due to a lack of information in the notes

- In 2006, despite the greater absolute number of patients, the proportion being staged has improved from 61% in 2001 to 72% in 2006.
- Stage II was the most common stage at which patients were staged in 2001 and 2006.
- In 2006, 22% of staged patients were recorded as Stage IV.

#### Highest PSA level before diagnosis for patients who were unstaged

| PSA level             | Number of patients (%) |              |              |  |  |
|-----------------------|------------------------|--------------|--------------|--|--|
|                       | 1996 (n=269)           | 2001 (n=170) | 2006 (n=220) |  |  |
| 0 to 3.9              | 21 (8%)                | 8 (6%)       | 23 (18%)     |  |  |
| 4 to 9.9              | 20 (9%)                | 21 (15%)     | 85 (38%)     |  |  |
| 10 to 19.9            | 34 (14%)               | 38 (22%)     | 55 (21%)     |  |  |
| 20 to 29.9            | 38 (14%)               | 19 (11%)     | 18 (7%)      |  |  |
| 30+                   | 151 (53%)              | 81 (44%)     | 33 (13%)     |  |  |
| No record of PSA test | 5 (2%)                 | 3 (2%)       | 6 (3%)       |  |  |

• In 1996 and 2001 unstaged patients were more likely to have higher PSA level at the higher end of the scale. By 2006, unstaged patients were as likely to have PSA levels 4-20 as over 30ng/ml.

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| Stage recorded (or assigned by TVOs) in the notes by hospital of diagnosis |  |
|--|--|
|--|--|

|                                     |               | -  |               |  |  |
|-------------------------------------|---------------|--|---------------|--|--|
| Hospital                            |               | Number of patients<br>(% of total diagnosed in hospital) |               |  |  |
|                                     | 1996 (n=380)  | 2001 (n=436)   | 2006 (n=782)  |  |  |
| Belfast City Hospital (BCH)*        | 17/60 (28%)   | 53/80 (66%)  | 187/247 (76%) |  |  |
| Mater Infirmorum Hospital (MIH)     | 7/19 (37%)    | 9/28 (32%)   | 42/46 (91%)   |  |  |
| Royal Victoria Hospital (RVH)*      | 5/9 (56%)     | 3/5 (60%)  | 3/4 (75%)     |  |  |
| TOTAL BELFAST TRUST                 | 29/89 (33%)   | 65/113 (58%)   | 232/297 (78%) |  |  |
| Ards Hospital (AR)**                | 0/4           | 0/0  | 42/49 (86%)   |  |  |
| Ulster Hospital (UH)*               | 13/53 (25%)   | 46/65 (71%)  | 22/34 (65%)   |  |  |
| Downe Hospital (DH)                 | 2/17 (12%)    | 10/21 (48%)  | 23/29 (79%)   |  |  |
| Lagan Valley Hospital (LVH)         | 0/2           | 15/20 (75%)  | 0/0           |  |  |
| TOTAL SOUTH-EASTERN TRUST           | 15/76 (20%)   | 71/106 (67%)   | 87/112 (78%)  |  |  |
| TOTAL EHSSB                         | 44/165 (27%)  | 136/219 (62%)  | 319/409 (78%) |  |  |
| Causeway Hospital (CAU)             | 10/26 (38%)   | 9/23 (39%)   | 34/52 (65%)   |  |  |
| Antrim Hospital (ANT)*              | 12/43 (28%)   | 7/19 (37%)   | 7/20 (35%)    |  |  |
| Mid Ulster Hospital (MUH)           | 4/9 (44%)     | 5/7 (71%)  | 2/3 (67%)     |  |  |
| Whiteabbey Hospital (WHA)           | 6/9 (67%)     | 0/0  | 0/1           |  |  |
| Braid Valley Hospital (BVH)         | 1/1 (100%)    | 0/0  | 0/0           |  |  |
| TOTAL NHSSB/NORTHERN TRUST          | 33/88 (38%)   | 21/49 (43%)  | 43/76 (57%)   |  |  |
| Craigavon Area Hospital (CAH)*      | 5/40 (13%)    | 18/39 (46%)  | 116/147 (79%) |  |  |
| Daisy Hill Hospital (DHH)           | 0/11          | 8/14 (57%)   | 7/9 (78%)     |  |  |
| South Tyrone Hospital (STH)         | 2/7 (29%)     | 0/0  | 0/1           |  |  |
| Banbridge Hospital (BBH)            | 0/1           | 1/1 (100%)   | 0/0           |  |  |
| Armagh Community Hospital (ACH)     | 1/1 (100%)    | 0/0  | 0/0           |  |  |
| TOTAL SHSSB/SOUTHERN TRUST          | SHSSB         | 8/60 (13%)   | 27/54 (50%)   |  |  |
| Altnagelvin Hospital (AH)*          | 12/30 (40%)   | 50/63 (79%)  | 56/111 (50%)  |  |  |
| Tyrone County Hospital (TCH)        | 12/19 (63%)   | 15/22 (68%)  | 1/2 (50%)     |  |  |
| Erne Hospital (ERN)                 | 1/17 (6%)     | 11/17 (65%)  | 0/0           |  |  |
| TOTAL WHSSB/WESTERN TRUST           | 25/66 (38%)   | 76/102 (75%)   | 57/113 (50%)  |  |  |
| Ulster Independent Clinic (UIC)     | 1/1 (100%)    | 3/4 (75%)  | 4/6 (67%)     |  |  |
| North West Independent Clinic (NWC) | 0/0           | 0/0  | 0/1           |  |  |
| TOTAL PRIVATE HOSPITALS             | 1/1 (100%)    | 3/4 (75%)  | 4/7 (57%)     |  |  |
| ALL HOSPITALS                       | 111/380 (29%) | 226/436 (61%)  | 562/782 (72%) |  |  |

\*Cancer Unit \*\*Changed to community health facility with no inpatient facilities by 2001

• Recording of stage was lower in the patients diagnosed in the Southern (50%) and Western Board (50%) than compared with the average.

#### Clinical stage component in patient risk assessment\*

| Risk level   | Number of patients<br>(% patients with risk information) |              |              |  |  |
|--|--|--------------|--------------|--|--|
|  | 1996 (n=24)  | 2001 (n=203) | 2006 (n=440) |  |  |
| T1-T2a   | 6 (25%)  | 58 (28%)     | 124 (28%)    |  |  |
| T2b-T2c  | 1 (4%)   | 56 (28%)     | 151 (34%)    |  |  |
| Unspecified T2   | 3 (13%)  | 10 (5%)      | 30 (7%)      |  |  |
| ТЗ-Т4  | 14 (58%)   | 79 (39%)     | 135 (31%)    |  |  |
|  | Number of patients<br>(% patients of all patients)       |              |              |  |  |
|  | 1996 (n=380)   | 2001 (n=436) | 2006 (n=782) |  |  |
| Disease not local** (% of all patients)                        | 82 (22%)   | 58 (13%)     | 121 (16%)    |  |  |
| Insufficient information on clinical stage (% of all patients) | 274 (72%)  | 175 (40%)    | 221 (28%)    |  |  |

\*see Table 1 page 9 \*\* 'Disease not local' means that there was a record of cancer spread to nodes or other parts of the body

• In 2006, 31% of patients had a clinical stage of T3-T4 which alone could classify them as 'high risk' (under NICE guidelines<sup>5</sup>) which was a decrease from 39% in 2001 and 58% in 1996.

• In general, the distribution of clinical stage between 2001 and 2006 was not dissimilar.

Gleason Score reading (Note: Gleason score measures the aggressiveness of the tumour)

| Gleason score | Number of patients (%) |              |              |  |  |
|---------------|------------------------|--------------|--------------|--|--|
|               | 1996 (n=380)           | 2001 (n=436) | 2006 (n=782) |  |  |
| 1 to 3        | 39 (10%)               | 24 (5%)      | 0            |  |  |
| 4 to 6        | 31 (8%)                | 164 (38%)    | 255 (33%)    |  |  |
| 7             | 15 (4%)                | 110 (25%)    | 210 (27%)    |  |  |
| 8 to 10       | 17 (5%)                | 78 (18%)     | 254 (32%)    |  |  |
| Not recorded  | 278 (73%)              | 60 (14%)     | 63 (8%)      |  |  |

• By 2006, 92% of patients had a recorded Gleason score, a further improvement from 2001.

• In 2006, 32% of patients had a Gleason score of 8 to 10 which alone could classify them as 'high risk' (under NICE guidelines<sup>5</sup>) which was an increase from 18% in 2001; this could represent a higher level of investigation of patients with advanced disease.

### **Multidisciplinary Team Meetings**

The effective management of prostate cancer patients requires input from a range of experts. Multidisciplinary team meetings (MDTs) involve a group of healthcare professionals meeting to discuss the diagnosis and treatment of patients. As there are a range of potential treatments that could be carried out, multidisciplinary discussions are of great importance. With respect to MDTs it should be noted that discussions among healthcare professionals, regarding the diagnosis and treatment of patients, may have taken place but may not have been recorded in the patient notes.

**Multidisciplinary team meetings recorded in the notes** (Note: A record of MDT in the notes was accepted without details of the MDT members)

| MDT                | Number of patients (%) |              |              |  |  |
|--------------------|------------------------|--------------|--------------|--|--|
|                    | 1996 (n=380)           | 2001 (n=436) | 2006 (n=782) |  |  |
| Yes                | 4 (1%)                 | 17 (4%)      | 458 (59%)    |  |  |
| No or not recorded | 376 (99%)              | 419 (96%)    | 324 (41%)    |  |  |

 In 2006, the proportion of patients receiving an MDT has increased from 4% in 2001 (n=17) to 59% (n=458) in 2006.

**MDT for patients by Board of residence** (Note: A record of MDT in the notes was accepted without details of the MDT members)

| Board of residence               | Number of Patients<br>(% all patients resident in Board) |         |           |  |  |
|----------------------------------|--|---------|-----------|--|--|
|                                  | 1996 (n=380) 2001* (n=435) 2006* (n=                     |         |           |  |  |
| NHSSB (Northern Area Trust)      | 1 (1%)   | 0       | 131 (65%) |  |  |
| EHSSB Total                      | 2 (1%)   | 12 (7%) | 205 (70%) |  |  |
| EHSSB (Belfast Trust)            | 1 (1%)   | 3 (4%)  | 90 (68%)  |  |  |
| EHSSB (South Eastern Area Trust) | 1 (1%)   | 9 (10%) | 115 (71%) |  |  |
| SHSSB (Southern Area Trust)      | 0  | 2 (3%)  | 26 (15%)  |  |  |
| WHSSB (Western Area Trust)       | 1 (2%)   | 3 (3%)  | 95 (87%)  |  |  |

\*a patient in each of 2001 and 2006 couldn't be assigned a postcode

• In 2006, patients in the Western Board were most likely to have been considered at an MDT at 87%; however, the proportion of recorded MDTs in the Southern Board was poor at 15%.

The NICE guidelines<sup>5</sup> state: "The results of all prostate biopsies should be reviewed by a urological cancer MDT. Men should only be re-biopsied following a negative biopsy after an MDT review of the risk characteristics including life expectancy, PSA, DRE and prostate volume".

#### MDT for patients who had a biopsy by Board of residence

| Board of residence               | Number of Patients<br>(% all patients who received biopsy in Board) |         |           |  |  |
|----------------------------------|---|---------|-----------|--|--|
|                                  | 1996  | 2001*   | 2006      |  |  |
| NHSSB (Northern Area Trust)      | 1 (9%)  | 0 (0%)  | 120 (82%) |  |  |
| EHSSB Total                      | 0 (0%)  | 12 (8%) | 187 (78%) |  |  |
| EHSSB (Belfast Trust)            | 0 (0%)  | 3 (4%)  | 82 (77%)  |  |  |
| EHSSB (South Eastern Area Trust) | 0 (0%)  | 9 (12%) | 105 (80%) |  |  |
| SHSSB (Southern Area Trust)      | 0 (0%)  | 2 (3%)  | 25 (17%)  |  |  |
| WHSSB (Western Area Trust)       | 0 (0%)  | 2 (3%)  | 87 (95%)  |  |  |

\*One patient in year 2001 couldn't be assigned a postcode

• In 2006, patients who have had a biopsy were highly likely to have had an MDT meeting in the Northern (82%), Eastern (78%), and Western Boards (95%); however, the proportion in the Southern Board was poor at 17%.

### Patient Management and Treatment

Management (Note: the minimum follow-up for all years was 9 months [2006])

| Management                      | Number of patients<br>(% of total) |           |           |  |
|---------------------------------|------------------------------------|-----------|-----------|--|
|                                 | (n=380)                            | (n=436)   | (n=782)   |  |
| Active surveillance (2006 only) | *                                  | —         | 133 (17%) |  |
| Radical Prostatectomy           | 3 (1%)                             | 43 (10%)  | 59 (8%)   |  |
| Hormone treatment               | 243 (64%)                          | 313 (72%) | 577 (74%) |  |
| Radiotherapy (palliative)       | 1 (<1%)                            | 21 (5%)   | 33 (4%)   |  |
| Radiotherapy (curative)         | 17 (4%)                            | 103 (24%) | 292 (37%) |  |

\*In 2006, 'active surveillance' referred to monitoring the aggressiveness of early-stage disease. In 1996 & 2001, a similar field also included patients with advanced disease who were monitored in order to time hormone or palliative treatment optimally. As the meaning of 'surveillance' was not consistent between years, it was decided to concentrate on the most recent data (2006).

In 2006,

- 133 patients (17%) were managed initially by active surveillance in the early stages of their disease.
- 37% of patients received radical radiotherapy reflecting an increasing trend since 1996; the number of patients receiving curative radiotherapy has increased markedly (+189) since 2001.
- 8% of patients received a radical prostatectomy, the number of patients receiving this treatment increased by +16 or 37%.
- An increased number of patients (+264) received hormone treatment from 2001 to 2006.

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| Age group | Number of patients (%)            |                                    |                                 |  |                                       |  |  |
|-----------|-----------------------------------|------------------------------------|---------------------------------|--|---------------------------------------|--|--|
|           | Active<br>surveillance<br>(n=133) | Radical<br>Prostatectomy<br>(n=59) | Hormone<br>treatment<br>(n=577) | Radiotherapy<br>(palliative)<br>(n=33) | Radiotherapy<br>(curative)<br>(n=292) |  |  |
| 0 to 59   | 18 (14%)                          | 35 (59%)                           | 41 (7%)                         | 2 (6%)                                 | 31 (10%)                              |  |  |
| 60 to 69  | 58 (44%)                          | 23 (39%)                           | 202 (35%)                       | 12 (36%)                               | 151 (52%)                             |  |  |
| 70 to 79  | 47 (35%)                          | 1 (2%)                             | 247 (43%)                       | 15 (46%)                               | 109 (37%)                             |  |  |
| 80+       | 10 (7%)                           | 0                                  | 87 (15%)                        | 4 (12%)                                | 1 (<1%)                               |  |  |

**Patient management and treatment by age group in 2006** (Note: the minimum follow-up for all years was 9 months [2006])

• In 2006, the majority (59%) of patients receiving a radical prostatectomy were under 60 years old.

- The majority of patients receiving hormone therapy were aged 70 years or over.
- 58% of patients that had 'active surveillance' management were under 70 years old.

**Breakdown of treatment received post 'active surveillance' (2006)** (Note: the minimum follow-up for 2006 was 9 months; patients can receive more than one treatment)





In 2006, of the patients on active surveillance:

- 4% subsequently had a radical prostatectomy, and 6% had radical radiotherapy.
- 7% had neo-adjuvant hormone therapy, while a further 7% had non-specified hormone therapy.
- No one proceeded to have palliative radiotherapy.
- 83% continued on active surveillance.
- 34% were staged Stage II and 2% Stage III, the remainder 64% had no recorded stage.
- 57% were less than 70 years old (48% of all patients are less than 70 years old).

Recorded treatment combinations\* (Note: the minimum follow-up for all years was 9 months [2006])

| Recorded treatment                                  | Nu           | mber of patients ( | %)           |
|---|--------------|--------------------|--------------|
|   | 1996 (n=380) | 2001 (n=436)       | 2006 (n=782) |
| Radical treatment only**                            | 15 (4%)      | 49 (11%)           | 54 (7%)      |
| Hormone treatment only                              | 237 (62%)    | 201 (46%)          | 253 (32%)    |
| Palliative radiotherapy only                        | 0            | 2 (<1%)            | 0            |
| Radical treatment and hormone                       | 5 (1%)       | 93 (21%)           | 291 (37%)    |
| Radical treatment and palliative radiotherapy       | 0            | 0                  | 0            |
| Hormone and palliative radiotherapy                 | 1 (<1%)      | 17 (4%)            | 32 (4%)      |
| Radical treatment, hormone, palliative radiotherapy | 0            | 2 (<1%)            | 1 (<1%)      |
| No record of any three above treatments             | 122 (32%)    | 72 (17%)           | 151 (19%)    |

\*Patients were assigned a treatment combination on the basis of positive recorded information \*\*Radical treatment refers to either radical radiotherapy or radical surgery (prostatectomy)

• In 2006, over a third of patients (n=291) received combined radical treatment (radical prostatectomy or radical radiotherapy) and hormone treatment.

#### **Surgical procedures**

| Procedure                                       | Number of patients (%) |           |           |  |
|---|------------------------|-----------|-----------|--|
|   | (n=380)                | (n=436)   | (n=782)   |  |
| Transurethral resection of the prostate (TURP*) | 228 (60%)              | 117 (27%) | 115 (15%) |  |
| Radical prostatectomy                           | 3 (1%)                 | 43 (10%)  | 59 (8%)   |  |
| No surgery recorded                             | 152 (40%)              | 278 (64%) | 603 (77%) |  |

\*TURP is a surgical procedure to remove tissue from the prostate gland, usually a non-cancerous enlargement called benign prostatic hypertrophy, BPH.

• Although the number of patients who received a prostatectomy increased in N. Ireland in 2006, the proportion declined to 8%.

• There is a continuing decline in the proportion of patients who receive a TURP operation reducing to 15% in 2006.

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#### Number of procedures Number of patients (%) 1996 2001 2006 3 (66%) 10 or more procedures 0 (0%) 1 (47%) 5 - 9 procedures 0 (0%) 2 (42%) 1 (16%) 2 - 4 procedures 1 (67%) 0 (0%) 3 (16%) 1 procedure 1 (33%) 5 (12%) 2 (3%) 9 2 8 Total named surgeons Total named consultants 2 8 8 3 58\* 43 Total procedures

#### Frequency of radical prostatectomy procedures by surgeon

\*One patient in 2006 had their radical prostatectomy performed outside N. Ireland

- Nine urologists performed radical prostatectomy on 58 patients in 2006.
- In 2006, the majority of procedures (66%) were carried out by surgeons who were doing 10 operations or more per year.
- 5 urologists were recorded as performing less than 5 radical prostatectomies, of whom 2 only did one prostatectomy each (one of them was a locum).

### **Timelines in the Patient Pathway**

#### Summary timeline

| Timeline               | Referral to presentation<br>at hospital |                 | Presen          | tation to dia   | ignosis         |                 |
|------------------------|---|-----------------|-----------------|-----------------|-----------------|-----------------|
| Year (total patients)  | 1996<br>(n=380)                         | 2001<br>(n=436) | 2006<br>(n=782) | 1996<br>(n=380) | 2001<br>(n=436) | 2006<br>(n=782) |
|                        | Νι                                      | Imber patient   | s whose time    | line not recor  | ded (% of tot   | al)             |
|                        | 1 (<1%)                                 | 30 (7%)         | 66 (8%)         | 0               | 21 (5%)         | 31 (4%)         |
| Days since start point | % pat                                   | ients seen (nu  | ımber)          | % patien        | its diagnosed   | (number)        |
| Day 1                  | 33%<br>(n=125)                          | 17%<br>(n=71)   | 13%<br>(n=95)   | 7% (n=28)       | 4% (n=18)       | 17%<br>(n=129)  |
| Day 14                 | 48%<br>(n=181)                          | 31%<br>(n=126)  | 21%<br>(n=148)  | 38%<br>(n=145)  | 25%<br>(n=103)  | 27%<br>(n=204)  |
| Day 31                 | 66%<br>(n=251)                          | 52%<br>(n=210)  | 35%<br>(n=254)  | 52%<br>(n=199)  | 42%<br>(n=175)  | 38%<br>(n=285)  |
| Day 62                 | 90%<br>(n=340)                          | 74%<br>(n=300)  | 56%<br>(n=403)  | 69%<br>(n=263)  | 57%<br>(n=238)  | 50%<br>(n=378)  |

- Over time, there has been an increase in the waiting times from referral to first seen at hospital; in 2001, 74% of patients (n=300) were seen within 62 days, in 2006 this had reduced to 56% (n=403), however, from 2001 to 2006, the (absolute) number of patients who were seen before 62 days increased by 103.
- The proportion of patients that were diagnosed within 62 days from presentation declined from 1996 to 2001; there was a further decline from 2001 to 2006 but this was not statistically significant (P=0.10). The number of patients who were diagnosed with 62 days of presentation increased by 59% in 2006 (n=378) from 2001 (n=238).

• The Eastern Board had the shortest delay for patients from referral to first seen (63% were seen within 62 days) (P<0.001), whereas the Southern Board had the longest delay (43% were seen within 62 days); a similar pattern was observed for the delay between presentation and diagnosis, 63% of patients in the Eastern Board were diagnosed within 62 days of presentation, 29% in the Southern Board (P<0.001).



| Timeline              | Referral for biopsy |                 |                 | First           | seen by urol                    | ogist           |
|-----------------------|---------------------|-----------------|-----------------|-----------------|---------------------------------|-----------------|
| Year (total patients) | 1996<br>(n=91)      | 2001<br>(n=378) | 2006<br>(n=622) | 1996<br>(n=183) | 2001<br>(n=335)                 | 2006<br>(n=767) |
|                       | Νι                  | umber patient   | s whose time    | line not recor  | ded (% of tot                   | al)             |
|                       | 1 (1%)              | 32 (8%)         | 55 (9%)         | 4 (2%)          | 22 (6%)                         | 60 (8%)         |
|                       | % patients          | (number) ha     | ving biopsy     |                 | oatients (num<br>een by urologi |                 |
| Day 1                 | 1% (n=1)            | 0%              | 0%              | 15%<br>(n=27)   | 6% (n=19)                       | 4% (n=30)       |
| Day 14                | 11%<br>(n=10)       | 7% (n=24)       | 2% (n=13)       | 34%<br>(n=61)   | 24%<br>(n=75)                   | 16%<br>(n=112)  |
| Day 31                | 26%<br>(n=23)       | 18%<br>(n=61)   | 6% (n=32)       | 49%<br>(n=89)   | 43%<br>(n=135)                  | 32%<br>(n=224)  |
| Day 62                | 47%<br>(n=42)       | 38%<br>(n=130)  | 18%<br>(n=101)  | 76%<br>(n=138)  | 60%<br>(n=188)                  | 52%<br>(n=366)  |

#### Summary timeline for biopsy investigation / first seen by urologist

• In 2006, waiting times from referral to receiving a biopsy increased; 18% (n=101) of patients had their biopsy within 62 days of referral, down from 38% (n=130) in 2001.

• Between 1996 and 2006, there has been an increase in the waiting time for being seen by a consultant urologist. In 2001, 60% (n=188) patients were seen by a urologist within 62 days of referral, whereas in 2006, it was 52% (n=366); note the doubling of absolute numbers being seen in 2006.

• 57% (n=146) of Eastern Board patients had their biopsy completed within 62 days of referral; this was significantly higher than in the Southern Board at 38%.



#### Summary timeline referral to first seen by urologist by Board of residence

| Timeline               | Time from referral to seen by urologist in 2006 |  |               |               |  |  |  |
|------------------------|---|--|---------------|---------------|--|--|--|
| Board (total patients) | NHSSB (n=203)                                   | EHSSB (n=293)  | SHSSB (n=176) | WHSSB (n=109) |  |  |  |
|                        | Number  | Number patients whose timeline not recorded (% of total) |               |               |  |  |  |
|                        | 20 (10%)  | 8 (7%)   |               |               |  |  |  |
|                        | % patients (number) who have seen urologist     |  |               |               |  |  |  |
| Day 1                  | 6% (n=11)                                       | 4% (n=11)  | 7% (n=12)     | 8% (n=8)      |  |  |  |
| Day 14                 | 17% (n=31)                                      | 17% (n=44)   | 14% (n=22)    | 14% (n=14)    |  |  |  |
| Day 31                 | 32% (n=59)                                      | 37% (n=95)   | 25% (n=40)    | 29% (n=29)    |  |  |  |
| Day 62                 | 56% (n=102)                                     | 57% (n=146)  | 39% (n=63)    | 53% (n=54)    |  |  |  |

• The time interval for patients from referral to being seen by a urologist differed between the Boards (P<0.01); patients resident in the SHSSB had the longest delay with 39% of patients seeing a urologist within 62 days.

#### Summary timeline from referral to first recorded definitive treatment\*

| Timeline              | Time from referral to first definitive recorded treatment  |              |              |  |  |
|-----------------------|--|--------------|--------------|--|--|
| Year (total patients) | 1996 (n=380)   | 2001 (n=436) | 2006 (n=782) |  |  |
|                       | Number patients whose timeline not recorded (% of total)   |              |              |  |  |
|                       | 88 (23%) 142 (33%) 87 (11%)                                |              |              |  |  |
|                       | % patients (number) who have received definitive treatment |              |              |  |  |
| Day 1                 | 0% (n=0)   | <1% (n=1)    | <1% (n=4)    |  |  |
| Day 14                | 11% (n=32)   | 4% (n=12)    | 5% (n=34)    |  |  |
| Day 31                | 24% (n=69)   | 12% (n=34)   | 9% (n=60)    |  |  |
| Day 62                | 39% (n=115)  | 23% (n=69)   | 14% (n=94)   |  |  |

\*First definitive treatment includes: radical prostatectomy, radical and palliative radiotherapy, hormone treatment, active monitoring, brachytherapy, and strontium

• Since 1996, there has been a progressive increase in the waiting times from referral to first definitive treatment; in 1996, 39% of patients (n=115) had their first definitive treatment within 62 days of referral, in 2006 this has fallen to 14% (n=91).



### **Information and After Care**

#### Information recorded in notes

| Information                            | Number of patients (%) |              |              |  |  |
|--|------------------------|--------------|--------------|--|--|
|  | 1996 (n=380)           | 2001 (n=436) | 2006 (n=782) |  |  |
| Multidisciplinary team meeting (MDT)   | 4 (1%)                 | 17 (4%)      | 458 (59%)    |  |  |
| Diagnosis discussed with patient       | 295 (78%)              | 324 (74%)    | 544 (70%)    |  |  |
| Treatment plan discussed with patient  | 295 (78%)              | 319 (73%)    | 684 (87%)    |  |  |
| Management discussed with urologist    | 178 (47%)              | 318 (73%)    | 626 (80%)    |  |  |
| Management discussed with oncologist   | 54 (14%)               | 171 (39%)    | 498 (64%)    |  |  |
| Referred to specialist urologist nurse | 5 (1%)                 | 62 (14%)     | 268 (34%)    |  |  |
| Referred to oncology centre            | 47 (12%)               | 168 (39%)    | 459 (59%)    |  |  |
| Clinical trial discussed with patient  | 0                      | 3 (1%)       | 13 (2%)      |  |  |
| Clinical trial recorded in notes       | 0                      | 3 (1%)       | 12 (2%)      |  |  |
| Patient unaware of diagnosis           | 45 (12%)               | 10 (2%)      | 9 (1%)       |  |  |

- By 2006, 87% of patients had recorded in their notes that their treatment plan was discussed with them.
- In 2006, MDTs were recorded as occurring for 59% of patients.
- In 2006, at least 4/5 patients had a record that their management had been discussed with a urologist, and almost 2/3 with an oncologist.
- The number of patients referred to the oncology centre increased from 39% in 2001 to 59% in 2006.
- Few patients were being entered into clinical trials (1% [n=3] in 2001 and 2% [n=12] in 2006).

#### Follow-up care details

This relates to information recorded in the discharge letter from hospital to GP.

#### Palliative after care recorded in hospital notes

(Note: patients may have had more than one type of referral)

| After Care                                       | Nu           | mber of patients ( | %)           |
|--|--------------|--------------------|--------------|
|  | 1996 (n=380) | 2001 (n=436)       | 2006 (n=782) |
| GP (for palliative care)                         | *            | 2 (<1%)            | 18 (2%)      |
| Community nurse                                  | 12 (3%)      | 5 (1%)             | 12 (2%)      |
| Macmillan nurse                                  | 7 (2%)       | 8 (2%)             | 35 (4%)      |
| Marie Curie nurse                                | 2 (<1%)      | 0                  | 3 (<1%)      |
| Hospice  | 9 (2%)       | 4 (<1%)            | 7 (<1%)      |
| Palliative care specialist                       | 3 (<1%)      | 14 (3%)            | 24 (3%)      |
| Psychologist referral                            | 0            | 0                  | 6 (<1%)      |
| Information on support groups/education supplied | 0            | 5 (1%)             | 0            |
| No onward referral recorded                      | 353 (93%)    | 412 (95%)          | 735 (94%)    |

\*not available

• Most patients were referred back to the care of their GP and only a small number had a palliative care referral.

#### Information in GP letter

| Information                      | Number of patients (%)             |           |           |  |  |
|----------------------------------|------------------------------------|-----------|-----------|--|--|
|                                  | 1996 (n=380) 2001 (n=436) 2006 (n= |           |           |  |  |
| Management plan                  | 369 (97%)                          | 400 (92%) | 749 (96%) |  |  |
| Prognosis                        | 64 (17%)                           | 272 (62%) | 136 (17%) |  |  |
| Diagnosis discussed with patient | 217 (57%)                          | 261 (60%) | 494 (63%) |  |  |
| Diagnosis discussed with family  | 56 (15%)                           | 79 (18%)  | 193 (25%) |  |  |

- From 1996 to 2006, there was an increasing trend in the proportion of patients with a record in their chart that their diagnosis had been discussed with their family although this still only happened in 25% of patients in 2006.
- Prognosis, although highly recorded in 2001, was poorly recorded in the GP letter in 2006 at 17%.
- In 2006, 96% of patients in 2006 had a management plan recorded.



### **Patient Outcomes and Survival**

#### **Patient outcomes**

Radical prostatectomy and radical radiotherapy have high rates of prostate cancer cure. Technology in both modalities has improved both the chance of cure and reduced the risk of complications. The main complications are incontinence and impotence while hormone therapy can also cause impotence. More recently nerve-sparing prostatectomy has been introduced which minimises these side effects. This type of surgery is only suitable for certain patients.

In the following table, it must be noted that it is difficult to accumulate all the outcomes from a retrospective review of the notes. In addition, median follow-up time for 2006 patients was 13 months, which is very short to analyse tumour control outcomes.

**Recorded outcomes by treatment 2006** (Note: This table reports the recorded information found in notes and may not reflect the true situation. Further analysis of this should be undertaken by a special study. The median follow up was 13 months, minimum 9)

| Outcomes               | Number of patients (%) |                               |                              |                    |                         |                 |
|------------------------|------------------------|-------------------------------|------------------------------|--------------------|-------------------------|-----------------|
|                        | Active<br>Surveillance | Radical<br>Prostat-<br>ectomy | Radical<br>Radio-<br>therapy | Hormone<br>Therapy | Palliative<br>Radiation | All<br>Patients |
| Year                   | 2006<br>(n=133)        | 2006<br>(n=59)                | 2006<br>(n=292)              | 2006<br>(n=577)    | 2006<br>(n=33)          | 2006<br>(n=782) |
| Urinary incontinence   | 5 (4%)                 | 14 (24%)                      | 10 (3%)                      | 24 (4%)            | 4 (12%)                 | 39 (5%)         |
| Erectile dysfunction   | 8 (6%)                 | 43 (73%)                      | 56 (19%)                     | 65 (11%)           | 0                       | 110 (14%)       |
| Local progression      | 0                      | 0                             | 1 (<1%)                      | 5 (<1%)            | 3 (9%)                  | 5 (<1%)         |
| Other urinary symptoms | 52 (39%)               | 27 (46%)                      | 133 (46%)                    | 238 (41%)          | 14 (42%)                | 310 (40%)       |
| Biochemical recurrence | N/A*                   | 4 (7%)                        | 13 (4%)                      | 16 (3%)            | 2 (6%)                  | 19 (2%)         |
| Distant metastasis     | 0                      | 0                             | 3 (1%)                       | 108 (19%)          | 31 (94%)                | 110 (14%)       |

\*N/A means not applicable

- The group of patients who received radical prostatectomy had after treatment higher levels of incontinence and erectile dysfunction than groups of patients categorised as having received other treatments.
- Except for patients on palliative radiation, less than 1% of patients experienced local progression after their treatment.
- The group of patients who were receiving hormone therapy had a high rate of metastasis at 19%; patients managed by 'active surveillance' or who had radical prostatectomy had zero levels of distant metastasis. These figures reflect patient selection.
- Across the various treatment groups, the proportion of patients who continued having other urinary symptoms was 40%.
- The high rate of urinary incontinence and erectile dysfunction recorded after radical prostatectomy may reflect the crude definitions used and short timescale monitored. This however requires further research.

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#### Patient survival (2 year follow-up)

It is important when comparing survival over time that any changes in the patient profile and the disease characteristics are considered. Patient changes include age structure and, linked with that, levels of patient comorbidity. The disease characteristics may be altered with changes in methods of diagnosis, e.g. increased use of PSA testing, while changes in investigative techniques, such as increased use of scans will result in more accurate staging information. Survival is also affected by treatment changes, e.g. increased use of hormonal therapy and also service organisation. It is difficult to distinguish the effects of each of these factors.

Survival estimates for prostate cancer will therefore be examined looking at:

- 1) Patient age and stage,
- 2) PSA level at presentation and impact of PSA testing,
- 3) Evidence of PSA screening,
- 4) Effect of improved investigations and stage shifts,
- 5) Survival by symptoms.

#### 1) Patient age and stage (all patients registered in N. Ireland)

- The average age at diagnosis of patients with prostate cancer fell from 74.4 years in 1996 to 72.9 years in 2001 and 70.5 in 2006.
- In 1996 only 29 patients were under 60 years, by 2006 this was 99 (56 in 2001).
- The average age of Stage I/II patients did not change from 1996 (69.3 years) to 2006 (69.9 years).
- While the average age of Stage III patients fell from 75.1 years in 1996 to 67.7 years in 2006 (P<0.01), the average age of Stage IV patients remained the same from 1996 (74.5 years) to 2006 (73.6 years).
- This change in the patient age profile will result in an improvement in survival as age is the greatest determinant of one's risk of dying.

#### 2) PSA level at presentation and impact of PSA testing

## Numbers of audited patients within various 'highest PSA (ng/ml) prior to diagnosis' groupings by year



- The number of patients with PSA  $\geq$ 20 ng/ml and  $\geq$ 30 ng/ml remained similar in all years.
- There was a five-fold increase in patients with PSA <10 ng/ml and a five-fold increase in patients with PSA <20 ng/ml.
- The increased number of patients diagnosed in 2006 with prostate cancer corresponds to the increase in patients with PSA levels in the lower range.

The average age of patients with various levels of PSA varied as shown in the following table:

## The average age of patients diagnosed in N. Ireland for various groups categorised by highest PSA level before diagnosis

| PSA level (ng/ml)        | Average age of patients (number of patients) |              |              | atients)  |
|--------------------------|--|--------------|--------------|---|
|                          | 1996   | 2001         | 2006         | Significant<br>(P-value)<br>decline from<br>1996 on |
| Less than 10             | 71.7 (n=48)                                  | 67.7 (n=84)  | 66.0 (n=250) | P<0.01  |
| Less than 20             | 73.5 (n=92)                                  | 69.5 (n=185) | 68.1 (n=469) | P<0.01  |
| Between 10–19.9          | 75.4 (n=44)                                  | 70.9 (n=101) | 70.4 (n=219) | P<0.01  |
| Greater than or equal 20 | 74.3 (n=279)                                 | 73.6 (n=246) | 74.0 (n=305) | P=0.39  |
| Greater than or equal 30 | 74.3 (n=238)                                 | 74.1 (n=194) | 74.5 (n=216) | P=0.80  |
| Between 20-29.9          | 70.4 (n=41)                                  | 71.7 (n=52)  | 72.8 (n=89)  | P=0.17  |

- Patients with prostate cancer presenting with higher PSA had an average age which remained unchanged.
- In patients who had a lower PSA level at diagnosis (<20 ng/ml) the average age fell from 73.5 years in 1996 to 68.1 years in 2006.
- This age change will affect survival estimates upwards for the latter years where PSA levels were lower and the average patient age fell.

### Survival of patients by level of highest PSA prior to diagnosis

In the following and similar tables the risk of death (or hazard, which is inversely related to survival) is compared for 2001 (or 2006) using 1996 as the baseline or where indicated 2006 with 2001 as baseline. If there is no change in the risk of dying, the risk (hazard) ratio will be 1. A figure less than 1 e.g. 0.59 represents a reduction in risk i.e. a better survival for 2001 compared to 1996, whereas a risk ratio greater than 1 indicates an increase in risk and lowering of observed survival. A significant risk (hazard) ratio will not contain 1 in its 95% confidence intervals (in brackets). All the hazard ratios presented in this report were adjusted for age, as the risk of dying increases with age, i.e. observed survival will decrease with age; the age covariate in the analysis was always significant (P<0.01) and was included in the models. All patients were followed up for a minimum of 2 years.

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| PSA level (ng/ml)               | Hazard ratio (95                                 | % confidence inte                                    | rval) & P-value**                                    |
|---------------------------------|--|--|--|
| Audit years compared            | 2001/1996  | 2006/1996  | 2006/2001  |
| PSA Less than 10                | 0.42 (0.19-0.92)<br>P=0.03<br>Survival improved  | 0.17 (0.08-0.37)<br>P<0.001<br>Survival improved     | 0.41 (0.17-0.97)<br>P=0.042<br>Survival improved     |
| PSA Less than 20                | 0.31 (0.17-0.55)<br>P<0.001<br>Survival improved | 0.19 (0.11-0.32)<br>P<0.001<br>Survival improved     | 0.62 (0.34-1.13)<br>P=0.116<br>No survival<br>change |
| PSA Less than 30                | 0.41 (0.26-0.65)<br>P<0.001<br>Survival improved | 0.19 (0.12-0.3)<br>P<0.001<br>Survival improved      | 0.46 (0.28-0.75)<br>P=0.002<br>Survival improved     |
| PSA Greater than or equal to 10 | 0.61 (0.47-0.8)<br>P<0.001<br>Survival improved  | 0.44 (0.34-0.57)<br>P<0.001<br>Survival improved     | 0.72 (0.54-0.96)<br>P=0.027<br>Survival improved     |
| PSA Greater than or equal to 20 | 0.74 (0.56-0.99)<br>P=0.039<br>Survival improved | 0.59 (0.44-0.78)<br>P<0.001<br>Survival improved     | 0.79 (0.58-1.07)<br>P=0.13<br>No survival<br>change  |
| PSA Greater than or equal to 30 | 0.73 (0.54-0.99)<br>P=0.046<br>Survival improved | 0.75 (0.56-1.01)<br>P=0.061<br>No survival<br>change | 1.03 (0.74-1.42)<br>P=0.878<br>No survival<br>change |
|                                 | Number of pa                                     | tients used in surviv<br>(average age)               | al calculations                                      |
| Less than 10                    | 48 (age=71.7)                                    | 84 (age=67.7)  | 250 (age=66.0)                                       |
| Less than 20                    | 92 (age=73.5)                                    | 185 (age=69.5)                                       | 469 (age=68.1)                                       |
| Less than 30                    | 133 (age=73.6)                                   | 237 (age=69.9)                                       | 558 (age=68.8)                                       |
| Greater than or equal to 10     | 323 (age=74.4)                                   | 347 (age=72.8)                                       | 524 (age=72.5)                                       |
| Greater than or equal to 20     | 279 (age=74.3)                                   | 246 (age=73.6)                                       | 305 (age=74.0)                                       |
| Greater than or equal to 30     | 238 (age=74.3)                                   | 194 (age=74.1)                                       | 216 (age=74.5)                                       |

## Comparing the survival using age-adjusted hazard ratio\* between years for audit patients for different highest PSA levels before diagnosis

\*hazard-ratio was adjusted with a significant (P<0.001) age covariate \*\*P-value <0.05 means that hazard ratio is significantly different from 1

- The number of patients with a PSA <10ng/ml and <20ng/ml at diagnosis increased by five fold from 1996-2006, respectively (with the bulk of increase between 2001-2006); the survival for these patients with low PSA improved over time.
- The number of patients with PSA over 20ng/ml or over 30ng/ml at diagnosis did not change 1996-2001-2006. For those with PSA at diagnosis over 30ng/ml at diagnosis survival did not change from 2001 to 2006 significantly.
- The improved overall survival seems to come from patients with PSA at the lower end of the range.

#### **Evidence of PSA screening**

The NICR has a database of all PSA tests undertaken in N. Ireland and has confidentially matched all, not just audit, prostate cancer patients to the database. A PSA test was considered 'diagnostic' if it occurred in the three months before presentation at hospital (or before diagnosis if date of presentation was missing), or thereafter. The patients were thus divided into two groups, those who only had 'diagnostic tests' and those who had 'other tests' as well (i.e. greater than three months before presentation). Survival analysis comparing these two groups could possibly give some insight into a group of patients whose prostate cancer suspicion was unlikely to be raised by ongoing PSA tests (similar to screening) but through a combination of symptoms and investigations.

## The numbers of all patients in N. Ireland who were either screened or unscreened in the audit years



| Comparing the survival using age-adjusted hazard ratio* between audit years for all patients |
|--|
| diagnosed in N. Ireland with or without PSA screening  |

| Screening                                    | Hazard ratio (95% confidence interval) & P-value**             |  |   |
|--|--|--|---|
| Audit years compared                         | 2001/1996  | 2006/1996  | 2006/2001   |
| "Unscreened"<br>Diagnostic PSA tests<br>only | 0.75 (0.57-0.99)<br>P=0.043<br>Survival improved               | 0.59 (0.43-0.79)<br>P<0.001<br>Survival improved | 0.78 (0.56-1.09)<br>P=0.149<br>No survival change |
| "Screened"<br>Other PSA tests                | 0.53 (0.37-0.75)<br>P<0.001<br>Survival improved               | 0.29 (0.2-0.42) P<0.001<br>Survival improved     | 0.55 (0.39-0.77)<br>P<0.001<br>Survival improved  |
|  | Number of patients used in survival calculations (average age) |  |   |
|  | 1996 (n=460)   | 2001 (n=565)                                     | 2006 (n=819)                                      |
| "Unscreened"                                 | 345 (age=73.8)   | 253 (age=72.3%)                                  | 311 (age=70.8%)                                   |
| "Screened"                                   | 115 (age=76.2%)  | 312 (age=73.5%)                                  | 508 (age=70.2%)                                   |

\*hazard-ratio was adjusted with a significant (P<0.001) age covariate \*\*P-value <0.05 means that hazard ratio is significantly different from 1

- The percentage defined as "screened" increased from 25% in 1996 to 62% in 2006. For the "screened" patients survival over the 24 month follow-up improved significantly with time.
- For the "unscreened" group, the number of patients varied little and the survival at 24 months improved marginally in 2001 compared with 1996, significantly in 2006 compared with 1996, but not between 2001 and 2006.

#### Effect of improved investigation and stage shifts

- The recording of disease stage improved between 1996 and 2006, however each year approximately 200 patients remained unstaged (see table below).
- The number of patients with Stage I/II disease increased from 11 patients in 1996 to 305 in 2006. Those with recorded Stage III/IV also increased but less so.

|           | Number of patients (%)                             |              |              |
|-----------|--|--------------|--------------|
| TNM stage |  | All patients |              |
|           | 1996 (n=111)                                       | 2001 (n=266) | 2006 (n=562) |
| 1         | 2 (2%)   | 10 (4%)      | 2 (<1%)      |
| I         | 9 (8%)   | 116 (43%)    | 303 (53%)    |
| III       | 11 (10%)   | 74 (28%)     | 134 (24%)    |
| IV        | 89 (80%)   | 66 (25%)     | 123 (22%)    |
|           | Insufficient data* for staging (% of all patients) |              |              |
|           | 1996 (n=380)                                       | 2001 (n=436) | 2006 (n=782) |
|           | 269 (71%)  | 170 (39%)    | 220 (28%)    |

#### TNM Stage (recorded in notes or Registry-assigned) for audit patients

\*Staging for these patients was not possible due to a lack of information in the notes

#### The number of audited patients with TNM staging by year



These improvements in stage allocation were possible due to increased levels of investigation including scans (see figure below).



The number of patients who received scans by year

The increased use of diagnostic scans over time will enhance the accuracy of staging so that patients previously allocated on clinical grounds to, for example, Stage II are found with CT scan to be, for example, Stage IV disease. This has the effect of removing the most serious early stage allocated cancer to a later stage. If survival is calculated, Stage I survival improves as the worst cases are allocated a higher stage, e.g. Stage II. Meanwhile the worst of Stage II go to Stage III. For Stage IV cancers, they have less severe i.e. not clinically apparent Stage IV cases within their group. So survival for each Stage group should improve. This is known as the "Will Rogers effect" and the survival improvement is simply due to better investigation of patients.

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| Stage                | Hazard ratio                                      | (95% confidence interva                          | l) & P-value**                                    |
|----------------------|---|--|---|
| Audit years compared | 2001/1996   | 2006/1996  | 2006/2001   |
| Stage I & II         | ***   | —  | 0.53 (0.23-1.22)<br>P=0.137<br>No survival change |
| Stage III            |   | —  | 0.37 (0.13-1.02)<br>P=0.055<br>No survival change |
| Stage IV             | 0.59 (0.39-0.89)<br>P=0.012<br>Survival improved  | 0.59 (0.42-0.83)<br>P=0.003<br>Survival improved | 1.00(0.67-1.49)<br>P=0.984<br>No survival change  |
| Unstaged             | 0.85 (0.65-1.11)<br>P=0.239<br>No survival change | 0.45 (0.31-0.66)<br>P<0.001<br>Survival improved | 0.53 (0.36-0.78)<br>P<0.001<br>Survival improved  |
| All patients         | 0.6 (0.49-0.75)<br>P<0.001<br>Survival improved   | 0.39 (0.31-0.49)<br>P<0.001<br>Survival improved | 0.64 (0.5-0.81)<br>P<0.001<br>Survival improved   |

## Comparing the survival using age-adjusted hazard ratio\* between years for patients diagnosed in N. Ireland within similar stage

\*hazard-ratio was adjusted with a significant (P<0.001) age covariate \*\*P-value <0.05 means that hazard ratio is significantly different from 1 \*\*\*very low number of patients in 1996 prevented analysis (see table above for number of patients)

- Note: there were too few patients with Stage I/II/III disease in 1996 to allow all calculations.
- Survival for Stage I/II/III/IV patients did not change significantly 2006 compared to 2001. For Stage IV patients survival improved in 2001 compared with 1996.
- Survival for Stage IV patients improved between 1996 and 2001 and 1996 and 2006 but did not reach significance for any change 2001-2006 possibly due to treatment changes 1996/2001 e.g. pharmaceutical hormone therapy and/or Will Rogers effect.
- Survival for unstaged patients improved between 2006 and the other years (possibly Will Rogers effect).
- Survival for the group 'all patients' improved for all years, driven partly from 1996-2001 by improvements for Stage IV patients (possibly related to treatment effects) but mainly by the survival improvements for the groups with earlier stage disease. Survival will also have been improved due to the younger age of patients in 2006 and 2001 compared with earlier years.

The survival improvement for Stage I,II and III could be due to

- 1) Real improvement.
- 2) Increased numbers of cases in younger men in whom survival will be better.
- 3) Lead time bias due to increased early disease detection with the introduction of PSA testing.
- 4) Length time bias where increased detection of non/slow progressing disease that will never be life threatening.
- 5) A mix of these.

Improvements in Stage IV survival could be due to

- 1) Improved treatments.
- 2) Stage shift (the Will Rogers effect), where due to enhanced staging investigations e.g. CT scan, MRI etc, staging is more accurate, this results in patients previously thought as Stage II or Stage III being correctly recognised as Stage IV. The effect is that those patients have early Stage IV compared with patients who have clinically apparent Stage IV disease and so survival for the category is improved.
- 3) A mix of the above.



#### Survival by metastasis

The number of patients diagnosed with recorded metastasis increased 20% from 1996 to 2006. This may reflect increased use of scans in patients' investigations.

## Comparing the survival using age-adjusted hazard ratio\* between audit years for patients diagnosed in N. Ireland with or without metastasis at diagnosis

| Metastasis           | Hazard ratio                                     | 95% confidence interval                          | ) & P-value**                                    |
|----------------------|--|--|--|
| Audit years compared | 2001/1996  | 2006/1996  | 2006/2001  |
| Metastasis           | 0.54 (0.35-0.84)<br>P=0.006<br>Survival improved | 0.6 (0.42-0.86)<br>P=0.005<br>Survival improved  | 1.11 (0.72-1.7)<br>P=0.641<br>No survival change |
| No metastasis        | ***  | —  | 0.45 (0.27-0.76)<br>P=0.003<br>Survival improved |
| Unrecorded           | 1.05 (0.8-1.39)<br>P=0.722<br>No survival change | 0.44 (0.3-0.65)<br>P<0.001<br>Survival improved  | 0.42 (0.28-0.63)<br>P<0.001<br>Survival improved |
| All patients         | 0.6 (0.49-0.75)<br>P<0.001<br>Survival improved  | 0.39 (0.31-0.49)<br>P<0.001<br>Survival improved | 0.64 (0.5-0.81)<br>P<0.001<br>Survival improved  |
|                      | Number o   | f patients used in survival c                    | alculations                                      |
|                      | 1996 (n=460)                                     | 2001 (n=565)                                     | 2006 (n=819)                                     |
| Metastasis           | 82 (age=74.7)                                    | 57 (age=70.5)                                    | 106 (age=69.4)                                   |
| No metastasis        | 26 (age=72.4)                                    | 290 (age=74.5)                                   | 467 (age=74.5)                                   |
| Unrecorded           | 352 (age=74.4)                                   | 218 (age=75.8)                                   | 246 (age=70.7)                                   |

\*hazard-ratio was adjusted with a significant (P<0.001) age covariate \*\*P-value <0.05 means that hazard ratio is significantly different from 1 (i.e. no difference in the disease hazard between years) \*\*\*Analysis omitted due to small numbers of patients in 1996

- Survival over 24 months improved for patients with metastasis between 1996 and 2001 and 1996 and 2006 but not significantly between 2001 and 2006.
- For the group with no metastasis, survival improved in 2006 compared with 2001.
- Numbers of patients with recorded metastasis increased little from 82 (1996) to 106 (2006), however the recorded number of cases without metastasis increased almost 18 fold.

#### Survival by symptoms at presentation

Number of audit prostate cancer patients in each year that had bone pain, retention or no urinary symptom on presentation



The number of patients presenting with bone pain remained the same in each year, as did the number presenting with urinary retention. There was no change in their average age from 1996 to 2006 for either bone pain (73.3 years, P=0.30) or urinary retention (76.6 years, P=0.71).

### The number of patients and their average age that were used in survival (hazard ratio) analysis below

| Symptom              | Number of patients used in survival calculations<br>(average age) |                  |                |
|----------------------|---|------------------|----------------|
| Audit years compared | 1996 (n=380)  | 2001 (n=436)     | 2006 (n=782)   |
|                      |   | With symptoms    |                |
| With bone pain       | 37 (age=74.5)   | 40 (age=72.4)    | 37 (age=73.1)  |
| With retention       | 88 (age=76.5)   | 81 (age=77.0)    | 82 (age=76.5)  |
|                      |   | Without symptoms |                |
| Without bone pain    | 343 (age=74.1)  | 396 (age=71.9)   | 745 (age=70.3) |
| Without retention    | 292 (age=73.4)  | 355 (age=70.8)   | 700 (age=69.7) |

• The number of patients presenting with no urinary symptoms increased over three fold from 48 to 173 between 1996 and 2006 (see graph above); the average age of these men fell from 73.6 to 68.9 (P<0.01).



Comparing the survival using age-adjusted hazard ratio\* between years for audit patients diagnosed in N. Ireland and followed up for 2 years with or without bone pain, or retention at presentation

| Symptom              | Hazard ratio (95% confidence interval) & P-value**               |  |   |
|----------------------|--|--|---|
| Audit years compared | 1996:2001  | 1996:2006  | 2001: 2006  |
|                      |  | With symptoms                                    |   |
| With bone pain       | 0.97 (0.51-1.83)<br>P=0.924<br>No survival change                | 1.11 (0.59-2.1)<br>P=0.750<br>No survival change | 1.14 (0.62-2.13)<br>P=0.671<br>No survival change |
| With retention       | With retention 0.66 (0.42-1.06)<br>P=0.086<br>No survival change |  | 1.07 (0.64-1.8)<br>P=0.793<br>No survival change  |
|                      | Without symptoms   |  |   |
| Without bone pain    | 0.54 (0.41-0.71)<br>P<0.001<br>Survival improved                 | 0.34 (0.26-0.44)<br>P<0.001<br>Survival improved | 0.63 (0.46-0.84)<br>P=0.002<br>Survival improved  |
| Without retention    | 0.57 (0.42-0.76)<br>P<0.001<br>Survival improved                 | 0.33 (0.25-0.44)<br>P<0.001<br>Survival improved | 0.58 (0.42-0.79)<br>P<0.001<br>Survival improved  |

\*hazard-ratio was adjusted with a significant (P<0.001) age covariate \*\*P-value <0.05 means that hazard ratio is significantly different from 1

 Patients who presented with late disease as judged by bone pain or retention did not show survival improvement from 1996 to 2006 while over two years survival improvements were recorded for patients without these symptoms.

#### Observed survival of prostate cancer patients in N. Ireland 1996, 2001, and 2006

| Years since diagnosis | Observed survival of cancer patients (95% confidence interval) |                |                |
|-----------------------|--|----------------|----------------|
|                       | 1996 (n=447)   | 2001 (n=565)   | 2006 (n=819)   |
| 1                     | 79% (75%, 82%)   | 87% (84%, 90%) | 92% (90%, 94%) |
| 2                     | 65% (61%, 70%)   | 77% (74%, 81%) | 87% (85%, 89%) |
| 5                     | 39% (35%, 44%)   | 58% (53%, 61%) | -              |
| 8                     | 28% (24%, 32%)   | 42% (37%, 47%) | -              |
| 10                    | 23% (19%, 27%)   | _*             | -              |
| 12                    | 18% (14%, 22%)   | -              | -              |

\* Patient follow up is not sufficient to calculate survival

• 1-year and 2-year observed survival improved from 1996 to 2001 (P<0.001) with a further increase from 2001 to 2006 (P<0.001).

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#### Concluding comments on survival changes in prostate cancer 1996, 2001, 2006

- The overall total survival has improved remarkably 1996-2001-2006, much more than any other cancer. This has coincided with an 78% increase in patients and an almost constant number of deaths. However, age standardised mortality rates, which take account of the ageing population, show a reduction over time which does not reach significance except for men aged 80-84. The increased number of cases coincides with the widespread use of PSA testing in N. Ireland. The improved survival seems to come from patients with PSA at the lower end of the range.
- Studies of the effectiveness of PSA testing have shown some reduction in mortality but only after 9 years<sup>9</sup>, a time span too long for the effects of PSA testing in N. Ireland to show any effect in reducing mortality.

## Observed survival of prostate cancer patients in N. Ireland 1996, 2001, 2006



- The average age at diagnosis has fallen. The change in the patient age profile with younger men being diagnosed has resulted in an improvement in survival as age is the greatest determinant of death risk.
- Survival did not change for the group of men who presented with late disease, as judged by bone metastasis, retention symptoms, or high PSA levels.
- Improvements for those diagnosed at earlier stages (I,II and III) and those who presented with no symptoms could be due to the effect of increased numbers of younger men in whom survival will be better, or the effect of lead time bias due to increased early disease detection with the introduction of PSA testing, or length time bias where there is increased detection of non/slow progressing disease that will never be life threatening, or a real improvement in survival, or a mix of all of these.
- We also have to take account of enhanced availability of staging investigations e.g. CT scan, MRI on the final stage of patients and how this varies over time, resulting in stage shifts and changes in survival by stage with no genuine change (Will Rogers effect).

#### Overall conclusion on survival

Prostate cancer survival as a statistic is so complicated by the many changes in the diagnosis, and investigation of the disease and the changing profile of patients that it is not possible to use it as a clear measure of service improvement. Other proxy measures should be used. In this report, we have documented increases in the numbers of patients assessed by urologists and/or oncologists, and discussed at MDT.



### SECTION III – PROSTATE CANCER SUMMARY

#### **STUDY PATIENTS**

• The number of men diagnosed with prostate cancer has increased by 78% between 1996 and 2006, with 819 patients diagnosed in 2006.

#### **REFERRAL AND PRESENTATION**

- In 2006, 75% of patients were referred to a specialist by their GP; this percentage is down from 2001 & 1996.
- In 2006, 51% of patients resident in the Northern Board and 16% of patients resident in the Southern Board presented in the Eastern Board Hospitals.
- 10% of patients in 2006 were under review with a urologist when they presented at hospital.
- In 2006, 69 patients presented as a surgical or medical emergency, a slight increase from 2001, but a significant reduction from 112 patients in 1996.
- In 1996, 380 patients presented to 22 hospitals; in 2001, 436 patients presented to 21 hospitals, and in 2006, 782 patients presented to 20 hospitals.
- In 2006, around 63% of patients presented to a Cancer Unit.
- In 2006, 36% of prostate cancer patients had attended Belfast City Hospital
- 64% of patients in 2006 attended more than one hospital for their investigation and treatments; this underlines the need for good communication.
- In 2006, the most common comorbidity among patients was myocardial infarction (15%); 12.6% of patients had diabetes.
- In 2006, 12% of patients had another malignancy, the most frequent were the following: nonmelanoma skin cancer 5.4% (of patients), bladder 1.7%, colorectal 0.9%, malignant melanoma 0.8%, lung 0.5%, upper GI 0.4%.
- One in eleven patients had a metastatic prostate tumour in 2006.
- 27% of patients in 2006 had a Charlson comorbidity score of less than 4.
- Frequency in the need to urinate, both by day (2006 only) and by night, was the most common symptom experienced by patients, with over half of them in all years experiencing nocturia.
- Each year approximately 40 patients present with bone pain.
- In 2006, over a fifth of prostate cancer patients (22%) diagnosed in N. Ireland have no urinary symptoms; the number of patients with no urinary symptoms has increased approximately 3.5 times since 1996.

#### INVESTIGATIONS

- From 1996 to 2006, there was a five fold increase in the prostate cancer patients with a PSA <10 ng/ml (P<0.001).
- The proportion of patients receiving an MRI scan increased markedly to 60% in 2006 up from 20% in 2001; four fifths of surgery patients received an MRI.
- The proportion of prostate cancer patients receiving a bone scan increased to 68% in 2006.
- In 2006, 622 patients had a prostate biopsy which is a 7 fold increase since 1996 (n=91) and a 65% increase from 2001 (n=378).
- In 2006, nearly all patients (98%) were recorded as having seen a urologist at some stage in their treatment pathway, an increase from 77% in 2001.
- In 2006, 64% of patients were recorded as having had their management discussed with an oncologist, an increase from 39% in 2001.

#### HISTOPATHOLOGY AND STAGING

- In 2006, 92% of patients had a histologically confirmed diagnosis of prostate cancer. This was 100% for surgery patients.
- Adenocarcinoma was the most common histological type, and the proportion of patients with this type has been increasing since 1996 at 76% to 92% in 2006.
- In 2006, despite the greater absolute number of patients, the proportion being staged has improved from 61% in 2001 to 72% in 2006.
- In 2006, Stage II was the most common stage at which patients were staged, however 22% of staged patients were being staged at Stage IV.
- Patients investigated in the Southern and Western Board were less likely to be staged than the average in N. Ireland.
- In 2006, 32% of patients had a Gleason score of 8 to 10 which alone could stratify them as 'high risk' (under NICE guidelines<sup>5</sup>) which was an increase from 18% in 2001; this could represent a higher level of investigation of patients with advanced disease.

#### MULTIDISCIPLINARY TEAM MEETINGS

- In 2006, the proportion of patients receiving an MDT has increased from 4% in 2001 (n=17) to 59% (n=458) in 2006.
- In 2006, patients in the Western Board were mostly likely to have been considered at an MDT at 87%; however, the number of recorded MDTs in the Southern Board was poor at 15%.
- In 2006, 64% of patients were recorded as having had their management discussed with an oncologist, an increase from 39% in 2001.
- 68% of patients under 60 years of age had their management discussed with an oncologist, an increase of 10% from 1996 (58%).

#### PATIENT MANAGEMENT AND TREATMENT

In 2006,

- 133 patients (17%) were managed initially by active surveillance in the early stages of their disease.
- 37% of patients received radical radiotherapy reflecting an increasing trend since 1996; the number of patients receiving curative radiotherapy has increased markedly (+189) since 2001.
- 8% of patients received a radical prostatectomy, the number of patients receiving this treatment increased by +16 or by 37%.
- An increased number of patients (+264) received hormone treatment, from 2001 to 2006.
- In 2006, over a third of patients (n=291) received combined radical treatment (radical prostatectomy or radical radiotherapy) and hormone treatment.
- There is a continuing decline in the proportion of patients who receive a TURP operation reducing to 15% in 2006.
- In 2006, the majority of radical prostatectomies (66%) are carried out by surgeons who are doing 10 operations or more per year.
- 5 urologists were recorded as performing less than 5 radical prostatectomies, of whom 2 only did one prostatectomy each (one of them was a locum).

#### TIMELINES IN THE PATIENT PATHWAY

- Over time, there has been an increase in the waiting times from referral to first seen at hospital; in 2001, 74% of patients (n=300) were seen within 62 days, in 2006 this had reduced to 56% (n=403), however, from 2001 to 2006, the (absolute) number of patients who were seen before 62 days increased by 103.
- The proportion of patients that were diagnosed within 62 days from presentation declined from 1996 to 2001; there was a further decline from 2001 to 2006 but this was not statistically significant (P=0.10). The number of patients who were diagnosed with 62 days of presentation increased by 59% in 2006 (n=378) from 2001 (n=238).
- The Eastern Board had the shortest delay for patients from referral to first seen (63% were seen within 62 days), whereas the Southern Board had the longest delay (43% were seen within 62 days); a similar pattern was observed for the delay between presentation and diagnosis, 63% of patients in the Eastern Board were diagnosed within 62 days of presentation, 29% in the Southern Board.
- In 2006, waiting times from referral to receiving a biopsy increased with only 18% of patients investigated by biopsy 62 days after referral.
- Between 1996 and 2006, there has been an increase in the waiting time for being seen by a consultant urologist. In 2001, 60% (n=188) patients were seen by a urologist with 62 days of referral, whereas in 2006, it was 52% (n=366); note the doubling of absolute numbers being seen in 2006.
- The Eastern Board had the shortest delays from referral to biopsy carried out, patients in the Southern Board experienced the longest delays.
- The time interval for patients from referral to being seen by a urologist differed between the Boards; patients resident in the SHSSB had the longest delay with 39% of patients seeing a urologist within 62 days.
- Since 1996, there has been a progressive increase in the waiting times from referral to first definitive treatment; in 1996, 39% of patients (n=115) had their first definitive treatment within 62 days of referral, in 2006 this has fallen to 14% (n=94).

#### **INFORMATION AND AFTER CARE**

- By 2006, 87% of patients' charts had a record that their treatment plan was discussed with them.
- In 2006, at least 4/5 patients' charts had a record that their management was discussed with a urologist, and almost 2/3 with an oncologist.
- The number of patients referred to the oncology centre increased from 39% in 2001 to 59% in 2006.
- Few patients were being entered into clinical trials (1% in 2001 and 2% in 2006).
- Most patients were referred back to the care of their GP and only a small number had a palliative care referral.
- From 1996 to 2006, there was an increasing trend in the proportion of patients with a record in their chart that their diagnosis had been discussed with their family although this still only happened in 25% of cases in 2006.
- Prognosis, although highly recorded in 2001, was poorly recorded in the GP letter 2006 at 17%.
- In 2006, 96% of patients in 2006 had a management plan recorded.

#### PATIENT OUTCOMES AND SURVIVAL

- The group of patients who received radical prostatectomy had after treatment higher levels of incontinence and erectile dysfunction than groups of patients categorised by having received other treatments.
- Except for patients receiving palliative radiation, less than 1% of patients experienced local progression after their treatment (follow-up 9-13 months).
- The group of patients who were receiving hormone therapy had a high rate of metastasis at 19%; patients managed by 'active surveillance' or who had radical prostatectomy had low levels of distant metastasis (≤1%). These figures reflect patient selection.
- Across the various treatment groups, the proportion of patients who continued having other urinary symptoms was 40%.
- The survival improvement for Stage I,II and III could be due to 1) real improvement, 2) increased numbers of cases in younger men in whom survival will be better, 3) lead time bias due to increased early disease detection with the introduction of PSA testing. 4) length time bias. 5) a mix of these.
- Improvements in Stage IV survival could be due to 1) improved treatments, 2) stage shift (the Will Rogers effect) due to enhanced staging investigations, 3) a mix of the above.
- The age-specific prostate cancer mortality rate for patients in N. Ireland aged from 80 to 84 years declined from 1993 to 2006 with an annual percentage change (APC) reduction of 2.2; suggesting that survival is improving for some patients.
- Prostate cancer survival has increased significantly overall in N. Ireland, e.g. observed 2-year survival increased from 65% for 1996 diagnosed patients to 87% for 2006 diagnosed patients; this survival improvement is however problematic to interpret as comparisons are made between different patient groups due to differences in the use of PSA tests.
- Prostate cancer survival as a statistic is so complicated by the many changes in the diagnosis and investigation of the disease and the changing profile of patients that it is not possible to use it as a clear measure of service improvement. Other proxy measures should be used. In this report, we have documented increases in the numbers of patients assessed by urologists and/or oncologists, and discussed at MDT.

### **CONCLUSIONS AND RECOMMENDATIONS**

The number of cases of prostate cancer has increased quite remarkably by 78% since 1996 reflecting the increased use of PSA testing in the detection of prostate cancer.

Despite the heavier workload that these patients present, the quality of their investigation and care has improved as evidenced by:

- The increased proportion of patients being assessed by a urologist (98%) and referred to oncology (64%) and specialist urologist nurse (34%).
- The increased and improved equity of access to diagnostic tests including MRI (60%).
- Over 90% had a pathological diagnosis.
- An increase in the proportion of patients staged to 72%.
- An increase in the proportion of patients having a Gleason score recorded to 92%.
- Almost 60% of patients had a record of MDT discussion.
- Increased numbers of patients having radical prostatectomy and curative radiotherapy.
- Improved communication with the patient.

However there is room for further improvement, in 2006:

- 5 out of 9 urologists were recorded as performing less than 5 radical prostatectomies.
- Only 2% of patients were entered into clinical trials.
- Patients in the Southern Board were less likely to be discussed at MDT than other Boards.
- Patients in the Southern and Western Boards had lower levels of staging recorded compared to the average.
- While the services saw more patients within defined times, the proportion of those diagnosed and treated within timescales fell. This reflects the increased patient burden and indicates a need for further resources in this area.

#### **Recommendations.**

- All patients should be discussed at an MDT.
- Consideration should be given to defining workloads for radical prostatectomies.
- The increased volume of patients should be recognised in the allocation of resources.
- A specific prospective study of side effects of treatment should be undertaken.
- Quality of life studies for prostate cancer patients should be undertaken.

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### **APPENDICES**

### APPENDIX A: Summary of recommendations of the 'Campbell Report', that is, Cancer Services: Investing for the Future<sup>1</sup>, 1996.

- 1. The management of patients with cancer should be undertaken by appropriately trained, organ and disease specific medical specialists.
- 2. All patients with cancer should be managed by multidisciplinary, multiprofessional specialist cancer teams.
- 3. A Cancer Forum should be established involving all key interests in the delivery of cancer services.
- 4. Cancer Units should, in conjunction with local GPs and other providers, develop an effective communication strategy.
- 5. Northern Ireland should have one Cancer Centre, which in addition to its regional role, should act as a Cancer Unit to its local catchment population of around half a million.
- 6. There should be four other Cancer Units, one in each Board area, each serving a population of around a quarter of a million.
- 7. Radiotherapy services, together with chemotherapy services, should be moved as soon as possible to the Belfast City Hospital and become an integral part of the regional Cancer Centre.
- 8. Each Cancer Unit should develop a chemotherapy service. This service should be staffed by designated specialist nurses and pharmacists, and should be overseen by the non-surgical oncologist attached to the unit, with back-up from a haematologist.
- 9. There should be a minimum target of 13 consultants in non-surgical oncology for Northern Ireland by 2005.
- 10. Any new appointments of trained cancer specialists should be to Cancer Units or to the Cancer Centre.
- 11. Guidelines should be drawn up and agreed for the appropriate investigation and management of patients presenting to non-Cancer Unit hospitals that turn out to have cancer.
- 12. The Cancer Centre and Cancer Units should each develop a specialist multiprofessional palliative care team.
- 13. There should be a comprehensive review of palliative care services in Northern Ireland.
- 14. The Northern Ireland Cancer Registry should be adequately resourced.

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#### APPENDIX B: Summary of comments/recommendations relevant to prostate cancer treatment in the Report of the Urological sub-group in Cancer Services – Investing for the Future – Cancer Working Group Sub-Group Reports<sup>2</sup> 1996.

The sub-group commented:

- Prostatic cancer is the most common urological cancer but the ideal management is difficult to define for several reasons. Many patients, who have prostatic surgery because of difficulty in passing urine, are found to have early cancer changes which do not usually produce a threat to life. Other patients present with cancer, which is confined to the prostate gland, which may be only slowly progressive, with death being due to another disease, while others present with widespread metastatic disease.
- The treatment options are surgical resection with either limited or radical prostatectomy, radiotherapy, hormonal manipulation and chemotherapy or a combination of these therapies.
- The most appropriate clinical approach is dictated by the patient's age and clinical state and also by the stage of the cancer as judged clinically, biochemically and radiologically (including the use of modern ultrasound equipment).
- Radical surgery is still being evaluated in the UK although this treatment is well accepted in the USA.

The sub-group recommended that:

- 1. Radical surgery for cancer of the prostate should be restricted to a small number of surgeons.
- 2. Strict criteria should be in place for investigation, assessment and case selection and a protocol for long term follow-up decided.
- 3. Where there is uncertainty in defining the optimum management, patients should be entered into clinical trials but it was recognised this will result in an additional workload.
- 4. There is not a strong case for population screening for cancer of the prostate.
- 5. Hormonal manipulation (including orchidectomy) is undertaken by the surgical specialist, and chemotherapy/radiotherapy is provided by the clinical oncologist. It was recommended that subspecialisation in the future would produce a "uro-oncologist".
- 6. Surgical units should have clinical systems in place which facilitate the collection of relevant data on urological cancers and the outcome of treatment.
- 7. Clinical activity, consultation, treatment and surgery should be under the direct supervision of specialist clinicians.
- 8. Available expertise in the surgical management of urological malignancies should continue to be utilised until adequate numbers of specialist urologists are appointed. It would be appropriate that such surgeons would dedicate 50% of their time to urology.
- 9. In the long term, urological malignancies should be managed by multidisciplinary teams having access to a Cancer Centre.
- 10. Guidelines for referral, investigation and treatment of significant urological symptoms should be developed.
- 11. Management protocols should be produced by clinicians involved in urological cancer care and these should be agreed and modified with increasing experience through involvement in "user groups" which meet on a regular basis.
- 12. To allow research, audit and trials to be conducted properly, research assistants will need to be employed.
- 13. The management of cancer should be concentrated in Cancer Units giving patients ready access to treatment close to their homes and more specialised treatment should be undertaken in a Cancer Centre supported by a major teaching hospital.

| Incidence and mor<br>N. Ireland 1993-20 |           | uropean age-standard                            | ised rates) of pro | state cancer in                                 |
|---|-----------|---|--------------------|---|
| Year                                    | Incidence | European age-<br>standardised<br>incidence rate | Mortality          | European age-<br>standardised<br>mortality rate |
| 1993                                    | 473       | 63.9  | 181                | 24.2  |
| 1994                                    | 486       | 64.5  | 211                | 28.2  |
| 1995                                    | 511       | 67.1  | 219                | 28.9  |
| 1996                                    | 460       | 60.1  | 206                | 27.2  |
| 1997                                    | 486       | 62.4  | 208                | 26.8  |
| 1998                                    | 499       | 63.2  | 222                | 28.1  |
| 1999                                    | 498       | 62.9  | 197                | 24.3  |
| 2000                                    | 581       | 72.1  | 209                | 25.8  |
| 2001                                    | 565       | 69.8  | 214                | 26.2  |
| 2002                                    | 668       | 80.9  | 192                | 22.7  |
| 2003                                    | 773       | 92.0  | 219                | 25.9  |
| 2004                                    | 797       | 93.2  | 240                | 27.0  |
| 2005                                    | 783       | 89.6  | 221                | 24.8  |
| 2006                                    | 819       | 92.1  | 217                | 23.1  |

### APPENDIX C: Incidence and mortality (including rates) of prostate cancer in N. Ireland 1993-2006.

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#### **APPENDIX D: Staging of Prostate Cancer**

Accurate staging is essential for the planning of appropriate treatment and for the comparison of the outcomes of such treatment (surgical and non-surgical). The TNM classification<sup>22</sup> of prostatic carcinoma (6th Edition) is shown in Table 1 (below). T or T size factor assesses the dimensions of the tumour itself, N or N factor assesses whether the cancer has spread to surrounding lymph nodes, and M or M factor stands for metastasis which considers if the cancer has spread to other organs of the body, close by or distant.

#### **Clinical staging**

Determining the tumour size (T) factor.

Assessment of the primary tumour includes Digital Rectal Examination (DRE) to determine if the tumour is palpable and if so, if one or both lobes are affected, if the prostatic capsule is breached and if so, has the tumour extended to other adjacent structures such as seminal vesicles, bladder or rectum.

Needle biopsy is performed to confirm the presence of tumour, the histological type and grade. Transrectal ultrasound guided biopsy (TRUS) can be used to locate and biopsy impalpable tumours. Tumours that are detected incidentally, typically when prostate resection has been performed to relieve symptoms of benign prostatic hyperplasia (a common condition in older men) the tumour is classified as T1a / T1b. When a tumour is detected by needle biopsy (usually because of a raised PSA alone) it is designated as T1c. When tumours are palpable or visible by imaging, but confined to the prostate, they are designated T2a, T2b or T2c depending on the percentage of lobe involved, and number of lobes involved (Table 1, below). Once the prostatic capsule is breached the tumour is classified as T3a or T3b. If the tumour invades adjacent structures it is classified as T4.

#### **Pathological staging**

Pathological staging adds significant information to this process. It is usually only possible if total prostatectomy with regional node sampling has been performed. This gives more exact information on the extent of the tumour (T) and detects the presence of metastatic tumour within the examined lymph nodes.

#### Determining the (N) factor

This can be determined clinically using imaging or pathologically if surgical resection and lymph node sampling has been performed. If a metastatic tumour is found in any nodes examined this is designated N1, and therefore Stage IV (Table 2, below).

#### Determining the (M) factor

Metastatic disease can be detected by clinical examination, imaging with or without laboratory investigations at presentation which will be designated M1. Subdivisions of M1 (M1a /M1b /M1c) indicate the site of distant metastases (Table1).

| Table 1 T | NM classification o | f prostate cancer <sup>22</sup> tumour  |
|-----------|---------------------|---|
|           | Tumour              |   |
| то        | ТО                  | no evidence of primary tumour   |
|           |                     |   |
|           | T1                  | tumour not palpable or visible by imaging   |
| T1        | T1a                 | tumour found as an incidental finding in less than 5% of resected tissue                                    |
|           | T1b                 | tumour found as an incidental finding in over 5% of resected tissue   |
|           | T1c                 | tumour identified by needle biopsy (eg. because of elevated PSA)  |
|           |                     |   |
|           | T2                  | tumour confined to the prostate   |
| т2        | T2a                 | tumour involves one half or less of one lobe  |
| 12        | T2b                 | tumour involves more than one half of one lobe  |
|           | T2c                 | tumour involves both lobes  |
|           |                     |   |
|           | Т3                  | tumour extends through the prostatic capsule  |
| Т3        | T3a                 | extracapsular extension, unilateral or bilateral  |
|           | T3b                 | tumour invades seminal vesicles   |
|           |                     |   |
| T4        | Τ4                  | tumour is fixed or invades adjacent structures such as bladder neck, rectum, levator muscles or pelvic wall |
|           |                     |   |
|           | Nodes               |   |
| NX        | NX                  | regional nodes not assessed   |
| N0        | NO                  | no regional nodes involved  |
| N1        | N1                  | regional nodes involved   |
|           |                     |   |
|           | Metastases          |   |
| M0        | MO                  | no distant metastases   |

| M0 | MO  | no distant metastases                          |  |  |
|----|-----|--|--|--|
|    | M1  | distant metastases                             |  |  |
| M1 | M1a | metastases to non-regional nodes               |  |  |
|    | M1b | metastases to bone                             |  |  |
|    | M1c | metastases to other sites with or without bone |  |  |

In order to facilitate survival analysis the assigned TNM profile is condensed into a stage group category of which there are 4 stages (I, II, III, IV, see Table 2).

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#### Histological grade (G)

The Gleason score is used to assess the aggressiveness of the tumour. When the pathologist examines the histological specimen they record a score which takes into account the variable histology that can be seen within one prostate biopsy. A score of 2-10 is possible. A Gleason score of 2 signifies a well differentiated tumour with good prognosis, while a score of 7 or above indicates a poorly differentiated tumour that is likely to behave in an aggressive manner. As the Gleason score has been shown to be a strong prognostic factor and can also affect decisions regarding appropriate therapy so it has been incorporated into the TNM stage group (Table 2). A Gleason score of 2-4 is mapped to grade 1 histology while a score of 5-6 is grade 2 and a score of 7 or more is a grade 3-4.

| Table 2 stage group prostate cancer |       |       |    |       |  |  |  |  |
|-------------------------------------|-------|-------|----|-------|--|--|--|--|
| Stage                               | т     | N     | М  | Grade |  |  |  |  |
| 1                                   | T1a   | NO    | MO | G1    |  |  |  |  |
| Ш                                   | T1a   | NO    | MO | G2-4  |  |  |  |  |
|                                     | T1b   | NO    | M0 | any G |  |  |  |  |
|                                     | T1c   | NO    | MO | any G |  |  |  |  |
|                                     | T1    | NO    | MO | any G |  |  |  |  |
|                                     | T2    | NO    | M0 | any G |  |  |  |  |
| ш                                   | T3    | NO    | MO | any G |  |  |  |  |
| IV                                  | T4    | NO    | MO | any G |  |  |  |  |
|                                     | any T | N1    | MO | any G |  |  |  |  |
|                                     | any T | any N | M1 | any G |  |  |  |  |

Example:

- palpable tumour involving both lobes. Radical prostatectomy confirms extension to seminal vesicles, therefore  $\mathbf{T} = T3b$ . Gleason score 8, therefore  $\mathbf{G} = G3-4$ .
- regional nodes sampled and are negative for metastases, therefore N = N0.
- clinically/radiologically there is no evidence of distant metastases and is therefore  $\mathbf{M} = \mathbf{M0}$ .

TNM profile is **pT3b pN0 cM0** (p = determined pathologically, c = clinically determined). This TNM profile is assigned to stage group III.

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N. Ireland Cancer Registry Centre for Public Health Research Mulhouse Building Grosvenor Road Belfast BT12 6BJ

**T:** (44) 028 9063 2573 **F:** (44) 028 9024 8017 **E:** nicr@qub.ac.uk **W:** www.qub.ac.uk/nicr