N. IRELAND Cancer Registry

Cancer Services Audit 1996 & 2001

Prostate

Queen's University Belfast

Cancer Services Audit 1996 & 2001
PROSTATE

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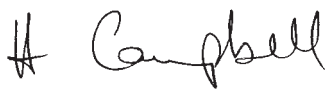
FOREWORD

Cancer services in Northern Ireland have improved in recent years. Developments have spanned prevention, early detection and screening, diagnosis, management and palliative care. The N. Ireland Cancer Registry has played an important role and made a vital contribution in monitoring this progress.

Since 1996 we have seen the establishment of five Cancer Units at Altnagelvin, Antrim, Belfast City, Craigavon, and Ulster hospitals and a regional Cancer Centre at the Belfast City Hospital working closely with the Royal Group of Hospitals. The Cancer Units are now the main focus for the delivery of services for people with the more common cancers. In addition, some services for other less common cancers are provided from Cancer Units, in conjunction with the Cancer Centre, on a shared care basis. These organisational changes have already made an impact on care.

This report on prostate cancer is very welcome. It is the third in a series that examines in detail the pathways of care for patients with cancer here. The reports provide a fascinating insight into how care has changed over the period. They will also facilitate the ongoing work of improving services and patient care.

This work marks a significant step in the evaluation of cancer care and confirms the great value of the Registry as a public health tool. I look forward to future reports in this series and regular five yearly snapshots of the changing process of cancer care.



Dr Henrietta Campbell
Chief Medical Officer

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- Eastern Health and Social Services Board
- Northern Health and Social Services Board
- Regional Medical Audit Group
- Research and Development Office
- Southern Health and Social Services Board
- Western Health and Social Services Board

The quality of data in this project is a result of the work of the Registry Tumour Verification Officers (TVOs) especially Kate Donnelly, Rosemary Ward, Helen Hanlon and Patricia Donnelly who meticulously extracted detailed information from clinical records for analysis and presentation in this report. The analysis of data was largely undertaken by John Hughes. A special word of gratitude to the Medical Records staff of all the hospitals in Northern Ireland who in the course of the audit for all sites pulled an estimated 10,000 charts.

We are grateful to the clinicians who commented on the detail of data to be collected, its interpretation and final presentation.

The work of the N. Ireland Cancer Registry including the production of this report is the result of the work of the team listed below:

Bernadette Anderson	Dr Lesley Anderson	Carmel Canning	Dr Denise Catney
Mr David Connolly	Kate Donnelly	Patricia Donnelly	Deirdre Fitzpatrick
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Susan McGookin	Dr Richard Middleton	Pauline Monaghan	Emma Montgomery
Dr Liam Murray	Giulio Napolitano	Dr Lisa Ranaghan	Dr Jeffrey Robertson
Breige Torrans	Rosemary Ward		

I wish also to record my thanks to the Management Group and Council of the Registry who guide that work.

This presentation, I feel, has been enhanced by the stories from patients who have walked the patient journey. A journey we have attempted to analyse and quantify with a view to identifying current practice so clinicians may be facilitated in improving care.

Anna Gavin.

A Gavin
Director, NICR
2005

PATIENT STORIES

"I was 57 when I was diagnosed last year. I was going to the toilet frequently. When I went to my GP, my examination was normal but my PSA blood test was raised slightly. I was referred to Urology and had a prostate biopsy. One out of eleven samples was found to have cancer cells. It took about 6-8 weeks for the results to come through and I was left all that time without advice. When I was told the result, the surgeon said it was up to me to decide what treatment I would have - I felt the onus was on me, the patient, to decide what to do. I felt I was in a deep hole with no ending. I hadn't a clue. I didn't have enough information about the options. When the surgeon was talking it was going over my head.

I was counselled by a nurse, who helped me a lot. When I thought it over, I took the decision to have my prostate removed. It was a big decision as it was the first operation I'd had for a long while. I live alone and needed somebody to look after me afterwards. There was no rehabilitation facility so I stayed in an old people's home and found that very distressing.

I now keep myself fit and have had two clear checkups. I attend a prostate information evening which is held regularly at my local hospital. A year later I still have some soreness around my scar. The impotence for me is a big problem and I am getting conflicting advice about what I should do and whether it is permanent."

~

"I was diagnosed three years ago at the age of 63. I was being monitored as there was a family history of prostate disease but not prostate cancer. I was having my PSA checked regularly. It had increased very slowly over several years and so, with my GP, it was decided that I should have a biopsy. At that time it was discovered that I had prostate cancer that involved both lobes and had a Gleason score of 8 which is considered high and denotes an aggressive tumour. I had various tests, scans and X-rays to determine whether the cancer had spread. It hadn't spread so I was referred to oncology where I was advised to have radiotherapy treatment. I had 32 sessions which began 6 weeks after my diagnosis. I only felt slight discomfort during the treatment but I felt tired as the treatment went on.

There is no pain or lumps associated with prostate cancer and it is hard for men to discover if they have it. It is also hard for men to discuss personal health issues, especially older men. I found there was great camaraderie among the patients in Belvoir and we were all in a similar position but with different diseases. It was good to talk and not to huddle the disease into oneself. It was good to compare and contrast our experiences as cancer is different in each patient."

~

"Before I went to see the surgeon I knew I had cancer as my GP had rung and discussed it with me. I knew the various tests would take 3-4 months before treatment was finally decided on. I had obtained information from the internet and also from a helpline in London. When I met the consultant I suggested I should take the drug Zoladex while I waited for treatment as I had read this on the internet. The consultant agreed. I felt locally there was a lack of co-ordination, information and guidelines about treatment and the urology department was a very busy one. I met with the urology nurse and with help we formed a support group which not only supports men but has worked to define and disseminate the referral guidelines etc."

~

INTRODUCTION

This Report is the third in a series which examines in detail the pathway of care for cancer patients in Northern Ireland. The prostate represents a major cancer site and the years 1996 and 2001 represent two points in time either side of the publication of the Campbell Report **"Cancer Services Investing for the Future"**[1].

The Campbell Report resulted from the work of many clinicians, service planners and patients who worked together with the aim of improving cancer services in Northern Ireland. The Campbell Report made 14 recommendations (see Appendix A).

Subsequent to the publication of the Campbell Report, a sub-group in Northern Ireland produced the Report of the **Cancer Working Group Sub-Group on Urological Cancer**[2] in 1996. In relation to prostate cancer they 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:

- Radical surgery for cancer of the prostate should be restricted to a small number of surgeons.

- Strict criteria should be in place for investigation, assessment and case selection and a protocol for long term follow-up decided.

- 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.

- There is not a strong case for population screening for cancer of the prostate.

- Hormonal manipulation (including orchidectomy) is undertaken by the surgical specialist, and chemotherapy/radiotherapy are provided by the clinical oncologist. It was recommended that sub-specialisation in the future would produce a "uro-oncologist".

- Surgical units should have clinical systems in place which facilitate the collection of relevant data on urological cancers and the outcome of treatment.

- Clinical activity, consultation, treatment and surgery should be under the direct supervision of specialist clinicians.

- 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.

- In the long term, urological malignancies should be managed by multidisciplinary teams having access to a Cancer Centre.

- Guidelines for referral, investigation and treatment of significant urological symptoms should be developed.

- 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.

- To allow research, audit and trials to be conducted properly, research assistants will need to be employed.

- 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.

A summary of the recommendations of a consensus document from the British Association of Urological Surgeons (BAUS) titled **Guidelines on the Management of Prostate Cancer**[3] published in 2000 is included in Appendix B.

PROJECT AIM

This Report aims to measure changes to care for patients with prostate cancer from a baseline in 1996 and to determine whether they are in keeping with the recommendations of the Campbell Report[1].

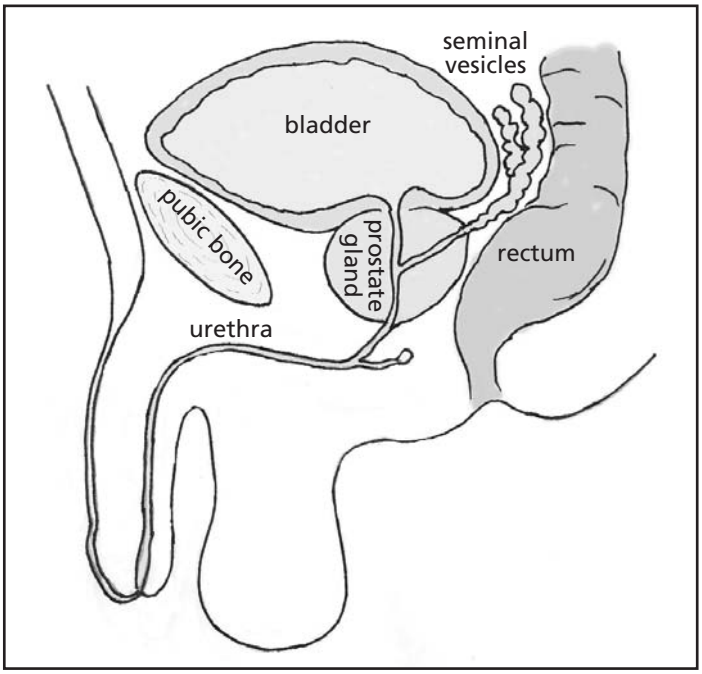
BACKGROUND

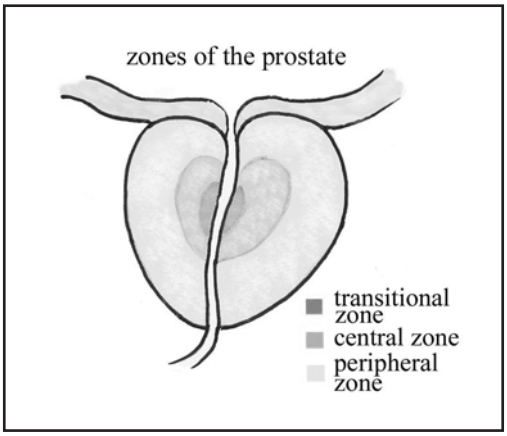
The incidence of prostate cancer is rising worldwide. It is the most commonly diagnosed cancer in men in the USA and in Western Europe with an estimated 198,000 newly diagnosed cases in 2001 in the USA[4] and an estimated 27,100 new prostate cancers in 2000 in the UK[5].

In Northern Ireland, on average (1993-99) 482 cases of prostate cancer were diagnosed. This has risen recently reflecting the increase in PSA testing in Northern Ireland[6]. Prostate cancer is the third most common cancer in males and the second most common cause of cancer death[7]. The majority of prostate cancers are slow growing and more men die **with** prostate cancer than **from** it. However, a proportion of prostate cancers behave in a more aggressive way with metastatic spread to distant sites, most commonly bone. These cases are associated with a poorer prognosis. Overall, relative survival is good, 84% at 1-year and 62% at 5-years[7]. Survival is strongly related to stage of disease at diagnosis, tumour grade, age at diagnosis and overall health.

HISTOPATHOLOGY

The vast majority of prostate cancers are adenocarcinomas mainly occurring in the peripheral zone of the prostate gland, whereas benign prostatic hyperplasia (BPH) usually arises in the transition zone of the gland close to the urethra. BPH is a very common condition in older men and causes enlargement of the prostate and symptoms of difficulty passing urine.





RISK FACTORS

Prostate cancer is largely a disease of older men. Half of all cases in Northern Ireland diagnosed in 2001 were aged 72 and over while 1% of cases occurred in males aged 50 and under[7]. The strongest risk factors are age, black race and family history of prostate cancer. Other risk factors include radiation exposure and a diet high in animal fat and protein.

PROSTATE SPECIFIC ANTIGEN (PSA) TESTING

The most widespread method of testing for prostate cancer is the PSA test - men with prostate cancer tend to have higher than normal levels of PSA in their blood. However, PSA testing is not completely reliable as:

- Some men who have prostate cancer, do not have raised levels of PSA (about 15%)[8].
- Two thirds of men who have raised levels of PSA, depending on the cut off level used, do not have prostate cancer.
- PSA levels in the blood can be raised by several other conditions that affect the prostate gland (eg Benign Prostatic Hyperplasia, prostatitis).
- PSA testing cannot distinguish between men who have slow growing prostate cancer and those who have a more aggressive disease (although sometimes serial PSAs may be able to facilitate such a distinction).
- It is likely that a high proportion of cancers detected initially through PSA testing would have caused no problems during a man's natural lifetime[9].

The NHS does not endorse routine PSA screening. The UK National Screening Committee concluded in 1997 that **"PSA tests could not reliably distinguish men with prostate cancer from those without and so a prostate cancer screening programme should not be introduced".**[10]

METHODS

DATA COLLECTION

Registry Tumour Verification Officers (TVOs) collected data by reviewing clinical notes of patients registered within the Northern Ireland Cancer Registry. Data was then entered into an electronic proforma, which had been developed with the guidance of relevant clinicians; copy available at www.qub.ac.uk/nicr

EXCLUSIONS & ANALYSIS

Patients were excluded if their records lacked sufficient information or if information was available only from a death certificate (DCO). After cleaning and validation, data analysis was carried out using SPSS. Chi-Square was used to test for significance throughout the report where appropriate. The Kaplan-Meier method was used for survival analysis.

RESULTS

Study patients

Patients	Number of Patients	
	1996	2001
Total patients	443	469
Exclusions – Death Certificate Only	2	0
Exclusions – lack of information	60	32
Total exclusions	62	32
Total reported on	381	437
Average age at diagnosis	74	71
Median age at diagnosis	74	72

- More than half of all cases were diagnosed in men over 72 years.
- Prostate cancer is the only cancer where the average age at diagnosis is falling rapidly. This is due to the increased detection of cases in younger men as a consequence of increased levels of PSA testing.
- Observed survival will be influenced upwards because the patients diagnosed in 2001 are younger and have a longer life expectancy than those diagnosed in 1996.

Socio-economic status of prostate cancer patients

Deprivation Quintile	Number of Patients (%)	
	1996 *(n=381)*	2001 *(n=437)*
Quintile 1 (most affluent)	102 (27%)	108 (25%)
Quintile 2	81 (21%)	113 (26%)
Quintile 3	75 (20%)	79 (18%)
Quintile 4	66 (17%)	69 (16%)
Quintile 5 (least affluent)	57 (15%)	68 (16%)

- If a disease is not related to deprivation then in the general population it is expected that 20% of all cases of disease would fall in each quintile.
- Our data showed that there was no difference in the levels of prostate cancer with deprivation in these populations ($\chi^2 = 2.768$, $p>0.05$). This probably reflects the relatively small numbers as, in previous N. Ireland Cancer Registry reports, a higher level of disease among affluent groups has been shown when data were combined from several years.[7]

Patients presenting within their own Board

Board of Residence	Number of Patients (% Presenting within their own Board)	
	1996	2001
NHSSB	89 (82%)	53 (53%)
EHSSB	142 (99%)	165 (99%)
SHSSB	55 (86%)	52 (64%)
WHSSB	63 (97%)	89 (99%)

- In 1996, the majority of patients (87%) presented to hospitals within their Health Board of residence. This, however, was less marked in 2001.

- In 2001, there were considerable proportions of Northern Board (42%) and Southern Board (30%) patients presenting to Eastern Board hospitals (not shown).
- Most patients (87%) were referred by their GP. Of these, the number recorded as emergencies halved from 30% in 1996 to 15% in 2001.

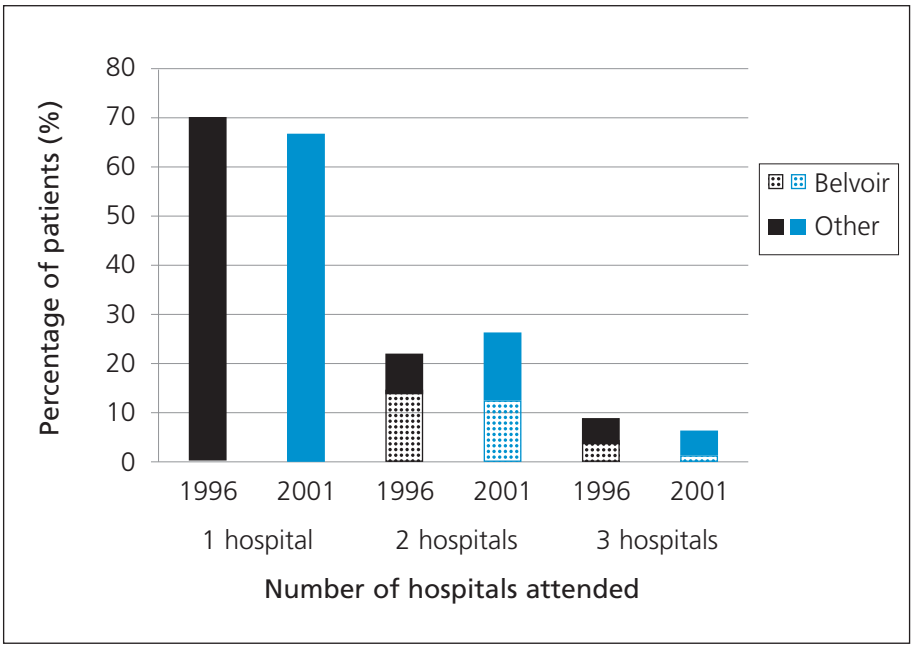
Hospital of presentation

Hospital	Number of Patients (%)			
	Including Emergencies		Excluding Emergencies	
	1996 *(n=381)*	2001*(n=437)*	1996 *(n=269)*	2001 *(n=374)*
Belfast City (BCH)*	58 (15%)	72 (16%)	42 (16%)	64 (17%)
Ulster (UH)**	54 (14%)	68 (16%)	36 (13%)	62 (17%)
Altnagelvin (AH)**	31 (8%)	53 (12%)	22 (8%)	49 (13%)
Craigavon Area (CAH)**	40 (10%)	39 (10%)	33 (12%)	28 (7%)
Antrim (ANT)**	38 (10%)	18 (4%)	27 (10%)	12 (3%)
Royal Victoria (RVH)	7 (2%)	10 (2%)	3 (1%)	4 (1%)
Mater (MIH)	19 (5%)	28 (6%)	14 (5%)	26 (7%)
Coleraine/Causeway (COL/CAU)	28 (7%)	27 (6%)	19 (7%)	23 (6%)
Tyrone County (TCH)	19 (5%)	23 (5%)	13 (5%)	16 (4%)
Downe (DH)	17 (4%)	21 (5%)	14 (5%)	21 (6%)
Lagan Valley (LVH)	3 (1%)	20 (5%)	0	19 (5%)
Erne (ERN)	18 (5%)	17 (4%)	15 (6%)	15 (4%)
Daisy Hill (DHH)	11 (3%)	13 (3%)	8 (3%)	12 (3%)
Mid Ulster (MUH)	10 (3%)	7 (2%)	8 (3%)	4 (1%)
Whiteabbey (WHA)	11 (3%)	2 (<1%)	4 (1%)	1 (<1%)
Waveney (WAV)	1 (<1%)	1 (<1%)	1 (<1%)	1 (<1%)
Belvoir Park Hospital (BPH)	2 (1%)	1 (<1%)	2 (1%)	0
Roe Valley (RV)	0	1 (<1%)	0	1 (<1%)
Banbridge (BBH)***	0	1 (<1%)	0	1 (<1%)
Ards Community (AR) ***	4 (1%)	0	4 (1%)	0
South Tyrone (STH)	7 (2%)	0	3 (1%)	0
Moyle (MLE)^{oo}	1 (<1%)	0	0	0
Braid Valley (BVH)***	1 (<1%)	0	0	0
Ulster Independent Clinic (UIC)****	1 (<1%)	12 (3%)	1 (<1%)	12 (3%)
North West Independent Clinic (NWC)****	0	3 (1%)	0	3 (1%)

**** Regional Urology Centre/Cancer Centre, ** Cancer Unit, *** Closed or designation changed between 1996 and 2001, **** The Ulster Independent Clinic and the North West Independent Clinic are private hospitals, ^{oo} Facility had 2 palliative beds in 2001.***

- 381 patients presented to 22 hospitals in 1996 (19 hospitals if emergency cases are excluded) and 437 patients presented to 21 hospitals in 2001 (20 if emergencies are excluded).
- In 2001, 57% of patients presented to a Cancer Unit/Cancer Centre.
- Fewer patients presented to Antrim Hospital, a Cancer Unit, in 2001 (4%), compared to 1996 (10%).
- By 2001, there was an increase in patients presenting to private sector hospitals (4%).

Number of patients attending one, two or three hospitals



- More than half of all patients who attended two hospitals received oncology treatment at Belvoir Park Hospital.
- Attendances for prostate cancer at Belvoir Park Hospital increased from 50 patients in 1996 to 88 patients in 2001.

Presentation (NOTE: patients may present with more than one symptom)

Symptom	Number of Patients (%)	
	1996 *(n=381)*	2001 *(n=437)*
Nocturia (Urinating frequently at night)	232 (61%)	223 (51%)
Terminal dribbling	151 (40%)	121 (28%)
Retention (Inability to urinate)	88 (23%)	82 (19%)
Incontinence (Loss of urinary control)	27 (7%)	30 (7%)
Haematuria (Blood in urine)	33 (9%)	39 (9%)
Bone pain	38 (10%)	40 (9%)
Weight loss	36 (9%)	24 (5%)
Lethargy	18 (5%)	36 (8%)
Leg oedema	9 (2%)	13 (3%)
No urinary symptoms	50 (13%)	99 (23%)
PSA test*	30 (8%)	64 (15%)
Incidental finding	19 (5%)	34 (8%)

Applies to asymptomatic patients only.

- About 20% of patients presented with urinary retention.
- 9% presented with haematuria and 10% presented with secondary bone pain.
- The percentage of patients who presented with no urinary symptoms, increased from 13% in 1996 to 23% in 2001. This may reflect increased use of PSA testing (8% in 1996 and 15% in 2001).

Investigations (NOTE: Patients may have received more than one investigation)

Investigation	Number of Patients (%)			
	All Patients		Prostatectomy Patients	
	1996 *(n=381)*	2001 *(n=437)*	1996 *(n=4)*	2001 *(n=43)*
PSA test prior to diagnosis	351 (92%)	423 (97%)	4 (100%)	43 (100%)
Prostate biopsy	94 (25%)	381 (87%)	0	43 (100%)
Digital Rectal Examination (DRE)	324 (85%)	334 (76%)	2 (50%)	29 (67%)
Bone scan	207 (54%)	254 (58%)	2 (50%)	13 (30%)
CT scan	46 (12%)	149 (34%)	3 (75%)	10 (23%)
MRI scan	5 (1%)	88 (20%)	0	7 (16%)
Transrectal ultrasound	1 (1%)	16 (4%)	0	1 (2%)

- The proportion of cancer patients having a prostate biopsy increased markedly from 25% in 1996 to 87% in 2001.
- The use of bone scans increased slightly so that by 2001, 58% of patients had a bone scan.
- Use of CT scan and MRI scan increased, reflecting better staging practice.

PSA TESTING

Highest PSA level before diagnosis

PSA Level	Number of Patients (%)	
	1996 *(n=381)*	2001 *(n=437)*
Under 4ng/ml	19 (5%)	17 (4%)
4-9.9ng/ml	28 (7%)	65 (15%)
10-19.9ng/ml	47 (12%)	104 (24%)
20-29.9ng/ml	35 (9%)	53 (12%)
30ng/ml or greater	235 (62%)	190 (43%)
Not recorded	15 (4%)	8 (2%)
No PSA test (pre or post diagnosis) in records	2 (1%)	0

- Patients were less likely to have a PSA of greater than 30ng/ml in 2001. This may reflect a pattern of early intervention at lower PSA levels.

HISTOPATHOLOGY

A histopathological sample can be obtained from a biopsy or a surgically resected specimen.

Histopathological Type

Type	Number of Patients (%)	
	1996 *(n=381)*	2001 *(n=437)*
Adenocarcinoma	298 (78%)	391 (89%)
Carcinoma	5 (1%)	16 (4%)
Other malignancies	4 (1%)	2 (<1%)
Not histologically verified	74 (19%)	28 (6%)

- By 2001, 94% of patients had a histological diagnosis, an increase from 80% in 1996.
- Adenocarcinoma was the most common histological subtype.

STAGING (see Appendix C)

- The recording of a stage in the clinical notes was poor and lower in 2001 (3%) compared to 1996 (12%) (not shown).

When stage was not recorded and there was sufficient information available in the clinical notes, Registry TVOs assigned a stage (Registry-assigned stage). The UICC TNM staging classification was applied[11].

TNM Stage (recorded in notes or Registry-assigned)

Stage	Number of Patients (%)			
	All Patients		Prostatectomy Patients	
	1996 *(n=381)*	2001 *(n=437)*	1996 *(n=4)*	2001 *(n=43)*
I	7 (2%)	7 (2%)	0	0
II	6 (2%)	115 (26%)	0	15 (35%)
III	11 (3%)	72 (16%)	0	21 (49%)
IV	96 (25%)	74 (17%)	0	2 (5%)
Insufficient data for staging	261 (69%)	169 (39%)	4 (100%)	5 (12%)

- While recording of information in notes to enable staging of patients improved substantially, by 2001 two fifths of patients still had insufficient information recorded in their notes to allow allocation of a stage.
- By 2001, more patients with earlier stage (I & II) tumours were being detected, 28% vs 4% in 1996. Also there were fewer stage IV patients recorded. This may reflect a stage shift due to increased PSA testing with a corresponding decrease in more advanced stages. This, however is difficult to determine with poor levels of staging.

Patients with insufficient data for TNM Staging

Area of Residence	Total unstaged in each area (%)	
	1996	2001
NHSSB	69 (63%)	46 (46%)
EHSSB	103 (72%)	61 (37%)
SHSSB	54 (84%)	38 (47%)
WHSSB	36 (55%)	24 (27%)
N.Ireland	261 (69%)	169 (39%)

- The percentage of patients for whom it was not possible to determine stage decreased substantially in all Boards with best levels of staging achieved for Western Board patients.

Gleason Score (also see Appendix C)

The Gleason score is used to assess the aggressiveness of the tumour. When pathologists examine the histological specimen they record a score which takes into account the variable histology that can be seen within a 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, it has been incorporated into the TNM staging of prostate cancer – see Appendix C.

Gleason Score recording

Gleason Score	Number of Patients (%)	
	1996 *(n=381)*	2001 *(n=437)*
2	19 (5%)	5 (1%)
3-4	43 (11%)	46 (11%)
5-6	9 (2%)	137 (31%)
7-8	23 (6%)	144 (33%)
9-10	8 (2%)	44 (10%)
Not recorded	279 (73%)	61 (14%)

- The percentage of patients for whom a Gleason score was recorded increased from 27% in 1996 to 86% in 2001. The data from 2001 are therefore more reliable in estimates of true population scores.

Multidisciplinary Team Meetings

The effective management of prostate cancer patients requires input from a range of experts. Multidisciplinary team meetings (MDMs) involve a group of healthcare professionals meeting to discuss the diagnosis and treatment of patients. As there is a range of potential treatments that could be carried out, multidisciplinary discussions are of great importance. With respect to MDMs 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 in recognised MDM format.

Multidisciplinary team meetings recorded in the notes

MDM	Number of Patients (%)	
	1996 *(n=381)*	2001 *(n=437)*
Yes	4 (1%)	17 (4%)
No	377 (99%)	420 (96%)

- The occurrence of MDMs was rarely recorded in the clinical notes. Only 4% of patients had a record of being discussed at a MDM by 2001.

PROSTATE CANCER TREATMENT

Decisions regarding optimum treatment of prostate cancer require assessment of risk, i.e. how likely is the cancer to spread beyond the prostate. This is generally determined by the following combination of factors; the disease stage, the Gleason score and the PSA level[12]. This enables patients to be categorised into one of three risk categories, low, intermediate or high. Treatment options are then based on the patients age and predicted life expectancy which is a key issue in deciding management[3]. Patients are generally categorised as having a life expectancy of over or under 10 years.

Localised prostate cancer

Treatment decisions are generally made on the basis of risk group and predicted life expectancy. For men who have a predicted life expectancy of over 10 years the chances of disease progression are high, therefore curative treatment which includes radical prostatectomy and/or radical radiotherapy is usually offered. For men who have a predicted life expectancy of less than 10 years, observation or 'watchful waiting' can be a valid management option as the chances of disease progression over the patient's lifetime are low, while the risks of radical therapy are considerable in these patients. 'Watchful waiting' involves actively monitoring the course of the disease with intervention if disease progresses. Radiotherapy using external beam therapy or brachytherapy (insertion of radioactive implants directly into the area of tumour) can also be an option in these patients.

Locally advanced stage disease

The optimum management of locally advanced prostate cancer remains problematic and is the subject of ongoing clinical trials. Treatment options include radiotherapy (external beam and/or brachytherapy), androgen blockade using hormone therapy alone, hormone therapy and radiotherapy, and radical prostatectomy in suitable patients with or without hormone therapy.

Metastatic disease

Lowering of testosterone levels using hormone therapy is a standard first line treatment for metastatic prostate cancer, although this can also be achieved surgically by removal of the testes. More than 80% of men with metastatic prostate cancer will have a response to hormone therapy. Radiotherapy may be used to control symptoms of bone pain.

Management*

Management	Number of Patients (%)	
	1996 *(n=381)*	2001 *(n=437)*
Watchful waiting ONLY	110 (29%)	71 (16%)
Radical prostatectomy	4 (1%)	43 (10%)
Hormone treatment	259 (68%)	313 (72%)
Radiotherapy	29 (8%)	126 (29%)

Except for 'Watchful waiting ONLY' patients may have had more than one treatment.

- There was a decline in the percentage of patients managed by 'watchful waiting' only, which may indicate a lowering of the threshold for active intervention.
- Rates for radical prostatectomy and radiotherapy increased markedly.
- Levels of hormone treatment were similar for both years. Twelve patients were recorded as having an orchidectomy in 1996 while none were recorded for 2001 (not shown).

Treatment Type*

Treatment	Number of Patients (%)	
	1996 *(n=381)*	2001 *(n=437)*
Radical prostatectomy alone	1 (<1%)	29 (7%)
Radical prostatectomy & hormone treatment	1 (<1%)	9 (2%)
Radical prostatectomy & radiotherapy	0	1 (<1%)
Radical prostatectomy & hormone treatment & radiotherapy	1 (<1%)	1 (<1%)
Hormone therapy alone	215 (56%)	186 (43%)
Hormone therapy & radiotherapy	19 (5%)	105 (24%)
Radiotherapy alone	8 (2%)	18 (4%)

**** Not all combinations are indicated e.g. patients having a prostatectomy after a period of 'watchful waiting' (1 in 1996, 3 in 2001)***

- By 2001, combined modality 'hormone therapy and radiotherapy' increased, with a quarter of patients receiving this combination.
- Use of hormone therapy alone decreased, which may reflect a lower proportion of patients with metastatic disease at presentation.

Surgical Procedures

Radical prostatectomy, a procedure where the entire prostate is removed along with pelvic lymph nodes, is the main surgical procedure used to treat prostate cancer. Transurethral resection (TURP) is a procedure used primarily to relieve symptoms associated with benign prostatic hyperplasia but may incidentally diagnose prostate cancer. TURPs are included for completeness. (NOTE: only TURPs performed in patients with prostate cancer are considered).

Surgical Procedures

Procedures	Number of Patients (%)	
	1996 *(n=381)*	2001 *(n=437)*
TURP	228 (60%)	117 (27%)
Radical prostatectomy	4 (1%)	43 (10%)
TURP & radical prostatectomy	4 (1%)	2 (<1%)
No surgery recorded	153 (40%)	279 (64%)

- By 2001, one tenth of patients had a radical prostatectomy, a marked increase since 1996 (1%). All patients who had a prostatectomy were aged under 70 years.

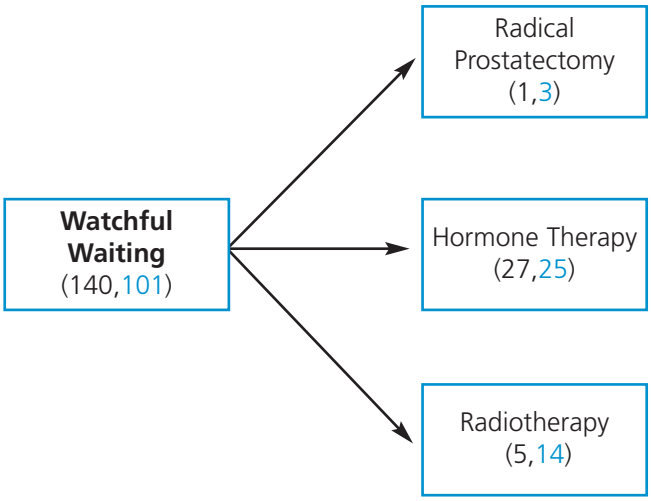
- Of the 43 prostatectomies performed in 2001, 31 (72%) took place in Belfast City Hospital, 10 (23%) were performed in Altnagelvin Hospital and two (5%) were carried out in Craigavon Area Hospital.
- Between 1996 and 2001 the percentage of patients having prostate cancer diagnosed during a TURP decreased, with a corresponding increase in diagnoses resulting from biopsy following raised PSA.

Frequency of radical prostatectomy procedures by surgeon

Procedures	Number of Surgeons (% of procedures)	
	1996	2001
10 or more procedures	0	1 (47%)
5-9 procedures	0	2 (42%)
2-4 procedures	1 (50%)	0
1 procedure	2 (50%)	5 (12%)
Total named surgeons	3	8
Total procedures	4	43

- By 2001, 89% of all patients undergoing a radical prostatectomy were operated on by three surgeons who performed 20, 9, 9 procedures respectively per year with the remaining five patients operated on by surgeons who performed one radical prostatectomy in that year.

Breakdown of treatment received post watchful waiting (1996, 2001)



- In patients whose management was 'watchful waiting', 24% in 1996 and 42% in 2001 had subsequent treatment. In 1996, 19% of 'watchful waiting' patients had hormone therapy compared to 25% in 2001. While in 1996, only 4% of patients subsequently had radical radiotherapy, by 2001 this had risen to 14%. This suggests that by 2001, more patients in the 'watchful waiting' group were subsequently treated with curative intent.

Stage of patients who received 'Watchful Waiting' only

Stage	Number of Patients (%)	
	1996 *(n=110)*	2001 *(n=71)*
Stage I	3 (3%)	5 (7%)
Stage II	1 (1%)	20 (28%)
Stage III	4 (3%)	2 (3%)
Stage IV	16 (15%)	10 (14%)
Insufficient data for staging	86 (78%)	34 (48%)

- For patients in whom stage was known, in 2001, 68% who were managed by 'watchful waiting' only had early stage (I & II) disease. 80% of these men were aged over 70 years at diagnosis.
- In 2001 approximately half of all patients managed by 'watchful waiting' only, had insufficient data for staging, of whom 82% were over 70 years.

Gleason score by treatment (2001 patients only)

Score	Watchful Waiting	Radical Prostatectomy	Hormone Therapy	Radiation
	(n=101)	*(n=43)*	*(n=313)*	*(n=126)*
2-4	26%	2%	8%	6%
5-6	31%	42%	28%	37%
7-10	27%	56%	50%	50%
Not recorded	17%	0%	13%	8%

Information recorded in notes

Information	Number of Patients (%)	
	1996 *(n=381)*	2001 *(n=437)*
Multidisciplinary team meeting (MDM)	4 (1%)	17 (4%)
Diagnosis discussed with patient	296 (78%)	323 (74%)
Treatment plan discussed with patient	296 (78%)	319 (73%)
Management discussed with oncologist	55 (14%)	171 (39%)
Referred to specialist urologist nurse	5 (1%)	62 (14%)
Referred to oncology centre	48 (13%)	168 (38%)
Clinical trial discussed with patient	0	3 (1%)
Clinical trial recorded in notes	0	3 (1%)
Treatment plan recorded	2 (1%)	16 (4%)
Patient unaware of diagnosis	45 (12%)	10 (2%)

- Generally there is good recording of discussion of diagnosis with patients yet this is not recorded for a quarter of patients.
- Recording of MDMs was poor (4% by 2001).
- Referrals to a specialist urologist nurse had increased to 14% by 2001.
- Referral to oncologists trebled so that by 2001, 38% of patients had such a referral.
- Only 1% of patients were entered into clinical trials.
- Although treatment plans were rarely recorded in notes, there was a record in the majority of patient notes that a treatment plan had been discussed with patients.

Follow-up Care Details

After care (NOTE: patients may have had more than one referral)

After Care	Number of Patients (%)	
	1996 *(n=381)*	2001 *(n=437)*
GP (General Practice)	365 (96%)	414 (95%)
Community nurse	12 (3%)	5 (1%)
Macmillan nurse	7 (2%)	8 (2%)
Marie Curie nurse	2 (1%)	0
Hospice	9 (2%)	4 (1%)
Palliative care specialist	3 (1%)	14 (3%)
Psychologist	0	0
Information on support groups/education supplied	0	5 (1%)
No onward referral recorded	14 (4%)	23 (5%)

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

Information recorded in discharge letter to General Practitioner

Information	Number of Patients (%)	
	1996 *(n=381)*	2001 *(n=487)*
Management plan	370 (97%)	400 (82%)
Prognosis	64 (17%)	272 (56%)
Diagnosis discussed with patient	218 (57%)	261 (54%)
Diagnosis discussed with family	56 (15%)	79 (16%)

- In 1996, a management plan was recorded in almost all letters to GPs (97%), however, this decreased to 82% in 2001.

- Apart from improved recording of patient prognosis, there was little change in the information included in discharge letters to GPs between the two time periods.
- Just over half of all discharge letters sent to GPs recorded that the diagnosis had been discussed with the patient. However, according to clinical notes, only 2% of patients were actually unaware of their diagnosis in 2001.

"I met with the urology nurse and with help we formed a support group . . . . which not only supports men but has worked to define and disseminate the referral guidelines etc".

Timelines/Waiting Times

Timelines were examined for all patients and all patients excluding emergency admissions.

Summary timeline for all patients

Time	Referral - First Seen at Hospital		First Seen - Diagnosis		Diagnosis - Radical Prostatectomy	
	1996 *(n=381)*	2001 *(n=437)*	1996 *(n=381)*	2001 *(n=437)*	1996 *(n=4)*	2001 *(n=43)*
Same day	125 (33%)	72 (16%)	28 (7%)	18 (4%)	1 (25%)	0
1 – 14 days	57 (15%)	55 (13%)	118 (31%)	86 (20%)	1 (25%)	0
15 – 42 days	106 (28%)	128 (29%)	76 (20%)	107 (24%)	0	11 (26%)
43 – 84 days	67 (18%)	95 (22%)	65 (17%)	57 (13%)	2 (50%)	20 (47%)
More than 84 days	25 (7%)	54 (12%)	94 (25%)	146 (33%)	0	12 (28%)
Not recorded	1 (<1%)	33 (8%)	0	23 (5%)	0	0

Including Emergencies

- By 2001, there were fewer emergency (same day) presentations, possibly reflecting earlier symptom reporting.
- The percentage of patients having their diagnosis confirmed within 2 weeks of presentation to hospital decreased to 24%, indicating pressure on urology services.
- The most marked changes were evident in WHSSB (not shown) where the percentages seen within 2 weeks of referral decreased from 57% to 22%. In addition, the percentage having their diagnosis confirmed within 2 weeks of presentation to hospital decreased considerably, from 37% to 23%.
- The time between diagnosis and surgery, in some cases, will be due to a 'watchful waiting' period prior to surgery and, in other cases, the use of other treatment modalities prior to surgery.

Summary timeline for all patients excluding emergencies

Time	Referral - First Seen at Hospital		First Seen - Diagnosis		Diagnosis - Radical Prostatectomy	
	1996 *(n=269)*	2001 *(n=374)*	1996 *(n=269)*	2001 *(n=374)*	1996 *(n=2)*	2001 *(n=43)*
Same day	19 (7%)	18 (5%)	19 (7%)	11 (3%)	0	0
1 – 14 days	52 (19%)	50 (13%)	53 (20%)	60 (16%)	0	0
15 – 42 days	105 (39%)	125 (33%)	57 (21%)	94 (25%)	0	11 (26%)
43 – 84 days	67 (25%)	95 (25%)	54 (20%)	50 (13%)	0	20 (47%)
More than 84 days	25 (9%)	53 (14%)	86 (32%)	136 (36%)	2 (100%)	12 (28%)
Not recorded	1 (<1%)	33 (9%)	0	23 (6%)	0	0

Excluding Emergencies

- Between 1996 and 2001 the percentage of patients seen within 2 weeks of referral decreased slightly from 26% to 18%, as did the percentage having their diagnosis confirmed within 2 weeks of presentation to hospital from 27% to 19%. This pattern was similar for patients aged under 70 years.

PATIENT OUTCOMES

Treatment Complications

Radical prostatectomy and radical radiotherapy can cause impotence and incontinence while hormone therapy can 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 (data on this were not available in this study).

Recorded outcomes by treatment 2001 (NOTE: 2-year follow up for 2001 patients)

Outcomes	Watchful Waiting	Radical Prostatectomy	Hormone Therapy	Radiation	All Patients
	(n=101)	*(n=43)*	*(n=313)*	*(n=126)*	*(n=437)*
Erectile dysfunction	3%	51%	4%	7%	7%
Incontinence	5%	28%	4%	2%	5%
Local progression	1%	5%	7%	9%	6%
Other urinary symptoms	4%	14%	11%	10%	10%
Biochemical recurrence	1%	5%	4%	5%	3%
Distant metastases	7%	2%	17%	14%	14%

(Patients may have had more than one complication)

Recorded outcomes by treatment 1996 (NOTE: 7-year follow up for 1996 patients)

Outcomes	Watchful Waiting	Radical Prostatectomy	Hormone Therapy	Radiation	All Patients
	(n=140)	*(n=4)*	*(n=259)*	*(n=29)*	*(n=381)*
Erectile dysfunction	0%	0%	2%	0%	1%
Incontinence	2%	0%	1%	4%	2%
Local progression	4%	0%	8%	21%	7%
Other urinary symptoms	21%	25%	23%	41%	22%
Biochemical recurrence	27%	25%	43%	45%	36%
Distant metastases	27%	50%	51%	66%	42%

(Patients may have had more than one complication)

- Levels of erectile dysfunction and incontinence for patients diagnosed 1996 were lower than those diagnosed 2001. This may reflect (1) poorer recording of these symptoms in 1996 and/or (2) reduction in these symptoms at 7-years of follow up compared with 2-years of follow up.
- In 2001 erectile dysfunction was recorded in 51% of patients following radical prostatectomy, while incontinence was noted in 28%.
- Local progression and distant disease were more likely to be recorded in patients receiving radiotherapy and reflects patient selection.
- At two years (2001 patients), 14% of patients had distant metastases recorded (2% for radical prostatectomy patients) while after seven years of follow up (1996 patients) this was recorded in 42% of patients, reflecting the longer period of observation.

Survival

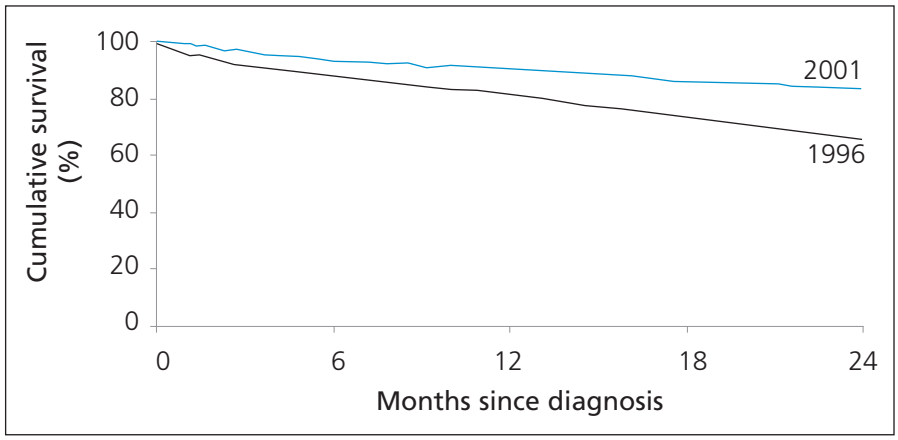
Survival analysis was performed on patients diagnosed in 1996 and 2001, with sub-group analysis for surgery patients and non-surgery patients for each year and for stage and Gleason score (both years combined).

Percentage of patients alive at various times after diagnosis

Time	All patients		Non-surgery patients		Surgery* patients
	1996 *(n=381)*	2001 *(n=437)*	1996 *(n=377)*	2001 *(n=394)*	2001** *(n=43)*
30 days	96%	99%	96%	98%	100%
60 days	94%	98%	94%	97%	100%
6 months	88%	94%	88%	93%	100%
1 year	81%	90%	80%	89%	100%
2 years	66%	83%	66%	81%	98%

**** Radical prostatectomy only ** Numbers (n=4 in 1996) too small for meaningful comparison.***

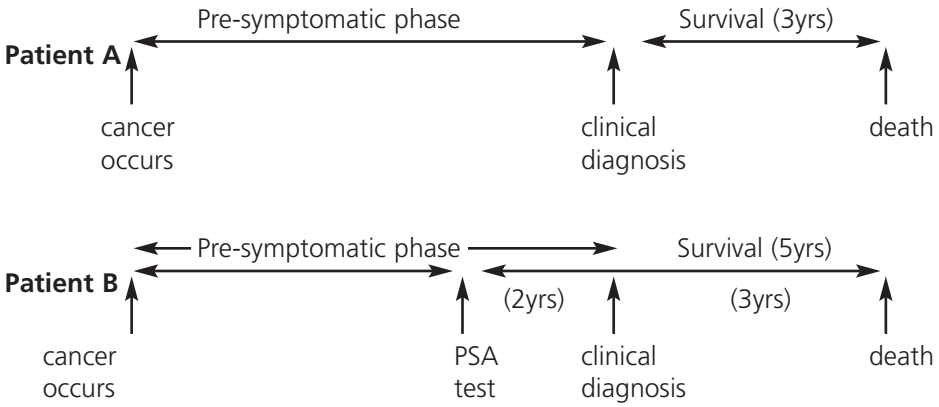
Observed survival by year – All patients



- Survival from prostate cancer is good and improved between 1996 and 2001 with 2-year observed survival of 66% in 1996 and 83% in 2001 (p<0.001).
- This survival improvement must be treated with caution as the patients diagnosed in 2001 were younger and had an earlier stage of disease than those diagnosed in 1996. These factors will all result in improved survival.
- In addition the higher levels of PSA testing in 2001 compared with 1996 is likely to have increased the diagnosis of asymptomatic prostate cancers that might never have been diagnosed in life, this could result in lead time bias (see diagram).

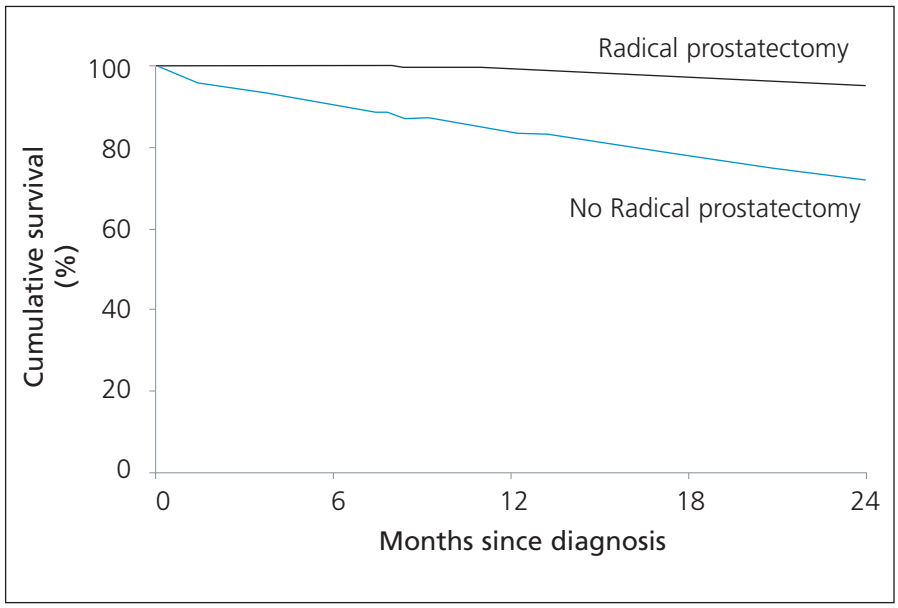
Lead Time Bias

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'.



- In this example both patients die at the same point in their illness. The patient with the PSA test will have known about his cancer for 5 years compared with 3 if he had not had a PSA test. The use of the PSA test has therefore led to an increase in calculated survival without any real increase in life expectancy. Patients don't live longer with their cancer but live longer with the knowledge that they have cancer.

Observed survival for radical prostatectomy patients 1996 & 2001



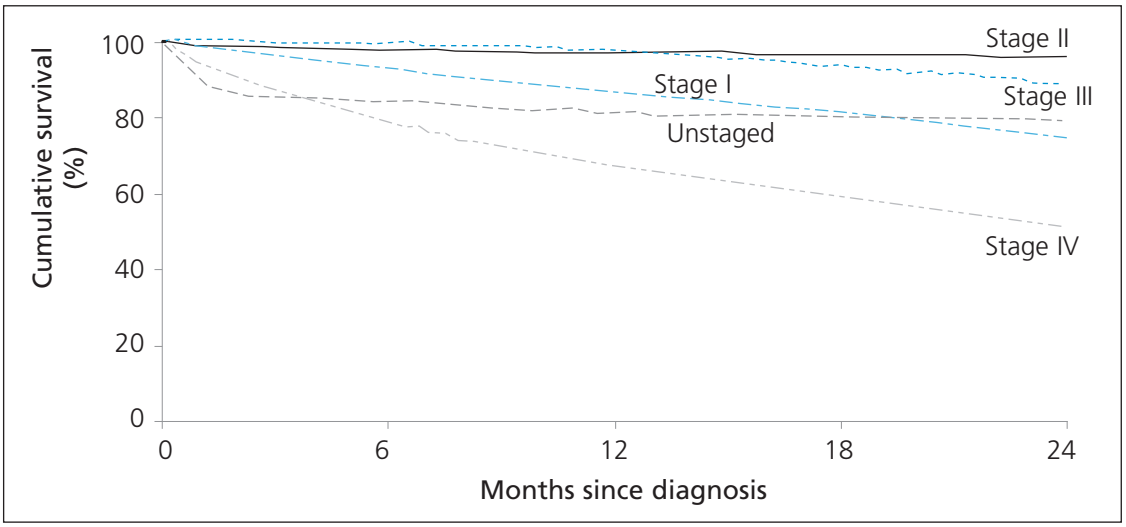
- As expected 2-year survival rates for patients who had a radical prostatectomy were better than those that did not (96% vs 74%) ($p<0.001$). This type of curative intent surgery is performed in selected patients who have good life expectancy and no known metastatic disease.

Percentage of patients alive at various times after diagnosis by stage – 1996 & 2001 combined

Time	Stage I	Stage II	Stage III	Stage IV	Unstaged
30 days	90%	99%	100%	94%	98%
60 days	86%	99%	100%	90%	97%
6 months	84%	98%	99%	79%	93%
1 year	81%	97%	97%	67%	87%
2 years	79%	96%	89%	51%	75%
Total patients	14	121	83	170	430

- As expected there was a highly significant survival difference for stage at diagnosis with patients with earlier stage disease generally having better survival ($p<0.001$).

Observed survival by stage 1996 and 2001 combined

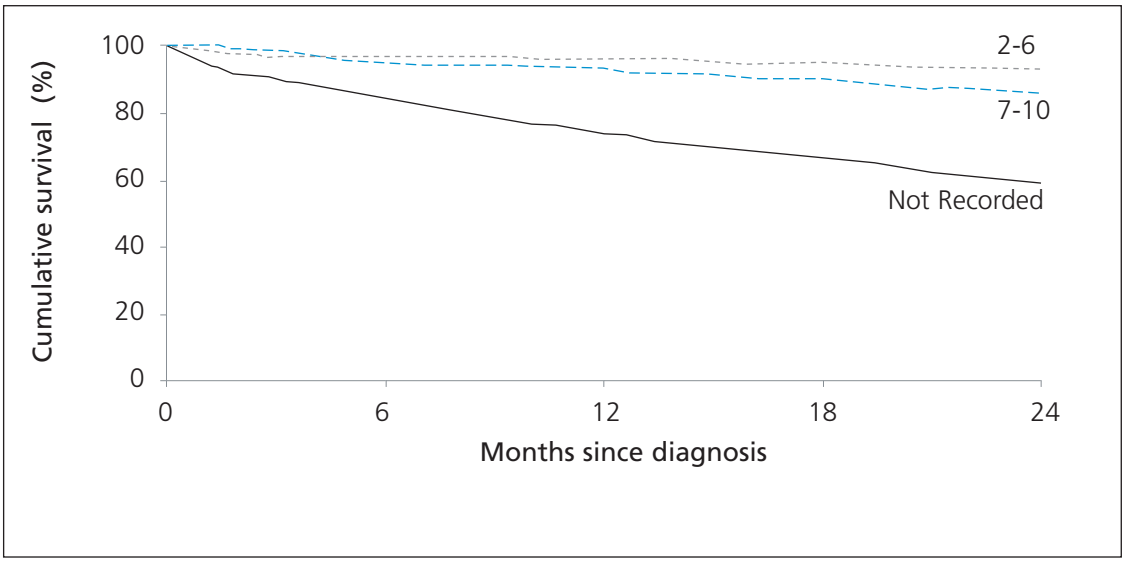


NOTE: The small number of stage I patients distorts the survival pattern.

Observed Survival by Gleason Score 1996 & 2001 combined

Time	2-6	7-10	Not Recorded
30 days	99%	100%	95%
60 days	98%	99%	92%
6 months	97%	95%	85%
1 year	96%	93%	74%
2 years	93%	86%	59%
Total patients	259	219	340

Observed Survival by Gleason Score



- The expected pattern of better survival for lower Gleason scores is apparent with patients having a lower Gleason score (2-6) experiencing a slightly better survival ($p<0.001$).

"I now keep myself fit and have had two clear checkups" . . . .

PROSTATE CANCER SUMMARY

PRESENTATION

- More than half of all cases were diagnosed in men over 72 years. The average age of diagnosis for prostate cancer is falling.
- In 1996, the majority of patients (87%) presented to hospitals within their Health Board of residence. This however, was less marked in 2001.
- In 2001, there were considerable proportions of Northern Board (42%) and Southern Board (30%) patients presenting to Eastern Board hospitals.
- Most patients (87%) were referred by their GP. Of these, the number recorded as emergencies halved from 30% in 1996 to 15% in 2001.
- 381 patients presented to 22 hospitals in 1996 (19 hospitals if emergency cases are excluded) and 437 patients presented to 21 hospitals in 2001 (20 if emergencies are excluded).
- In 2001, 60% of patients presented to a Cancer Unit/Cancer Centre.
- Fewer patients presented to Antrim, a Cancer Unit, in 2001 (4%), compared to 1996 (10%).
- Attendances for prostate cancer at Belvoir Park Hospital increased from 50 patients in 1996 to 88 patients in 2001.
- The percentage of patients who presented with no urinary symptoms, increased from 13% in 1996 to 23% in 2001. This may reflect increased use of PSA testing (8% in 1996 and 15% in 2001).
- 20% of patients presented with urinary retention, 9% with haematuria and 10% with secondary bone pain.

INVESTIGATIONS AND STAGING

- The proportion of cancer patients having a prostate biopsy increased markedly from 25% in 1996 to 87% in 2001.
- The use of bone scans increased slightly so that by 2001, 58% of patients had a bone scan.
- Use of CT scan and MRI scan increased, reflecting better staging practice.
- While most patients had a PSA test prior to diagnosis, patients were less likely to have a PSA of greater than 30ng/ml in 2001. This may reflect a pattern of early intervention at lower PSA levels.
- The recording of a stage in the clinical notes was poor and lower in 2001 (3%) compared to 1996 (12%).
- By 2001, more patients with earlier stage (I & II) tumours were being detected 28% vs 4% in 1996. This may reflect a stage shift due to increased PSA testing with a corresponding decrease in more advanced stages. This, however, is difficult to determine with poor levels of staging.
- While recording of information in notes to enable staging of patients improved substantially, by 2001 two fifths of patients still had insufficient information recorded in their notes to allow allocation of a stage.
- The percentage of patients for whom it was not possible to determine stage decreased substantially in all Boards, with best levels of staging achieved for Western Board patients.

HISTOLOGY & GLEASON SCORE

- By 2001, 94% of patients had a histologically confirmed diagnosis, an increase from 80% in 1996.
- The percentage of patients for whom a Gleason score was recorded increased from 27% in 1996 to 86% in 2001.

RECORDING OF MULTIDISCIPLINARY TEAM MEETINGS

- The occurrence of MDMs was rarely recorded in the clinical notes. Only 4% of patients had a record of being discussed at a MDM by 2001.

TREATMENT

- By 2001, one tenth of patients had a radical prostatectomy, a marked increase since 1996 (1%). All patients who had a prostatectomy were aged under 70 years.
- Between 1996 and 2001 the percentage of patients having prostate cancer diagnosed during a TURP decreased, with a corresponding increase in diagnoses resulting from PSA followed by biopsy.
- By 2001, 89% of all patients undergoing a radical prostatectomy were operated on by surgeons who performed 9 or more procedures per year, with the remaining 5 patients operated on by surgeons who performed one radical prostatectomy in that year.
- There was a decline in the percentage of patients managed by 'watchful waiting' only which may indicate a lowering of the threshold for active intervention.
- By 2001, combined modality 'radiotherapy and hormone therapy' increased with a quarter of all patients receiving this combination.
- Use of hormone therapy alone decreased, reflecting a lower proportion of patients with metastatic disease at presentation.
- In patients whose management was 'watchful waiting', 24% in 1996 and 42% in 2001 had subsequent treatment. This suggests that by 2001, more patients in the observation group were subsequently treated with curative intent.

TIMELINES

- By 2001, there were fewer emergency (same day) presentations, possibly reflecting earlier symptom reporting.
- The percentage of patients having their diagnosis confirmed within 2 weeks of presentation to hospital decreased to 24% indicating pressure on urology services.
- The most marked changes were evident in the Western Board where the percentages seen within 2 weeks of referral decreased from 57% to 22%. In addition, the percentage having their diagnosis confirmed within 2 weeks of presentation to hospital decreased considerably from 37% to 23%.
- The time between diagnosis and surgery, in some cases, will be due to a 'watchful waiting' period prior to surgery and, in other cases, the use of other treatment modalities prior to surgery.

ONWARD REFERRAL

- Referral to a specialist urologist nurse increased to 14% by 2001.
- Referral to oncologists increased to 39% of patients by 2001.
- Few patients (1%) were entered into a clinical trial.
- Most patients (95%) were referred back to the care of their GP and only a small number had a palliative care referral.

COMMUNICATION

- In 1996, a management plan was recorded in almost all letters to GPs (97%), however, this decreased to 82% in 2001.
- Apart from improved recording of prognosis of patients there was little change in the information included in discharge letters to GPs between the two time periods.
- Just over half of all discharge letters sent to GPs had a record that the diagnosis had been discussed with the patient. However, according to clinical notes, only 2% of patients were actually unaware of their diagnosis in 2001.
- Three quarters of patients had a record that their diagnosis and treatment had been discussed with them.

OUTCOMES

- Erectile dysfunction was recorded for half of patients who had radical prostatectomy while over a quarter had incontinence post operatively.
- Side effects such as erectile dysfunction (7%) and incontinence (2%) were lower for those undergoing radiation treatment compared with radical prostatectomy.
- At two years (2001 patients) 14% of patients had distant metastasis (2% for those having radical prostatectomy). By seven years (1996 patients) 42% of patients had a record of distant metastases.
- Survival from prostate cancer is good and improved between 1996 and 2001 with 2-year observed survival of 66% in 1996 and 83% in 2001 ($p<0.001$). This may reflect lead time bias due to increased PSA testing resulting in the diagnosis of earlier stage tumours which are known to have a better prognosis.
- As expected observed survival at 2-years was significantly better for patients having a radical prostatectomy (96% vs 74%) ($p<0.001$) as this type of curative intent surgery is performed in selected patients who have a good life expectancy, and no metastatic disease.
- As expected there was a highly significant survival difference for stage at diagnosis ($p<0.001$) with patients with earlier stage disease having better survival.

CONCLUSION & RECOMMENDATIONS

CONCLUSION

- 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 detection of asymptomatic disease in younger men.

RECOMMENDATIONS

- 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.

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APPENDIX A

Campbell Report[1] recommendations regarding cancer services in Northern Ireland 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 who 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.

The above recommendations outlined the change that was necessary to improve cancer care.

APPENDIX B

Summary of British Association of Urological Surgeons (BAUS) consensus document on the management of prostate cancer (2000).

- Population screening should only be performed in the UK within the context of a controlled trial.
- PSA testing in asymptomatic men is not recommended for routine clinical use, and after request should only be offered following full counselling about the implications.
- Counselling prior to PSA estimation should include the following information:

  1. That the test may detect a cancer at a stage where curative treatment can be offered.
  2. That the test may detect early prostate cancer in around 5% of men aged 50 to 65 years old.
  3. That the test will fail to detect some early tumours.
  4. PSA testing and subsequent treatment of early prostate cancer may incur risk and may not improve life expectancy in all men.

- Patients with significant lower urinary tract symptoms should not be denied access to a PSA test.
- Patients in whom the initial assessment suggests a possible diagnosis of prostate cancer should have rapid access to appropriately trained surgeons for further investigation.
- Isotope bone scans may be omitted from the routine staging investigations in a patient with a well differentiated tumour and a PSA less than 20ng/ml.
- In general, patients should have a diagnosis made histologically. Exceptionally, patients with overriding evidence of advanced carcinoma of the prostate may require treatment without histology.
- Transrectal biopsy of the prostate should always be covered by the appropriate antibiotics.
- The Gleason system has wide support, facilitating comparison of results. In centres where it is not used, consideration should be given to substituting it for, or adding to the current system.
- Both sampling and/or reporting protocols should be dated and reviewed periodically.
- The presence of high grade Prostate Intraepithelial Neoplasia (PIN) on biopsy is not in itself an indication for treatment but requires careful follow up and early re-biopsy.
- Before undergoing total prostactectomy, patients should be counselled about the risks of impotence and incontinence.
- Total prostatectomy should only be performed by locally designated surgeons with the appropriate training to enable them to do so.
- Before undergoing radiotherapy, patients should be counselled about the risks of bowel or bladder damage and impotence.
- Radical radiotherapy should be supervised by locally designated oncologists with a declared special interest in prostate cancer and with appropriately resourced supporting services.
- Surveillance is advised in men with early T1a tumours and predicted life expectancy of under 10 years.
- Neo-adjuvant or adjuvant hormone therapy should be considered for patients with locally advanced (T3-4) disease who are to be treated with radical radiotherapy.

- Patients commencing hormone therapy should be offered a choice which would normally be between orchidectomy or Lutenising Hormone Release Hormone (LHRH) analogues as the first line therapy. In particular orchidectomy should be considered where a co-incidental surgical procedure is to be performed e.g. transurethral resection of prostate (TURP).
- Combined androgen blockade should not be used routinely based on current evidence.
- Patients with metastatic disease causing bone pain or significant systemic effects should have immediate hormone treatment.
- Spinal cord compression should be treated as an oncological emergency, and should be managed with an agreed protocol in consultation with a named surgeon with an interest in spinal disease.
- In the management of hormone-refractory disease, strontium 89 or hemibody radiation should be considered for bone pain.
- Patients have the right to information about their disease, its treatment and prognosis and they should control the level of information they and others receive about their condition.
- Patient information should be available in the form of leaflets etc.
- Links should be established between urologists treating prostate cancer and oncologists with an interest in urological cancers.
- Parallel clinics and multidisciplinary meetings are desirable to optimise patient care.
- Referrals to continuing care services should be made where appropriate to support patients with symptomatic problems and not just with terminal care.
- Patients should have the opportunity to participate in clinical trials.
- To allow research, audit and trials to be conducted properly, research assistants will need to be employed.

APPENDIX C

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 of prostatic carcinoma (6th Edition)[11] is shown in Table 1.

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).

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).

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 **TNM classification of prostate cancer**[11]

	Tumour	
T0	T0	no evidence of primary tumour
T1	**T1**	tumour not palpable or visible by imaging
	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	**T2**	tumour confined to the prostate
	T2a	tumour involves one half or less of one lobe
	T2b	tumour involves more than one half of one lobe
	T2c	tumour involves both lobes
T3	**T3**	tumour extends through the prostatic capsule
	T3a	extracapsular extension, unilateral or bilateral
	T3b	tumour invades seminal vesicles
T4	**T4**	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	N0	no regional nodes involved
N1	N1	regional nodes involved
	Metastases	
M0	M0	no distant metastases
M1	M1	distant metastases
	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).

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. A Gleason score of 2-4 corresponds 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.

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).

Table 2 Stage Group Prostate Cancer

Stage	T	N	M	Grade
I	T1a	N0	M0	G1
	T1a	N0	M0	G2-4
II	T1b	N0	M0	any G
	T1c	N0	M0	any G
	T1	N0	M0	any G
	T2	N0	M0	any G
III	T3	N0	M0	any G
IV	T4	N0	M0	any G
	any T	N1	M0	any G
	any T	any N	M1	any G

Example:

- Palpable tumour involving both lobes. Radical prostatectomy confirms extension to seminal vesicles, therefore **T** = T3b. Gleason score 8, therefore 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 **M** = 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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