

PCaSO

Prostate Cancer Network

The Prostate Cancer Experience

**Report
on a Questionnaire
from a survey of 230 members of PCaSO**

September 2009

PCaSO Prostate Cancer Network, PO Box 66, Emsworth, Hants PO10 7ZP

Helpline: 0845 650 2555

Email: info@pcaso.com

www.pcaso.com

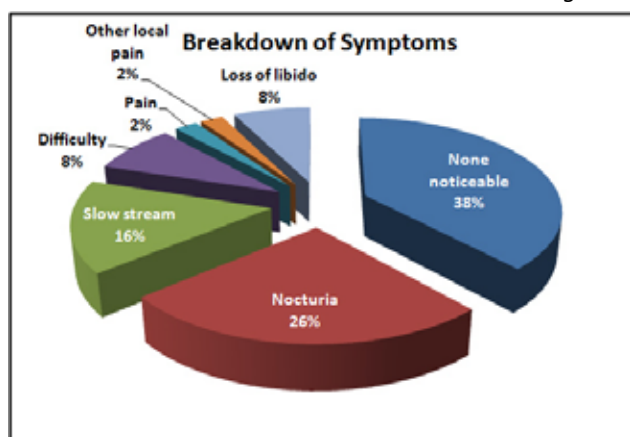
PROSTATE CANCER QUESTIONNAIRE REPORT

This is a report on the results of a questionnaire sent to the membership of PCaSO Prostate Cancer Network in March 2009. We had 230 responses out of a total membership of about 630 men with a diagnosis of prostate cancer, both from PCaSO and from PCaSO Dorset Branch.

1. SYMPTOMS

We found that 38% of men that were subsequently diagnosed to have prostate cancer had *no noticeable symptoms*; 41% of this group were found to have locally advanced, rather than early stage disease. One man reported diagnosis of advanced stage cancer with no symptoms. This is a significant proportion, and confirms the need for awareness and early diagnosis. The most common symptoms that prompted a GP visit were night-time trips (nocturia) and slow stream. Fig. 1 below shows the breakdown of symptoms.

Figure 1



2. THE GP VISIT

55% of men were unaware of the PSA test before the GP visit, and 45% knew enough about it to ask for the test. Only 32 men (14%) reported any unwillingness on the part of their GP to give them the test, but significantly in very many cases (55%), the GP appeared not to explain the weaknesses of the PSA as a diagnosis for prostate cancer, nor to point out the 'pros and cons' of the test, as advised by government guidelines. These statistics, we feel, are significant, but in spite of this, many rated their GP highly in their care and concern over their problems (see Table 1 opposite). The comments we received on this aspect of the prostate cancer journey, however, do reflect a wide range of concerns. A selection of these is given below; further information, including age at diagnosis where relevant, is given in brackets.

'My GP didn't appreciate my concern – my father died of it aged 60; I am 54.'

'The inadequate response by my first GP will possibly cost me my life. The consultant said: "If caught earlier, a cure might have been possible" [age 51, initial PSA=235].

'I asked for a PSA test but the GP referred me to the clinic at ----- hospital. This resulted in a 3 month delay before I found that my PSA was 83.6' [age 66, 2001].

'I was told it was contrary to NHS protocol to give a PSA test at first visit. After 2 more visits I was given a PSA test which showed a reading of 86. The GP said she

would not follow the protocol in future' [2002].

'He did not consider that I needed a test, as no symptoms were present' [age 62, PSA=12, later Gleason 6].

'I was told there was nothing wrong. I went to my GP four times before I could get a PSA' [PSA result=13].

'I was 45 – was told "no one under 50 gets prostate cancer: it's an old man's disease for over 65s". [The patient paid for a private PSA; cancer was later found to be locally advanced and aggressive].

'GP just gave me a urine test and said: "No blood, you're OK". Only on my insistence that there was problem did he give me a blood test with a PSA reading of 44'.

'My GP was very thorough – he told me he gives PSA with other tests to every man approaching 50'.

'Very glad my GP referred me, as it turned out that the cancer affected most of my prostate despite my having NO symptoms'.

'My GP was very supportive and pro-active'.

'The pros and cons [of the PSA test] were printed off and given to me as bedtime reading'.

Table 1: GP Ratings

1 (poor)	2	3	4	5 (v. good)
12%	8%	21%	25%	34%

As expected, the majority of first PSA readings taken at the GP visit were below 10, but a significant number were high – two of which were over 1000 (see Table 2 below).

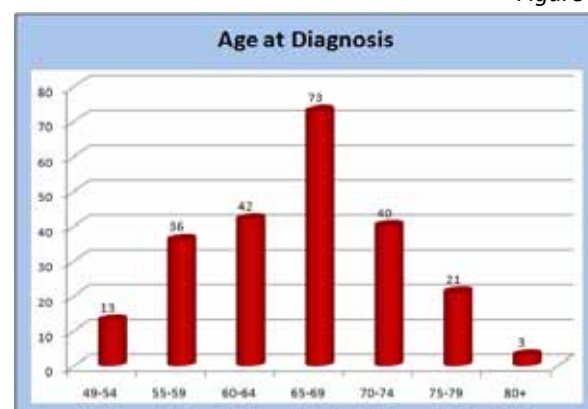
Table 2: PSA Results

<9	10-19	20-49	50-99	100-499	500-999	1000+
107	45	18	13	7	1	2

3. CONSULTANT REFERRAL AND DIAGNOSIS

Turning to the consultant visit and the diagnosis, a remarkable number of patients had private treatment – 27% as opposed to 73% receiving NHS treatment. Despite this, there was very little difference between the waiting times for referral. As expected, most men were in the 65-69 age range at diagnosis. Nevertheless, Fig. 2 shows a significant number being diagnosed in their early 50s.

Figure 2

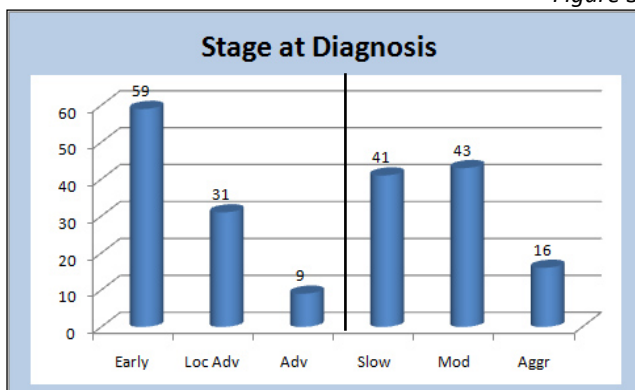


16 men contracted some form of infection following biopsy – a surprising number, considering the now normal practice of giving antibiotics. However, only 38 men (18%) found the experience painful, while 42% described it as ‘uncomfortable’ and 40% as ‘not too bad’. Two comments on the biopsy experience were:

‘I was given no warning as to the extent of the bleeding and ended up driving home soaked in blood’.
‘The consultant and nurse at -- ----- made every effort to reduce the unpleasantness of the experience.’

It is clear that most men understood or had explained to them the Gleason system and knew their Gleason score, though the stage of the cancer was sometimes neither given nor fully explained. Figure 3 below shows the stage at diagnosis of the men responding (expressed as percentages), which perhaps encouragingly does not reflect the accepted national statistics (43% early stage, 34% locally advanced and 23% advanced), and the aggressiveness of the cancer. An encouraging number (over two thirds) sensibly had a wife/partner/friend present, but about 14% felt they could not understand the consultant’s explanations, or felt unable to ask questions. However, 67 (28%) were not given any literature to take away with them, which seems a disturbing number, although we have not analysed how recently these patients were diagnosed.

Figure 3



Only 54% were seen by a nurse specialist, though we know that few private patients have the opportunity for a CNS consultation; nor do we know how many men were diagnosed before specialist nurses became established in hospitals. Of those that saw a nurse specialist, their rating was very high (see Fig. 4). The consultant rating was, however, more varied, as can be seen from Figure 5.

Figure 4



The man’s experience with his consultant was the next area of concern, judging by the comments we received, a selection of which is appended below:

‘The junior doctor advising me of the biopsy result said “You have had cancer for some years. Normally you would have 15 years to live, but your expectancy could be 8 years.”

‘The consultant was blunt and insensitive’

‘I was seen by a junior medic who was frankly hopeless and scared the life out of us. I demanded to see the actual consultant and managed to get a reasonable explanation of my condition’.

‘The worst part was being told that my treatment was “only palliative”. I now realise I could have been much more sensitively informed and helped with the emotional aspect’.

‘The junior said: “If the treatment doesn’t work [i.e. radiotherapy] you can have an orchidectomy”. When this was explained it was rather shocking’ [age 54].

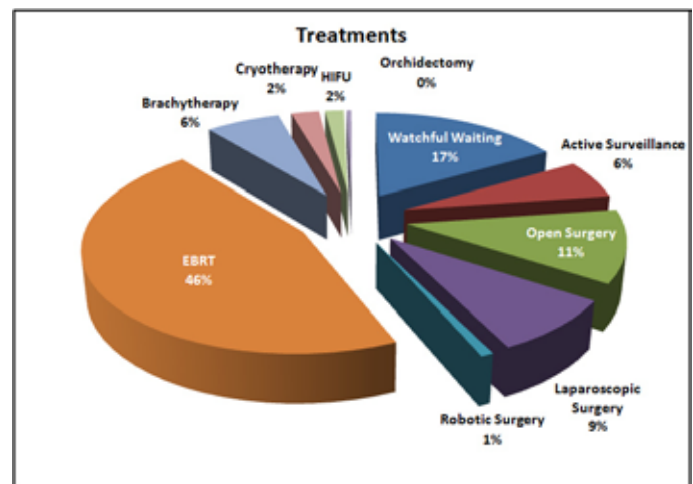


Figure 5

4. TREATMENT

The following chart shows the treatment options taken by the 251 responses to this section (some may have had more than one treatment), from which we can see that external beam radiotherapy is by far the most common. It is surprising the number of men that have had laparoscopic surgery – almost as many as for open surgery. The 2% figure for cryotherapy and HIFU represents 5 and 4 men respectively; for robotic surgery two, and orchidectomy one man. 12 had brachytherapy.

Figure 6



Although two thirds of the men felt that they were given no choice of treatment, in nearly all cases men felt satisfied that they had made the right choice. There were, of course, a few exceptions:

The consultant ... failed to explain the full implications of radical prostatectomy. Had this been done I would have chosen another option. Now totally incontinent and with ED'

'I'm on Watchful Waiting, seeing my PSA climb. I've asked repeatedly to go on Active Surveillance, but they are not keen at -----, unlike [neighbouring] -----. Knowing what I do now, I realise I should have pressed for radiotherapy some time ago – while two friends have died suddenly and quickly after 8 years or so on hormones; ... their PSAs were low when they died.'

Overall, 77% felt that their treatment was fully successful, 19% partially so, and only 5 respondents felt that their choice had not been a success.

The skills of the surgical and oncology teams were generally highly rated, although the nursing care was more variable. One member, after robotic surgery, gave 5 (excellent) to the surgeons and 0 for the ward nurses (our lowest rating being 1=poor). Of radiotherapy, a member described it as 'a bit of a sausage factory – but very pleasant and considerate'.

In deciding on their option, one third of the responses in this section felt that all feasible alternatives were not fully explored. 42% felt on their own in making a decision, and it was the internet that most turned to for help (see Table 3).

Table 3 Seeking Advice Seeking Help

Advice from GP	17%	Internet	43%
Friend/relation	35%	Library	15%
Support Group	18%	Other patients	21%
None	30%	Help Line	23%

Two recurring themes came through from comments made. Firstly, the concern over the patient alone having to make the treatment decision, with no professional advice:

'I was surprised to be asked to decide what treatment I would like when one has no idea of the problem.'

'I was told to look on the internet for information!'

Secondly, the lack of information on alternative treatments:

'No information given or offered on HIFU, LRP or robotic RP – no encouragement to explore other avenues.'

'I was told what treatment was necessary, and I was given no choice. The consultant was blunt and insensitive.'

One man, aged 76, was given open surgery, and was not advised of any alternative treatment.

5. QUALITY OF LIFE

About half of those with early stage prostate cancer have made changes to diet and lifestyle, and for those with locally advanced or advanced cancer, the percentage was much higher – 68%, with a greater number making more radical dietary changes. Although they are very subjective, quality of life ratings are shown for the two groups in the following tables (1=minimally affected, 5=severely affected). They are surprisingly similar in many respects (see Tables 4a & b).

Table 4a: Those treated for Early Stage prostate cancer

1	2	3	4	5
45%	19%	12%	15%	9%

Table 4b: Those treated for Locally/Advanced prostate cancer

1	2	3	4	5
30%	23%	23%	16%	8%

Unsurprisingly, as the prostate is a sexual organ, erectile dysfunction and lack of libido were recurring features in members' responses. Some disturbing comments were:

'With hormone therapy – mood swings, depression and ED badly affect quality of life and thence my wife's QoL. (Suicide sometimes contemplated).'

'Loss of sexual function and the relationship between my wife and me is not the same.'

'It was a rollercoaster! At the nadir (about 3-5 years after diagnosis) I had to seek marriage guidance. OK now.'

This shows the real need for partners to talk about the effect that prostate treatments can have on relationships, and for partners to be understanding of each other – counselling can play an important part in this aspect, which appears not often to have been offered or taken up.

Others have taken a positive approach to life after (or with) prostate treatment:

'I have recently completed 10,000 miles of long-distance walking ... to counter the weakening effects of Zoladex on bone and muscle.'

One member commented on the apricot kernel theory:

'I tried Vitamin B17 (apricot kernels) and was on this treatment both before and when my Zoladex treatment stopped for 6 months. The fact that my PSA rose ... convinced me that the full B17 treatment was useless.'

Here's a useful tip from another member:

'I was given acupuncture for hot flushes – it helped.'

6. HORMONE THERAPY

Some may be aware of the Prostate Cancer Charity's report on a recent survey they conducted on men having hormone therapy treatments called 'Hampered by Hormones?' (June 2009). It is available on their website www.prostate-cancer.org.uk, or a copy can be obtained direct from the PCC. Only 322 men throughout the UK responded to their survey, but in general our findings were broadly similar to those of the charity. Of our 230 responses (gratifyingly more than a third of our membership of men with prostate cancer) 68 were having hormone – or in very few cases chemotherapy – treatment, so our figures are based on this smaller number.

Of these, about two-thirds (63%) were being treated for locally advanced prostate cancer, while for the remainder (37%) the cancer had reached the advanced stage. For most (75%) this was their first diagnosis, while for the remaining 25% the cancer had recurred after initial primary treatment. Many may be aware of intermittent hormone therapy, whereby treatment is stopped for a period until the PSA begins to rise. This is thought to delay the time when hormone treatment may cease to become effective. Only 14

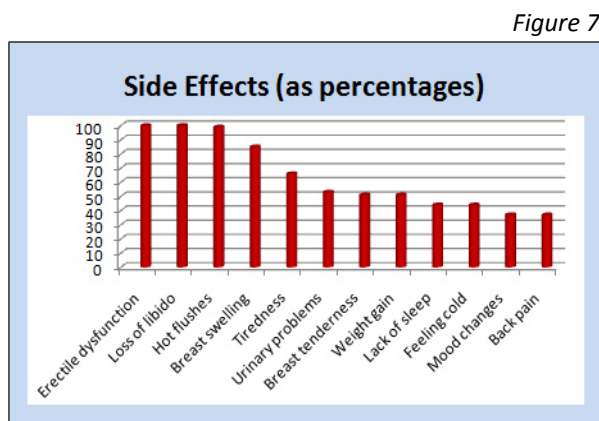
men (23%) were having this form of treatment.

We asked whether members had been offered counselling for their hormone treatment, and only 24 men and their partners (of the 82 responses to this question) had been offered this service. This is a major point that the Prostate Cancer Charity survey makes: there was too little information given on the side effects of hormone therapies, and too many men were not told about these before starting treatment.

We also asked about bone health, and 67% were given bone scans before starting their treatment, but in only 20% of cases was the bone density monitored.

Side effects of hormone therapy

We found, unlike the PCC survey, that in all 68 cases men suffered hot flushes, erectile dysfunction and loss of libido (sexual desire) during the treatment – i.e. 100% each, while breast swelling occurred in 85% of cases. The PCC survey figures were 85%, 83%, 80% and around 52% respectively, this last only obtained from a rough graph in their publication. This nevertheless confirms that these often debilitating side effects should be expected with the treatment. The following graph (Figure 7) shows the percentages of our members who experienced the listed side effects during their treatment:



We asked our members to give a subjective rating from 1 to 5 of the degree of distress from each side effect (1 being minimal, 5 being unbearable), and it can be seen that in general men felt more able to cope with hot flushes, breast problems and mood changes, and least able to manage the sexual aspects. This agrees with the PCC's findings, but in Figure 8 we give a more detailed analysis of the severity each side effect. For clarity, ratings 1 + 2 (least affected), and 4 + 5 (most affected) have been amalgamated, giving three bands instead of five; they are shown in Figure 8 opposite in order of the most debilitating (i.e. the top red cylinder bars) and the least concerning (the bottom green box bars).

Some comments we received on treatment side effects were:

'I have some depression and frustration, irritable moods and anxiety.'

'If I'd believed the first consultant/Macmillan nurse I'd be down and out. The second consultant was far different, so I live as normal a life as possible without thinking too much about my condition.'

'I have a positive attitude and an understanding wife and family.'

'My sexual life is most distressing.'

'Sex and desire have gone. With a less understanding spouse it could have been destructive to our relationship.'
And from a 56 year old diagnosed with a PSA of 235:
'Am unable to work because of fatigue – social life is limited.'

Some commented on the fact they were not told of the effects of hormone treatments beforehand:

'No information or advice on sexual implications of hormone treatment given.'

Figure 8



We next isolated the patients that had the various primary treatments to assess how satisfied they were with their choice of treatment, its apparent success, the side effects experienced, and the quality of life after treatment. The sample numbers we used were: watchful waiting and active surveillance 16, open surgery 22, laparoscopic and robotic surgery 20, external beam radiotherapy 60, and brachytherapy 12. With only 5 responses for cryotherapy and 3 for HIFU, the sample was too small for any meaningful figures.

7. WATCHFUL WAITING AND ACTIVE SURVEILLANCE

Although a small sample, several men listed urinary and other symptoms under side effects. Some found the regime difficult to cope with: 'Watchful Waiting is extremely stressful' was one comment. Others were taking more direct action:

'I put myself on a vegan diet with supplements and my PSA has slowly halved to 3.5.'

8. SURGERY (RADICAL PROSTATECTOMY)

These men were split into two groups – those who had open surgery and those who had keyhole surgery, to see if there were any different conclusions from roughly equal numbers.

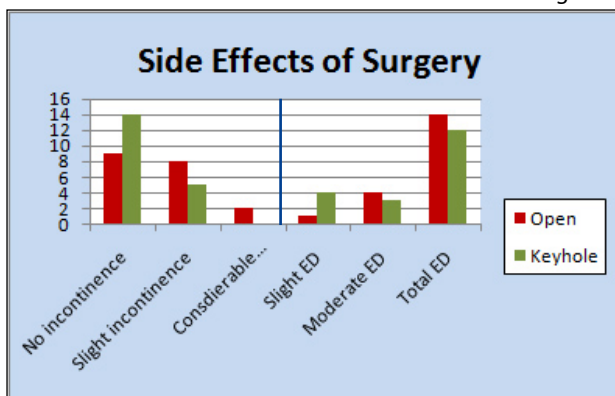
Three men who had open surgery were totally dissatisfied with their choice of treatment. One, aged 67 and treated in 2000, was not offered any alternative treatment; another (aged 62 in 1999) was left totally incontinent, the consultant apparently failing to explain the full implications of the operation; another has been fitted with an artificial sphincter. The remaining men were confident or fully confident that they had opted for the right treatment. Apart from these three cases, both groups felt that their operation had been a success:

Table 5

	Fully successful	Partly successful	Not successful
Open	15	3	3
Keyhole	16	1	0

The following chart (Figure 9) shows the responses to the two main side effects of surgery. As can be seen from the chart, keyhole surgery patients seem to come out slightly better in the incontinence stakes, with none having 'considerable' incontinence problems 6 months after the operation; while erectile dysfunction statistics seem to be about the same, or perhaps slightly worse for the laparoscopic procedure. However, these are small numbers, and we failed to ask how many chose, or were advised, not to have nerve-sparing surgery.

Figure 9



9. EXTERNAL BEAM RADIOTHERAPY

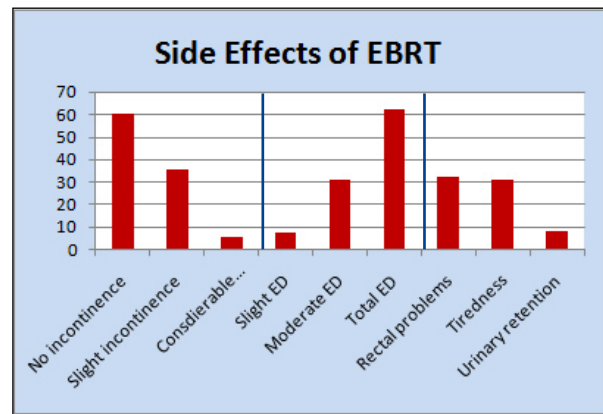
This was by far the most common option from our survey, with 46% of members responding having had EBRT.

No one felt that they had made the wrong choice, with most being either reasonably satisfied (33%) or wholly satisfied (55%) that they had chosen wisely. 73% felt that the treatment was a success, 25% partially so, with only 2 dissatisfied with its success. Quality of life after radiotherapy was generally reasonable, as can be seen from the final comparative charts (Figure 12b).

Incontinence was generally not a problem with EBRT. Of the 51 responses, 30 had no problems, 18 reported slight incontinence, while only 3 had considerable problems. With erectile dysfunction, however, the situation was almost an exact reversal. Of the 42 responses, 26 had total ED, 13 partial ED, and 3 suffering from slight problems. One third

of the replies (20), however, had continuing rectal problems, and a similar number suffered ongoing tiredness. Figure 10 shows this in percentage terms:

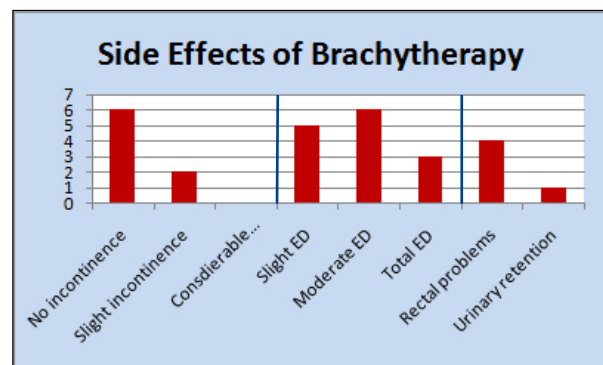
Figure 10



10. BRACHY THERAPY

We analysed the side effects of the 12 men who had opted for prostate brachytherapy. Nearly all were satisfied that they had made the right choice and felt that the procedure was a success. Most felt their quality of life after the operation was good or, in two cases, satisfactory. However, of the side effects, ED was the most significant, to which can be added, in a few cases, rectal problems and some urinary retention (presumably after the initial period immediately following the procedure).

Figure 11



11. COMPARISON OF TREATMENTS

Finally, we compared the satisfaction of the members who had the different treatments and their own subjective assessment of quality of life for each, dividing them into those treated before 2004 and those treated from 2004 to 2008, to see if there was any discernable improvement in satisfaction and quality of life. It should be borne in mind, however, that brachytherapy had low sample numbers, so the figures will almost certainly not be representative. A much larger sample is needed for meaningful results. Of the 5 cryotherapy responses, some did not rate the success of the treatment (one totally successful, another only partially) while, of the 3 HIFU patients, in one case it was totally successful with no continuing side effects, another had several side effects, whilst a third case (after failed radiotherapy) was left totally incontinent after an unsuccessful procedure.

Splitting the two main primary treatment options (surgery and EBRT) into those men treated pre- and post 2004, figures 12(a) and 12(b) illustrate for the two groups patient satisfaction of their choice, and their perceived quality of life after treatment.

Figure 12(a): Surgery

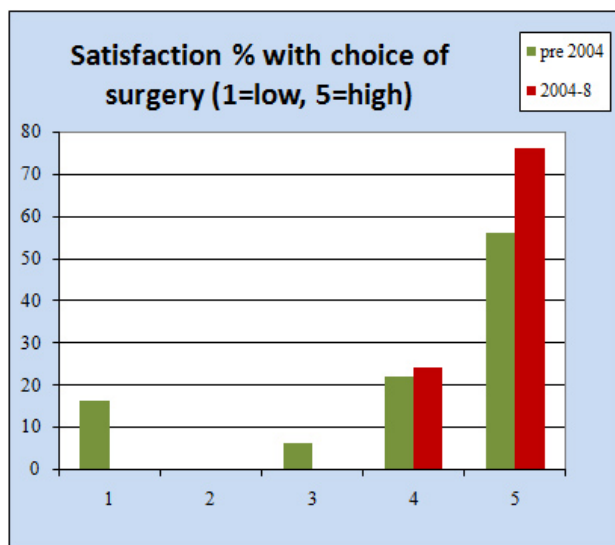
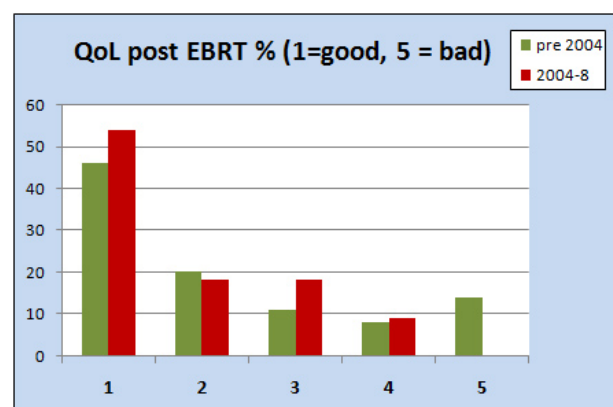
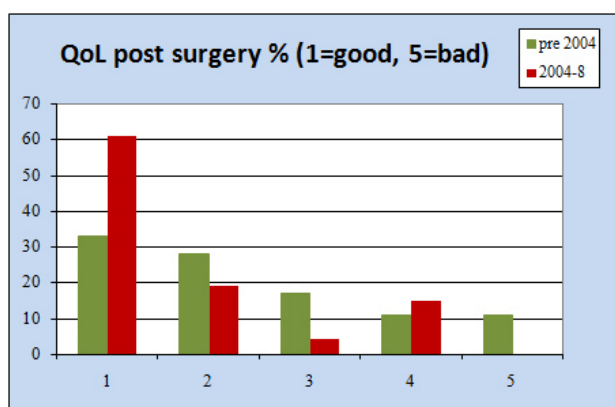
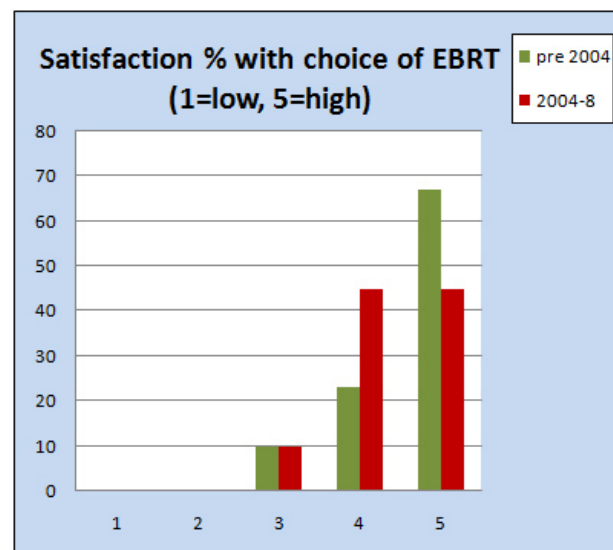


Figure 12(b): External beam radiotherapy



12. CONCLUSIONS

It appears that there is very little difference between the perceived success of the main first-line treatments and a patient's quality of life afterwards, and only in exceptional cases did men feel that they had made totally the wrong choice. Those treated after 2004, however, appear to be more satisfied with their choice and quality of life, and this may well be due to improving surgical skills and/or better equipment and techniques.

For those men treated for locally advanced or advanced prostate cancer, however, the choice of treatment is limited, and those having hormone treatments do appear to have a somewhat less satisfactory quality of life than those treated at the primary stage, as can be seen in Table 6.

Table 6:

Quality of life after all treatments (1=minimal effect, 5=unbearable), expressed as percentages, with total sample numbers in brackets

Rating:	1	2	3	4	5
Hormone therapy (58)	26	22	27	17	4
Surgery (40)	48	32	8	10	2
EB Radiotherapy (59)	47	25	7	6	3
Brachytherapy (12)	75	8	17	0	0

These are relatively small samples, however, and it may be that a national survey based on PCaSO's questionnaire could be undertaken by other patient organisations.

Acknowledgments:

The analysis was undertaken by members of the PCaSO executive committee David Smith, Ray Marsh, Michael Hollingworth and Norman Last.

Charts were prepared by David Smith and Michael Hollingworth.

This report was compiled by Ian Graham-Jones.

PCaSO

Prostate Cancer Network

is a patient support group which provides free and confidential help, support and information to anyone concerned about this disease

Patrons:

**The Duke of Richmond and Gordon
The Very Reverend Nicholas Frayling
Baron Palumbo of Walbrook
Bill Beaumont, OBE**

Founder and Life President:

David Rowlands

Medical Advisors:

**Mr Christopher G. Eden, MS, FRCS (Urol.)
Mr Simon A. V. Holmes MS, FRCS (Urol.)
Dr Chris Parker, BA, MRCP, MD, FRCR**

Don't get caught out!