

PiCTure Study-An All-Ireland Study

Prostate cancer treatment, *your experience* of living with and beyond prostate cancer – what we have learned

A summary of findings for participants

During 2012, men in both the Republic of Ireland and Northern Ireland, who had been diagnosed with prostate cancer between 1995 and 2010 were invited to complete a study questionnaire. This examined the treatment received for prostate cancer and what effects, if any, the cancer and/or treatment had physically, emotionally or financially. We had a great response and are very thankful to you because without your contribution this would not have been possible. This is the first such study to be carried out among prostate cancer survivors in Ireland.

Funding for our study was from the Health Research Board in the Republic of Ireland, Prostate Cancer UK and the Research & Development Office in Northern Ireland. After receiving ethical approval, a steering group was set up which included patient representatives, urologists, nurses and researchers. Furthermore, at many points during this study, input was obtained from Men Against Cancer (MAC) and from men attending prostate cancer support groups.

More than half (54%) of those contacted took part, kindly giving us important information on how they were diagnosed, treatments they received and any physical effects they experienced following their diagnosis. They also told us how health-related quality of life was affected by their prostate cancer diagnosis and/or treatment. Some men found the questionnaire upsetting and we appreciate them taking time to complete it. Some found completing it helpful, and hoped that by telling us about their experience it would benefit others in the future. Many people reported that prostate cancer had not affected their quality of life greatly, while others found life following their diagnosis and treatment difficult. During the course of this study, almost one thousand men rang the freephone number and gave us extra information about both their good and bad experiences of having prostate cancer. We have included some of their quotations.

"It's a terrible shock to be diagnosed with cancer of the prostate"

Some results

- Information was returned by 3,348 men with prostate cancer, (2,338 men in the Republic of Ireland and 1,010 men in Northern Ireland).
- Overall, the most common treatments received by men with prostate cancer in Ireland were; radiotherapy with hormone therapy (32% of men), surgery to remove the prostate (19% of men) and radiotherapy without hormone therapy (17% of men). Less than one-in-ten men had hormone therapy alone (9%), monitoring of their cancer through either watchful waiting or active surveillance (5%), or internal radiotherapy (i.e. brachytherapy, 3% of men).
- Almost one-quarter of men reported that they had no physical effects from their prostate cancer at the time of completing their questionnaire.

- However, when surveyed, three in five men reported ongoing erectile dysfunction/impotence (59% of men) and half had a loss of interest in sex (47% of men). Less than one in five men reported urinary incontinence (16%), bowel problems (15%), hot flashes or sweats (17%) or changes in their breast tissue (10%).
- One-quarter of men experienced fatigue or tiredness (23% of men) and 10% reported depression.

"Prostate cancer had only a small impact on my finances."

"I am suffering from radiation cystitis which is having quite an impact on my day to day life."

"Prostate cancer has only slightly affected my quality of life. I only think about it when I have to have blood tests and return to hospital every six months for a check-up."

Quality of Life of prostate cancer survivors

- The quality of life of prostate cancer survivors in Ireland is similar to that of men with prostate cancer in other countries.
- Men who were aged between 60 and 69 years at diagnosis had the highest quality of life of all men. Men who were married and those who were working when they were diagnosed also had a better quality of life than those who were not married or those who were not working when they were diagnosed.
- Men who experienced some adverse effects following their diagnosis and treatment had a lower quality of life than men who did not experience any adverse effects.

"I had to learn to take life easier. Moderation in food, dancing...difficulty in stooping. Had to stop grass cutting and hedge clipping. Cannot lift or carry heavy items.."

Financial effect of prostate cancer

- Some men reported that their prostate cancer diagnosis did not affect them financially however others experienced some difficulties due to, for example, changes in their work situations and increased medical and general bills.
- Detailed information on costs from men and healthcare professionals is being used to estimate the cost of diagnosis and treatment of prostate cancer in the Republic of Ireland.

What next.....

The findings have been presented to the project steering groups, national and international conferences, the National Cancer Control programme (Republic of Ireland), the Health Research Board (Republic of Ireland) and Prostate Cancer UK and will hopefully inform good practice and service improvements. Also, the rich information contained in these questionnaires will be produced for wider distribution, along with scientific papers in international journals.

Thank you for your invaluable contribution to this study

From Dr Frances J Drummond, Dr Heather Kinnear, Dr Anna Gavin and Professor Linda Sharp at the National Cancer Registry Ireland and Northern Ireland Cancer Registry.