



STUDY SUMMARY

**PROSTATE
CANCER
OUTCOMES**

LIFE AFTER
PROSTATE CANCER
DIAGNOSIS



The Life After Prostate Cancer Diagnosis study was funded by the Movember Foundation, in partnership with Prostate Cancer UK, as part of the Prostate Cancer Outcomes programme, grant number BO26/MO. The programme was delivered in partnership between the University of Leeds, Queen's University Belfast, University of Southampton, Oxford Brookes University and Public Health England.



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**PROSTATE
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LIFE AFTER
PROSTATE CANCER
DIAGNOSIS



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CONTENTS

- About the study 2
- Main messages 3-4
- Publication summaries 5-13
- Papers in preparation 14-15
- Thank you 16

ABOUT THE STUDY

The Life After Prostate Cancer Diagnosis (LAPCD) study was designed to investigate the quality of survival of men living in the UK 18-42 months after diagnosis of prostate cancer. The survey was distributed to men managed by a multidisciplinary team (MDT) within English NHS Hospital Trusts, Welsh Health Boards, Scottish Cancer Networks and Northern Irish MDT-Led areas between October 2015 and January 2018.

82% of NHS Trusts in England participated (n=111) and 100% of all providers in Northern Ireland (n=5), Scotland (n=14) and Wales (n=6) participated. A total of 35,810 men from England, Scotland, Northern Ireland or Wales responded to the first postal survey (58,930 men invited - response rate 60.8%).

Across the UK, the average age of the men who responded to the survey was 71 years. The majority of men (58.0%) received a diagnosis of prostate cancer after attending their GP with symptoms. However, a third of men (33.9%) were diagnosed without symptoms after receiving a PSA test. Of men where cancer registration records had information on stage at diagnosis, 63.8% were diagnosed with localised (stage I or II) disease, 23.5% had locally advanced disease (stage III) and 12.7% had stage IV prostate cancer. The most common treatments were combined external beam radiotherapy (EBRT) and androgen deprivation therapy (ADT) (20.9%), surgery alone (19.7%), ADT alone (8.7%) and active surveillance (AS) (8.2%). Men were re-surveyed 12 months later. 85.4% of men completed this follow-up survey. In England, a second separate cohort of men was surveyed in 2016. This survey offered men the option of online completion.

146 of the men who responded to the survey, and 33 partners, were also interviewed by telephone. Twelve months later, follow-up interviews were conducted with 38 of these men, giving a total of 217 interviews. Interviewees came from across the UK and included men with a range of treatment pathways and treatment outcomes, and men of varying ages, sexual orientation and ethnicity. The interviews allowed more detailed exploration of the topics covered by the questionnaire.

More detail on the findings can be found in our UK-wide Summary Report which you can download via www.lifeafterprostatecancerdiagnosis.com

The protocol paper which outlines the full methodology can be found via Downing A, Wright P, Wagland R, et al. Life after prostate cancer diagnosis: protocol for a UK-wide patient-reported outcomes study BMJ Open 2016;6:e013555. doi: 10.1136/bmjopen-2016-01355



MAIN MESSAGES: SURVEY RESPONSES

Functional outcomes

Functional outcome scores tended to be high (indicating good function) for bowel function, urinary irritation and urinary incontinence (mean UK-wide scores 89.0, 86.0 and 82.7 out of 100 respectively). The sexual function scores were considerably lower (mean = 25.2 out of 100) and just under half of men reported experiencing moderate or big problems with sexual function (45.3%). Smaller proportions of men reported moderate or big problems with their bowel or urinary function (9.0%; 13.1%). Just under a quarter of men reported moderate or big problems with lack of energy (23.3%) and 10% of men reported problems with depression.

Intervention(s) to aid sexual function

Just over half of men reported they were not offered intervention(s) to help with sexual function such as medications, devices, or specialist services (55.8%). Of those who were offered (44%), men were most likely to have been offered medications (41.3%) and were least likely to have been offered specialist services such as counselling, psychosexual clinics or psychology (14.8%).

Health-related quality of life

Men were asked to rate their overall health on a scale of 0-100. Across the UK, the average self-assessed health score was 76.6. Men most commonly reported problems with pain/discomfort (42.0%), usual activities (37.7%), mobility (36.1%) and anxiety/depression (33.6%), and were least likely to report problems with self-care (14.3%). Just over 60% of men reported at least one problem on any of these five domains (62.0%).

Social distress

A minority of men reported experiencing overall social distress (9.4%) in the past month. Social distress comprises three subscales as follows: Everyday Living (e.g. domestic chores, caring for family), Money Matters (e.g. problems with finances or welfare benefits) and Self and Others (e.g. body image, communicating with those closest to you). Just over 10% of men reported problems with Self and Others or with Money Matters (11.7% and 11.2% respectively). Around 14% of men reported problems with everyday living.



MAIN MESSAGES:

INTERVIEWS WITH MEN

Interviews explored the physical and psychological impact of diagnosis and treatment, men's experiences of health services, the support they received, and the impact on partners.

Men's experiences of treatment decision-making were varied. Where clinicians promoted a shared approach to decision making, men generally reported feeling comfortable with their treatment decisions. However, respondents often undertook greater responsibility for deciding their treatment pathway than they desired, often reporting that no clinical recommendations were offered or that they received conflicting recommendations.

In those men experiencing psychological distress following diagnosis and treatment, contributing factors centred around a theme of loss: loss of self (identity, masculinity, self-confidence); loss of function (sexual, urinary, bowel); loss of connection (partner, family and friends) and loss of control (over lives and future). Interviews also revealed inadequacies in the way men's needs relating to sexual dysfunction are addressed and highlighted barriers to the use of medications / sexual aids and counselling services.

Men who were on active surveillance or watchful waiting had generally adjusted well. However, those with poorer adjustment were less able to accept and normalise the diagnosis and often described receiving insufficient information and support, and a lack of confidence in their health care team. Interviews with Black men revealed a reticence amongst some to disclose prostate cancer-related problems and a strong desire to appear positive and optimistic, often masking their concerns.

Interviews highlighted the pivotal role partners have in helping men self-manage the impact of PCa and treatment side effects. Younger couples (men ≤ 65 years) often described disruption to their relationship as a couple, family functioning, parental roles, and work lives.

Follow up interviews found that little changed for most men over 12 months with regards the problems they faced, and while some became increasingly resigned to them, or found comorbidities became more important, for others the physical and psychological impact of unresolved problems remained undiminished.

The interview findings have generated a number of important implications for practice.

More detail on the findings can be found in our UK-wide Summary Report which you can download via our website www.lifeafterprostatecancerdiagnosis.com



PUBLICATION SUMMARIES INDEX

Please note that further publications are currently in press. As articles are released, go to www.prostatecanceruk.org for further details.

Bennett et al. (2018). Factors Influencing Job Loss and Early Retirement in Working Men with Prostate Cancer. *Journal of Cancer Survivorship*.

Collaco et al. (2018). Prostate Cancer and the Impact on Couples: a qualitative metasynthesis. *Supportive Care in Cancer*.

Donnelly et al. (2018). Treatment for erectile dysfunction among older men in Northern Ireland. *International Journal of Clinical Practice*.

Donnelly et al. (2018). Urinary, bowel and sexual health in older men: a general population study. *British Journal Urology International*.

Downing et al. (2019). Quality of life in men living with advanced and localised prostate cancer in the UK: A population-based study. *Lancet Oncology*.

Matheson et al. (2016). A qualitative metasynthesis exploring the impact of prostate cancer and its management on younger, unpartnered and gay men. *European Journal of Cancer Care*.

Rivas et al. (2016). Ethnicity and the prostate cancer experience: a qualitative study. *Psycho-Oncology*.

Wagland et al. (2018). 'Very difficult for an ordinary guy': Factors influencing the quality of treatment decision-making amongst men diagnosed with localised and locally advanced prostate cancer: findings from a UK-wide mixed methods study. *Patient Education and Counselling*.



Bennett et al. (2018) Factors Influencing Job Loss and Early Retirement in Working Men with Prostate Cancer.

Journal of Cancer Survivorship.

Main findings

- We found a number of clinical factors which increased the risk of men becoming unemployed following their diagnosis of prostate cancer, including having late-stage cancer, having bowel or urinary problems or having other health problems. Other social and personal factors such as living in deprived areas or in Scotland or Northern Ireland and being divorced/separated also increased their risk of becoming unemployed.
- However, men who retired early following their diagnosis of prostate cancer did not differ much in terms of clinical symptoms, such as urinary or bowel problems, from men who stayed in employment.
- We have identified risk factors for becoming unemployed in prostate cancer survivors, which can be used to help men following diagnosis.

What we already know

Work can be important for men recovering from cancer as it allows them to support themselves and their families, socialise with colleagues and regain a sense of normality which can help them to 'move on'. However, we do not know if a diagnosis of prostate cancer has much effect on employment, and particularly unemployment and early retirement. This study aimed to find factors which were linked to becoming unemployed or retiring early in working age men in the UK who were recently diagnosed with prostate cancer.

What did we do?

The LAPCD survey was sent to men in England, Wales, Scotland and Northern Ireland and asked them what their life is like after prostate cancer. From the large group who answered the survey, we chose men of working age (60 years and younger) to see if a number of social, economic, personal and clinical factors made them more likely to either become unemployed or to retire early compared to men who stayed in employment.

What did we find?

Men with late-stage cancer and those with major bowel or urinary problems were at least twice as likely to become unemployed. Men with other health problems, those from more deprived areas or who were divorced or separated and those living in Scotland or Northern Ireland were also more likely to become unemployed. Men who were older, from Northern Ireland, with late stage cancer or had caring responsibilities were more likely to retire early. Self-employed and non-white men were less likely to retire early.

How will these results be used?

This study found risk factors for job loss in prostate cancer survivors which can be used to support men following diagnosis. This will allow support to be targeted to men who most need it and may help engagement with these men, their families and their employers.



Collaco et al. (2018). Prostate Cancer and the Impact on Couples: a qualitative metasynthesis. Supportive Care in Cancer.

Main findings

- The impact of prostate cancer and its management affects both members of the couple, their lives, identity and relationship.
- Tailored information and support that is relevant to the impact that prostate cancer and the side effects of treatment pose to relationships is needed.

What was the question?

To explore what is already known in the scientific literature regarding the experiences of couples affected by prostate cancer.

What did we do?

We searched the scientific literature to find research articles that explored the impact of having a prostate cancer (PCa) diagnosis on couples. From this, we found 37 articles. We looked at these articles in depth for common themes across these articles.

What did we find?

A common theme from the articles we looked at was the challenges couples faced relating to sexual intimacy. Due to one of the side effects of treatment causing erectile dysfunction, some couples found it difficult to maintain intimacy in the relationship and engaged in other practices to preserve their relationship (kissing, hugging, use of sexual aids/toys). Couples engaged in various strategies to help them move forward as a couple. Some of these strategies included acceptance of changes to their relationships, reassurance and using laughter as a way to get through their experience, and openly communicating with one another. Sometimes couples chose not to tell one another how they were truly feeling to protect their partner from further upset. Some couples commonly avoided communication about their feelings to their partner and sometimes led to conflict in the relationship.

Partners were considered crucial to the man with PCa's recovery of health and provided emotional and practical support. However this sometimes led to partners neglecting their own health to tend to the needs of the man with PCa. Partners often felt unable to express their concerns or feelings in healthcare consultations that they attended with the man with PCa and sometimes felt they were not included.

Couples sometimes felt that the experience of PCa brought them closer together as the impact of illness and its management affects both members of the couple.

What does this mean?

Health professionals need to be aware that PCa impact on both the man with PCa and their partner and therefore ensure both members of the couple are included when directing support services that may be useful for them to move forward together.

Information and support needs to be tailored to the needs of the couple, in particular self-management strategies for couples relating to the impact of PCa and side effects of treatment on their relationship.



Donnelly et al. (2018). Treatment for erectile dysfunction among older men in Northern Ireland. *International Journal of Clinical Practice*.

Main findings

- In Northern Ireland 46.5% of men aged 60+ reported moderate/severe erectile dysfunction.
- 25% of these men reported being offered treatment to improve erections in the past 3 years.
- Of those men offered treatment 29% said that they currently use it and find it helpful.

What we already know

Erectile dysfunction (ED) is common among older men. However, the number of men diagnosed and treated for the condition is low compared to the number of men that report it. We aimed to identify the degree to which older men are offered treatment for the condition. This will help define the level of unmet need among men living in Northern Ireland (NI).

What did we do?

Ten thousand men from NI were sent a survey by post during September and October 2016. Responses were received from just under one third of men. The questions in the survey covered a range of topics. Firstly, characteristics of the men were collected. These included routine items such as age, marital status and employment status. Height, weight, and amount of physical activity taken each week were also requested. Secondly, topics on general health were covered. The most important of these was having a long-term medical condition such as a heart condition, high blood pressure or diabetes. More specific questions were asked relating to sexual problems and being offered treatment for these problems. While personal in nature, completeness of these questions was high. Using this data we reported on treatment levels for ED among older men living in NI. We also investigated how receipt of treatment for the condition varied between men with different characteristics, such as their age and health.

What did we find?

Almost half of older men living in NI reported ED to a moderate or big degree. However, only one quarter of these men reported being offered treatment to improve erections over the past three years. The proportion of men being offered treatment decreased as age increased. Men reporting a higher level of interest in sex, or more long-term medical conditions were more likely to receive treatment. Among men reporting ED who were offered medication, just over one quarter found it helpful and currently use it. Overall nine out of ten men who reported ED had no help with it due to not being offered treatment or not finding the treatment helpful.

How will these results be used?

Despite high levels of ED among older men, the majority of men with the condition do not get help with it. This may be a consequence of lack of availability of treatment through the NHS in NI compared to other parts of the UK. However, it also suggests that health care professionals need to engage more proactively with older men. They need to discuss sexual health routinely and follow up those treated for the condition. This is particularly important given the already established relationship with other medical conditions such as heart disease.

Donnelly et al. (2018). Urinary, bowel and sexual health in older men: a general population study. British Journal Urology International.

Main findings

- Among men aged 60 and over from Northern Ireland (NI) 9% reported urinary problems, 7% reported bowel problems and 33% reported sexual problems.
- These problems all increased with increasing age, number of long-term health conditions, obesity and lack of physical activity.

What we already know

Prostate cancer survivors can experience urinary, bowel and sexual problems after treatment. These problems also occur in the general population as a result of age or other health problems. In order to help assess the impact of treatment on the quality of life of prostate cancer, up to date information on these conditions in the general population is required.

What did we do?

A survey of 10,000 older men was conducted in NI by post during September and October 2016. These men were asked a range of questions on their general health as well as specific questions relating to urinary, bowel and sexual problems. Further information on the characteristics of these men was asked such as age, marital status, employment status, height, weight, physical activity level and whether they experienced a range of specific long-term medical conditions (e.g. heart condition, high blood pressure, diabetes). Using this data we report on the frequency of urinary, bowel and sexual problems in the NI population and investigate how these conditions vary by the attributes of older men.

What did we find?

One in three men aged 60 and over reported sexual problems to a moderate or big degree, while one in eleven reported urinary problems, and one in fourteen reported bowel problems. In all, two out of five men reported at least one of these problems and one in fifty reported all three. These problems were associated with increasing number of long-term medical conditions, low physical activity levels, higher body mass index (BMI) and unemployment. Urinary and sexual problems also increased with increasing age.

On a scale of 0 to 100, where 100 is the best possible health, men reported an average score of 77. Health declined with a range of factors: increasing age, living in deprived or urban areas, unemployment, and greater number of long-term medical conditions, obesity and lack of physical activity. Men reporting urinary, bowel and/or sexual problems were also more likely to report poorer general health.

How will these results be used?

These data provide an insight into sensitive issues seldom reported by elderly men, but could be addressed given adequate service provision. The relationship between urinary, bowel and sexual problems, raised BMI and low physical activity offers the prospect of additional health gain by addressing public health issues such as obesity. The results also illustrate that these problems are not uncommon among the older male population. This will facilitate better understanding of the impact of surgery, radiotherapy and hormone therapy on the quality of life of prostate cancer survivors and help redress any overvaluation of the potential side effects of these treatments.

Downing et al. (2019). Quality of life in men living with advanced and localised prostate cancer in the UK: A population-based study. Lancet Oncology.

Main findings

- We looked at physical problems and general health in men still alive 18-42 months after being told they had prostate cancer.
- 81% of men reported poor or very poor sexual function and 56% were not offered any help for this.
- Men who had hormone treatment had more problems - especially with hot flushes, lack of energy and weight gain.
- Nearly a quarter of men with metastatic prostate cancer (that has spread to another part of the body) reported no problems with their general health.

What we already know

Many men survive for a long time after having prostate cancer. A big challenge is to understand the problems these men have after treatment for their cancer. In particular, we don't know much about the problems faced by men living with advanced (late stage) cancer.

What did we do?

The Life After Prostate Cancer Diagnosis study sent surveys to men in England, Wales, Scotland and Northern Ireland. The men were still alive 18-42 months after being told they had prostate cancer. The survey asked the men about what their life is like after cancer. It also asked about the treatments they had. In this current study, we looked at the physical problems reported by the men, such as problems with going to the toilet, sexual problems, and tiredness. We also looked at how the men rated their general health. We wanted to compare the level of problems in men with different stages of cancer and who had different types of treatment.

What did we find?

35,823 men filled in a survey (61% of all men invited). 64% of the men had early stage (localised) cancer, 23% had locally advanced cancer and 13% had metastatic cancer (cancer that has spread to another part of the body).

Function: Problems with sexual function were very common in men with all stages of prostate cancer. 81% of the men said they had poor or very poor sexual function. Over half of the men (56%) had not been offered any help for this (such as medication, devices or counselling). Problems with going to the toilet were less common and were linked to the type of treatment a man had. For example, men who had surgery had more problems with leaking urine. Men who had hormone treatment reported more problems in all areas, but especially with hot flushes, lack of energy and weight gain.

General health: Men with early stage and locally advanced prostate cancer reported similar general health. Men with metastatic cancer reported worse general health, but about a quarter of these men didn't have any problems with their general health.

How will these results be used?

In this large study, we found that sexual problems are very common after prostate cancer. Most men are not offered any help for this. Men treated with hormones report more problems in all areas. These results will be fed back to doctors and others who provide care. Changes to services are needed to address the sexual problems and the effects of hormone treatment.

Matheson et al. (2016). A qualitative metasynthesis exploring the impact of prostate cancer and its management on younger, unpartnered and gay men. *European Journal of Cancer Care*.

Main findings

- Men who are not the 'typical' patient with prostate cancer – those who are younger (under 65 years), without a partner, and/or gay, have specific needs for support and information.
- Men from these groups can feel marginalised, a sense of loneliness, and struggle to accept the impact on their sexual relationships, identities and work life.
- Health professionals should provide men with tailored information and support that is relevant to their age, stage in life, marital status and sexuality.

What was the question?

To explore what is known already in the scientific literature regarding the experiences of men with prostate cancer who are a) younger b) single and/or c) gay or bisexual.

What did we do?

We searched the scientific literature to find research articles that explored the impact of having a prostate cancer (PCa) diagnosis. From this, we found 171 articles. We then looked at which of these studies included men with PCa who were a) under 65 years old (7 articles) b) without a partner (17 articles) and c) gay or bisexual (11 articles). We looked at these articles in detail for common themes for each of these groups of men with PCa.

What did we find?

A common theme for these groups of men included a sense of being marginalised or 'out of sync' from other men with PCa or from their communities. Some men reported a sense of stigma and loneliness.

Younger men in particular felt they had aged before their time, and struggled to accept the change in sexual function. They also struggled with the change to their identities, physical fitness, work life and the emotional impact of PCa.

Themes for single men included fears over their ability to have future sexual relationships due to sexual dysfunction. These men also reported lower confidence to approach potential partners. Some single men felt they were well supported, while others appeared lonely, and relied strongly on the clinician when making treatment decisions.

Gay men reported a sense of stigma in their communities after having the PCa diagnosis, due to sexual problems. This was particularly the case for gay men who were also single. Some gay men felt that their health care was geared towards heterosexual men and did not address the needs and concerns of gay men.

How will these results be used?

Health professionals need to be aware that men who are younger (under 65), single and/or gay with PCa may have specific needs for information and support.

Information that men receive should be tailored and relevant to their age, stage in life, marital status and sexuality.

Men from these groups may require further support regarding the impact on work, identity, sexual relationships and emotional changes due to PCa.

Rivas et al. (2016). Ethnicity and the prostate cancer experience: a qualitative study. *Psycho-Oncology*.

Main findings

Cultural beliefs and ways of socialising have an effect on the prostate cancer experience of men from black and minority ethnic groups and their partners. So do things that are more likely in men from black and minority ethnic groups, though they could affect anyone, such as a lack of job benefits (for example health insurance in the US).

What we already know

Studies have shown that men from black and minority ethnic (BME) groups with prostate cancer have less good outcomes than other men in countries such as the US and UK. Studies in the UK also show that men in BME groups have different care for their condition and are often unhappy with their care.

What did we do?

We decided to combine the results from all the studies published between 2000 and 2015 that we could find that asked men from BME groups directly about their experiences with prostate cancer and its care. This review of studies involved making a list of all the themes (or topics) that the men themselves raised, the themes the study authors raised, and then combining these lists and summarising them into a much smaller list that could be easily considered by healthcare teams trying to help these men in the future.

What did we find?

What did we find? We found 13 relevant studies of men from BME groups in the US and UK (we did not exclude other countries but found no relevant studies from them). We found that compared with other men, men from BME groups were more likely to talk about:

- problems in communication with and trust in health care staff
- forming a 'spiritual alliance' with God that helped them to cope with the cancer and also to make decisions about treatment
- carrying on living on for others (generally to promote prostate cancer awareness), which they often connected to spiritual regrowth.

Men from BME groups were also particularly likely to be concerned about and want to hide the sexual problems they had as a result of the cancer or its treatment. Initially, this stopped men from telling others about their cancer but eventually they learned to focus more on other aspects of their lives. We also found evidence of social inequalities that affected the ability of men from BME groups to cope with their cancer. For example, men from BME groups often had particularly low salaries and in the US no health insurance as a result, which reduced their coping. They also had experienced a lot of racism that had taught them to be strong in dealing with the problems life threw at them.

How will these results be used?

Health care staff can use our findings to develop a more sensitive understanding of the way that men from BME groups are feeling and thinking. This should help them to give better care that matches what the men need.

Wagland et al. (2018). 'Very difficult for an ordinary guy': Factors influencing the quality of treatment decision-making amongst men diagnosed with localised and locally advanced prostate cancer: findings from a UK-wide mixed methods study. Patient Education and Counselling.

What we already know

The treatment decision-making (TDM) process for men diagnosed with localised or locally advanced PCa is particularly difficult, as there are often several equally effective treatment options available, each of which have associated side effects that can have long-term impact upon men's quality of life. These side effects can include sexual and urinary dysfunction following surgery, bowel dysfunction, loss of libido and urinary irritations following radiotherapy, and gynecomastia, mood disturbances, weight gain, penile shrinkage, loss of libido and hot flushes following hormone therapy. Active surveillance avoids or delays active treatment and associated side effects, but men can nevertheless become anxious about not treating the cancer and worry it will spread.

What did we do?

Men alive 18–42 months following prostate cancer diagnosis in participating Trusts were identified through population-based cancer registries in England, Wales, Scotland and Northern Ireland, and mailed surveys from their treating Trust/Board. Respondents indicated on the survey their willingness to be contacted and invited for interview. The survey asked respondents whether they thought their views were taken into account when their doctors and nurses were discussing which treatment they should have. Telephone interviews were then conducted with a selected sample of respondents who had received a range of treatments to further explore their treatment decisions.

What did we find?

Most men who completed the survey (68.8%) indicated their views had 'definitely' been taken into account during the TDM process. Fewer men (17.8%) indicated their views were 'to some extent' taken into account, suggesting they were not fully involved with the TDM process. Very few (3.3%) indicated their views were 'not taken into account'. Interviews found men were often unhappy about the TDM process because they did not receive enough information about various treatment options or possible side effects, or they felt rushed into making a decision or were expected to take more responsibility for decision making than they desired. Men often had personal preferences for specific treatment options associated with priorities around work, personal and social lives, and had perceptions of how 'intrusive' some treatments would be. Others overwhelmingly desired surgery to 'cut out' the cancer. What helped a good TDM process was good communication between men, clinicians and their partners, accessibility to tailored, easily understood information about what to expect during and following treatment, and honest recommendations about best treatment when this was requested. Unchallenged preferences, absence of or conflicting recommendations and inadequate preparation for treatment side-effects sometimes led to decision regret.

How will these results be used?

Men should be informed of exactly which appropriate treatment options are available and why others are not, and the prevalence and potential severity of associated side effects. Use of patient decision aids should be encouraged. Some men desire greater direction from clinicians about the most appropriate treatments, and where possible this should be respected. Expecting men to take greater TDM responsibility than desired can for some men inhibit rather than facilitate patient empowerment. All clinicians involved in a patient's care should be cognizant of each other's views and ensure patients do not receive conflicting recommendations. Men with firm treatment preferences should be encouraged to discuss these with clinicians to prevent potential subsequent decision regret.

PAPERS IN PREPARATION

The following papers are currently in preparation for publication:

Bennett et al. *Emotional wellbeing and mental distress in older men in Northern Ireland - the influence of urinary, bowel and sexual function and socioeconomic, demographic and physical characteristics.*

Butcher et al. *Evaluation of the impact of patient and public involvement in the LAPCD project.*

Donnelly et al. *Regional variations in quality of survival among men with prostate cancer across the United Kingdom.*

Donnelly et al. *Quality of survival among symptomatic compared to PSA-detected prostate cancer survivors - Results from a UK wide patient-reported outcomes study.*

Donnelly et al. *Quality of life of prostate cancer survivors by marital status, ethnicity, and sexual orientation.*

Donnelly et al. *The association between comorbidities and the quality of life of prostate cancer survivors.*

Horton et al. *Measuring quality of life in prostate cancer – using Rasch methods to optimise the psychometric properties of the EPIC-26.*

Hounsome et al. *Feedback from a prostate cancer PROMs survey highlights high quality of cancer registration in the U.K.*

Mason et al. *A paper looking at how HRQL changes in prostate cancer patients who were resurveyed one year later.*

Matheson et al. *The psychological impact of being on a monitoring pathway for early stage prostate cancer: a UK-wide mixed methods study.*

Matheson et al. *Loss of self, function, connection and control: understanding psychological distress in men with prostate cancer - A qualitative exploration.*

PAPERS IN PREPARATION

Matheson et al. *Conceptualising dimensions of self-management and adjustment to advanced prostate cancer- a qualitative study.*

Smith et al. *Deprivation, rurality and patient reported outcomes for men diagnosed with prostate cancer in the UK.*

Wagland et al. *Quality of life following treatment for prostate cancer: Analysis of free text responses to a UK-wide survey.*

Watson et al. *Access to and experiences of medication, devices and support for sexual dysfunction in men with prostate cancer: findings from a UK-wide mixed methods study.*

Wagland et al. *Adjustment strategies amongst black African and black Caribbean men following treatment for prostate cancer: findings from the Life After Prostate Cancer Diagnosis (LAPCD) study.*

Wilding et al. *Electronic versus paper surveys to optimise PROMs data collection: A methodological paper exploring response rates.*

Wilding et al. *Factors associated with decision regret in men with non- metastatic prostate cancer: Findings from the UK-wide Life After Prostate Cancer Diagnosis (LAPCD) study.*

Wilding et al. *Cancer-related symptoms, mental well-being and psychological distress in men diagnosed with prostate cancer treated with Androgen Deprivation Therapy.*

Wright et al. *Key factors associated with social distress after prostate cancer: results from the national cross-sectional Life After Prostate Cancer Diagnosis (LAPCD) survey.*

THANK YOU

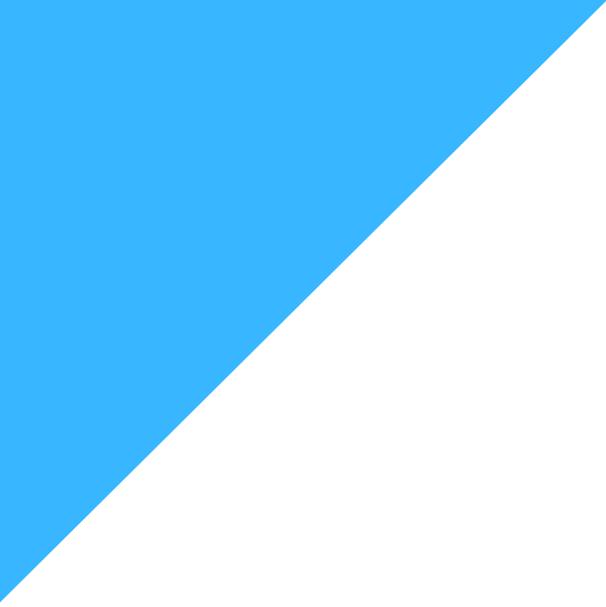
The Life After Prostate Cancer Diagnosis Study investigated the full range of issues that could affect a man after he has been diagnosed with prostate cancer.

The study was the country's largest ever patient-reported outcomes study for the disease and involved over 30,000 men across the United Kingdom.

We thank all those men, their partners, and the hospitals across the United Kingdom who took part and helped in a vital research project which has the ultimate aim of improving the lives of men with prostate cancer.



The LAPCD Study Team





Public Health
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