

East Lancashire Prostate Cancer Support Group Newsletter



Volume 10 Issue8

Date August 2021



The Physical Impact of Prostate Cancer “A Study”

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UNIVERSITY OF LEEDS

To whom it may concern,

I am a Clinical Psychology Doctoral student at the University of Leeds. I am investigating the long-term psychological needs of men with prostate cancer.

I am writing to ask for your help with my study which aims to understand the psychological needs and quality of life of men with prostate cancer, in the UK.

Understanding the psychological impacts of cancer and its treatment has been identified as a top 10 research priority by The National Cancer Research Institute. However, there is a particular lack of this kind of research in men with prostate cancer.

Therefore, we would like to invite UK men who have had a diagnosis of prostate cancer for 1 year or more to complete a brief online survey. The survey takes approximately 20 minutes to complete. The survey will ask questions about quality of life, anxiety, depression, illness



representations (the way a person thinks about their illness), body image and masculinity.

This is an important area of research as it may contribute to scientific understanding and help to identify potential interventions that could be used to improve wellbeing.

I am kindly requesting your support in circulating the attached poster, and survey link to your mailing list, or to post them on your online forum, social media or website. Participation is entirely voluntary, and access to the survey is via this link:

<https://leeds.onlinesurveys.ac.uk/exploring-the-long-term-psychological-needs-of-men-with-pr>

Further information can also be found via the link.

This study has been reviewed by the School of Medicine Research Ethics Committee, University of Leeds (MREC 20-046), and has received ethical approval.

The results of the research study will be written up for the submission of a thesis for the Leeds Doctorate in Clinical Psychology by Summer 2022. The findings will also be presented at academic conferences and submitted for publication in a scientific journal.

I thank you in advance for your support.

If you require any further information please contact myself, Jennifer Kirby (the Doctoral student who is completing this research) on umjlak@leeds.ac.uk. You can also contact the supervisors of this project, Dr Matthew Mulvey (m.r.mulvey@leeds.ac.uk) or Dr Fiona Thorne (f.m.thorne@leeds.ac.uk).

Kind regards,

Jennifer Kirby
Trainee Clinical Psychologist
University of Leeds



Have you experienced prostate cancer?

We are looking for people who are over 18 to take part in a short online survey which will take approximately 20-30 minutes to complete. The survey is completely confidential and does not require you to disclose any identifiable information.

Why take part?

People who experience prostate cancer can unexpectedly be faced with long-term health-related and psychological consequences, which can impact on quality of life. We hope to raise awareness and understanding of the psychological needs of people in the UK who have experience of prostate cancer. Doing so can help us to identify ways to reduce the impact of the long-term consequences of prostate cancer on everyday life and wellbeing.

Can I take part?

You can take part if you are:

1. Over the age of 18
2. Have previously had a diagnosis of prostate cancer
3. The time since diagnosis is 12 months or more

How to take part?

If you are interested in taking part in the research you can follow the link:

<https://leeds.onlinesurveys.ac.uk/exploring-the-long-term-psychological-needs-of-men-with-pr>

or scan the QR code below which will both take you to the online survey. You will be presented with an information sheet which will provide you with more information about the study.



Who has reviewed this study?

This study has been reviewed by the School of Medicine Research Ethics Committee, University of Leeds (MREC 20-046).

At the end of the survey, as a thank you for completing it, you will be given the option to enter into a prize draw for the chance to win a £30 Amazon voucher.

If you require any further information or have any questions you can contact Jennifer Kirby via email: umjlak@leeds.ac.uk. Thank you for taking time to read this.



“I’m not facing this alone” Luton Town legend sends an important message to fans.

Much loved by Luton fans and staff, Assistant Manager Mick Harford was a fearsome centre-forward for a variety of clubs, including Chelsea, Bristol City, Derby County and Birmingham City. He also played twice for England.

Big Mick, 62, was diagnosed with prostate cancer late last year and recently started a course of radiotherapy treatment.

His diagnosis provoked an outpouring of support from the football family, including Hatters fans, supporters of clubs across the UK and even Sir Alex Ferguson. It highlighted the importance of our partner The League Manager's Association's work. The LMA look after the health and wellbeing of over 600 managers, encourage everyone to wear our Man Of Men badge, and fund our Specialist Nurses.

In response, Mick has written a heartfelt letter to LMA members, and sent a message to football fans everywhere.

READ MICK'S HEARTFELT LETTER

Men, we are with you.



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<https://youtu.be/lo3J6ubOfl4>

Watch the interview with the above link



The PSA home testing kit survey

GFCT Ltd (formerly The Graham Fulford Charitable Trust).
Registered Charity number 1109385.
Founders, owners and operators of the mypsatests booking site

University Of Manchester

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PSA home testing kit survey

Background

The survey was hosted online within the GFCT Ltd (formerly The Graham Fulford Charitable Trust) website (<https://www.mypsatests.org.uk>). Men who used the PSA home testing kit service were asked to complete the 10 Qs survey. This project commenced on the 12th of May and we received the responses by the 31st of May 2021.

Data processing

Data was exported from source in the XML format and processed further for data quality control check. For quantitative data, the analyses were performed using STATA statistical program version 15. Distribution and percentages are presented. For open ended questions, the analysis was carried out using IBM SPSS Text Analytics for Survey4. Graphical presentation was created using Microsoft Excel.

Results

Overall PSA home kit service rating

The average of service rating score is 4.6 out of 5 with 5 representing excellent service. 67% of respondents rated the service as "Excellent" and almost 22% rated as above average. Only 6% assess the service rating as low/below average (Table 1 and

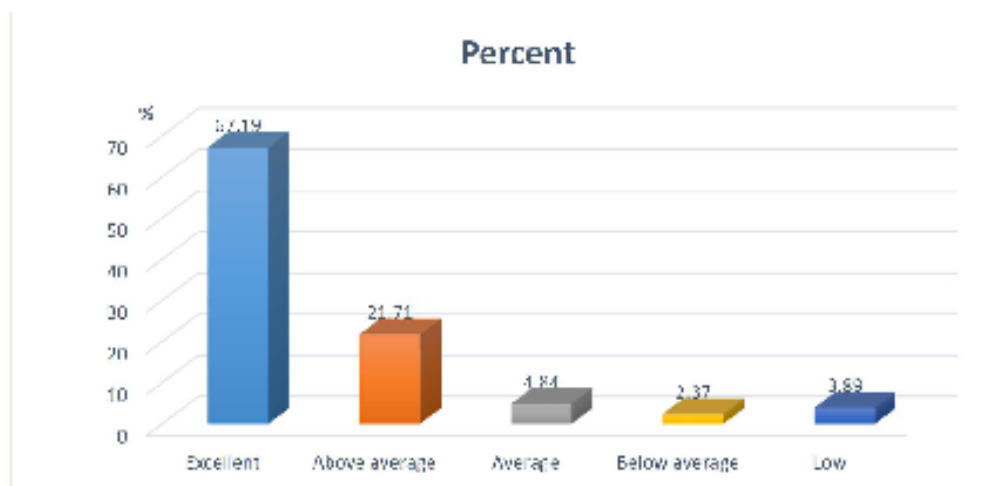
Figure 1).

Table 1 overall rating of the service

Rate Home Testing Kit service	Freq.	Percent
Excellent	1278	67.19
Above average	413	21.71
Average	92	4.84
Below average	45	2.37

Low	74	3.89
Total	1902	100.00

Figure 1 Home Testing Kit service rating



About the service

There are two questions related to the service provided.

Table 2 Distribution of the completion of the PSA home kit test - successfully

Managed to complete the test successfully	Freq.	Percent
Yes	1691	88.91
No	211	11.09
Total	1902	100.00

Almost 89% reported using the home kit test successfully.

There were 211 men that reported they did not complete the test successfully. Two hundred men provided a reason as shown in Table 3 and Figure 2.

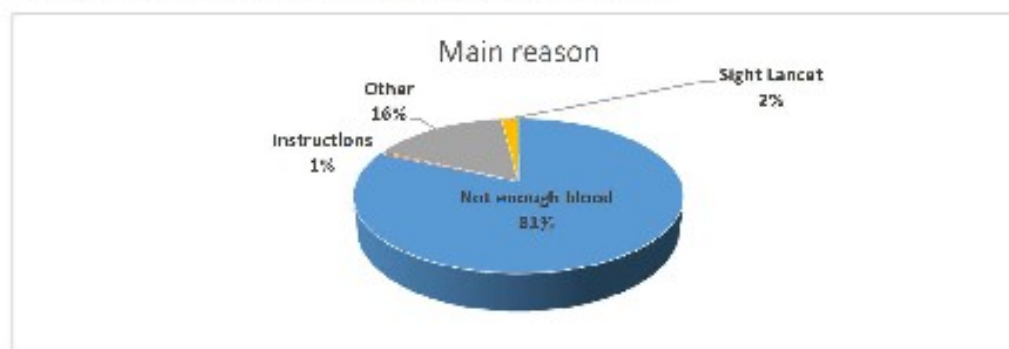
Table 3 Distribution of the main reason for an unsuccessful home kit test

The main reason	Freq.	Percent
Insufficient Blood	165	81.50
Instructions (not enough or not clear)	1	0.50
Other reasons	32	16.00
Sight Lancet	4	2.00
Total	200	100.00

11 missing

81.50% reported they did not provide a big enough sample of blood to complete the test.

Figure 2 Main reasons for not completing the test successfully



About the returned result

The next two questions are about the satisfaction regarding receiving the result. Table 4 shows men's views about the result being returned to them in an acceptable time. 93% reported they were happy with the turnaround time. The same percentage was reported with the result format (men can understand the result - see table 5).

Table 4 Distribution of returned result within an acceptable time.

Got the result within an acceptable period of time	Freq.	Percent
Yes	1765	92.80
No	137	7.20
Total	1902	100.00

Table 5 Distribution of result format being understood

Result came in a format you could understand	Freq.	Percent
--	-------	---------

Yes	1779	95.58
No	123	6.42
Total	1902	100.00

The next question asked if men agreed that the system automatically generating retesting reminders at suitable intervals was a good thing. Most participants agreed that automated reminders are a good thing.

Table 6 Distribution of retesting reminders

Retesting reminders are a good thing	Freq.	Percent
Yes	1835	96.48
No	67	3.52
Total	1902	100.00

Recommending the service to others

Results from table 7 below suggest that 90% of men will use the home kit PSA test again.

Table 7 Distribution of the use of home kit test service again

Use service again	Freq.	Percent
Yes	1712	90.01
No	190	9.99
Total	1902	100.00

Ninety two percent of respondents will recommend this service to their friends and other members of their family.

Table 8 Distribution of Recommendation of service to others

Recommend this service to others	Freq.	Percent
Yes	1745	91.75
No	157	8.25
Total	1902	100.00

Genetic risk assessment

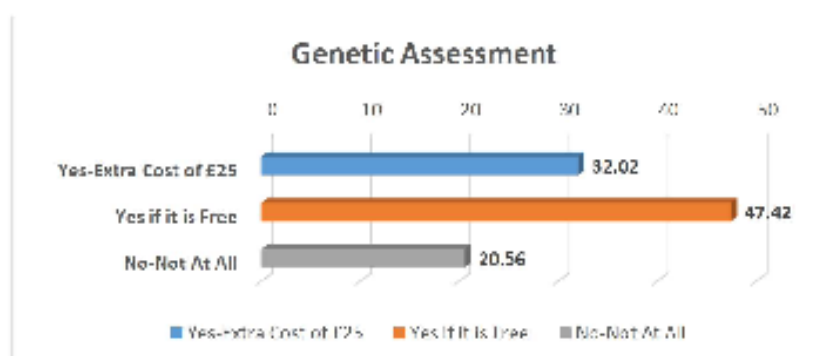
. Almost 80% of men are willing to take a genetic risk assessment. Within the men who reported yes to the test, 47% will take the test if there is no cost implication.

Table 9 and Figure 3 present distribution of men's opinions of genetic risk assessment. Almost 80% of men are willing to take a genetic risk assessment. Within the men who reported yes to the test, 47% will take the test if there is no cost implication.

Table 9 Distribution of genetic risk assessment

Genetic Risk Assessment	Freq.	Percent
Yes-Extra Cost of £25	609	32.02
Yes if it is Free	902	47.42
No-Not At All	391	20.56
Total	1902	100.00

Figure 3 Genetic risk assessment opinion



Broadening the test to cover a wider check of prostate health

About 72% of respondents agreed that the test could be broadened to other prostate health issues (Table 10).

Table 10 Distribution of broader prostate health check

Broader check of your prostate	Freq.	Percent
Yes	1363	71.66
No	539	28.34
Total	1902	100.00

87% reported that they would consider taking a test for other medical conditions via a postal system (Table 11).

Table 11 Distribution of consideration of other medical tests via postal system.

Consider taking a test for other medical conditions	Freq.	Percent
Yes	1658	84.17
No	244	12.83
Total	1902	100.00

Open-ended comment-Text analysis

Out of 1902, 626 respondents provided comments with a significant majority giving positive feedback.

Below comments are extracted to highlight positive comments.

"This was the first time that I had used this test. I was very impressed by how easy it was to carry out and how quick I received the results. Absolutely first class service."

"Excellent service apart from the fact that they sent a covid 19 test first, which they wouldn't check. After I complained the PSA test went perfectly."

"Excellent, easy to use and peace of mind without the jaff of going to a doctor."

"Excellent service thank you very much especially as the doctors surgeries don't appear to want to help."

"It was just an excellent way of getting the test done. Much better than travelling to a centre, having to queue etc. The test kit was quite easy to use and the instructions were very clear."

"Excellent and rapid service"

"I thought the service was very good, clear, concise and easy to understand. I shall be using this service again. I have recommended it to friends. May not have done a retest, had I got to pay again. Unfortunately test was correctly done first time."

"Great to have a free test, thank you."

"I found it easy to do, well organised and quickly received, very good."

"Used this service as Lockdown prevented our normal local testing sessions and found it easy to use and that it provided speedy results at a reasonable cost. If local testing does return I will use that as the cost is covered by Burgess Hill Town."

"Very well organized, and simple to use, certainly recommend your service."

"Very good"

"I found the procedure non invasive and results were returned very quickly."

"Good service received answer quickly."

"The time between my home test kit being delivered and results returned to me were very quick. This in turn led me to have a RAMP in December 2020. I have since had two follow up PSA blood tests with PSA being undetectable. An excellent outcome"

"Easy to use and postage time to results was very quick."

"Very quick service"

"Quick and efficient."

"Think was a fast and efficient service. I recommended into a big group and friends and colleagues. Sparked a debate about the accuracy of the test and the dilemma of what to do next if psa number raises. All useful conversations in my book."

"Very straight forward and results very quick. A very reassuring service."

"Easy fast service"

"I was very pleased with kit and instructions provided. The kit was easy to use and the results came via e mail the day after posting."

"This service is great no queuing at a venue for the test and fast results too. Thank you all 🍀"

"Great idea the way forward saves all the hassle of going to the doctors"

"Well done - excellent team service"

"Brilliant service and home testing kit makes this accessible for all."

"From posting the sample to getting the result by email was less than 24hrs. very impressive!"

Earlier I join's Club group test was cancelled due to Covid. Your test result was positive and I have since had a prostatecomy. Probably saved my life!"

There are comments which are also helpful for consideration to improve certain aspects of the home testing service.

"The test results were returned very promptly which was most appreciated. My one recommendation is to emphasize VIGILANCE where the lance should be stuck in the finger...I had 3 tries before success to get the blood sample causing a bit of stress."

"Yes found the suggestion to prick finger on side difficult to load the sample vial, would be better if at end of finger as could then smear blood into it."

"A very good service. If the blood sample size could be reduced, I'd welcome that. Being on blood thinners, creating such a volume did cause me some concern, but the painure did heal relatively quickly".

"This may be a personal issue with the blood flow in my fingers, but it took a lot of manipulation (and all the supplied lancet:) to extract enough blood from my fingers to fill the tiny vial."

"In the instructions make it clearer that the "side of the finger" for the prick sample, means the "middle of the finger print area" and not the literal side of the finger (i.e.: not adjacent to the side of the finger nail)."

Conclusion

The PSA home kit test service has been launched due to the limitations of public events with men attending PSA test events organized by GFCT and supporting groups and various organisations. The survey was carried out to seek men's opinion on the PSA home kit test service and to explore what elements of the test could be improved. Overall, men were very happy with the service and almost 80 percent of men were willing to do a genetic test either if it is free or with an extra cost. Comments provided were positive. Some men provided feedback for improvement. Almost 90% of respondents rated the service as excellent or good resulting in an average score of 4.6 out of 5.

In summary, the PSA Home kit test service works very well and could potentially be expanded further.

From: riley.d7
Sent: 03 August 2021 12:35
To: Iean Wright
Subject: Fwd: Medical Detection Dogs August 2021 L News

Sent from my iPhone

Begin forwarded message:

From: Medical Detection Dogs <marketing@medicaldetectiondogs.org.uk>
Date: 3 August 2021 at 11:51:14 CEST
To: Dave <riley.d7@sky.com>
Subject: **Medical Detection Dogs August 2021 E-News**
Reply-To: Medical Detection Dogs <marketing@medicaldetectiondogs.org.uk>

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Medical 
Detection Dogs
Patron: HRH The Duchess of Cornwall

**Projects to resume in our
training room**



Dear Dave

We are delighted to see many different noses coming through the doors of our training room once again. Our focus has of course been on the COVID-19 project for the last few months but as we are now working on the next phase of that – training dogs in public places – we can restart some other projects. First up will be *Pseudomonas*, the most common cause of lung infection for those with Cystic Fibrosis and one which frequently reoccurs and develops resistance to antibiotics. Two years ago we found that compared with existing technologies, dogs may ultimately prove more sensitive and affordable for screening lower airway infection in Cystic Fibrosis and we are excited to research this further and help save more lives.

[Bio Detection Dogs](#)

New noses to the ground



It's exciting to be able to progress many of our young dogs to their Early Scent Training now. We start them off with a simple game of seeking a tennis ball in the paddock, asking ourselves do they enjoy the game? Have they got the drive? How is their stamina? If this comes naturally to them and their noses and enthusiasm match up then we move them to a training odour. This part happens in the training room, to see how they react to that environment, and they search for the odour under metal pots to get them used to the equipment we use. Once they are reliably finding the training odour, no matter how small, we move them to human samples containing a disease such as cancer or Parkinson's. These super sniffers are our next generation of life savers and having so many dogs getting closer to being fully qualified is extremely encouraging.

[Bio Detection Dogs](#)

A new Chair



We are pleased to announce that we have appointed a new Chair of Medical Detection Dogs, Clive Everest. He has volunteered as a Trustee for us over the past two years and enjoyed a career as an accountant and auditor where he specialised in working with charities, universities and government bodies. Clive says: "I was keen to continue working in a voluntary role with charities I feel passionate about. I jumped at the opportunity to become a trustee at MDD and was shown clearly what the charity's dogs could do when my dog Mitch and I were (very) soundly beaten by a Cocker Spaniel being trained for MDD in a scentwork competition!

We would like to thank the Hon. Lady Betsy Duncan Smith, who Clive succeeds, for all her hard work and dedication as Chair for almost 5 years, and we look forward to regularly seeing her at our Centre as a fosterer to Bio Detection Dogs, Jobi and Hetty.

[Our People](#)

Hello Herbert



We have a new Sponsor Puppy, Herbert, who's training to become a Medical Alert Assistance Dog that you could help with for as little as £5 per month. Herbert is a Lhaso Apso x Spaniel and full of beans, confident and cuddly. He's been getting to know his neighbour, a very large and fluffy cat called Casper, who doesn't faze him at all, as well as learning some of the basic cues such as sit, wait and down. Before we know it, he'll be a fully-fledged lifesaver and you could make a real difference by supporting his journey.

[Sponsor a puppy today](#)

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International Assistance Dog Week – a time to celebrate

It's International Assistance Dog Week starting on August 1st and a time for us to celebrate every single one of our working assistance dogs that save and enhance the lives of our clients each day. We asked clients what sort of things our dogs enable them to do, that they wouldn't otherwise even be able to consider...



[Medical Alert Assistance Dogs](#)

[DONATE NOW](#)





March the Month with Katherine, Graham and many more across the UK.

Many of our Marchers love to get their steps in with friends, partners or colleagues. Katherine and her husband Graham, who was diagnosed with prostate cancer in 2017 at 47, are taking on our [March the Month challenge together this September](#) for a second year.

Katherine told us why they're so dedicated, and why they want you and your friends and family to join them to [March the Month this September](#).



“This is not just an old man's disease.”

Katherine says, "Graham was diagnosed in late 2017 at the age of 47, his only real symptom being a frequent need to urinate. We discovered Prostate Cancer UK online and through his Specialist Nurses at the hospital. We've been fundraising in many ways since then and trying to encourage younger men to understand their risk."



“We’ve been together since school. It’s only natural we march and wear our t-shirts with pride together too.”

"Graham runs regularly, so he can easily clock up the 11,000 steps a day. Working full time, I spread walks through the day. Before work, at lunchtime and in the evening, and our old beagle Poppy joins for one very slow walk every day. If the weather is shocking, we're marching circuits around the house!

We love the March the Month Facebook group too. Many of the members have become friends, it feels like we have known them a lifetime. I would encourage anyone to get involved and post your thoughts, struggles and milestones along the way."

David, will you hit 11,000 steps a day this September and help save men's lives?

Take on the challenge alone or in a team and track and share your progress using JustGiving's fitness tracker. Watch your steps stack up and donations rush in.

[SIGN UP TO MARCH THE MONTH](#)

Men, we are with you.



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Family and friends lost Lloyd too soon. You can help give men like him more time.

As we make progress against COVID-19, prostate cancer remains as big a threat as ever. **Every year, more than 11,800 men die from the disease.**

Last year, Lloyd Pinder was among these men. He was just 49 years old. He was a father, a husband, a son and a friend. Lloyd was lost far too young.

With a diagnosis of advanced prostate cancer, he knew a time would come when treatments would eventually stop working. And heartbreakingly, Lloyd's condition took a turn for the worse at the brink of the pandemic.

Lloyd's combination of treatments, and his reaction to them, meant he had reduced immunity and was unable to hug or get close to his family in his final few months. He passed away in September of last year.

We are desperate to give men like Lloyd more time with their families. Will you help?

YES, I'LL HELP



“Over the years he endured treatment after treatment, with the hope each one would give him longer with Tina and his girls.”

Jeff Stelling

The friendship between legendary Sky Sports presenter, Jeff Stelling, and Lloyd Pinder bloomed after they first met at Jeff's March and bonded over their determination to stop prostate cancer being a killer. A year on from Lloyd's death from prostate cancer, Jeff reflects, "When I think about what Lloyd was going through, it weighs heavy on my heart. He knew he wasn't going to be around for those meaningful family moments. No man should have to endure that."

"The [money we raise is making a huge difference](#), I've seen it myself in the research labs. Scientists like Dr Jiménez-Vacas are taking huge steps to stop this disease wrecking lives. He's finding ways to keep lifesaving treatments working for longer, which could have made all the difference to someone like Lloyd."



“Lloyd is an example of a man whose life could have been different with my research. If we’d understood why his disease was becoming resistant, maybe we could have stopped it.”

Dr Juan Jiménez-Vacas

Dr Juan Jiménez-Vacas, hopes his project on treatment resistance can help deliver the progress men so desperately need. His work could have a major impact for men with advanced prostate cancer, helping them grow old with, or even be cured of, their disease.

Research like Dr Jiménez-Vacas’ has the potential to be game-changing for men with prostate cancer. But it’s only possible with the support of people like you.

David, will you donate today to continue funding vital research to keep more men with their families for longer?

YES, I'LL HELP DR JUAN JIMENEZ-VACAS

Thank you for all your support to date. I hope you will join me, Dr Jiménez-Vacas and the many thousands of others who are united in the fight against prostate cancer.

Dr Matthew Hobbs
Director of Research
Prostate Cancer UK

Men, we are with you.



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From Left to Right Hazel Goulding (Treasurer) Leon D Wright (IT Admin) Stuart Marshall (Secretary) Steve Laird (Vice Chairman) Dave Riley (Chairman)

We are a group of local people who know about prostate cancer. We are a friendly organisation dedicated to offering support to men who have had or who are experiencing the effects of this potentially life threatening disease.

The East Lanc's Prostate Cancer Support Group offers a place for free exchange of information and help for local men and their supporters (family and friends) who may be affected by this increasingly common form of male cancer.

At each meeting we strive to be a happy, supportive and upbeat group of people; encouraging open discussion on what can be a very difficult and perhaps for some an embarrassing subject. We have lively, informative, interactive, sharing and above all supportive meetings.

