PROSTATE CANCER RESEARCH CENTRE

PCRC SUPPORTER SURVEY 2018-2019

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PROSTATE CANCER RESEARCH CENTRE

Summary

A survey, consisting of seven questions regarding supporter's preferences on PCRC research funding, their preferred level of involvement with our decision-making processes, and the information and support they would like to receive. Most people support us due to direct experience of the disease, mostly due to having had it themselves. Research into finding and testing new treatments was considered the most import, followed by clinical trials. Many respondents did not answer the question about how involved they would like to be in deciding which research we funded, but of those who did, most preferred to review lay abstracts as part of a committee. People felt that peer-support groups, printed information booklets and telephone helplines were important supports for people with prostate cancer, and preferred to receive updates on cancer research and factual information on prostate cancer. Newsletter, email and website were the top three ways people prefer to hear from us.

Background

As a tightly-focused research charity, Prostate Cancer Research Centre has had little engagement with prostate cancer patients. Any engagement with patients is usually following a donation or a request for the Patient Information Booklet. PCRC Projects have been decided and led by people within the organisation with little to no input from patients or the people who surround them. The Association of Medical Research Charities, of which PCRC is a member, reported in 2017 that most medical and healthcare research tend to focus on areas which non-patients perceive as important for patients. PCRC recently launched an ambitious five-year development plan which includes: diversifying and increasing funding streams; reforming its approach to selecting the research to fund; increasing the number of research projects funded; and significantly improving its communications to prostate cancer patients, their carers, their families and communities.

A stronger understanding of the needs of our community will enable us to become and remain much more patient-centric. The purpose of the PCRC Community-Focused Research Questionnaire was to act as a starting point for the 'Patient Voice' Project. The aim of this project is to make our charitable activities much more patient-centred, and to involve people directly affected by prostate cancer in our decision-making.

The survey was used as to form the basis of beginning to understand the needs and opinions of our community. We were aiming to understand what our supporters want, whether they are patients or not, from PCRC in terms of support, information and input into our research projects.

Survey Design

The November 2018 issue of the biannual *Lifeline* newsletter presented a good opportunity to conduct this survey. Given that the November 2018 *Lifeline* was sent to 5,031 people by post and just 584 opted to receive it by email, and that pen and paper surveys have been reported to get higher responses, we designed the survey as a double-sided A4 insert. An online version was also created using Google Forms and linked to on our new website. One survey was included with each newsletter, and the information at the top pointed to the online version and gave instructions on how to receive further paper copies.

Open questions give more and less biased information, but carry the risk that people will perceive them as more time-consuming or difficult. Closed questions give data which is much easier to quantify, but carry a risk that we may miss important insights by not giving respondents any opportunity to set out their own answers.

A mixed approach involving a ranking question, and mostly closed/MCQ questions with an "Other" option was used. Qualitative research is planned at a later stage which will provide an opportunity to ask more open-ended questions and receive a wider breadth of data.

Kidney Research UK carried out a patient needs survey in which they listed research priorities and asked patients to rank them. This approach was taken with our question on research.

Research options were based on a document by Professor Colin Cooper (PCRC Scientific Advisory Committee) setting out potential future research areas for the PCRC Research Strategy, which was in preparation at that time, and quality of life issues such as financial and psychological impacts of prostate cancer. A question on patient involvement was based on PPI activities of other AMRC members. Options for supports and information were based on supports and information available from other providers (e.g. Macmillan, community peer groups, CRUK). Demographic questions are based on ONS recommendations.

Questions were prepared by Naomi Elster (NE; Communications Research Executive), with input from Oliver Kemp (OK; CEO) and Rachel Lund (RL; Development Director).

A section on the bottom provided the opportunity to sign up for future community-based research, including taking part in a longer, more detailed survey, telephone and in-person interviews, and focus group participation.

Dissemination and Response

The November 2018 *Lifeline* was printed late and arrived in mid-December. DG3, who print our newsletter, included the survey without an additional charge.

A total of 204 responses were returned between the 14th December and the 28 January. 180 of these were pen and paper, 24 online. The majority of the surveys were returned very soon after the newsletter was received, or over the Christmas holidays. 64 people signed up to be contacted about qualitative research. 83 surveys were returned blank. 1 person wrote that the writing was too small for them to read.

Social media posts were published on 5 separate days between 8 December 2018 and 1 January 2019 to promote the survey; only 5 responses out of 24 coincided with dates of social media posts. The webpage for the survey received 163 views (0.7% of total website traffic) in December and January. Dwell time was over 2 minutes, which suggests people read all the content on that page.

Table 1: When survey responses were received

Period	Paper Responses	Online Responses	Total Responses
Mid-late December	90	9	99
Christmas holidays (22 Dec – 4 Jan; date stamp 2n Dec)	27	13	40
Early January	53	1	54
Mid-late January	10	1	11
Total	**180**	**24**	**204**

Data entry was carried out by Emma Greenwood (temp/administrator) and analyzed by NE and Hannah Wray (HW; Fundraising Intern) using Pivot Tables in Microsoft Excel.

Five surveys were returned after data entry and analysis was complete. These were not used, although contact details were logged from the two respondents who had signed up to be contacted about qualitative research.

PCRC Community Focus Research Questionnaire Results

Prostate Cancer Status: Which of the following applies to you?

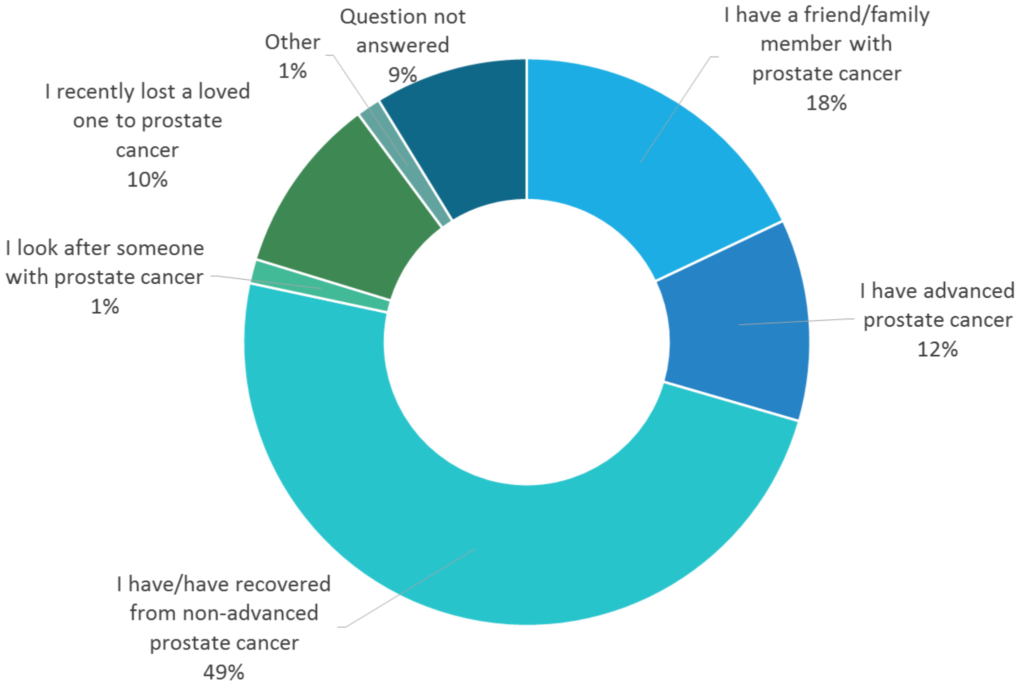

Figure 1: Responses to Question 1. 204 responses, with some respondents selecting more than one answer.

Almost half (48.85%) of respondents have or have recovered from non-advanced prostate cancer. This was overwhelmingly the largest group, followed by people who have a friend or family member with prostate cancer (17.97%). Of the "other" responses, 1 person stated they were "interested in prostate cancer as a disease," 1 was a GP, and 1 person did not have prostate cancer but has fluctuating PSA levels (9.7 to 19.5).

Research Priorities: Which research do you think we should fund? Please rank the following 1-10, with 1 being your highest priority.

Table 2: Responses to question 2. Showing the average ranking of each research type. 1 designates the highest priority and 10 the lowest.

Rank	Response	Average Ranking	Number of answers
1	Finding and testing new prostate cancer treatments	1.52	174
2	Clinical trials	2.40	148
3	Improving medical imaging for prostate cancer	2.74	186
4	Minimizing the side effects of current treatments	3.26	173
5	Psychology of coping with advanced prostate cancer	4.60	174
6	Survivorship - research into how to live as fully as possible despite advanced prostate cancer	5.14	155
7	Other	5.59	152
8	Financial impact of advanced prostate cancer	5.91	17

Finding and testing new prostate cancer treatments was ranked as the highest priority on average by survey respondents. The lowest ranked were: financial impact of advanced prostate cancer; survivorship (research into how to live as fully as possible despite advanced prostate cancer); and other.

Finding and testing new prostate cancer treatments was ranked the highest overall and was ranked as the highest priority for 119 respondents. This research type was also the most answered, with 188 responses.

The second most popular research type was ‘clinical trials’, with 175 selecting it as an option and 63 respondents ranking it as their number 1 priority.

The lowest ranked research type was ‘financial impact of advanced prostate cancer’. Although it was ranked by 148 people, only 25 ranked it 4 or higher.

There were 23 respondents who included written responses for this question, of which 17 were included in the ‘other’ section. There was not a clear common thread between these written responses but ‘early diagnosis’ and ‘diagnostic tools’ were mentioned 4 times.

This was by far the hardest question to analyse, with so many variables and with different calculations needed to gather the data. The data is now organised and it is fairly easy to pull information from it. All the pivot tables and calculations are saved in the HW PCRC survey analysis excel file.

Involvement: How involved would you like to be in decisions about what research we fund?

Table 3: Respondent's preferred involvement with PCRC

Ranking	Preferred Involvement	Respondents % (Number)
1	Question not answered	59% (120)
2	I would like to review a short paragraph in everyday language about the proposed research, and a paragraph on the possible impact of the research for patients, from applications for PCRC funding and vote on them as part of a committee	19% (39)
3	I would like to help the PCRC select research projects from a final shortlist of projects	12% (25)
4	I would like to provide feedback on future PCRC Research Strategies	10% (21)
5	I would like to work with other patients, carers, scientists and clinicians to set PCRC research priorities	10% (21)
6	I would like to attend and give feedback on presentations from PCRC researchers at the start and half-way point of their project	9% (19)
7	I would like to have a say in how research findings are shared	9% (18)
8	I would like to meet with PCRC scientists for a discussion on patient needs as part of a small group	7% (14)
9	I would like to meet with PCRC staff for a discussion on patient needs as part of a small group	6% (13)
10	I would like to review complete applications for PCRC funding and vote on them as part of a committee	4% (8)
11	I would like to have a role in designing research studies	2% (5)
12	Other	1% (3)

Once the questions not answered have been excluded, the preference is for reviewing lay abstracts as part of a committee, which is in line with how other PPI programmes operate. Very few people wished to have a role in designing studies or reviewing complete applications. There wasn't much difference between the other options presented.

14 respondents left written comments either instead of or in addition to selecting some of the options. Of these, 3 people reported feeling too old to take part. 4 people stated they did not feel qualified to take part, and 5 people stated they didn't want to get involved. 2 people didn't want to get involved but stated they wanted to be kept up to date with what was happening.

A large number of people did not answer this question, possibly due in part to the reasons mentioned in the written responses.

Support: What supports do you think are important for people with prostate cancer?

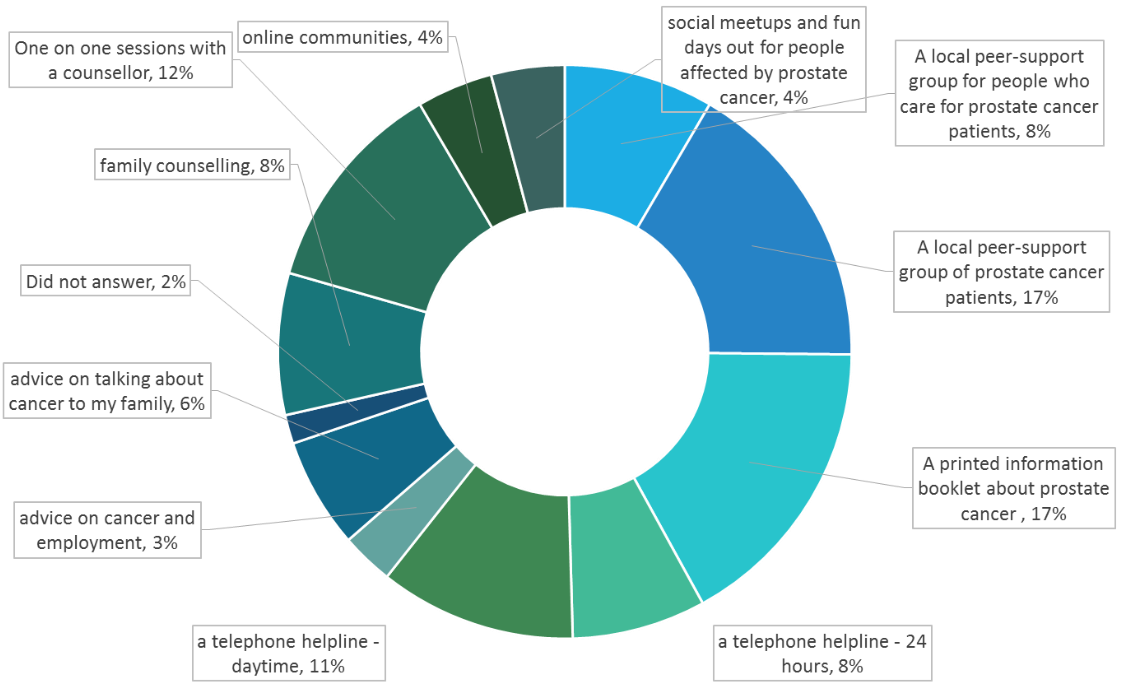

Figure 2: What supports do you think are important for people with prostate cancer? 204 respondents, with many selecting more than one answer. The graph represents each option as a % of total answers given.

Table 4: Table showing how many people selected each option

Answer	Number of responses	Percentage of responses
A local peer-support group of prostate cancer patients	115	16.99%
A printed information booklet about prostate cancer	114	16.84%
One on one sessions with a counsellor	82	12.11%
A telephone helpline - daytime	75	11.08%
A local peer-support group for people who care for prostate cancer patients	57	8.42%
Family counselling	54	7.98%
A telephone helpline - 24 hours	51	7.53%
Advice on talking about cancer to my family	42	6.20%
Online communities	29	4.28%
Social meetups and fun days out for people affected by prostate cancer	27	3.99%

Advice on cancer and employment	20	2.95%
Did not answer	11	1.62%

The chart above shows the breakdown of how many positive responses the types of support received. A number of people selected multiple options as important types of support and the percentages shown are the percentage of all answers given (677). On average, people selected 3 options they felt were important for people with prostate cancer.

The two highest answers were: a local peer-support group of prostate cancer patients with 115 responses (17% of overall responses); and a printed information booklet about prostate cancer with 114 responses (17% of overall responses). In terms of how many people selected each of these, 56% of respondents selected 'a local peer-support group' and 55% of respondents selected 'a printed information booklet about prostate cancer'.

There were two different options which involved a telephone helpline, one being 24 hours and one being a day time service. Combined, 126 people selected a helpline as a type of support they feel is important. This makes it the highest response at 61% of respondents selecting it. A daytime helpline was more popular than a 24-hour one.

The least popular answers were advice on cancer and employment with 20 responses and social meetups and fun days out for people affected by prostate cancer with 27 respondents. 11 respondents did not answer this question.

Information: What information would you like to be available from PCRC?

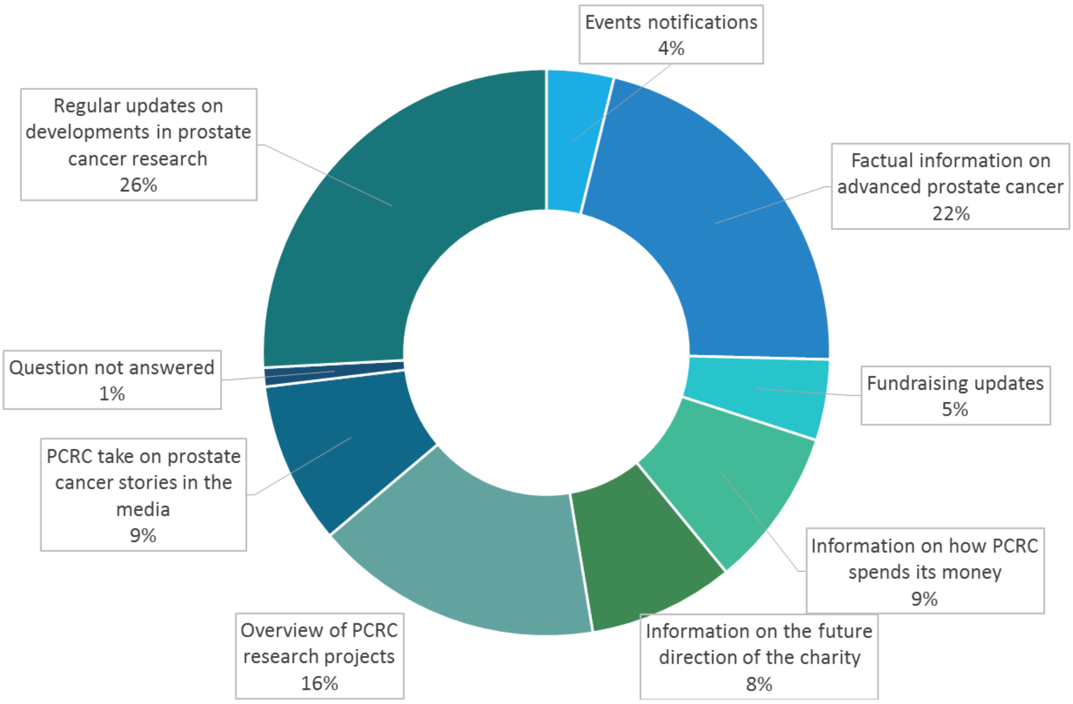

Figure 3: The information respondents would prefer to receive from PCRC. The chart represents each answer as a % of the total answers given, with many respondents choosing more than one answer.

Table 5: The information respondents would prefer to receive from PCRC. The table represents each answer in terms of how many respondents selected each one.

Information	Respondents % (number)
Regular updates on developments in prostate cancer research	82% (168)
Factual information on advanced prostate cancer	68% (140)
Overview of PCRC research projects	52% (107)
PCRC take on prostate cancer stories in the media	29% (60)
Information on how PCRC spends its money	29% (59)
Information on the future direction of the charity	26% (54)
Fundraising updates	15% (30)
Events notifications	12% (25)
Question not answered	3% (7)

Regular updates on developments in prostate cancer research was the information our respondents are most interested in (26%), followed by factual information on prostate cancer (22%). There was less interest in research specific to PCRC (16%), and people were generally less interested in charity-specific information, such as events notifications (4%), fundraising updates (5%), or information on the future direction of the charity (8%), or how PCRC spends its money (9%).

The only written comment on this section was a complement: "Your news mag is excellent."

Information: How would you like to receive this information?

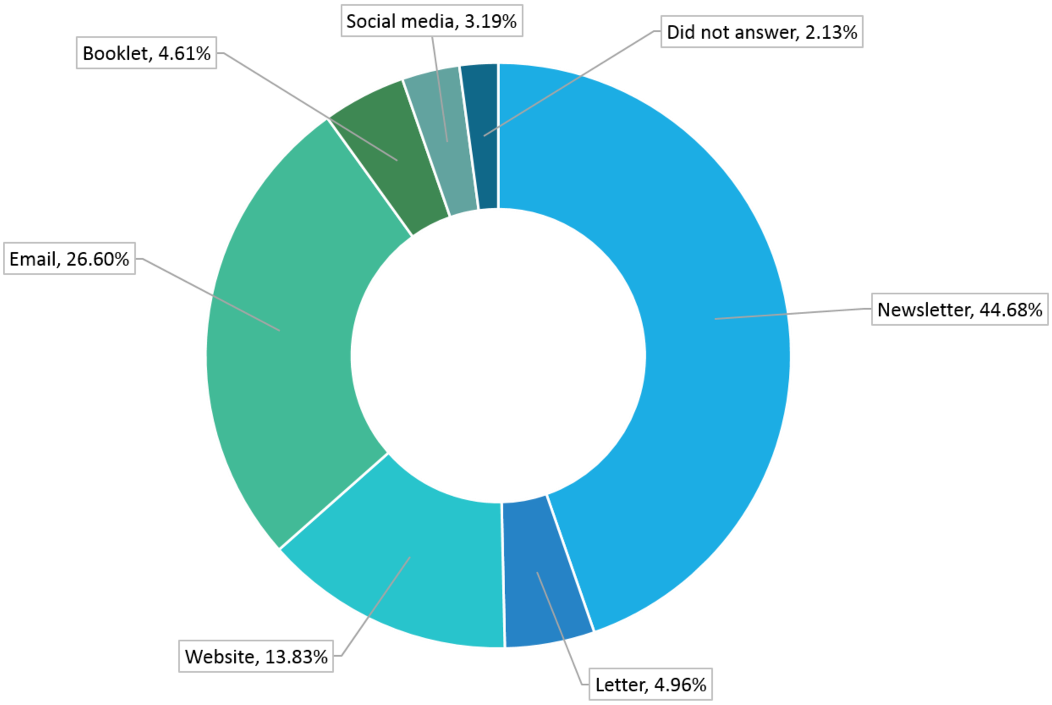

Figure 4: How respondents would prefer to receive information from PCRC.

The above chart shows a breakdown of ways to access information from PCRC and which people wanted. A number of people selected multiple ways of accessing the information and the percentages shown are the percentage of all answers given (282).

These included some of our current contact preference options and also included: website; booklet; and social media.

By far the highest response was for the newsletter with 126 respondents (61%) answering that they would like to receive information in that way. Email was the second most popular with 75 respondents (36%) wishing to receive information via Email.

There were 6 written responses to this question, 4 of which were detailing the type of social media they wished to use to access information, with Facebook being the most popular. One person noted that 'the PCRC newsletter is excellent' and one commented that they wished to access information in 'the most cost effective way for the charity'.

Charity: Why do you support PCRC?

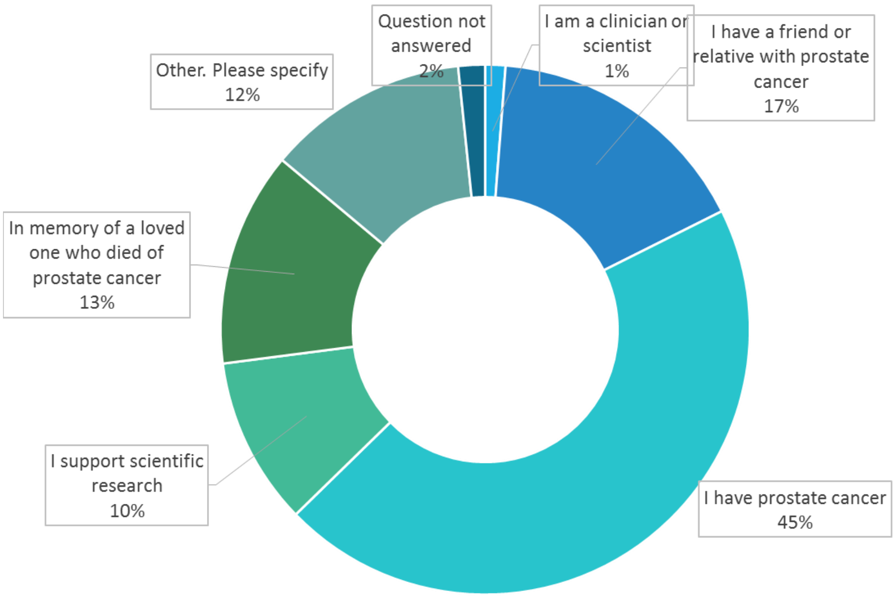

Figure 5: Reasons respondents support PCRC

Almost half our respondents have prostate cancer (45%, 110), and others have a friend or relative with the disease (17%, 40), or support us in memory of a loved one who died of prostate cancer (13%, 32). 10% (25) of respondents support scientific research.

We received 44 additional comments in response to this question. Of these, over half (26) had survived the disease themselves, whilst 7 have prostate problems and/or had had a scare. One of the latter wrote that he was unsure of what his PSA results really mean. Loss of friends or family was mentioned twice; friends were mentioned 2 more times but it wasn't clear how they had been affected. The prevalence of prostate cancer/relevance to many men was mentioned 3 times. Being "a good cause" was mentioned twice, helping those affected by cancer (cancer as opposed to prostate cancer) was mentioned once, medical research was mentioned once, and the specific need for more funding for prostate cancer was also mentioned once.

Demographics

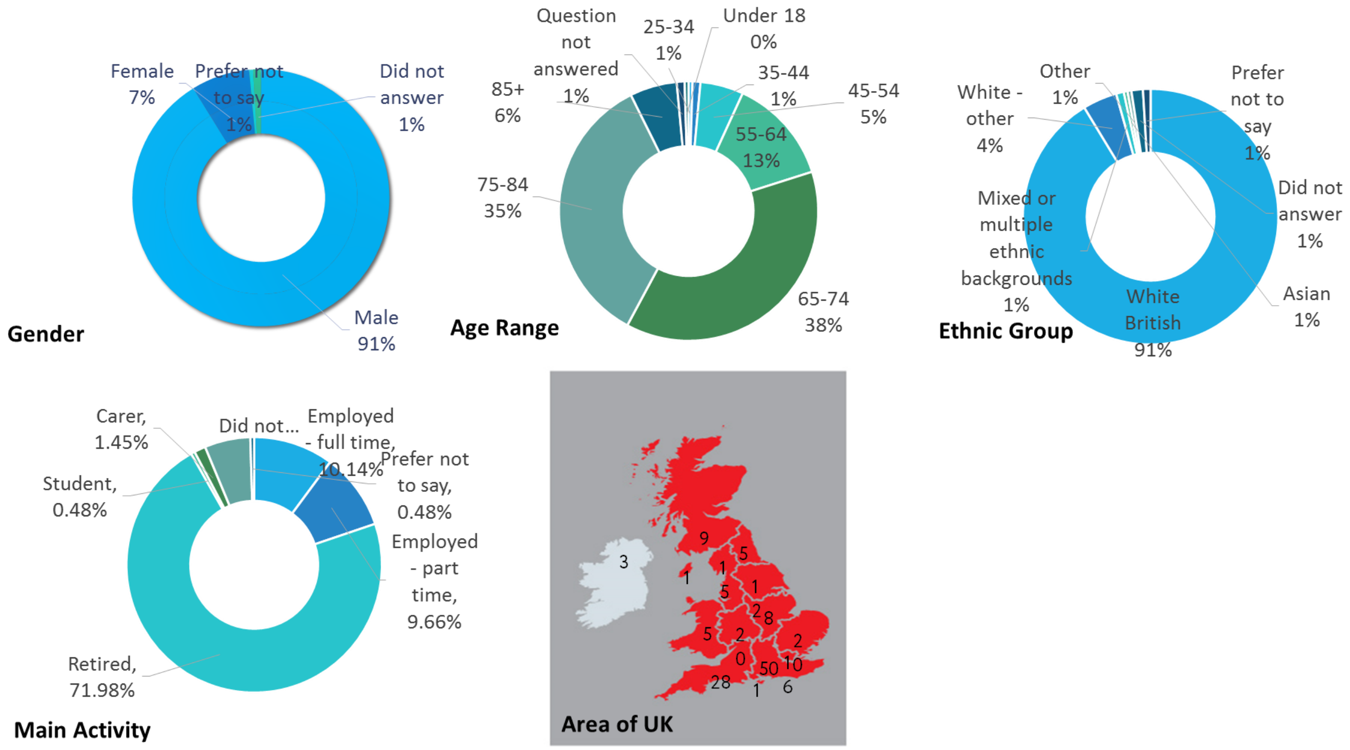

Figure 6: Demographic profiles of our survey respondents

Most of our respondents fit the profile of men affected by the disease; 91% were male, 71% retired, almost 80% were over 65 (6% 85+, 35% 75-84, 38% 65-74). Most of our respondents are concentrated in the South East, although we did have a spread of respondents across the UK. 91% of our respondents considered they belonged to the "White British" ethnic group.

Recommendations

Process

The process of writing the questionnaire and choosing which questions to answer came entirely from PCRC staff. This was the only feasible option for us at the time, but it does mean that there was no patient input on the questions asked, which should be a key improvement we make should we undertake a survey again. We did not offer any incentive to fill it in, which is reflected in the 3.5% response rate. While larger numbers would significantly increase our confidence in the insights we have gained, we feel the number of respondents is large enough, and the range of the questions broad enough to guide internal development.

We may have missed options or could have worded the options slightly differently. For example, diagnosis was an issue raised by respondents but was not listed an option for the type of research other than as 'improve medical imaging for prostate cancer'.

There was no question on household income. Asking this would have enabled us to interpret the question on financial information and to gain more understanding on the socio-economic demographics of PCRC's supporters.

The survey was disseminated via the Lifeline Newsletter, sent in November 2018. Each of the newsletters included one survey, with an option to request more if desired. It was also available to fill out on the PCRC website. No one requested additional copies, and we received very few responses from carers, family members and friends. In future, sending more than one survey per newsletter may get more responses from other members of the family, although it will increase the cost.

Supporter Insights: Disease Status, Reasons for Support, Demographics

We learnt that a large number of our supporters have non-advanced prostate cancer, rather than advanced prostate cancer. It may be that they are interested in the work PCRC does in order to keep informed, if their cancer does progress, or that they are keen to support research into advanced prostate cancer for men they perceive as being "not so lucky" as themselves. However, it may also be that there is a lack of clarity on PCRC's USP. As a charity solely focused on new treatments for *advanced* prostate cancer, we should be reaching more people affected by advanced prostate cancer. However, this could prove challenging and may not be as easy as reaching people affected by non-advanced prostate cancer.

In future, when PCRC plans to have a far greater patient involvement in research, the fact only a small number of our supporters (12%) have advanced prostate cancer. If we move forward and create a small Patient Committee, we need to keep in mind that they may not be looking at it from the perspective of someone with advanced prostate cancer. Furthermore, we should aim to have at least one member of any committee who is suffering from advanced prostate cancer.

The reasons people support us largely mirrors the question related to disease status. 45% of respondents have prostate cancer, 17% have a friend or relative with prostate cancer and only 1% are a clinician or scientist. It may be that because we sent only one survey, any family members or friends who received it simply passed it on to the person with prostate cancer. It is important to increase the number of people we reach who have a friend or family member with prostate cancer as the disease is one that affects the whole family. These people can also provide different insights into what it is like living with prostate cancer. When recruiting for focus groups and interviews, HW has invited friends and family members to also speak to us, in order to gain the opinion of this group.

Research

Finding and testing new prostate cancer treatments was generally what our supporters considered their top priority. This is the closest option to what we currently do, so it is possible that our supporters were initially drawn to us for this focus, and that a wider sample size might not feel the same way.

Clinical trials was the next preference. Funding clinical trials is beyond our resources (and beyond the resources of most if not all charities), but we could consider clinical trial support, which has relatively low costs, or studies which spin-off a clinical trial, or which have high potential to progress into clinical trial in the short- to medium-term. We should also make some communications content about the drug discovery and development process, clinical trials and where our research fits in that pipeline.

Improving medical imaging and minimising side effects are relevant both in terms of quality of life for patients and scientific innovation. Side effects specific to radiotherapy were mentioned once, and both the need for tests other than PSA and arguments that all men should undergo PSA were themes in the comments left, as well as general commentary on the need for earlier diagnosis.

Better diagnostic tools would have an impact against advanced prostate cancer, even if we currently focus more on the disease when it is already late stage. Tools which not only diagnose but can also predict which tumours are likely to become aggressive and therefore need more treatment are also an unmet need, and potentially relevant to our mission.

The financial impact of advanced prostate cancer was the lowest ranked, although we don't have information on our respondents' household income which would help us to interpret this. Some of the written comments were so specific (e.g. provision of alternative scans for people with metal from spinal surgery) that it was different to draw overall conclusions or recommendations from them.

Currently, our data does not suggest any justification to amend our research strategy, or for targeted calls or commissioned research. We should however be clear about why we choose to fund the research we do, and the potential impact it will have for men with prostate cancer and their families.

Patient and Public Involvement

We asked one question about being involved in PCRC decision-making and also gave people the option to sign up to learn more or take part in future community-focused research.

A number of people responded to the question 'how involved would you like to be in decisions about what research we fund?' by stating that they did not feel qualified to be involved in the process. In future, it would be useful to stress both that no special knowledge, medical or otherwise, is required to be involved in decision-making and also that there is no expectation for people to become involved.

Further to the issue of people feeling that they were not qualified to be involved in the decision-making process surrounding research, we are likely to encounter other issues in regards to accessibility. The majority of the respondents were aged over 60, with 41% being over 75, which means they may not want or may not be able to travel to London to take part in any interviews or focus groups (qualitative research) or committees (for PPI in our grants process). For the forthcoming qualitative research, we have tried to mitigate this by offering both to cover transport costs and to take into consideration where they are from and possibly arrange groups outside of London if there is sufficient demand.

Support

The types of support that people felt were important were mostly things currently not offered by PCRC. The highest response was a 'local peer-support group of prostate cancer patients', with 115 people selecting it. It is currently beyond the scope of PCRC to organize and facilitate such groups and we also understand that PCUK used to run a number of similar groups but this has now wound down.

When we met with David and Catherine Matheson, David suggested that PCUK used to run a number of successful support groups for people with prostate cancer but have since scaled these down. According to the survey results, there is a clear need for these types of groups.

We do offer our Patient Information booklet, of which approximately 20,000 are distributed every year despite no active promotion on our part. We should more actively promote the booklet. Other types of support, such as telephone helplines and counselling, are not within our remit as a research charity but we could improve our signposting to where these supports are offered.

The demographic profiles of our respondents are not representative of the UK population (Figure 7). Prior to the survey, we were not aware that we were not reaching a broader mix of people. We should now proactively attempt to build partnerships with other communities as Patient Voice continues, and across the charity as a whole.

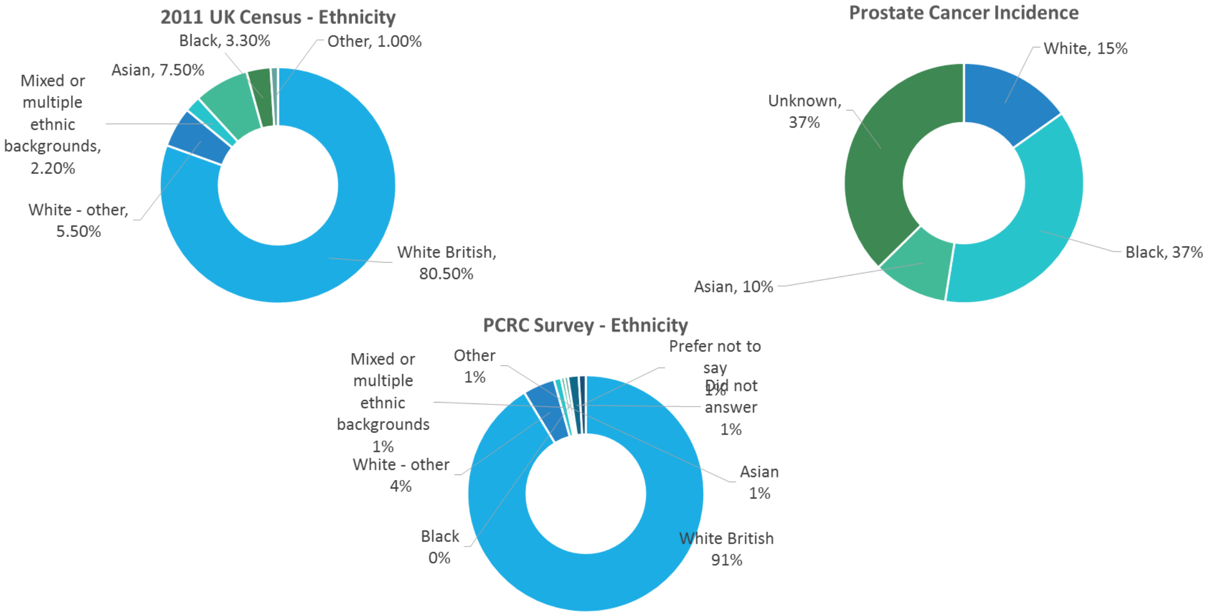

Figure 7: Ethnic profile of the UK as recorded on the UK census 2011; prostate cancer incidence by ethnicity, and ethnicity of our survey respondents

Information

More people were interested in general cancer research updates than PCRC projects specifically. This is not surprising, especially given our small portfolio. We should continue to do a roundup of science and research news in the newsletter, but we should also stress the ownership that our supporters should feel of our PCRC projects more strongly. The second strongest preference was for factual information about prostate cancer. This again suggests we should do greater promotion of the booklet. The new website also has more factual information about prostate cancer on it, and a recent study by Macmillan, which received press interest, stressed that cancer patients prefer factual language rather than emotive phrases around “fighting” and “battling.”

Comments to several questions indicated a great degree of confusion regarding PSA tests. A blog post written in response to this proved to be successful. We have also implemented a regular review of prostate cancer news stories to keep the organisation more up to date with developments, to streamline future newsletters, and for social sharing. While charity, events and fundraising updates were significantly less popular, it is important that these are shared to some extent to maintain transparency.

The newsletter was the most popular channel by which supporters wished to receive information. This is probably biased, as the survey was distributed with the newsletter. However, email and website were also popular options. This is in line with PCRC current donors and supporters, who most often choose to receive a newsletter from PCRC in the post, although more people have been requesting emails recently. We currently email a PDF version of the newsletter but don't offer an email newsletter. There is an email sign-up option on the website and an email newsletter should be made available, especially as the printed newsletter is biannual and an email would be a good way to touch base with our supporters in between newsletters. However, with one person managing both communications and research, this may need to be implemented in the medium rather than short-term.

Appendix A: Survey

PROSTATE CANCER
RESEARCH CENTRE

Welcome to the PCRC Community-Focused Research Questionnaire

Prostate Cancer Research Centre (PCRC) believe that the combination of patient and carer voices with scientific expertise will lead to the most meaningful research. We are undertaking community focused research to update our understanding of the needs of our community. To begin this process, we are inviting you to complete the following short survey and return it to us by freepost by Wednesday, 2 January 2019. Alternatively, you can complete this survey online at http://www.pcr.org.uk /community-survey

The survey will consist of a section on what you think the PCRC should focus on, followed by some questions about you. This will help us to make sure we are meeting the needs of all our community. The information will be kept entirely confidential and will never be traced back to you as an individual. It will be for statistical and research purposes only and will be stored securely.

Which of the following applies to you?

- ☐ I have advanced prostate cancer
- ☐ I have or have recovered from non-advanced prostate cancer
- ☐ I look after someone with prostate cancer
- ☐ I have a friend or family member with prostate cancer
- ☐ I recently lost a loved one to prostate cancer

What research do you think PCRC should fund? Please rank the following 1-10, with 1 being your highest priority.

- ☐ Clinical trials
- ☐ Financial impact of advanced prostate cancer
- ☐ Finding and testing new prostate cancer treatments
- ☐ Improving medical imaging for prostate cancer
- ☐ Minimizing the side effects of current treatments
- ☐ Psychology of coping with advanced prostate cancer
- ☐ Survivorship - research into how live as fully as possible despite advanced prostate cancer
- ☐ Other. Please state ☐

How involved would you like to be in decisions about what research we fund? Please tick all that apply.

- ☐ I would like to work with other patients, carers, scientists and clinicians to set PCRC research priorities
- ☐ I would like to review complete applications for PCRC funding and vote on them as part of a committee
- ☐ I would like to review a short paragraph in everyday language about the proposed research, and a paragraph on the possible impact of the research for patients, from applications for PCRC funding and vote on them as part of a committee
- ☐ I would like to help the PCRC select research projects from a final shortlist of projects
- ☐ I would like to have a role in designing research studies
- ☐ I would like to provide feedback on future PCRC Research Strategies
- ☐ I would like to meet with PCRC staff for a discussion on patient needs as part of a small group
- ☐ I would like to meet with PCRC scientists for a discussion on patient needs as part of a small group
- ☐ I would like to attend and give feedback on presentations from PCRC researchers at the start and half-way point of their project
- ☐ I would like to have a say in how research findings are shared

What supports do you think are important for people with prostate cancer?

- ☐ A local peer-support group of prostate cancer patients
- ☐ A local peer-support group for people who care for prostate cancer patients
- ☐ One on one sessions with a counsellor
- ☐ Family counselling
- ☐ A printed information booklet about prostate cancer
- ☐ A telephone helpline – daytime
- ☐ A telephone helpline – 24 hours
- ☐ Advice on talking about cancer to my family
- ☐ Advice on cancer and employment
- ☐ Online communities for patients, families and care-givers
- ☐ Social meetups and fun days out for people affected by prostate cancer

What information would you like to be available from PCRC?

- ☐ Factual information on advanced prostate cancer
- ☐ Overview of PCRC research projects
- ☐ Regular updates on developments in prostate cancer research
- ☐ Information on the future direction of the charity
- ☐ Events notifications
- ☐ Fundraising updates
- ☐ Information on how PCRC spends its money
- ☐ PCRC take on prostate cancer stories in the media

How would you like to access this information?

☐ Newsletter
☐ Letter
☐ Website
☐ Email
☐ Booklet
☐ Social media (please specify) ____________

Why do you support PCRC?

☐ I have prostate cancer
☐ I have a friend or relative with prostate cancer
☐ In memory of a loved one who died of prostate cancer
☐ I am a clinician or scientist
☐ I support scientific research
☐ Other. Please specify ____________

Demographics Section

Are you...

☐ Male ☐ Female ☐ Prefer not to say

Please tell us your age range

☐ Under 18
☐ 18-24
☐ 25-34
☐ 35-44
☐ 45-54
☐ 55-64
☐ 65-74
☐ 75-84
☐ 85+
☐ Prefer not to say

How would you describe your main activity?

☐ Employed - full time
☐ Employed - part time
☐ Retired
☐ Homemaker
☐ Student
☐ Carer
☐ Prefer not to say

To which of the following groups do you consider you belong?

☐ White - British
☐ White - Irish
☐ White - Gypsy or Irish Traveler
☐ Any other white background. Please describe ____________
☐ Mixed - White and Black Caribbean
☐ Mixed - White and Black African
☐ Any other mixed or multiple ethnic background. Please describe ____________
☐ Asian - Indian
☐ Asian - Pakistani
☐ Asian - Bangladeshi
☐ Asian - Bangladeshi
☐ Asian - Chinese
☐ Any other Asian background. Please describe ____________
☐ Black - British
☐ Black - African
☐ Black - Caribbean
☐ Any other black background. Please describe ____________
☐ Other - Arab
☐ Any other background. Please describe ____________
☐ Prefer not to say

Please tell us the first part of your postcode ____________

Please complete this slip if you are interested in learning more or taking part in our future community focused research.

Name ____________
Address ____________
Email ____________
Telephone ____________
How would you prefer to be contacted? ____________

Please tick all that you are interested in:

☐ Taking part in a longer, more detailed survey
☐ Discussing your experiences with our staff on the telephone
☐ Taking part in a face-to-face interview
☐ Taking part in a focus group

Where travel is involved, expenses will be reimbursed.

Appendix B: When Survey Responses were received

Table 6: Dates upon which survey responses were received

Date	Paper Responses	Online Responses	Total Responses
14th December	0	2	2
15th December	0	1	1
16th December	0	1	1
17th December	14	1	15
18th December	22	0	22
19th December	37	4	41
20th December	28	0	28
21st December	15	0	15
22nd December	0	1	1
26th December	0	4	4
27th December	0	1	1
1st January	0	1	1
2nd January	0	5	5
3rd January	0	1	1
4th January	39	0	39
5th January	4	1	5
7th January	2	0	2
8th January	1	0	1
10th January	4	0	4
11th January	1	0	1
14th January	2	0	2
17th January	2	1	3
19th January	7	0	7
23rd January	1	0	1
28th January	1	0	1
TOTAL	**180**	**24**	**204**

Appendix C: Written Reponses to Survey Questions

Question One: Which of the following applies to you?

- ID#23: Locally advance prostate Cancer
- ID#65: Two Friends
- ID#84: Prostate Reduction (HOLEP)
- ID#88: I am a GP
- ID#101: under active surveillance since 2009
- ID#104: None of those
- ID#114: Had
- ID#121: None - PSA varies from 9.7 to 19.5
- ID#139: Slow growing, low grade
- ID#145: 2003
- ID#147: friend
- ID#180: None, but my father was treated sucessfully for PC about 5 years ago
- ID#183-3: I have had a sucessful op for my BPH. My dad died of prostate and bladder cancer at the age of 67
- ID#185-5: Interested in Prostate cancer as a disease

Question Two: What research do you think PCRC should fund?

Written responses next to the ‘other’ option:

- ID#12: ‘training surgeons in robotic ops’ and ranked it 2.
- ID#36: ‘support for family of cancer patients’ and ranked it 6.
- ID#46: ‘raising awareness of PSA testing as a probable indicator of prostate cancer’ and ranked it 1.
- ID#: ‘diagnosis early’ and ranked it 2.
- ID#61: ‘early diagnosis tools’ and ranked it 1.
- ID#119: ‘targeted publicity campaigning’ and ranked it 7.
- ID#171: ‘provision of CT scans for those like me who cannot have an MRI scan due to metal work from spinal surgery’ and ranked it 8.
- ID#177: ‘developing a reliable diagnostic test’ and ranked it 1.
- ID#173: ‘more awareness’ in the other section but did not rank it.
- ID#178: ‘psychology and advice on how to cope with results and ED’ in the ‘other’ section but did not rank it.
- ID#84: ‘education of early activities to help to minimise probability of getting PC’ in the ‘other’ section but did not rank it.

- ID#97: ‘tell all men to get tested’ in the ‘other’ section but did not rank it.
- ID#98: ‘all good’ in the ‘other’ section but did not rank any of the responses.
- ID#99: ‘speed up diagnosis’ in the ‘other’ section but did not rank it.
- ID#114: ‘all should be funded’ in the ‘other’ section but did not rank any of the responses.
- ID#162: ‘better info on the signs and symptoms given to men at the right age’ in the ‘other’ section but did not rank it.

Written responses alongside all other answers:

- ID#125: ‘No preferences? No idea. Sorry!’
- ID#65: ‘can’t really comment’.
- ID#176: ‘finding and testing new prostate cancer treatments’ ranked 1 and wrote ‘I don’t have quals or experience to prioritise beyond this, but can PCRC pursue all GP practices to give all male patients over say 40(?)’.
- ID#24: ‘improving medical imagining for prostate cancer’ ranked 2 and commented ‘tests for prostate cancer rather than the PSA’
- ID#46: ‘minimizing the side effects of current treatments’ ranked 2 and commented ‘like from radiotherapy’
    - Same ID#: ‘survivorship - research into how to live as fully as possible despite advanced prostate cancer’ ranked 8 and commented ‘while important there are other information for this’.

Question Three: How involved would you like to be in decisions about what research we fund?

- ID#46: I am involved in other charity work to which I think my contribution is more effective
- ID#48: Happy to read what is happening
- ID#51: regret too old
- ID#57: you know best
- ID#88: None of these
- ID#121: leave it to the professionals
- ID#125: Not at all, Sorry
- ID#162: Most of these I am not qualified enough to be involved
- ID#171: too old for me
- ID#176: Bit too old to do more than advertise family and friends how important early discovery was in my case

- ID#180: I am not qualified to take part in any of the below
- ID#187-7: I am not qualified to take part in PCRC activities in this section
- ID#188-8: Happy to leave it to PCRC
- ID#194-14: to be kept informed of future developments

Question Four: What supports do you think are important for people with prostate cancer?

- ID#10: All are relevant
- ID#24: I found the printed booklet very useful in understanding prostate cancer. I had prostate cancer in 2011 and had the op for removal and 3 sessions of radiotherapy and feel very well
- ID#31: booklet including information about talking to family about cancer
- ID#136: Get on with life
- ID#178: For ED issue
- ID#184: Currently find support from wife, family, medical staff and friends
- ID#186: Currently get support from PC UK
- ID#189: Current support from MacMillan, PC UK, Hospital
- ID#191: Currently supported by Prostate Hotline Scotland
- ID#201: Currently gets support from a support group and family
- ID#204: Current support from friends and family

Question Five: What information would you like to be available from PCRC?

- ID#176: I find your 'News' mag interesting

Question Six: How would you like to access this information?

- ID#6: Whichever is more cost effective for the charity
- ID#86: Facebook
- ID#119: Facebook, Twitter
- ID#145: Facebook
- ID#148: The PCRC newsletter is excellent
- ID#177: Facebook

Question Seven: Why do you support PCRC?

- ID#2: Have an enlarged prostate
- ID#3: Its important to all men
- ID#4: Had prostate cancer
- ID#6: I have an enlarged prostate and being monitored

- ID#12: Friends died recently
- ID#16: I had a partial prostectomy 29 years ago
- ID#19: Prostate Cancer Survivor
- ID#26: I have recovered from prostate cancer
- ID#32: I believe we need to help those affected by cancer
- ID#34: HAD
- ID#42: Prostate cancer research needs more funding
- ID#48: It's important! And will help many men
- ID#51: I NO LONGER HAVE IT!
- ID#65: two friends
- ID#72: Recovering from Prostate Cancer
- ID#87: I have recovered from Prostate Cancer
- ID#89: I have had prostate cancer
- ID#90: Prevalence of Prostate Cancer
- ID#92: Had
- ID#99: I have prostate problems
- ID#112: I had a scare recently and have regular PSA bloods
- ID#114: Had
- ID#115: also had it myself
- ID#119: I have a pre-cancerous condition
- ID#120: No reason- Apart from helping a needed cause
- ID#121: I am uncertain of what PSA results mean
- ID#122: I am a survivor
- ID#124: I have had prostate cancer
- ID#129: Have HAD
- ID#131: I had prostate Cancer
- ID#133: HAD
- ID#134: HAD
- ID#136: I have had prostate cancer very advanced Ipswich Hospital current in Dr Scratic PSA every year since all clear
- ID#140: I have had prostate cancer
- ID#141: I have had my prostate taken out + 33 follow up days of radiation + 2 years on Prostap
- ID#147: Friend
- ID#151: medical research
- ID#155: Because PCRC is a good cause

- ID#156: Hopefully recovered
- ID#162: I have had PC and was treated at Oxford
- ID#167: I survived prostate cancer
- ID#173: Recovering surgery
- ID#176: and hope it has been cured
- ID#189-9: I had the op and think ahead to future possibilities
- ID193-13: I lost my dad to Prostate Cancer and when I got my PSA tests done it took 4 tests and 7 mths before they could say my reading was high and I had an enlarge prostate at the age of 42. I have a PSA test done every 3 years to keep a check

Question Eleven: To which of the following groups do you consider you belong?

- ID#10: Jewish
- ID#57: British mother and Irish father
- ID#130: White & Indian
- ID#180: New Zealand