A study of the support and information needs of men using the 'Your Prostate' service

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DRAFT

BACKGROUND

Prostate cancer incidence is high across Europe (A White et al, 2011). It is the most common cancer in men in many European countries (CRUK, NCIN, MHF, Leeds Metropolitan University, 2013) and around 3 million men were living with prostate cancer in 2008 (A White et al., 2011).

In general men are less well informed about the signs and symptoms of cancer than women, (Robb, K., et al., 2009). Men's knowledge about prostate health in general, and BPH symptoms in particular is low. "It is estimated that as many as 24 million European men aged 50 and over experience bothersome urinary symptoms. (European Commission, 2012; de la Rosette, 2009) Yet, despite experiencing symptoms, men typically wait nearly two years before speaking to their doctor (GSK 2011).

Health information available to men about their prostate health is limited and different health professionals may have varying opinions about the value of PSA tests and how to proceed.

APPROACH: THE DEVELOPMENT OF THE `YOUR PROSTATE' SERVICE

The European Men's Health Forum (EMHF) developed an e-service for men to ask questions about any aspect of their prostate health: www.yourprostate.eu.

The intention was to identify the main concerns that men have, the gaps in information and support available to them, and to make an analysis of the language used by men in their questions and to compare this across countries. The service is supported by specialist urologist nurses and consultants in English, Spanish and German. From September 2013 it will be available in French too.

A bespoke database was designed to enable questions and answers to be automatically entered exactly as they had been written into the database. Within 48 hours a nurse or consultant answers questions.

They inform service users about signs and symptoms to watch out for; advise them to see their GP or consultant if their symptoms suggest this is necessary; provide up to the minute information about different treatments and options which are available and what is known about progress in the field of research. They do not make recommendations about specific treatments or courses of action and they do not suggest any specific diagnosis. Rather, men use the information provided to inform their "next step".

This poster will present preliminary findings and the work is on-going.

EMHF'S RESEARCH APPROACH

Quantitative analysis of how many:

- Questions were asked and to rank the question by type and the age of the user
- Users were male/female
- Users previously sought medical attention and/or received any treatment

Qualitative analysis included:

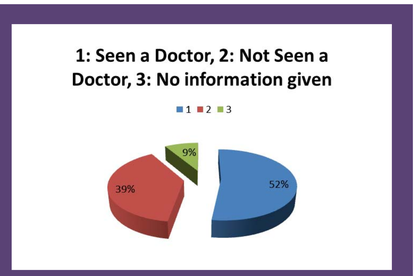
- Content analysis
- Categorisation of questions by topic
- Consideration of analysis of European Union National Cancer Plans.

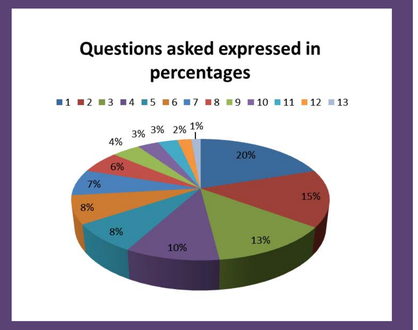
RESULTS

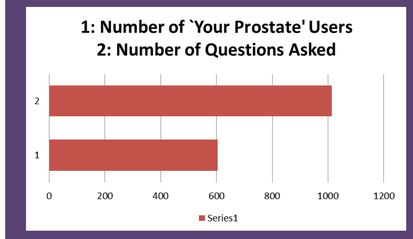
Between December 2010 and June 2013, 1,013 questions were asked by a total of 604 unique users. 561 men and 43 women. Fifty-two per-cent of users had previously seen a doctor, thirty-nine per-cent had not, 9 per-cent declined to say.

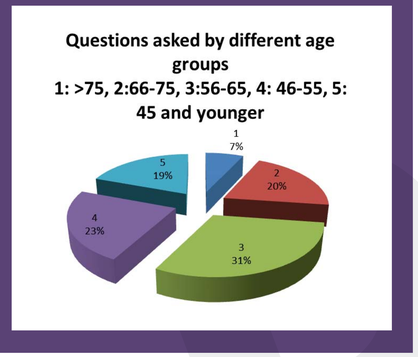
Users asked the most questions about urination disorders (twenty per-cent of all questions asked) and about treatments and tests that they were considering (fifteen per-cent), with erectile dysfunction (thirteen per-cent) and prostate cancer (10 per cent) coming next.

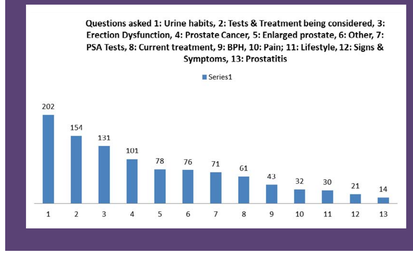
Users who were 46 – 65 years old asked most questions, accounting for fifty-four per-cent of all questions; twenty per-cent of questions were asked by 66-75 year olds; nineteen per-cent were asked by users under the age of 45, seven per-cent by users over age 75.











QUESTION CATEGORIES: TYPES OF QUESTIONS ASKED

Prostate Cancer

Family history

"I am a 54 year old male. My 57 year old brother has recently been diagnosed with an aggressive form of prostate cancer. I would like to have a test. Can you advise where this can be arranged?"

"My father has had prostate cancer. Does this put me at a higher risk with family history? If so how often should I have a PSA test?"

Symptoms

"Can you please tell me what I should look out for in case I may get prostate cancer? Many friends have had an operation for it but they felt well when they were diagnosed. I have had blood tests and check-ups with my G P and they have always been ok. Thank you"

"Does prostate cancer give pains on the bladder?

Diagnosis and treatment choices

"I have blood tests every 6 months and my PSA varies between 6.0 and 8.0. A biopsy and MRI scan have confirmed that I have prostate cancer. My consultant and I have decided to just continue with active monitoring. I try to consume the right foods i.e. tomato ketchup walnuts and green tea. I have recently read that a small daily dose of aspirin would be a wise precaution; do you agree? Also would it help to visit a practitioner of prostate massage?"

Cancer survivor's thoughts about the future

"I had radiotherapy in 1998 and last year was signed off at the hospital. My question is: having received radio therapy, if I experience further prostate trouble is any further treatment available to me? The reason I ask is an increasing frequent need to pass water which is variable and an increasing urge in the daytime to urinate when I actually then pass fairly small amounts of water. Thank you"

"I had brachytherapy in December 2007 and have had 6 monthly PSA tests since then. There has been a regular increase in PSA levels from January 2011 to December this year. Can this simply be that my prostate has recovered from the brachytherapy and is producing PSA again, or must it be a regrowth of the tumour? I am 67."

PSA Tests

Not clear how reliable the PSA Test is?

"We hear the PSA test is not reliable. What other tests are more reliable? Is any prostate test 100% accurate?"

"My workplace is offering prostate cancer test by testing urine. How accurate are these tests please? Can you have false positives or negatives?"

Should I have a PSA Test?

"My GP has refused a PSA blood test and says I don't need it. This is after allowing a test every year up until now. I am 74 and have an enlarged prostate. My argument is that I need the test more now as I am in the age group where these cancers are most prevalent. In the past these test have revealed other prostate problems for which I was treated. Why would my GP suddenly refuse to give me a PSA test and what can I do to change his mind?"

"Hi ... How often should I have a PSA test ... I am 58 years old and do I have a right for my local GP to carry out one ... I cannot remember when I was last tested ....".

What do the results of my PSA Test mean?

"My PSA is 13.88 the prostate gland is 32 gms.no pain. urinate 2 to 3 times at night. Steady stream. No discharge or leaking. Had ultrasound. Was told to have TRUS biopsy. Had finger test by specialist. Doctor suggested MRI. Taking Norflox 2 times a day. Could have an infection or cancer"

Urination habits

Changing urination habits: what do they mean and what can be done to improve matters?

"Difficulty in passing urine. Having to get up more often at night to urinate. Having to pass urine more frequently. Finding it difficult to postpone urination. What can I do?"

"Are there bladder exercises (or 'tricks') that help/strengthen the urinary flow?"

Treatment and tests being considered

"I had difficulties with my prostate. Since around a year am taking [a named medicine]. When I began with the therapy the symptoms improved and I felt better. But this has changed recently. Is there any other medicine I can take?"

"The Doctor at my hospital is suggesting injecting me with botox to stop my going to urinate so often (especially at night).The botox would presumably be in the bladder region. Have you heard of this procedure before?"

Erection Dysfunction: Causes and cures

"I have been told I have an enlarged prostrate. Could this be the reason that I have problems getting an erection?"

"Since having the opp I cannot get an erection or climax. Is there a way I can cure this?"

LIMITATIONS OF THE STUDY

Your prostate is offered in English, Spanish and German. From September 2013 it will be offered in French. To date the majority of questions have been asked in English and this limits the type of comparison between countries, and in particular to compare what men are most concerned about.

DISCUSSION

It is clear from evidence that men do not know signs and symptoms; face difficult decisions about PSA tests, treatments, and that many find recovering from interventions stressful and life changing.

Users asked the most questions about urination disorders and about treatments and tests that they were considering. Many of the symptoms could indicate a variety of urological conditions, including prostate cancer or benign prostatic hyperplasia; some could be the result of previous treatment.

Signs and symptoms for prostate cancer and benign prostatic hyperplasia are similar. Prostate cancer symptoms: needing to pass water often, especially at night; difficulty in starting to urinate; pain when passing water or during sex when an orgasm is reached; and some less common symptoms - pain in the lower back, hips or pelvis; blood in the urine. These signs and symptoms are almost identical for benign prostatic hyperplasia.

Recommendations

EMHF would like to see European Health Care Systems put significant resource into improving men's access to good, targeted, information and services.

National Cancer Control Plans (NCCPs) should lay-out specific actions designed to raise awareness of cancer signs and symptoms among men, target information tailored for them (for example by age group, ethnic background) and make this available in places and through media that men frequently use.

Health care systems should set in place comparable methods of collecting data about men's awareness, access to services, types of treatment taken-up, outcomes, and evaluation of interventions data in the future.

Acknowledgements

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