

INTRODUCTION

At ZERO, we are dedicated to ending prostate cancer. We believe that it is possible to have a generation without prostate cancer and while we work hard everyday to support efforts and initiatives that will lead to cure or prevention, we are equally committed to supporting men and their families who are living with the disease.

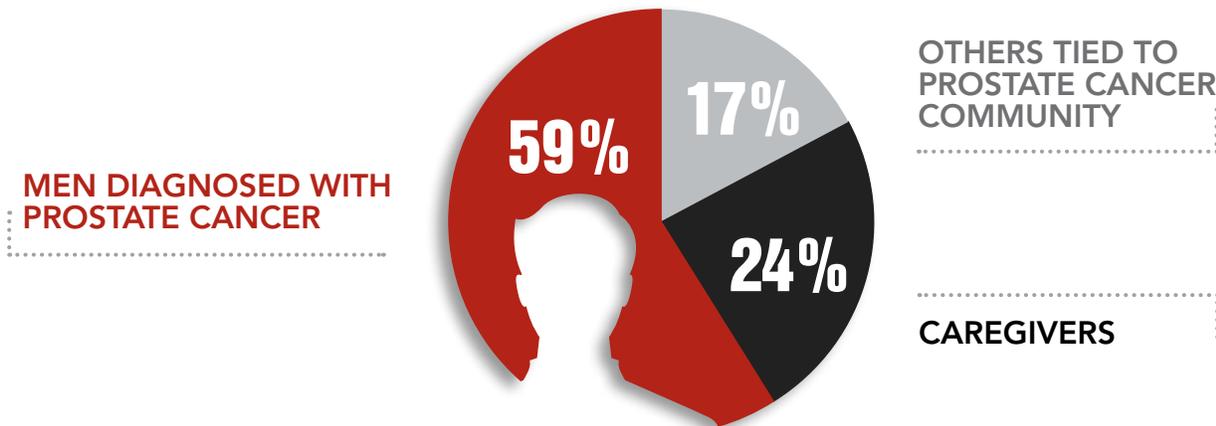
A goal for ZERO in 2014 is to develop a series of prostate cancer patient education materials that give people the information that they want. Why would we do this? Because people have different needs at the time they are diagnosed than they do later down the line, be it one month, one year, eight, or even 15 years afterwards. So, we took to the internet and asked men who had been diagnosed with prostate cancer about what information they wanted when they were diagnosed, what information they want now. We learned about who comprised their medical team, what mattered when making treatment decisions, how they found out they had prostate cancer, and where they went for information. We didn't stop there. Prostate cancer is a disease that affects more than one person, it affects a partner/spouse/loved one, it affects children and co-workers, it affects families, it affects everyone even if they don't know it. So, we asked those who have loved or taken care of men with prostate cancer about their experience, what information did they need and how did they find it, how much time did they spend, and what was the toll.

This report includes the highlights of what we learned about the prostate cancer journey by those who took our survey. Our survey was open online from November 20, 2013 through January 21, 2014. Anyone touched by prostate cancer was encouraged to take the survey and share their experience. It was a lengthy survey but we had more than 1,400 people participate and we are proud of the response. Men and their families care about sharing their experience and want to pay it forward.

Our findings are interesting and we will use them to enhance our materials and programs and to guide development of new materials. The results of the survey support what we thought about the informational needs of those touched by prostate cancer. The most important thing we found out in our survey is that men and their loved ones with prostate cancer need patient education and support and they are looking to ZERO for this.

ABOUT OUR SURVEY

From November 20, 2013 through January 21, 2014, ZERO – The End of Prostate Cancer conducted an online survey to better understand the experiences of those affected by prostate cancer and learn about their educational needs. The survey was open to the public and respondents were recruited using personal outreach to ZERO’s constituents and our social media networks.

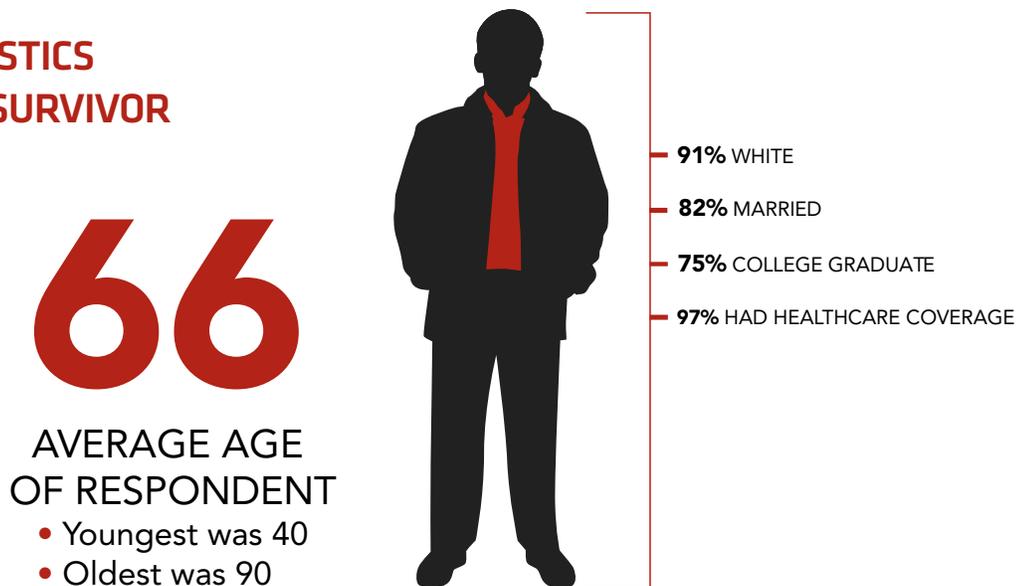


ABOUT OUR PROSTATE CANCER PATIENTS AND SURVIVORS

We had a very homogenous group of prostate cancer patients and survivors answer our survey. But their responses tell us that every diagnosis of prostate cancer is different and the journey a man must travel once diagnosed is uniquely his own.

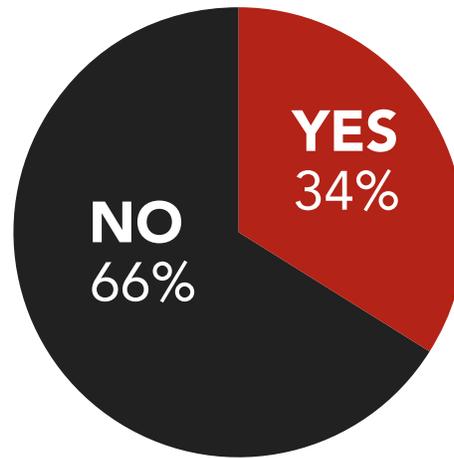
Just the Facts:

CHARACTERISTICS OF PATIENT/SURVIVOR



ARE YOU CURRENTLY FIGHTING CANCER?

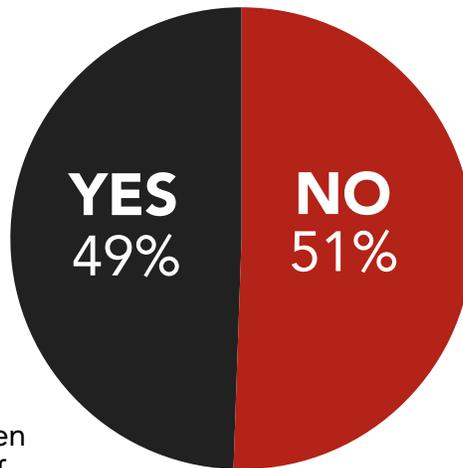
Have been treated for prostate cancer but no longer in treatment



Currently have prostate cancer

HOW LONG AGO WERE YOU DIAGNOSED WITH PROSTATE CANCER?

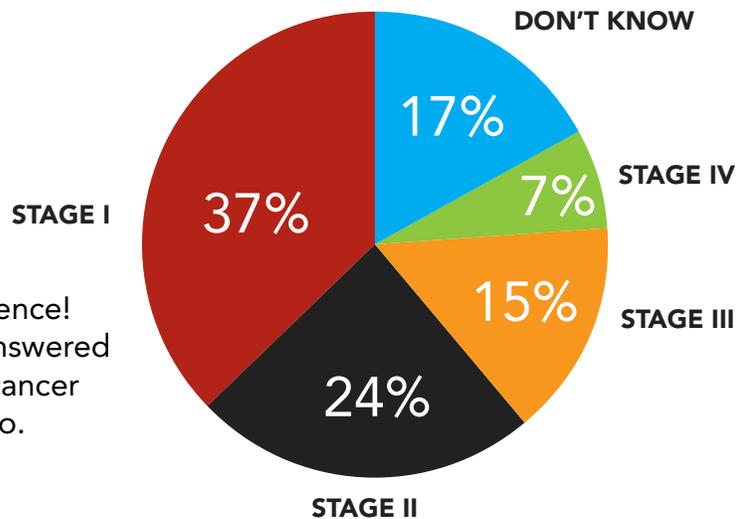
Forty-nine percent had been diagnosed in the past five years. The other 51 percent had been diagnosed five or more years ago.



This is positive news, it shows us that there are men living for a long time after receiving a diagnosis of prostate cancer.

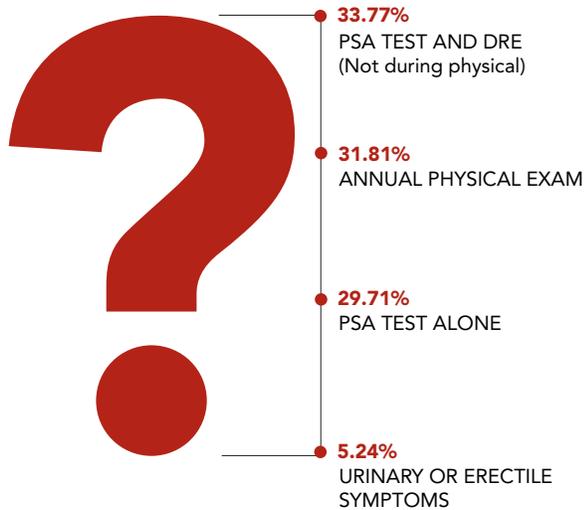
AT WHAT STAGE WAS YOUR PROSTATE CANCER DIAGNOSED?

Cancer is not an immediate death sentence! Check it out: 19 percent of men who answered our survey who had Stage IV prostate cancer were diagnosed more than 10 years ago.



Now that we know about the facts about our men we want to know more about their journey from diagnosis, making treatment decisions, and who was there through the journey.

Learning You Have Cancer: HOW DID OUR MEN FIND OUT?



We know that there is controversy around the Prostate Specific Antigen (PSA) test and recommendations for testing. ZERO is advocating every day for more research to find a better test. But given the absence of symptoms in early stage disease we recommend men talk to their doctor to understand their risk for prostate cancer and make a plan for screening.

Most prostate cancer is found as a result of prostate cancer screening, most likely a PSA and Digital Rectal Exam (DRE).

Making a Treatment Decision is Not Done in a Vacuum

After learning you have prostate cancer there is a new language to learn, people to meet, and then a treatment decision to be made. We asked men to identify what factors helped them make their treatment decision. The top three most important factors were:

- Personal research
- Doctor said it was the best treatment choice
- Chances of survival seemed best

We asked men if anyone other than their treatment team helped make decisions about prostate cancer and a little more than half said someone else was included. Most of the time, this was the wife but many men indicated a friend helped them make decisions. Adult children and other family members helped too, but not nearly as much.

Side Effects Matter

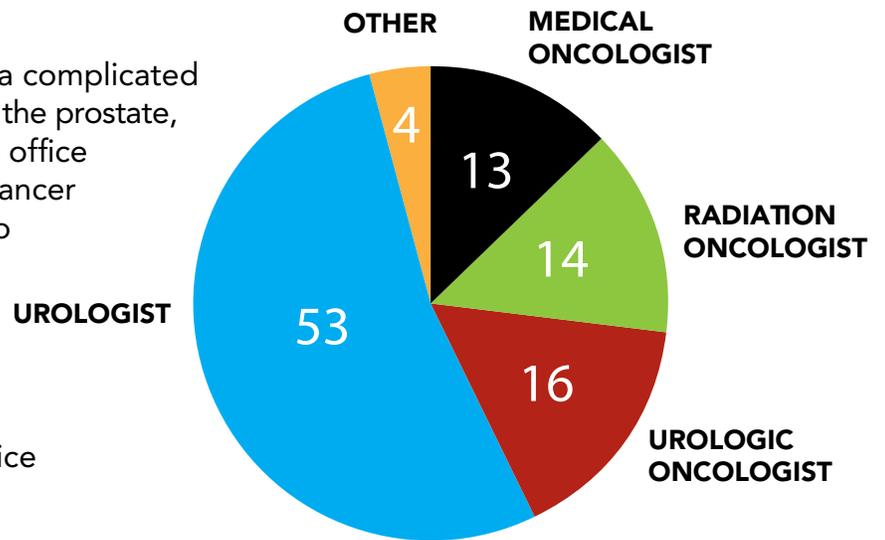
Side effects from prostate cancer and treatment for the disease can cause significant life interruptions and stress. Therefore, it is important to understand potential side effects to make an informed decision about treatment. Fifty-four percent of men told us that avoiding certain side effects was a consideration when they made their treatment choice.

Certain common side effects of treatment can negatively affect a man’s identify, confidence, and personal life. The side effects that men wanted to avoid most included:

- Urinary incontinence
- Erectile dysfunction
- Loss of libido

What’s Up Doc?

Prostate cancer, like most cancer, can be a complicated disease to treat. Because of the location of the prostate, many men are managed in the urologist’s office from beginning to end of their prostate cancer journey. It is important to include a visit to an oncologist so that you are educated about all of your treatment options. Using a multidisciplinary approach to treating prostate cancer ensures you have several experts working together to help you make the best treatment choice for you and deliver care.

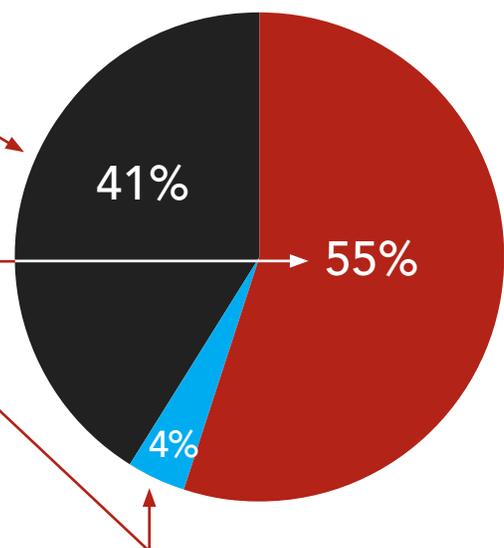


More than half of our respondents indicated that their care was managed primarily by a urologist. This makes sense considering that more than half of the men who responded to our survey were diagnosed at Stage I or II when surgery is most effective.

Because we think it is important to consider a medical oncologist in the treatment decision making process, we asked the 71 percent who were treated either by a urologist, radiation oncologist, or other if they were ever referred to a medical oncologist and if they saw one.

Were you referred to a medical oncologist at any point during your prostate cancer journey?

- **41%** were referred to an oncologist
 - 39% acted on that referral
 - 2% did not act on the referral
- **55%** were not referred to an oncologist
 - 8% went ahead and saw one anyway
 - 47% did not see one on their own
- **4%** did not remember a referral



Mind, Body, and Wallet

While life might temporarily come to a screeching halt with the words prostate cancer, it will continue to move forward, bringing new challenges to many aspects of a man’s life. Fortunately there are specialists in the medical community who support the physician’s efforts and work to improve the lives of patients and families. We found out that our respondents did in fact take advantage of these specialists. Specialists most seen were:

- Nutritionists
- Social worker
- Complementary medicine specialist
- Financial specialist

PATIENT EDUCATION

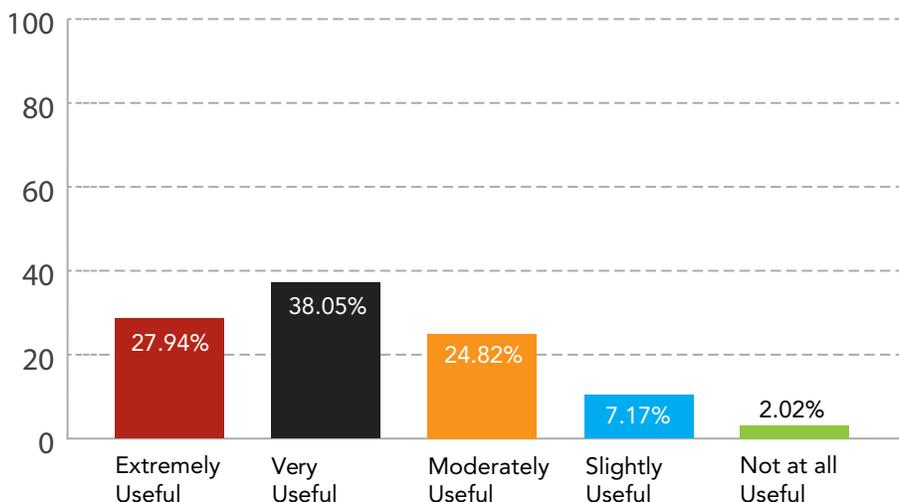
Thank You Doctor for the Information!

Doctors are a trusted resource for information such as disease specifics, treatment options, and side effects. Frequently when a man is diagnosed with prostate cancer, he is offered this type of information. We wanted to know if men received information at the time of their diagnosis, what they received, and if they found it helpful.

Nearly 80 percent of the men said they had received information from their healthcare team and most found it useful.

When asked what they received, the most common answers were “booklets, brochures, pamphlets, information about treatment, what to expect with surgery, and what is prostate cancer.”

Of those that received information, most of them found it at least moderately useful.

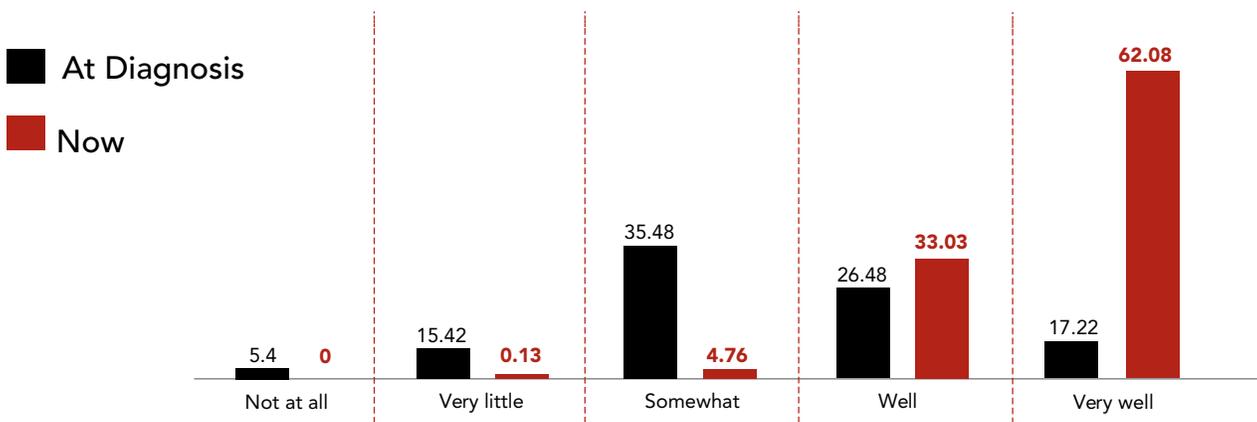


Understanding the Disease State

At ZERO, we know prostate cancer is a complicated disease. At the time of diagnosis, there is a lot to digest and learn. We’ve all heard the words cancer, staging, prognosis, surgery, remission, etc., but when you’ve been diagnosed with prostate cancer, these familiar and frequently used words and concepts factor into understanding your disease state.

We wanted to know how well men understood their disease state at the time of diagnosis and then asked them to tell us how well they understood their disease now, at the time of the survey. Not surprisingly, the results showed that over time, understanding of their disease increased

DISEASE STATE UNDERSTANDING AT TIME OF DIAGNOSIS AND NOW (%)



What Information Did You Need?

To help men better prepare for their prostate cancer journey, we wanted to know what information they most needed when they were diagnosed. Even though our survey respondents indicated they had some understanding of their disease at the time of diagnosis, they indicated what they most needed. And because prostate cancer may have a long time impact on a man, we wanted to know what information men were looking for now.

TOP THREE EDUCATION TOPICS MEN WANTED	
AT TIME OF DIAGNOSIS	NOW
<ul style="list-style-type: none"> • Information about prostate cancer • Treatment options • Side effects 	<ul style="list-style-type: none"> • Clinical trials information • Treatment options • Survivorship/life after treatment

We Know What You Want, Now How do You Want it?

So now that we know the most needed information at different points in the prostate cancer journey, we wanted to learn just a little more. We asked men to tell us what is the best way to get prostate cancer information, using ZERO's available resources, and this is what they said:

- Online – website, newsletter, emails from ZERO
- Print materials
- Videos
- Blog
- Webinars

TOOTING OUR OWN HORN

We wanted to know just a little more about how we are known in the prostate cancer community by our survey respondents.

Great news, more than 87 percent of respondents would recommend ZERO to colleagues, friends, and family impacted by prostate cancer!

Add to that, ZERO was rated as the most frequently used resource for services and prostate cancer information by patients and survivors. Other regularly used groups included the Prostate Cancer Foundation, Us TOO International, and the American Cancer Society.

ABOUT CAREGIVERS

The American Society of Clinical Oncology defines a caregiver as anyone who provides important physical, practical, and emotional support to a person with cancer.

Prostate cancer is a family disease and those men and women who answered our questions for caregivers just further reinforced that. The caregivers shared similar demographic characteristics with the men who had been diagnosed with prostate cancer and answered our survey. But as we learned in our survey, caregiving for a loved one with prostate cancer takes time and can add stress to one's life.

CHARACTERISTICS OF THE CAREGIVER

50

AVERAGE AGE OF RESPONDENT

- Youngest was 21
- Oldest was 72



85% WHITE

64% COLLEGE GRADUATE

To best understand the caregiver and their experience, we wanted to know who with prostate cancer they care for.

75%
 CAREGIVER FOR 1 - 5 YEARS

27% TAKING CARE OF HUSBAND

18% TAKING CARE OF FRIEND

36% TAKING CARE OF FATHER

12% OTHER

More than one third are caring for loved ones with advanced disease.

When we looked at the relationship of caregivers to their loved one, initially more caregivers indicated they cared for a father, however as disease severity increased, so too did the percentage of people caring for a husband/spouse/partner with Stage IV prostate cancer.

Of those that are cared for, 33 percent were diagnosed at Stage IV, 9 percent at Stage III, 16 percent at Stage II, and 14 percent at Stage I.

Seventy-five percent of caregivers indicated that their loved one was diagnosed with prostate cancer in the past five years.

Caregivers Gender



When we looked at the sex of caregivers by stage of their loved one, initially there were more men than women, but as disease severity increased, the ratio shifted and the majority of caregivers were female.

STAGE	MALE	FEMALE
I	55%	45%
II	47%	53%
III	25%	75%
IV	22%	78%

CAREGIVING

Just as each man’s prostate cancer journey is unique, so too is that of the caregiver of a man with prostate cancer. There are unifying characteristics that pull together the collective experience.

We asked the caregivers to estimate how much time they spend weekly providing support to their loved one with prostate cancer. The majority, more than 60 percent, indicated they spent up to 10 hours per week in this role while 20 percent indicated they spent 30 hours or more per week.

We then asked the caregivers what activities they were most frequently involved with in supporting their loved one. They said:

- Emotional support
- Treatment decisions
- Appointments
- Transportation
- Daily activities
- Managing finances
- Home healthcare

Caring for the Caregiver

Caring for a loved one strains even the most resilient of people. To better understand the stress prostate cancer caregivers are facing, we asked them to indicate how much additional stress they feel as a result of prostate cancer. We asked people to rate their level of additional stress on a 1 to 5 scale and we found out that more than 40 percent experienced a great deal of stress due to caregiving.

Then we asked them how they found support and relief for themselves through several different activities. The most common ways to deal with the stress:

- Doing activities they enjoy
- Regular exercise
- Getting proper rest and nutrition
- Seeking support from friends and family

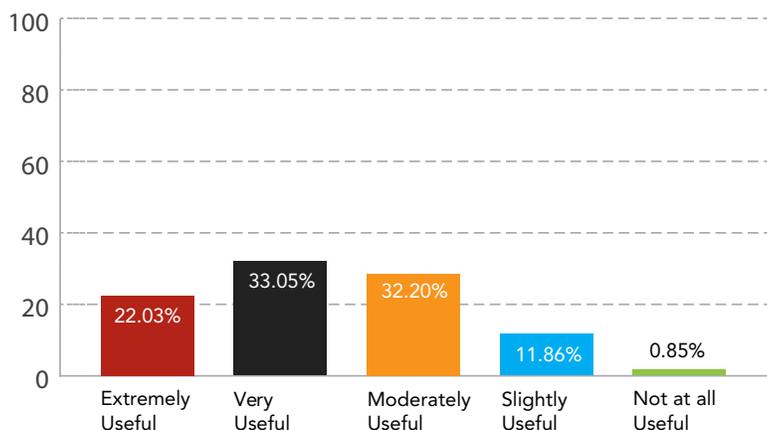
Patient Education

To help complement the information provided by the patients and survivors who responded to our survey, we wanted to know what information they most needed when their loved one was diagnosed. And because prostate cancer may have a long time impact on a family, we wanted to know what information caregivers want now.

TOP THREE EDUCATION TOPICS CAREGIVERS WANTED	
AT TIME OF DIAGNOSIS	NOW
<ul style="list-style-type: none"> • Information about prostate cancer • Resources for emotional support • Treatment options 	<ul style="list-style-type: none"> • Clinical trials information • Survivorship/life after treatment • News and information about the prostate cancer community

We posed the same question to caregivers as patients/survivors, asking if they received information from their healthcare team. Sixty percent indicated that they had received information and most found it useful.

HOW USEFUL WAS THE INFORMATION FROM YOUR HEALTHCARE TEAM



When asked what they received, the most common answers were “booklets, brochures, pamphlets, information about treatment, what to expect with surgery, and what is prostate cancer.”

And lastly, we asked our caregivers what hat they wore, caregiver, patient, or health professional when they first looked for information on prostate cancer. They told use that nearly 40 percent of the time they ALWAYS look for materials for patients, 14 percent of the time ALWAYS look for information for caregivers, and 19 percent of the time they ALWAYS look for materials for healthcare professionals.

WHAT’S NEXT

We are fortunate to have collected so much rich information from the prostate cancer community! We will use the information from the survey to create new materials and update existing ones, create programs for patients and their loved ones, and continue to serve as a valued resource in the prostate cancer community.

Visit www.zerocancer.org for new materials and regular updates.