

Working with Patient Communities

Monica Smith, Bladder Cancer Advocacy Network
Brian Loew, Inspire

*Social Media Regulatory Affairs Summit
June 24, 2015*

Our discussion today

- Patients have more information about their healthcare options today than ever before
- Modern day treatments are discussed in patient forums months (and even years) before they're even submitted for approval
- Forums can facilitate interaction between drug and device companies, providers and patients in a way that benefits everyone



BCAN: Our Mission



The Bladder Cancer Advocacy Network's mission is to increase public awareness about bladder cancer, advance bladder cancer research, and provide educational and support services for the bladder cancer community.

As the leading voice for bladder cancer, BCAN is cultivating a community of hope and support for people touched by the disease.

Our Programs

Support & Awareness	Education	Research
<ul style="list-style-type: none">• Bladder Cancer• National Bladder Cancer Awareness Month• BCAN Connection Information & Referral Line• Survivor 2 Survivor Phone Support• Inspire Online Community• The Walk for	<ul style="list-style-type: none">• Patient Handbook – “Bladder Cancer Basics for the Newly Diagnosed”• Patient Insight Webinars• “Conversations” Video Series• “The New Normal” Video Series• Patient Tip Sheets• Clinical Trials Dashboard	<ul style="list-style-type: none">• Bladder Cancer Think Tank• Patient Survey Network• Young Investigator Awards• Bladder Cancer Research Innovation Award

Bladder Cancer: The Most Common Cancer You've Never Heard Of.

- The 5th most commonly diagnosed cancer
- 75,000 people diagnosed annually and 16,000 deaths
- More than 500,000 people living with the disease
- Three times more common in men
- Women are often diagnosed later and have a worse prognosis
- Recurrence rate of 50-80%
- 30% of patients are diagnosed with muscle-invasive disease and may face urinary diversion
- Average age of diagnosis is 73
- Major risk factors include smoking and toxin exposure
- Invasive testing and diagnosis

Reaching Our Audience

Challenges

- Older demographic
- Male demographic
- Reluctance to discuss “below the belt” disease
- Lack of public awareness
- Lack of notable spokesperson
- Limited resources for media
- Managing multiple communication channels

Assets

- Engaged caregivers
- Active medical professionals
- Dedicated community volunteers
- Established website

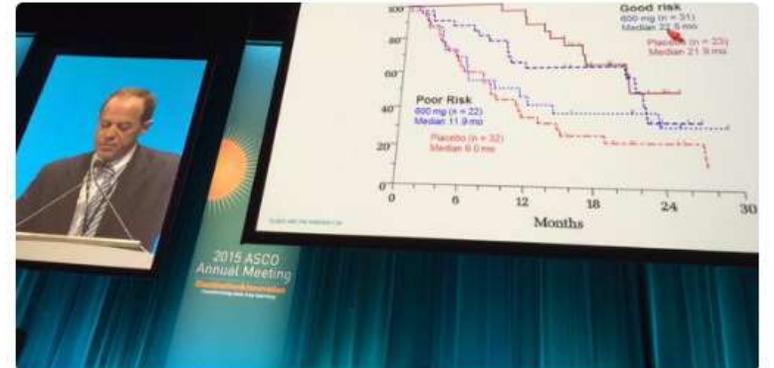
BCAN retweeted
Elizabeth Plimack MD @ERPlimackMD · Jun 1
#bladdercancer team waiting to present at #ASCO15 GU oral abstract session. @B_C_A_N

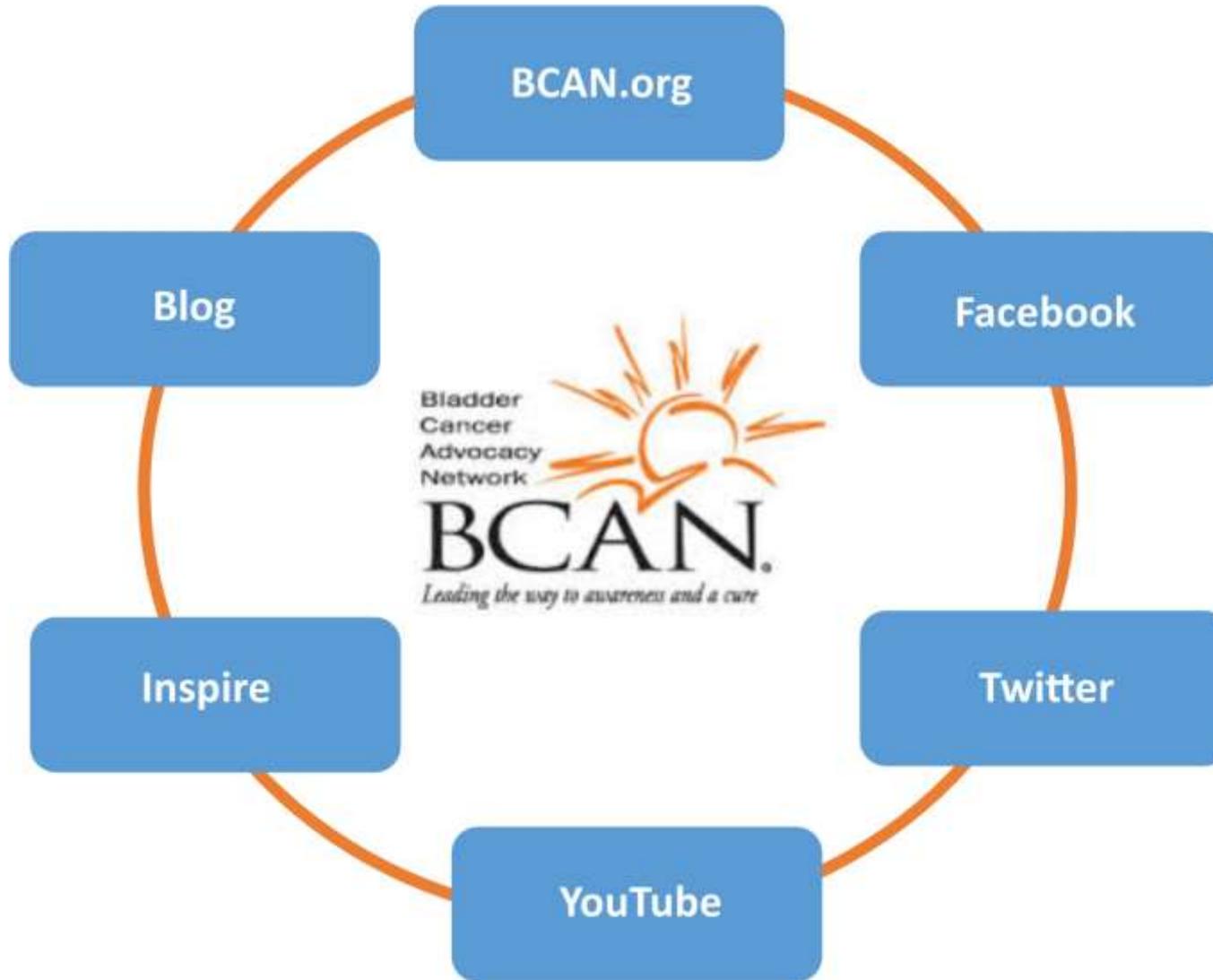


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[View photo](#)

BCAN retweeted
Sumanta Pal @montypal · Jun 1
@OncoBellmunt @DanaFarber presents @OncoGenexPharma apatersen; OS better in poor risk Pts #ASCO15 @B_C_A_N





Reaching Our Audience

Facebook

- Raising Awareness
- Recognizing Volunteers
- Sharing legislative actions
- Nearing 5,000 likes – more than 50% in one year.

Twitter

- Largely comprised of medical professionals
- Sharing research news
- Live feeds from events
- New focus on increasing followers

YouTube

- Storing and sharing educational videos



Bladder Cancer Advocacy Network (BCAN)

May 29 at 8:14am · 🌐

Bob and Susan Brubake are riding their bikes across country this summer to raise awareness about bladder cancer. Read here to learn more about their story: <http://www.news-sentinel.com/apps/pbcs.dll/article...>



Couple's cross-country bicycle ride to raise stroke and bladder cancer awareness - News-Sentinel.com

In the blink of an eye, or in this case several hours of a day, lives can be changed or lost forever. For Bob and Susan Brubaker of Van Wert, Ohio, a tear of Bob's...

NEWS-SENTINEL.COM

Like · Comment · Share

👍 Chad's Chronicles with Bladder Cancer, Steph Cisne, Marge Coffin and 60 others like this.

↪ 4 shares



Diane Schnee They are such strong people with a lot of strength and a positive attitude. I know in my heart they will all succeed on their journey. God bless them.

May 29 at 8:30am




FIND ANSWERS


ADVANCE RESEARCH


GET INVOLVED



Understanding Bladder Cancer
Learn the facts about bladder cancer.

Online Resource Library
We are building one of the most comprehensive collections of bladder cancer resources on the web.

Clinical Trials Dashboard
A searchable database to provide direct patient access to promising research.

Donate & Change a Life
Help transform the lives of those touched by bladder cancer.

 **WHAT'S NEW**

Meet Stephanie Chisolm – Director of Education and Research

A cancer diagnosis is terrifying for anyone to hear. Helping people understand a disease that threatens their health, has always been an important part of my professional and personal mission.

[Read More...](#)

Press Release – 2015 BCAN Research Awards Announced

The Bladder Cancer Advocacy Network (BCAN) announces a \$500,000 investment in research for 2015 demonstrating the organization's commitment to a bladder cancer cure.

[Read More...](#)

National Bladder Cancer Awareness Month Recognized

Thank you to Senator Menendez (D-NJ) with co-sponsors Senator Isakson (R-GA) and Senator Brian Schatz (D-UT) for introducing and passing SRF 407 to



Press Release
2015 Research Awards Announced

New Survivor Videos
"The New Normal: Living with a Urinary Diversion"

New Release
2014 BCAN Financial Documents



 **DONATE TO BCAN**

Inspire Sign up for our online community for those affected by bladder cancer
Get support! [Join the conversation now.](#)

Bladder Cancer Clinical Trials Dashboard
Patient Access to Promising Research

Be heard
Join the Patient Survey Network



The Bladder Cancer Advocacy Network Support Community connects patients, families, friends and caregivers for support and inspiration...

[More about this group](#)

I am afraid to go swimming



By Sekao1019 · New reply 4:17 pm
Discussion in Life after radical cystectomy · 4 replies

Good Day: 26 months ago I had RC with Ileal conduit. I wear Hollister 2 piece wafer/pouch. Ever since I have had major anxiety about going to water aerobics or swim at the wellness club at my local hospital ...

4th BCG Treatment and Short Term Disability Paperwork



By lolamoon · New reply 3:44 pm
Discussion in Raising awareness · 4 replies

My husband just had his 4th BCG treatment past Wednesday and now he starting to feel some of the side effects and they are really getting to him .Feeling achy, run down, diarrhea and the urgency when ...

Seeking Alternative Medicine Information

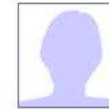


By Scottie1 · New reply 3:40 pm
Discussion in Living with invasive bladder cancer · 4 replies

I am seeking alternative medicine remedies and or a program with trail studies. My mother is 71 with stage 4 cancer in the bladder, invasive to the liver. Please respond and GOD Bless ...

Iliac lymph node surgery and Immunology research

Members



Uu



Donsari



nas50001

[See all members](#)

Things you can do



[Start a discussion](#)



[Post a journal entry](#)



[Meet others like you](#)



[Update your profile](#)

Support BCAN

Help the Bladder Cancer Advocacy Network reach its goals and support people like yourself by making a donation today.

[Donate](#)

BCAN Inspire Community

- Began in 2007
- Over 13,500 members
- 160 countries represented
- 30% of members identify themselves as caregivers

In a one month period

- 324 new discussions
- 3,340 replies

Top five discussion categories:

1. Life after radical cystectomy
2. Newly diagnosed
3. Treatment choices
4. Living with non-invasive bladder cancer
5. Raising awareness

Inspire Community – Influence

Discussion Subjects

- *Mushrooms - another 'bullet' for cancer?*
- *I'm afraid to go swimming*
- *Newbie - still trying to decide on type of diversion*

BCAN Programs

- *The New Normal 1 & 2 Patient Insight Webinar*
- *What I Wish I Had Known Before Surgery Webinar*
- *“The New Normal: Living with a Urinary Diversion” Survivor Video Series*



Inspire Community – Influence

Discussion Subjects

- *Mushrooms - another 'bullet' for cancer?*
- *Is there a correct diet with BC?*
- *The Health Benefits of Curcumin*

BCAN Patient Insight Webinars

- *Debunking Nutrition Myths*
- *The Role of Nutrition in Surgery & Chemotherapy Bladder Cancer Treatment*

Follow Up Post – “Last Night’s Webinar – Turmeric”

Last night's BCAN webinar on Myths about Nutrition for Bladder Cancer Patients was pretty good. The topic of daily turmeric/curcumin supplements came up, and was praised as beneficial by all of the experts on the panel. Does anyone take turmeric daily to suppress inflammation? I am thinking about doing this in pill form, and taking it with milk. Any comments appreciated.

Patient Survey Network



- Patient-Centered Outcomes Research Institute (PCORI) Engagement Award
- Initiative led by Angela Smith, MD, MS of UNC Chapel Hill and John Gore, MD, MS of the University of Washington
- Actively engage bladder cancer patients and caregivers in the research prioritization process
- Program will elicit meaningful research questions from patients and caregivers
- These questions will be delivered to funding agencies so that they can incorporate this information into their decision to fund specific research projects
- Goal 500 patients and loved ones – 750 currently enrolled



We want you! To Tell Us What to Research



By BCAN_Staff · January 12, 2015 at 11:14 am · 36 replies

In Raising awareness | Change

 Stop following  More options

 Shared with the public  Email this discussion

Please take a look at this BCAN guest blog post from Dr. Angela Smith
Available below and here: <http://www.bcan.org/want-tell-us-research/>
-The Staff at BCAN

We want you! To tell us what to research
January 8, 2015
by Angela Smith, MD, MS

When you hear about bladder cancer research do you ever wonder how the research topics are chosen and if anyone ever asks actual patients what they think? Bladder cancer is currently the 6th most commonly diagnosed cancer in the United States. An estimated nearly 75,000 people were diagnosed last year. Researchers are investigating many topics in bladder

BCAN
Patient Webinar Series

Patient Insight Webinar Series

Patient Survey Network

Friday, March 27th

This webinar begins at 11AM ET/8AM PT

For technical issues please contact Citrix GoToWebinar Tech Support at: 888-621-0537

Please type all questions for presenters in the Question box in the GoToWebinar Control Panel. We ask that you keep your questions relevant to tonight's topic and presentation.

This webinar is being recorded

Featured Presenters:

Angela Smith, MD, MS
Assistant Professor
Department of Urology
University of North Carolina

John Gore, MD, MS
Associate Professor
Department of Urology
University of Washington

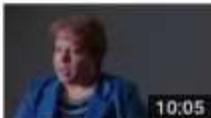
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Be Heard! Join the Patient Survey Network

<https://www.youtube.com/watch?v=IF14YTrK5NA> Bladder Cancer Advocacy Network

Up Next

Autoplay

-  **Prophecy- The end times, illumine the mark of the beast RFID chip**
by mmawildal
2,843 views
9:44
-  **The New Normal - Female, Indiar**
by Bladder Cancer Advocacy Network
109 views
10:05
-  **The New Normal - Male, Neobladder**
by Bladder Cancer Advocacy Network
276 views
7:01
-  **The New Normal -Female, Ileal C**
by Bladder Cancer Advocacy Network
233 views
12:44
-  **The New Normal - Male, Indiana**
by Bladder Cancer Advocacy Network
143 views
14:19
-  **The New Normal - Male, Ileal Cor**
by Bladder Cancer Advocacy Network
283 views
4:24
-  **Just the Job Video - Pharmacy T**
by pharmacy

Browser address bar: <http://www.bcan.org/want-tell-us-research/>

Navigation: CONNECT WITH BCAN (Facebook, Twitter, Google+, YouTube, Pinterest) | ABOUT BCAN | DONATE | CONTACT | SEARCH



Bladder Cancer Advocacy Network
BCAN
Leading the way to awareness and a cure

 **FIND ANSWERS**

 **ADVANCE RESEARCH**

 **GET INVOLVED**

Home > Blog > We want you! To tell us what to research

We want you! To tell us what to research

January 8, 2015
by Angela Smith, MD, MS

When you hear about bladder cancer research do you ever wonder how the research topics are chosen and if anyone ever asks actual patients what they think? Bladder cancer is currently the 6th most commonly diagnosed cancer in the United States. An estimated nearly 75,000 people were diagnosed last year. Researchers are investigating many topics in bladder cancer but there has never been a deliberate effort to ask bladder cancer patients and caregivers – the people directly impacted by this disease – what research questions they think are most critical to address.

This year we're launching a new project called, "Engaging Patients in Bladder Cancer Research Prioritization" to make sure the patient voice is heard in determining important bladder cancer research topics. Our goal is to engage bladder cancer patients in the research process in a meaningful way. We are aiming to recruit patients and caregivers to join the Patient Survey Network (PSN). Those that have joined the PSN will be asked to rank research questions and share their own ideas. We will use these responses to help identify and prioritize topics for future research.

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Contact Information

Monica Smith

Executive Director

Bladder Cancer Advocacy Network

msmith@bcan.org

301-215-9099 ext. 201

About Inspire

A social network, organized by health condition, that connects pharmaceutical companies with patients and caregivers in a safe, permission-based manner.

11,000,000 unique visits/yr

625,000 members (+12K/mo)

208 health communities

100+ advocacy partners

7 Million posts (+4K/day)

As of June 2015



The screenshot shows the Inspire website interface. At the top, there is a navigation bar with a login field containing 'adam@inspire.com', a password field, a 'LOG IN' button, and links for 'Forgot password?' and 'Keep me logged in'. A 'Not a member? JOIN NOW' button is also present. Below the navigation bar is the Inspire logo with the tagline 'together we're better', a 'Browse Our Health Communities' link, and a search bar. The main content area features a large banner with the text 'Become a Member' and 'Join many others who understand what you're going through and are making important decisions about their health.' Below this text are two buttons: 'BROWSE OUR COMMUNITIES' and 'JOIN NOW'. To the right of the text is a portrait of a smiling woman. At the bottom of the banner, there is a 'FEATURED PARTNER' section for Amy Porter, Executive Director & CEO of the National Osteoporosis Foundation, with a testimonial: 'We partnered with Inspire to better understand first-hand the long-term effects of broken bones. We found our members are eager to have their voices heard.'

Inspire -- the largest health community

Over **1 billion** words written by members

200,000 members affected by cancer

200,000 members affected by rare disease

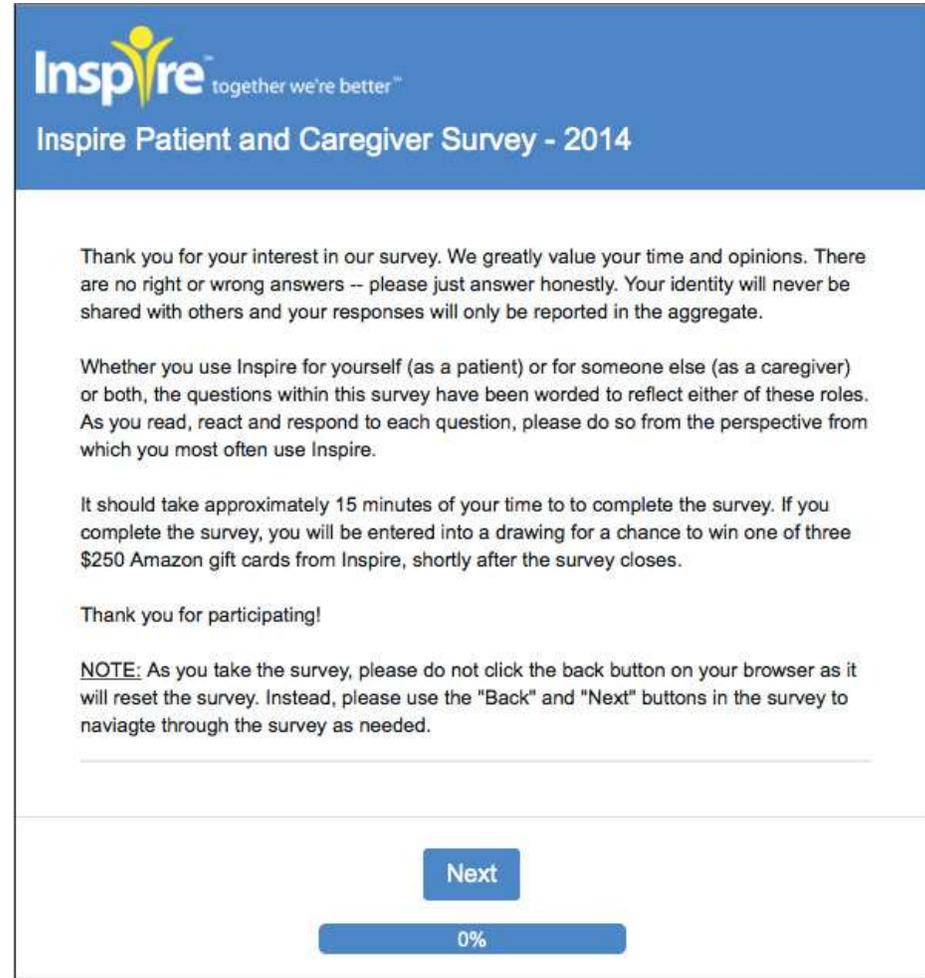
The voices of Inspire members

“I learned more here about what to expect with (my husband’s cancer) diagnosis and treatment and how to cope with the myriad changes and challenges in our lives than from any other source.”

“I was very fortunate to have found this group before my permanent ileostomy surgery. They calmed my sheer terror, taught me almost everything I know, and they were right, everything's worked out fine.”

“Even though I've been working biotech/pharmaceutical research for MANY years, I never heard about sarcoidosis and never met anyone who I knew had one until the doctor brought up this possibility with me.”

Insights from Inspire Annual Survey



The screenshot shows the top of a survey page. At the top left is the Inspire logo with the tagline "together we're better™". Below it is the title "Inspire Patient and Caregiver Survey - 2014". The main content area contains several paragraphs of text: a thank you message, instructions on how to answer questions, a statement about the survey duration and a prize drawing, and a note about browser navigation. At the bottom, there is a blue "Next" button and a progress bar showing "0%".

Inspire™ together we're better™
Inspire Patient and Caregiver Survey - 2014

Thank you for your interest in our survey. We greatly value your time and opinions. There are no right or wrong answers -- please just answer honestly. Your identity will never be shared with others and your responses will only be reported in the aggregate.

Whether you use Inspire for yourself (as a patient) or for someone else (as a caregiver) or both, the questions within this survey have been worded to reflect either of these roles. As you read, react and respond to each question, please do so from the perspective from which you most often use Inspire.

It should take approximately 15 minutes of your time to to complete the survey. If you complete the survey, you will be entered into a drawing for a chance to win one of three \$250 Amazon gift cards from Inspire, shortly after the survey closes.

Thank you for participating!

NOTE: As you take the survey, please do not click the back button on your browser as it will reset the survey. Instead, please use the "Back" and "Next" buttons in the survey to naviagte through the survey as needed.

Next

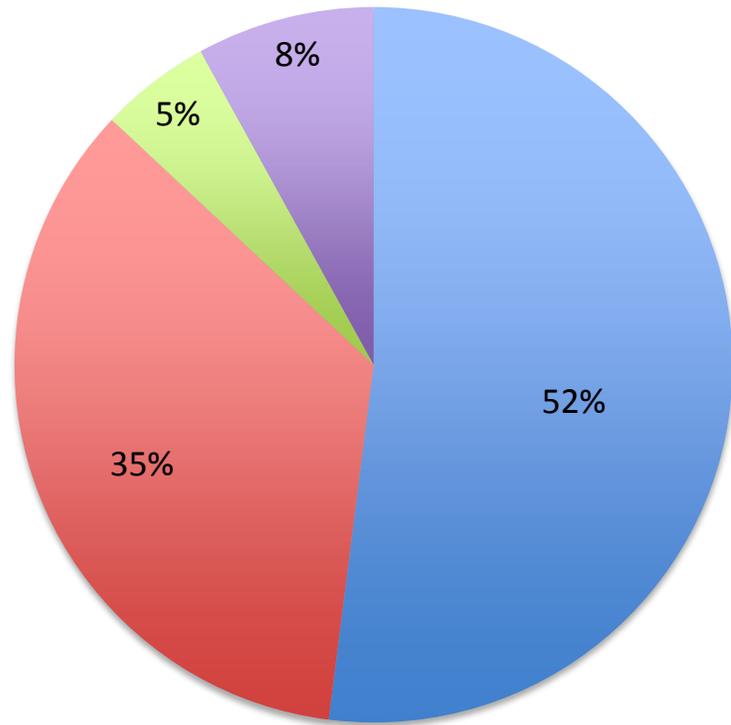
0%

Purpose:

To bring the perspectives of patients and caregivers to life on a large scale

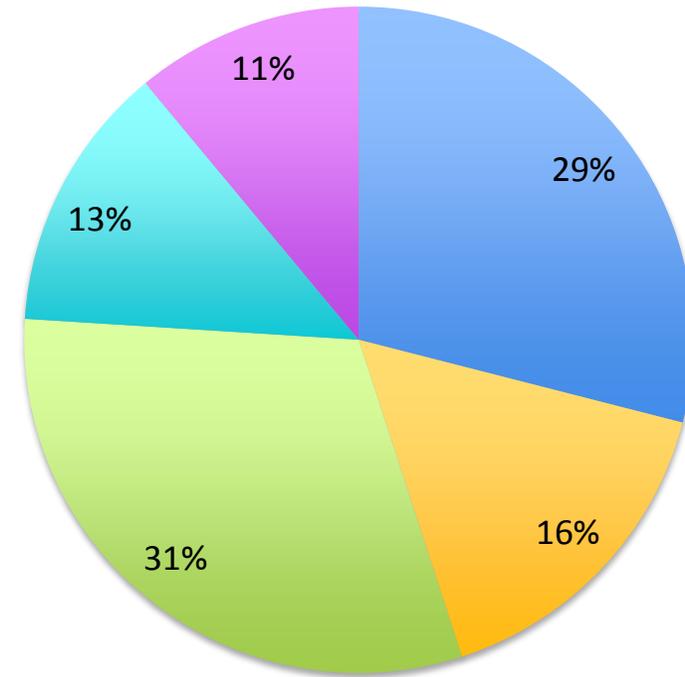
Ask your doctor about...

These patients/caregivers are largely responsible for initiating new treatment discussions, and...



■ You ■ A doctor ■ Other ■ No new Tx discussions

...will ask about new treatments and fairly frequently



■ At every visit ■ Every other visit
■ A couple times a year ■ Once a year
■ Never

Making Treatment Decisions

The e-patient plays a large role in making treatment decisions, regardless of the health condition(s) which affect them

In collaboration: 69%



Patient-driven: 20%



MD-driven: 11%



“Brand” Awareness in Pharma

Despite regular usage of their various medications, the majority of respondents had limited, if any, knowledge of pharmaceutical company behind production of their treatment

35%

35% didn't know any of the pharma companies that make the products they use

37%

37% knew some of the companies that make the products they use

17%

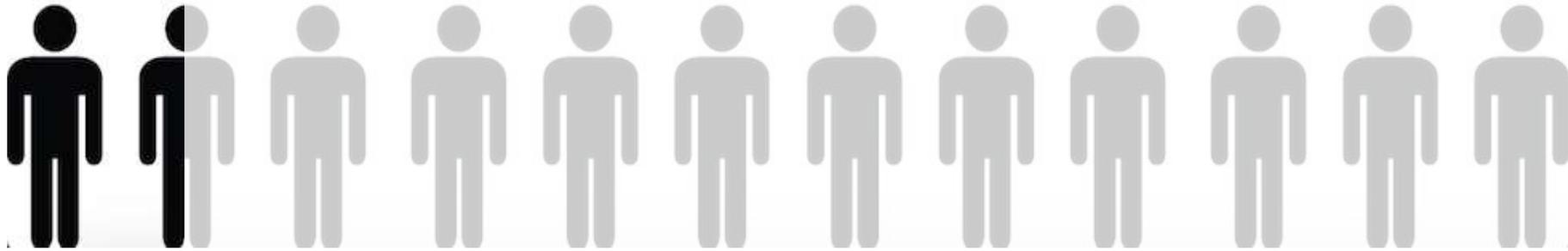
17% knew most of the companies that make the products they use

10%

Only **10%** knew all of the pharma companies that make the products they use

Relationship with Pharma

Although a patient-centric model is where US healthcare is going, serious inroads must be made to strengthen the relationship between patients and the industry

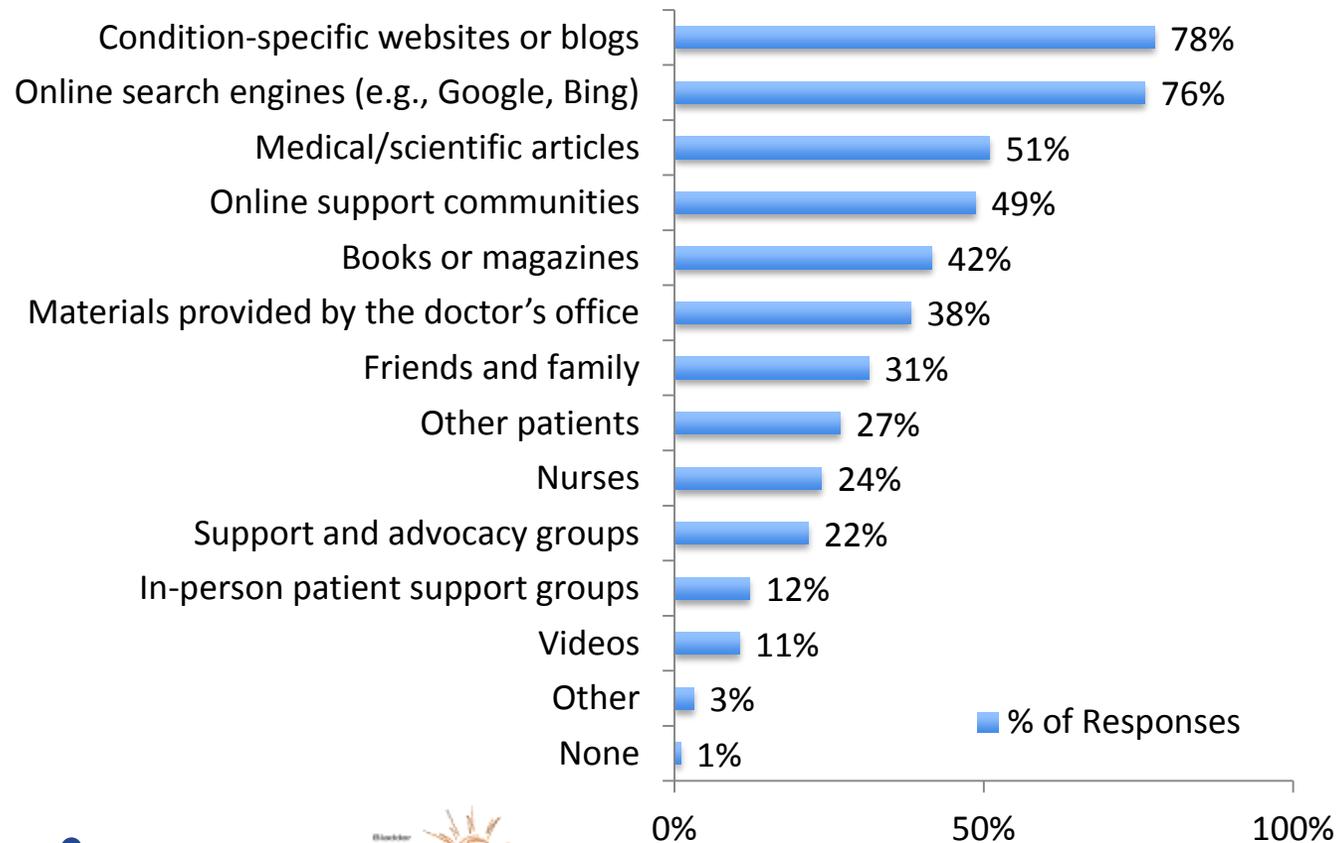


12% of respondents felt like they indeed had a relationship with the companies that made their medications; at best, it is said to be a ‘limited’ connection

Seeking Medical Information

Patients turn to a number of online sources to obtain information about their health conditions

Sources of information used for health conditions



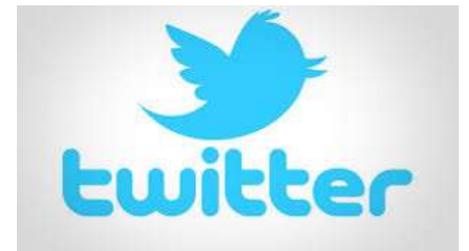
Condition-specific websites or blogs was also reported to be the **most helpful** source of information used to better understand patients' health conditions

#IWishMyDoctorKnew

“I wish doctors understood the devastation of living with side effects to meds. My primary doc does, but my cardio and rheumatologist don't.”

“I hope my doctors know how much I appreciate that they allow me to be a true partner in decisions about my breast cancer treatment.”

“I plan on living a long time with MBC. I am not giving in to this disease and will be whatever trial out there to give me more time.”



Takeaways

Many patients want to contribute to research, but they need better pathways to access researchers.

Technology matters a great deal.

Technology doesn't matter at all.