

# Cancer Patients – An Online Behavioral Study

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Feedback and Corrigan Consulting recently completed online research on the Consumer Decision Process, Online Support Forums and Key Influencers of Cancer patients seeking/selecting a health care provider.

The objective of the study was to understand the consumer community landscape online with four key questions:

- Where do existing and potential patients discuss Cancer services?
- What are they discussing?
- How are they discussing it?
- Are discussions influencing provider selection?

The ethnographic study was conducted entirely online by passively listening and observing behaviors. Thousands of posts and interactions were observed on dozens of notable channels where local residents and cancer patients asked questions, exchanged information and recommendations, and discussed options. The study was conducted by those with anthropological and sociological backgrounds and reliant on trained researchers rather than software algorithms to determine sentiment. The research began with an intense discovery period where researchers embarked on a platform and channel-agnostic search to determine where individuals having conversations about cancer, in a designated geography, were finding and asking for information, and followed with a mining phase of behavioral analysis.

## **Primary Channels**

The nature of the channels where discussion occurred in some ways framed our findings. In order of volume, the channels where we found cancer discussed by those in observed conversations were:

- Geographic-based forums
- Facility-specific reviews and review sites
- Condition-specific forums.

Geographic-based forums are those where location sets the stage for all other discussions; these include sites such as City Data, Topix, and other location-first channels. Strong local areas can have thriving geographic-specific forums where

healthcare recommendations are made to both longtime residents and newcomers. When they are weak, whether unpopulated and untended or distracted by politics, they require those seeking local recommendations to seek answers elsewhere.

Facility-specific reviews and review sites are also geographically centered, but are deliberately segmented by the name of the local brand, facility, or service and can take form within Facebook reviews, Yelp, Angie's List, and other sites. These outlets can provide lengthy, substantial narratives of full experiences that outline every moment – from intake to discharge to seeking a second opinion. However, for the most part there was limited discussion on the reviews themselves. These were opinions that stand relatively soiled and alone and are not a substitute for actual discussion, especially within cancer services and related issues where so much discussion and reassurance is necessary.

The final combined strength and weakness of reviews was the simple fact that one must already be familiar with the actual name of the facility (or the branded service) in order to stumble across these testimonials. Conversations in these forums are specific to brands and facilities – however, consumers would need awareness of these services or locations in order to find the conversations (here complex-branding issues can rear their head in unwelcome naming conventions or incorrect listings).

Condition-specific forums (i.e. Breast Cancer) are generally national (and at times, international) in nature and then segment into geographies only when necessary within the discussion. They focus on a specific issue or diagnosis and all issues related with a broad coalition of active users from many varying locations. From Bladder Cancer Support to Melanoma Research Foundation, these forums feature survivors, family, friends, and more discussing every aspect of the medical and emotional journeys ahead of those diagnosed with cancer. These are the strongest forums in terms of support and advice, but they have one crucial weakness based on how they are designed: they cannot support acute advisement on local resources or facilities because the number of people present from your local region at any one time would be so rare.

The most in-demand specialization discussions in this particular study included:

- Myeloma
- Melanoma
- Breast cancer
- Sarcoma

- Bladder cancer
- Lung cancer

Not only were these spoken of the most, but also aligned with those most willing to travel for specialized treatment services.

While these types of channels aren't unique when studying cancer discussion across the US, their specific use can change radically depending on the population lens used. We found in one study that a particular region lacked in-depth discussion by cancer patient (and related cohorts) on a local-geography level, which created an unusual situation for those seeking information, validation, or peers battling the same challenges. The result was a fractured decision journey that left those with questions at the mercy of the chance that someone from their local area in a large national condition-specific forum would happen to see their inquiry and respond with advice.

### **Audiences, Behavior, and Influence**

Condition-specific forums provide the clearest glimpse into cancer-audience behavior of any channel. Here participants they are among friends and reveal details others in geographic-specific and review sites would likely not understand. Within most discussions, at the bottom of their posted text copy is a footnote (the "signature" portion) where they reveal their history with cancer, with treatment types and dates, in the same way that those on computer forums list machine specs or as members of travel sites will list where they have visited – a shorthand to reveal details quickly so they can get to the process of exchanging information and get past pleasantries quickly.

We found all typical audience groups participating in conversations, from patients to family members, survivors to the simple wellness-seeker or family-history curator.

All cohorts also follow the three typical behavior roles that are important to acknowledge:

- *Participant* – An engaged consumer who posts textual commentary, opinions, statements, and more
- *Endorser* – Engages largely through endorsing actions such as Likes or Favorites; can also include, "This Review Was Helpful" buttons
- *Passive Participant* – Only there to read or gather information, often satisfied with finding similar questions and scanning for answers. May not join communities, and representative of those seeking but not comfortable engaging yet

Every social media user exhibits one or more of these behavioral roles when they interact online, but in looking at the consumer decision process of cancer – particularly at regional differences – the roles can take on more significant meanings. For example, in situations where participation is high, passive participants can find answers to their questions without asking; often this is because longtime threads or conversations are constantly updated with new experiences and opinions, whereas in situations where participation is light, passive participants and seekers have to continue to move on to find those opinions. An good example of this is the regional cancer center where locals had to ask for opinions on national message boards where few with direct experience in their geography could respond. This also has the adverse effect of ceding discussion to those with more national reputations by sheer volume of experience and repetition of the name.

The subject of influence then naturally arises from any study of the channels, people, and behaviors surrounding cancer – but the actual influencers are far more varied by name than any simple mention of a blog or a Twitter user with a million Followers. Influence within cancer discussions in this study was squarely with existing or former patients and/or their caregivers. Direct peers within online communities held the firmest sway, particularly if they had been diagnosed with the same condition. They may be carrying or relaying information from elsewhere (medical information given by physicians or supplied by a healthcare facility), but the important relay was that it came from a peer.

### **Factors Influencing Choice of Providers and Services**

The most important and influential factors expressed by those we observed were:

- Kind, attentive, and personal care
- Concentrated network of specialists focusing on particular cases
- Accepted financial coverage
- Breadth of specialized knowledge and professional experience
- Quality of the facilities
- Subjectively ethical practice philosophy

From these factors we could see there was an intense preference for a broad network of available specialists, be they inside or outside of a given facility. This also translates into a poor opinion of smaller treatment centers or practices that are perceived by many to provide recovery with the most common and well-treaded cancer manifestations, and/or show benefit from only the most generic methods. Given the importance of the condition-specific community, it was no surprise to see an eventual emphasis on dedicated cancer centers. While initial preference (and even framing of questions) leaned toward “local” as the defining factor, the whole of

discussion, especially by those later in treatment, focused on larger centers. This powerful preference for a broad network of available specialists considers the knowledge resources provided by specialized oncologists, the medical teams at their immediate disposal (having highly reputable specialized surgeons, etc.) and even private oncology practices run by specialists. Private practices, if they have strong connections to the large and successful centers and resources in case complications arise, are seen as worlds better than the heavily stigmatized “generic, canned, treatment kit.”

### **The Decision Journey**

Through the study we were able to document the specific journey that we saw these patients taking online – with their peers, family, friends, and more.

Patient journeys for the locality we studied followed a distinct pattern of:

- Pre-Diagnosis Stage
- During/Post-Diagnosis Stage
- Post Initial Treatment

The Pre-Diagnosis Stage contained general wellness-seekers aware of family health concerns and those concerned with potential symptoms. No action was necessarily taken in this stage except for research and investigation leading to an eventual visit for a more specific diagnosis. This stage takes place largely within common channels where the participants are already comfortable – be those geographic-specific or major general channels such as Facebook.

In the During/Post-Diagnosis Stage, assuming the diagnosis is cancer, we see an open discussion of “where to go for treatment.” A recommendation from the doctor who gives the diagnosis, scaling with their comfort with the doctor, heavily factors into treatment decisions. As diagnostic work is often not instantaneous, here we see patients considering alternatives in the midst of their actual diagnosis. They begin to branch outward from their geographic boundaries (especially in some observed regions) into the condition-specific message boards.

They create inquiries, chime in on existing threads and questions, and also silently lurk in discussions related to the suspected cancer type (often later engaging and admitting they did so early on). Their inquiries are quite often met with suggestions to consider distant options outside of their regional comfort zone. This particular suggestion surrounds itself with testimonies of those who initially sought local treatment. Some regret it, others do not – but it showcases the power of geography

and the local option always being considered first. Between this stage and the next is where most insurance coverage and cost concerns arise.

The final discussion-behavior stage of note was the one focusing on Post Initial Treatment. After initial treatment has begun, many variables can come into play, from expeditious and successful treatment to harrowing complications, which may persuade the patient to stick with their current center. At any point after the initial treatment has begun, desperate patients may switch centers – and in our study we found this likelihood to be documented far more than expected. Especially as local cancer resources (peer suggestions and reviews) dry up, many who switch document this frustration and willingness to travel. Since individual struggles can range indefinitely into the future until, ultimately, successful treatment is or isn't found, this point can stretch on for years and contain any number of facility changes. As such, many report back within these stages and document their journeys completely – all to be found by even the newest diagnosis. This was especially true within the condition-specific message boards. Caregivers can also be very involved in these discussions and can continue participating, sharing, and answering beyond the loss of their loved one.

This lends itself to reiterate the earlier point from the study on how a lack of local or regional discussion infrastructure around cancer can create a vacuum that the condition-specific boards try to fill. The expertise within these boards was entirely made up of those with a visceral connection to the condition at hand. Secondly, there was the experience with discreet doctors, facilities, treatment programs, and services they have each experienced – which immediately spirals into a massive web of recommendations if looking for specifics. In fact, the acknowledgement that their experience was anecdotal was often a first conceit in any response; however, it does allow the quality of their opinion to gel into major conceptual areas such as: being open to second opinions, not being satisfied with inferior care or a weak relationship with one's doctor, and being willing to compromise with other aspects (such as travel) in order to receive superior care.

### **Considerations for Health Systems and Providers**

The study raises significant questions as to how providers should approach and understand their audiences, particularly around cancer services. How does your local area fare with cancer discussion, particularly in the various stages? What role do you or your competition play in the questions themselves and how are you spoken of? But even before exploring those specific issues we can see special areas of consideration for *any* system or provider:

*Be where patients are naturally* and understand how they are utilizing the various channels, testimonies, and channels differently based on where they are in the decision journey. Understanding the impact of these opinions, from a strength and timing perspective, will be key to understand how you can join the conversation.

To that end, we feel it is crucial for you to *contribute and respond to conversation* – and to participate as an expert partner, or facilitator. Consider the roles involved in truly communicating to your audiences and from whom they are sharing and taking advice. How can your advice be shared? It may be that a direct representative is not the most appropriate ambassador. In fact, *patient peer ambassadors* bring the strongest influence on every level and on every kind of channel.

Finally it is important to ensure your *on-line presence is authentic and aligned with the provider brand* in more ways than simply the URL. From the content you provide, to allowing reviews – ensure that you are allowing yourself to be spoken of in the most aligned and correct ways. In several instances of our study we found Angie's List entries with misconnected names or Facebook Pages that didn't allow reviews – these facilities are stubbornly fighting against a tide that can easily pass right by them in the consumer choice discussions that are occurring – whether they participate or not.

Understanding consumer behavior as it relates to cancer services is important as it is one key service where highly specific conversations can influence consumer behaviors. Questions for your health care system to consider:

- 1) Where are cancer patients in our community having conversations?
- 2) What information are they seeking?
- 3) Are you participating in the discussion – how should you be?
- 4) What is the proper representative or voice of your brand?
- 5) Are you enabling conversations from your existing patients about your service offerings?

Take all of these elements into consideration as you consider how you can support cancer patients in your community and grow your patient base.

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If you would like to discuss these findings, or learn more about how this process can help your healthcare organization and its marketing efforts, we invite you to contact on the following individuals:

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