

Analysis of online community strategy: Pancreatic Cancer Action Network

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The Pancreatic Cancer Action Network is a national non-profit organization supporting the conquest of pancreatic cancer in a wide-ranging manner. The multi-faceted approach includes: backing private research for future treatments, supporting patient's needs, encouraging higher levels of public consciousness and increased government attention on financing cures for this type of cancer. The investment in research will enable scientists to advance early detection methods thereby providing improved treatments choices for patients. Supporting patient's needs help provide higher quality of life for those people that suffer from pancreatic cancer. Funding from the Pancreatic Cancer Action Network provides a voice in Washington DC to support federal funding. One program offered by the Pancreatic Cancer Action Network is called 'Know Your Tumor' which provides personalized information on the biology of the specific tumor a patient has in order to focus treatment in a tailored manner (Pancreatic Action Network, 2016).

This is important for four reasons:

1. Information assists in determining treatments that might not have been considered otherwise and could improve the quality of life for the patient.
2. Clinical trials could be improved by this information.
3. Oncologists and patients can make better treatment decisions.
4. Future research and development for new therapies and diagnoses for pancreatic cancer are enhanced.

The Pancreatic Cancer Action Network has teamed up with Perthera, a personalized therapy company, in an attempt to coordinate tumor testing and expand personalized medicine. Personalized medicine analyzes the molecular profile of a tumor to obtain improved understanding of how specific tumors function and develop ways to prevent them from growing that are tailored to the specific tumor.

The Pancreatic Cancer Action Network has created an online community through their national website, www.pancan.org. From the site community members can connect with local chapters of the organization to get involved with events in their area. For the state of New Jersey they have two chapters, one for northern New Jersey and the other for central New Jersey. The writers focused on the Northern New Jersey Pancreatic Cancer Action Network, https://www.pancan.org/section_get_involved/volunteer/affiliate_details.php?id=70. The local chapter has developed ways to reach out to the community and connect with those interested in the organization. This has been done through several different websites:

- Purplestride - <http://www.purplestride.org/newjersey>
- Facebook - <https://www.facebook.com/PanCAN.NewJersey>
- Twitter - <https://twitter.com/PanCANNJ>

These sites are used as tools to accomplish their goals of supporting research for treatments, filling patient's needs, enhancing public consciousness of the disease and increased government focus on pancreatic cancer. Through these online platforms and the events Purple Stride, a 5K walk/run, and Purple Light, a vigil for those that lost someone to pancreatic cancer, the Pancreatic Action Network further their community outreach program to recruit volunteers across the United States (Pancreatic Action Network, 2016). The affiliate chair of the Pancreatic Cancer Action Network for Northern New Jersey, stated that she actively promotes social media in her efforts (personal communication, March 16, 2016). She goes on to say that it is her role to recruit and retain volunteers in the organization. This is important because according to Richard Millington in his book entitled "Buzzing Communities, How to Build Bigger, Better and More Active Online Communities", it is less of a challenge to get someone to participate in an online community two or three times than it is to get them to be steady, vigorous members in the

community (Millington, 2012, p. 62). The affiliate chair said that the Pancreatic Cancer Action Network is used to promote their signature fundraising event, PurpleStride NJ. This event is used to solicit funds for research and governmental support (personal communication, March 16, 2016). PurpleStride is significant because according to Millington events are critical to the evolution and progress of communities (Millington, 2012, p.163). He continues by saying events bond members and generates the social basis for expansion (Millington, 2012). The affiliate chair believes one of the biggest assets of the online community is that it provides information to those affected by the disease that can provide immediate relief during the troubling time (personal communication, March 16, 2016). She has been a volunteer since her mother passed away in July 2011 and is able to provide valuable insight for patients and family.

In an interview with the social media coordinator for the Pancreatic Cancer Action Network for Northern New Jersey, he discussed what he does to promote the organization and keep everything updated. The structure of the Pancreatic Cancer Action Network of national and local chapters work together to keep their information current. At the national level they have administrative rights over the Facebook pages of the local chapters; however, the social media coordinator is able to post to the local Facebook page, which he does about once a week. On a monthly basis he stated that he changes the Facebook page to reflect upcoming holidays, which is similar to what is done on the national level. The social media coordinator did not believe that the changes increase the number of views of the page, but he did say it keeps the page, “fresh and prevents it from going stale. [It is important] to keep it new so that people go back to it over and over” (personal communication, March 17, 2016). Similar to the Facebook page, he tries to post to Twitter on a weekly basis, often times using similar messages.

Another approach that the social media coordinator uses to keep the content of the pages constantly changing is the implementation of “Meet Me Monday”. On Facebook, a different volunteer is profiled. Recently one of the profiles received over 100 likes and 400 shares, which is above the usual amounts. The concept of profiling also occurs in the fall as they approach the date of their annual Purple Stride event when different teams are highlighted. This helps generate more traffic on the site, which in turn helps to promote the fundraising event. The practice of profiling volunteers along with posting and changing the Facebook page content in a regular frequency is aligned with Millington’s (2012) recommendation to maintain a steady pace in the publication of content and consider what elements are more popular. As a social media manager he has been able to identify the profiling of volunteers and community members as a contributing factor to the success of the page (personal communication, March 17, 2016).

Another method to help promote the organization in the social media world is the use of hashtags. The hashtags used by the Northern New Jersey chapter are aligned to those utilized on the national level. The main hashtags used are #wagehope, #purplestride, and #purplelight. The last two help promote two key events the chapter hosts every year.

When asked about the different resources being made available to doctors, caregivers, and patients on the website, the affiliate chair responded that this is not considered on the local level. She continued to say that over the past year the national site was changed to provide a portal for these groups regarding clinical trials. Previously the national headquarters had to be contacted in order to obtain this information.

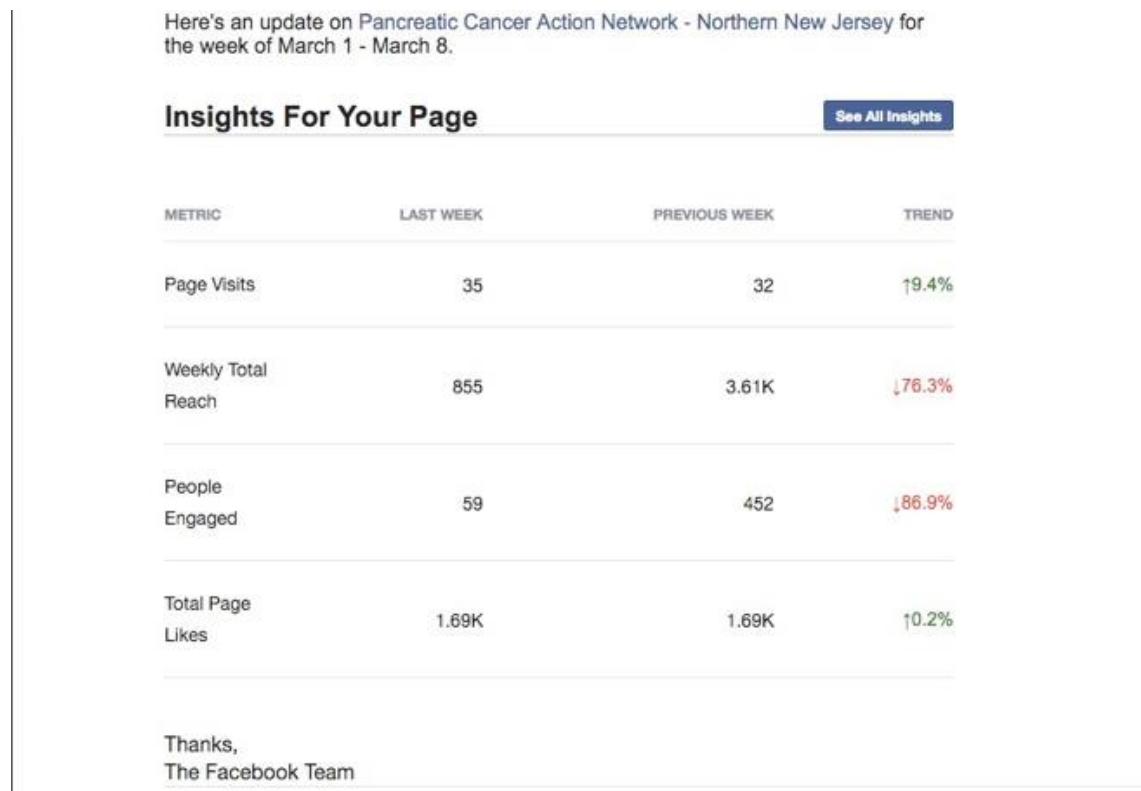
The three main websites utilized by the Pancreatic Cancer Action Network for Northern New Jersey include the one for Purple Stride, Facebook, and Twitter. Each of these sites is capable of providing some sort of metric as to how they are used. First, the Purple Stride site is

not actually organized and managed by the local chapter. Instead it is operated on the national level and contracted out to Kintera, an organization that assists non-profit groups with fundraising; therefore, the local chapter is not able to provide any analytics about the site except for what they witness in teams signing up and funds raised for the annual walk/run event.

For Facebook and Twitter the information can come from the programs themselves and most of what they rely on is easily viewable by the public. One of the main items the social media coordinator checks is the number of likes each site has received. The affiliate chair estimated that they have one or two additional members each day based upon the email communication she receives from people with questions about their organization. She continues to say that the traffic on the site increases quite a bit as they approach events that are sponsored.

Both Facebook and Twitter make it easy for others to share information and according to the social media coordinator, this is how many people become involved in their online community. People will either post or share information from the sites. He stated that he is unable to track how long someone stays on the site, but the affiliate chair mentioned that she is aware that new contacts take the time to read everything on the site and explore each link that is made available.

The social media coordinator was able to provide us with a snapshot of a report he receives weekly from Facebook (Figure 1). From this report you can see the number of page visits compared to the previous week along with the number of people that were engaged and liked the site. These numbers can help shape future Facebook postings. He did not have information regarding their Twitter account except to say that he mainly focuses on the number of followers the account has.

Figure 1 - Facebook report for the week of March 1 - March 8.

In an article for Sprout Social, an online platform that provides social media analytics tools (Sprout Social, 2016), Alicia Johnston (2015) reports on strategies recommended by five social media branding experts. The strategies are: defining the role of social media in the communications strategy, determining the primary goals (e.g. retaining donors vs. generating brand awareness), identify the target audience and avoid generalizing to public in general, choosing the social networking platforms that best suit the goals of the organization, creating a content strategy by selecting appropriate content and frequency of information dissemination, prioritize engagement as establishing social relationships is the foundation of a social networking site by responding to posts and using hashtags, empowering community members and promote content across platforms, and finally, track and measure results (Johnston, 2015).

In reflecting upon the use of the Pancreatic Cancer Action Network - Northern New Jersey Chapter, both the affiliate chair and the social media coordinator have clear goals for the online community. They are looking to raise awareness of this insidious disease and raise funds to find the cure. The social media platforms are used to keep members informed of local events and fundraising. The target audience is clearly comprised of volunteers who are either suffering the illness, know someone who is, or have lost a loved one to pancreatic cancer. The social networking tools of Facebook and Twitter are also appropriately selected to meet the organization's goals and the content is shared at an appropriate frequency. The use of hashtags is evident with the selection of phrases such as #wagehope #purplestride and #purplelight and their community is empowered through posts where volunteers are featured and allow for cross-promoting the content. However, as explained by the social media coordinator (personal communication, March 17, 2016) although data about the followers on the social media accounts is available it is not tracked or analyzed. A recommendation of the writers is the consideration of online tools such as the ones provided by Sprout Social or Google Analytics (Johnston, 2015) as it could provide the organization with reports that shed light on areas such as donations patterns, audience changes and engagement. Looking at this information would allow the Pancreatic Cancer Action Network - Northern New Jersey Chapter measure progress towards their goals and make adjustments to their social media strategy in order to maximize their efforts and focus on the plan of action that yields the best results.

References

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Appendix A

Transcript of interview with Social Media Coordinator

Transcripts of the telephone conversation with the social media coordinator on Thursday, March 17, 2016 at 4:40 (duration 27 minutes) by Ericka Collado.

He was called as agreed in an e-mail exchange previously to the interview day. When he answered the phone he was in the process of answering the online survey so we decided that he would submit the portion that he had completed of the survey and we would discuss the answers to the rest of the questions over the phone.

Answers to the online survey:

What is your title within PANCAN?

Social Media Coordinator

Do you work or volunteer with PANCAN?

Volunteer

What are your responsibilities within PANCAN?

I am responsible for posting information to social media and monitoring the social media sites for our affiliate.

How long have you been with the PANCAN?

I have been with the Pancreatic Cancer Action Network since 2007.

What is PANCAN hoping to accomplish through their online community?

Pancan is hoping to raise awareness about the disease as well as inform the public in order to achieve the ultimate goal: advance research, support patients and create hope for those affected by pancreatic cancer.

What is PANCAN hoping to accomplish through their online community?

*This questions was left unanswered as he reported that the was on question #7 so the phone conversation started by asking question #7

How many visitors do you get a day on the site?

*This question was not asked (see comment on question #5) but based on information provided further it can be inferred that he doesn't track the amount of visitors a day

How many new visitors do you have each day?

* In an effort to answer this question he offered to send the most recent report from Facebook via e-mail. The screenshot of the e-mail is enclosed below.

Here's an update on Pancreatic Cancer Action Network - Northern New Jersey for the week of March 1 - March 8.

Insights For Your Page

[See All Insights](#)

METRIC	LAST WEEK	PREVIOUS WEEK	TREND
Page Visits	35	32	↑9.4%
Weekly Total Reach	855	3.61K	↓76.3%
People Engaged	59	452	↓86.9%
Total Page Likes	1.69K	1.69K	↑0.2%

Thanks,
The Facebook Team

What is the average length of stay on your website?

N/A – he wouldn't be able to tell.

How often does the design of the site change? How have these changes benefited PANCAN and the online community?

The social media coordinator changes the look of the Facebook page once a month as he customizes it for the different holidays during the year. This practice is based on how the Facebook page for PANCAN at the national level is managed. He doesn't believe that these changes produce and increase in views but it keeps the page "fresh and prevents it from going stale. [It is important] to keep it new so that people go back to it over and over."

What support is available to community members should they have difficulty with the website?

[They can] email the affiliate and there is also a toll free number they can call for the PurpleStride website

Do you track data?

No, I don't track data. [other than] people posting questions or comments

What is the most popular area of the site? Does this change throughout the year?

In Facebook is the newsfeed section and it doesn't change.

How can community members take on a larger role within the online community?

They can post comments or pictures and share the postings [this helps] broaden the reach

There is not much needed in Twitter [but followers] can post and retweet.

How do community members interact with both the organization and each other using your site?

They post things to the site and send messages through the page.

Are active members of the community rewarded for their participation?

There is a volunteer appreciation month [I believe that] sharing information and learning new things [is the reward] For some people sharing their story it is a reward [as well as to] interact in the forum. There are contests thru PurpleStride website. For example, a VIP tour to the Met Life Stadium or an iPad for the people that raise the most funds. (But this is all handled at the national level).

Have people removed from your online community? If so, can you share why?

We don't track that. [They probably] stop following because they move (Since the online websites pertain to local activities the social media coordinator's opinion is that if they move out of NJ then they need to follow a local chapter in the new location).

How do you measure if an aspect of your community is working as planned?

By the increase in likes (Facebook and Twitter).

Additional comments:

The following comments were part of the conversation and are relevant to the project but did not necessarily fit a question in particular.

- There are initiatives (in lack of a better term) on Facebook like:
 - “Meet Me Monday” where they profile a volunteer. This helps in increase the views on the page and broaden the reach. For example, the social media coordinator explained that the most recent post of this type got 100 likes and 400 shares. He explained that this exceeded the usual amount of likes and shares.
 - Leading to the Purple Stride event in November they profile team members (NJ affiliate) in order to generate traffic.
- Use of hashtags: It is based on what the national association uses but are:
 - #wagehope
 - #purplestride – Purple Stride is the 5k walk/run in November. Last year 2,400 people participated and they raised \$370,000.00
 - #purplelight – Purple Light is a vigil that takes place on April 3rd (this year) where people that have lost someone to pancreatic cancer gather. The names of the deceased are read and the loved one raises a glow stick. At the end there is a multitude of sticks that glow in the dark in honor of those who lost the battle to pancreatic cancer. The last gathering brought together 300 people.
- Social Media accounts at the time of the conversation:
 - Facebook – page was created five years ago (2011) and has 1,691 follower
 - Twitter – page was created three years ago (2013) and it has 635 followers
 - The social media coordinator aims to post once a week on both accounts. He usually posts on Facebook and it is automatically posted on Twitter. Sometimes he edits the post for Twitter.

- The Facebook account at the national level posts 2-3 times a week.
- PANCAN at the national level guides the use of social media by the state chapters. As reported by the social media coordinator there are 50 Facebook pages in the United States. The association at the national level is able to post to the local chapter Facebook pages. The social media coordinator is not sure how they do it but the national association has administration rights to post to the Facebook pages of the local chapters. There is a Twitter account at the national level but the posts are different from the local chapter accounts.
- Purple Stride website – This website is set up at the national level and it is managed through the Kintera site. It is a platform where people can sign up to raise funds and/or support a team. Individuals and teams are able to set up a page within the platform. The donations go directly to PANCAN at the national level.

Appendix B
Transcript of interview with the Affiliate Chair

Initial contact was done via email and she agreed to answer an online survey. Questions and answers are below.

What is your title within PANCAN?

Affiliate Chair

Do you work or volunteer with PANCAN?

volunteer

What are your responsibilities within PANCAN?

My main role is overseeing all Affiliate core leadership roles and activities, offering support as needed, keeping Affiliate on track to meet our goals and stay within our budget. To that end, I encourage and facilitate collaboration and cooperation among the core roles, I keep them up to date with National news and updates, I work closely with each one to assist them to meet (or exceed) their goals, I keep an active eye on all of the general volunteers and work closely with the Volunteer Chair to encourage new volunteers and retain current volunteers, I attend and promote participation in all of our awareness events and PurpleStride, I am available for media events and actively promote our social media, I represent the Affiliate at many and various other events, I am often the first contact a person will reach out to when they are looking for pancreatic cancer information - I try to respond as soon as possible as most are in a crisis state, among other responsibilities. I set an example for the core roles as well as our general volunteer community.

How long have you been with the PANCAN?

I became a general volunteer in 2011, after my Mother passed in July of that year.

What is PANCAN hoping to accomplish through their online community?

We reach out to connect with people, either just entering the pancreatic cancer nightmare or those already immersed, to offer information about our patient support services, our local and national advocacy for both awareness and research funding, our local activities (non-fundraising) and our signature fundraising event, PurpleStride NJ. We hope to extend our collective reach, so that anyone confronting this horrible disease, will know where to turn for help and guidance. We hope to make the color purple as recognizable to pancreatic cancer as pink is to breast cancer. And, ultimately, we hope to change the course of this disease by finding a means of early detection and viable options for a cure because an 8% five year survival is just unacceptable.

How many visitors do you get a day on the site?

I do not know. Those numbers would be available to our Social Media Chair and our Media Relations Chair. I do know our numbers increase exponentially with a "sponsored" event posting.

How many new visitors do you have each day?

Again, those specifics are not available to me. Based on email inquiries I receive, I would guess, locally 1 or 2, and nationally many.

What is the average length of stay on your website?

Again, this specific information is not available to me. I do know, from communications with new contacts, that they read it all, click on all links and take it all in.

How often does the design of the site change? How have these changes benefited PANCAN and the online community?

Our design changes have both a seasonal as well as current topical basis. So, the main National site information categories remain consistent, unless and until new information becomes available, but the eye-catching pictorial focus changes as our topical focus changes. On a local level, we change our pictorial information (substantive info is constant) quite often to highlight our activities and promote upcoming events.

What support is available to community members should they have difficulty with the website?

We have support on both a local and National level. I personally, have been on the phone, talking a volunteer through the registration process for PurpleStride. They had met me, had my contact information and felt comfortable asking for help.

Do you track data for the different types of users, for example, do patients display different habits on the website than doctors or caregivers? If so, how have you modified the design of the website or other media to reflect these differences.

That is monitored on a National level, not on a local level. Last year, National modified the National website to open a portal for doctors, patients and caregivers to access our clinical trials database, which previously was only available through our National office.

What is the most popular area of the site? Does this change throughout the year?

The area of interest to an individual depends on their area of concern and current status of their disease journey. So, for example, the newly diagnosed and their families are only interested in our patient services as well as credentials. As they proceed through diagnosis and treatment, depending on their path and personal interests, they look into our other information.

How can community members take on a larger role within the online community?

By sharing our information with their personal communities. Pancreatic cancer can affect anyone at any time... you never know who will need our help next.

How do community members interact with both the organization and each other using your site?

Typical communications and sharing of information.

Are active members of the community rewarded for their participation?

National will highlight community members from time to time within the focus of the current topic. On a local level, we encourage as much exposure as they are willing to give, and honor our active volunteers annually.

Have people removed from your online community? If so, can you share why?

Yes, people leave occasionally, mostly because their grief, frustration and anger at the disease has resolved to a point where they decide to move on. The pancreatic cancer community is a rare combination of victims (powerless against their disease), survivors (who are forever changed from the process) and family members and friends of both of the preceding (many have lost their loved one), who have a need to actively work, in whatever capacity, to create change for the overall picture of this horrible disease.

How do you measure if an aspect of your community is working as planned?

Feedback from the community as well as results.

Additional Comments