

INNOVATIONS CONFERENCE -- NATIONAL CANCER INSTITUTE

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GRAMA: I'm Lakshmi Grama from the Office of Communications and Education at the National Cancer Institute.

So at NCI, we have, over the past few years, used many different things. And, in a way, it's -- it seems like dabbling, but it's a learning process, because the tools themselves are coming on board. We're trying to learn what the unique aspects of those tools are, and how -- which tools to pick for what purpose.

So one of the first areas that we looked at was what you might call episodic interaction with communities, with stakeholders, with groups. You have a question, you have some issues, you want input. And what are the kinds of tools that you might use for that kind of episodic interaction?

I have here an example. I didn't have a screenshot from when we used it at NCI as part of our project to improve our website. So this is IdeaScale, one of the ideation tools that you just heard about.

And IdeaScale is a tool where you can post ideas, you can open it up to a community of people, ask them for their ideas on various topics, and give people the ability to vote, to agree, disagree, comment, take the thread further.

At the same time, along the same lines, at NCI, when Dr. Harold Varmus became director of the NCI, one of his major interests was in developing what he called the provocative questions. And this was kind of what would shape next generation of research, what are the key questions that need to be answered. He approached it pretty much with -- I mean, this was his vision and he used workshops and he asked us to set up a website, where people could come and researchers, interested members of the cancer research community, patients could come and post difficult, complex questions that they thought needed to be answered.

We didn't use a fancy ideation tool for that. We used a website. And people came in, put their comments, commented on ideas that other people had provided.

These were then analyzed by the project team. I was not part of the project team, but this was analyzed by the project team and ultimately led into an RFA that hit the street last month, that were these -- several of these questions that emerged from the online and offline discussions, went into this RFA. So that's an episodic interaction that happened.

But what I'm going to talk more about is the engagement with communities of practice, because these are groups of people that are engaged on a more, you know, in a -- in a very different timeline. It's an ongoing engagement.

These are people who come together to share ideas, share expertise, share experiences and best practices. And that is, again, a very important part of making sure that these communities are able to implement the things that they need to implement.

The -- another community that we found very successful was the U.S.-Latin American Cancer Research Network. Now this was a challenging community because these were people spread out over Latin America and the U.S., many of whom had never really been involved in communities -- of online communities of practice.

The project leader at NCI was himself very skeptical. "How can I go to these people, researchers in Latin America and tell them, 'you've got to be on this Facebook-like thing'? This is not going to work." But it was interesting. We tried it.

And, overall, it's been -- it's been successful primarily because these people wanted to discuss very specifically things about clinical trials protocols. They wanted to talk about it in a safe, secure place, in a confidential way. And a lot of -- there's been a lot of discussion.

I don't know yet whether, as a result of this, they've come together to actually launch clinical research protocols. But there is a lot of comments and discussion. And as Chris said before, they're, -not everyone is commenting and participating to the same level.

But there are a lot more views of what's happening than there is active participation in the discussion. So that was, again, going to using off-the-shelf platform, some challenges there. Suddenly, one day, we found out that initially when we started, Ning was free. You didn't need to -- you didn't have to pay.

And then, suddenly one day, we found out you've got to pay to have your network on this platform. And then we had to figure out how do we pay a company that's never done really business with the government?

So it all got into procurement related issues. They don't know how to deal with, you know, our acquisition mechanisms. So it was a learning experience, but we managed. And we were able to continue the network.

Then we came to a more challenging question, and this is an example of this. Within -- at the National Cancer Institute, one of the major programs is cancer control, as you might imagine. And cancer control in community settings is a very important part of our research agenda.

And we've had, for a very long time, a Web -- it's almost like 10, 12 years, I think -- a website called Cancer Control Planet, which was supposed to bring together a lot of the community-based interventions as well as evidence-based interventions that have worked in communities so people would be able to use them in their own communities.

So there are -- there's -- there are many steps to implementing these community-based cancer control programs.

One of the things that people felt was there was -- it was a static kind of thing, where you pushed out information. You were not able to engage the community. So this is what we did at that time, was

a forum, a community of practice called Research to Reality. And it was really a combination of many different things.

We started off by looking at what communities of practice needed. We looked at what were the things that would strengthen communities of practice, and one of them was you needed to bring them together with a very focused project, and then use that to start discussion and conversation.

So we started what we called cyber-seminars, where we had these, you know, discussions about various topics or presenters presenting topics, and then used the Research to Reality discussion forums to continue the conversation that had been started through these cyber-seminars.

Again, we use Drupal -- I'm talking about technology, so I wanted to give you an idea of what lies under the hood of some of these things. Drupal is an open source free content management framework that is actually supported by a very large community of developers. And you get a lot of these different modules that, you know, developers can put into your website, your forum.

So there -- it comes with its own discussion module, events modules, blogging, all of these aspects. So some of that we've incorporated into the Research to Reality, which is an online community of practice. Again, it's -- it needs a great deal of effort to keep the community of practice going.

You need to have people who are feeding conversations, who are providing -- you know, getting people to talk about different issues, and also trying to, as we did with this, we launched a new mentorship program as part of this, where we were pairing up experienced cancer control people with new young people who wanted to get into the field of cancer control. And they're -- that became its own mini-community within the larger community.

But, really for us, the key takeaways have been that, you know, communities of practice, in order for them to work, they need to have a need to come together regardless of the tool. There needs to be a problem, an issue that they care about, that they're passionate about. And without that, there's no point in having the tool.

The tool is only one channel of fostering knowledge sharing and development of best practices. We've used it with newsletters. We've used it with cyber-seminars. So it is just one aspect.

And, certainly, making sure that we have sustained and engaged community leadership and main management is critical. Knowing what are the hot button issues for your community, being able to develop content related to those hot button issues as to feed that conversation, as you said, to have that happen, and then getting people to weigh in.

And then, at the end of it, almost, taking an approach where you have someone summarizing the conversation, so it's not just these bits and pieces of conversation from different groups, but that there is some sense of, OK, here's what we learned from this exercise. So all of that has been, again, possible only because we've had people who have been dedicated to sustaining and keeping that community engaged.

Thank you.

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