Global BC Impact Advocacy Webinar Series

Webinar 4: Focus on Health Literacy

Patti Fine Jewell, *Pfizer*: So we have come together today to talk about health literacy. This is a topic that we chose to focus on because we see that there's data that shows that overcoming health literacy barriers can improve patient outcomes. Having information that patients can understand can empower us to become more active participants in our healthcare. It can enable better shared decision making and even help us achieve greater health equity over time.

So, I really want to thank our Planning Committee, if you can go to the next slide. We have five advocacy leaders from around the world that we at Pfizer have spoken to about what topics would be of most interest to the advocacy community. What would be helpful for us to dig into in order to learn more about and showcase examples of advocates doing programs around the world that we can all learn from each other on. So thank you, Bertha, Conchi, Renate, Shirley and Ranjit. We always appreciate your insights and guidance and advice.

So to lead our discussion today, I'm very happy to introduce Renate Haidinger. Renate has been, if you can go back one slide please. Thank you. Renate has been a breast cancer survivor since 2000. She's a medical journalist and the founder and president of the German Breast Cancer Association. She specializes in educating the lay audience about breast cancer through doing interviews with experts. Renate serves as an active member of committees for the ABREAST Registry, the SUCCESS trial and a large German study group. Renate also serves as president of the General Assembly of the ABC Global Alliance. So, without further ado, Renate over to you, to lead our conversation today.

Renate Haidinger, *German Breast Cancer Association*: OK. Thank you very much Patti, for introducing me and welcome everybody to our webinar and we hope that you all get ideas on how to support patients to understand whatever their healthcare providers will tell them and to make then good decisions. So personal health literacy. And there is a difference. The degree that a person can find, understand and use information and services related to their health. So it's very important in the beginning you learn or you hear a lot of terms that are difficult to understand and we want to support altogether, want to support patients to enable them to do that better, but there is also organizational health literacy. So what that means it's the degree to which an organization and people within – healthcare providers, physicians, nurses and so on – equitably help people find and use information and services related to death. To health. Sorry. And so that's what we want to talk about.

And we have three wonderful speakers today who developed programs and a video to support patients in doing so. So who are the speakers? It's Ranjit Kaur. She's a breast cancer survivor and patient advocate from Malaysia. She is a board member of the ABC Global Alliance and on the Board of Directors of Reach to Recovery International. Also Sue Friedman was a practicing small animal veterinarian when she was diagnosed with breast cancer at age 33 and afterwards learned she carried an inherited BRCA2 mutation. After treatment, she founded the nonprofit organization Facing Our Risk of

Cancer Empowered, or FORCE, to help people and families facing hereditary cancer. As Executive Director of FORCE, Sue directs their education, research and advocacy programs. As an advocate, Sue has a passion for improving health communication between patients and their healthcare teams by improving health literacy in society as a whole. And the third speaker will be Reagan LaBor. She's a patient advocate from North Carolina, USA. She has been a member of Team PEN, the Patient Empowerment Network, for two years, and helps to bring valuable resources to the cancer community. Remember, after the three presentations, we will have time for questions and answers, for Q&A. So write into the chat if you have any questions. Thank you very much. So now Ranjit, the floor is yours. Tell us about the video that you developed.

INFORMATION AND NAVIGATION FOR TREATMENT OF BREAST CANCER IN UNIVERSITY OF MALAYA MEDICAL CENTRE

Ranjit Kaur, *Breast Cancer Welfare Association Malaysia*: Thank you for introducing me, Renate, and I'm really pleased and I would like to thank the organizers for inviting me to talk about this health literacy project that I have done. And may I have the next slide please. So this was done in the University Malaya Medical Center. It's a Medical Center that provides services to all for all kinds of diseases. And in this particular aspect we were doing, we did an information and navigation tool for treatment of breast cancer in that particular Medical Center itself.

Next slide. And breast cancer is the most common cancer in Malaysia. Like other countries. Next slide. So there was some studies done and one of them was the grounded explanation of why women present late with advanced breast cancer in the same university, next slide. So there were some top ten supportive care needs that breast cancer patients had at that time from that study, and some of them were a lot of fears about return, the cancer returning, cancer spreading, financial issues and various other issues, but mostly also to do with delay in treatment and diagnosis.

Next slide. So the rationale to set up this health literacy tool was really for advanced breast cancer presentation, which may include diagnosis and treatment delay, and also low breast health literacy among the patients, and shortage of resources to cope with emotional distress, and improving of adherence to treatment, which may improve survival of breast cancer patients. Next slide. And issues that led to this particular tool was inadequate doctor-patient communication, complexity of the hospital set up the different departments, patients requiring numerous tests, which is difficult to understand, inability to understand doctor's language and the multi-modular treatments in cancer, and also losing confidence and momentum to continue with treatment which can take months, limited consultation time with the doctor.

Next slide. So the project objective was really to improve health literacy using a linguistically appropriate tool which is in the form of a video, and this was all about breast cancer, navigation and orientation for new patients in admission in the hospital and also multi-modular treatment processes. So to provide support for women undergoing breast cancer treatment, to provide information on treatment of breast cancer to the public as well.

Next slide. The action and implementation actually started from recruiting myself as a manager and we started with script writing which was done by the doctors, and recording which is in October to December 2013. And the production of the footage was completed in April 2014 and then a pilot study was done to see whether this really worked, and this was in June to August 2014 and the implementation was in 2015. Next slide. And so let's talk about the script writing. The doctor-patient-advocate partnership was very interesting. There were some challenges: we had to have numerous discussions and it was a learning experience for all of us and then also recruiting a model patient. She was actually a patient who was a nurse. She was a past patient, so a survivor. And she was previously a nurse in that same hospital. And the first draft of the script, which was done in English by the doctors, had a lot of medical jargon. So we had to go through some a few rounds of a revision of the draft, which was done through discussions between the patient advocate like myself and trying to change that to lay language and also recruitment of doctors as narrators and script translation.

Terms used in other languages – it was very interesting because this was a challenge where we found that different doctors were using different terms. Like for example for chemotherapy, one doctor was using one term in the Chinese language and in the same language another doctor was using a different term. So it was interesting and this was a learning experience.

Next. The footage was designed in lay language in three languages, the Malay language, English language and Chinese language, and we limited it to 12 minutes in each language so that it doesn't it, it creates a sort of like a good attention span for the patient who is newly diagnosed as well. Next slide. So challenges and preproduction preparation was first of all, getting approval from the Medical Center authorities and Security Department to ensure that we were not breaching any of the rules in that particular Medical Center and then engaging the production crew. And distribution of tasks for various people and screen tests for the doctors, nurses and the model patient recce the scenes and venue. So we had to go around to look for which venue to be used for different scenes within the Medical Center itself, and ensuring that the wardrobe of the speakers was appropriate for shooting the footage, and also the different type of props. And then we developed call sheets for each session like date, time, description of scene, location, props, the talent and also the cameras, sound control and floor plan within the Center. Next slide. And then we had shoot and postproduction. So we had to do the scenes and the events. The actual shoot was just four full days which had a timetable for the healthcare professionals. We had to make sure they were available for that particular time and come in and we quickly do the shoot. Now the shoot was actually done during the actual hours of the hospital itself. So we did not sort of do a shoot at non appropriate hours. So everything was done as and when the situation was happening in real, real situation. So there was a lot of cutting that had to take place while the shoot was done because there was noise sounds from the patients and things like that. So it was interesting, but then we did not shoot any other people you know just to respect that and also to follow the rules. And there was offline and online preview which we had to keep doing. There was a revision of the online work that we had done and post-revision preview, and then we had to do the designing of the DVD cover. So it was a lot of teamwork and a completion and development of the DVD which was prepared for the patients and then we had also later on posted it on the YouTube.

Next slide. And the information in the footage itself was all about treatment, preparing for surgery, during surgery, after surgery, preparing for chemo, during and after, and radiotherapy and the other treatments as well, including hormonal treatment and navigation through the Medical Center in the different departments to make sure that they know where to go and also the survivorship period as to how life can be lived after treatment is over, like importance of eating well and also physical activity and the follow up and surveillance of recurrence and new cancers. That's how it ends, the footage ends.

Next slide. So the DVD was given to patients in the Medical Center upon diagnosis, and there was also, there is also orientation for the new patient at the breast clinic when the patient will watch the footage in the presence of the nurse. And it is freely available at the Medical Center website and you can also see it on YouTube as shown here. Next slide. And with that, I wish to thank you for listening to me.

Renate Haidinger: Ranjit, thank you very much. There seem to have been a lot of challenges around the video filming and maybe we talk about later and go on at the moment. So Sue Friedman, so please tell us about XRAY, your program you have.

EXAMINING THE RELEVANCE OF ARTICLES FOR YOU (XRAY)

Sue Friedman, *Facing Our Risk of Cancer Empowered (FORCE)*: Yes. First, I want to thank you for inviting me to speak about a topic and a program that we are passionate about at FORCE. So the name of our program, it's, it's an acronym, we call it XRAY and that stands for eXamining the Relevance of Articles for You. And it's meant to be really a digital

health literacy tool to help bridge that gap between the information that comes out in scientific journals and then how the media covers it. So I will talk about that in a second. And I just want to say, XRAY, the idea was, you know X-rays look behind things. They look into your body and inside. So the idea was we're X-raying the news to help people find the facts.

Next slide. So this is our XRAY program website and you can see there are some cancers that we focus on and these are the main cancers that we focus on at FORCE. These are cancers that are associated with having an inherited mutation and that is our focus at FORCE.

Next slide. So why did we create XRAY? You know, if you look at the two examples on the left, these are peer reviewed journal articles and these are just the titles. But you can see they're full of jargon. They're not very accessible to people who don't have a scientific background. And even some people who do. And so that's challenging for people to get to. But that's where a lot of the vetted and accurate information is. On the other hand, on the right side, you can see the media stories and how the media covers it, and oftentimes the way the media covers the same science is full of hyperbole. It's exaggerated. It can be inaccurate, so it's not reliable sources of information, and it can be very sensational. So our program was meant to kind of bridge the gap between those two extremes.

Next slide. So here's an example. On the left is just the title of a peer reviewed journal article, and this article was looking at an amino acid. So something in your diet called Asparagine and they were looking at it as a model in a lab, not in people, to see if it affects, if large amounts of this amino acid asparagine, can affect metastasis in breast cancer in mice. And so that was the journal article and it was important science, but it was very basic science. And then next thing you know, there's the media report that's saying bunk this veggie, stop eating asparagus. Well, that's not what the science said. Asparagine is found in many different foods, not just asparagus. And the way the study was designed, it wasn't designed to look at people eating asparagus to see if that caused their breast cancer to spread. So we were many years away from, if ever, being able to make recommendations about what people should eat, and yet here's how the media covers it.

Next slide. So for XRAY review, that's kind of where we start. We look at how the media covered an article and then we look at the peer reviewed journal article and we write it up and summarize it in plain language. And sometimes that takes a few different iterations. We have to go back and forth to bring the language down, but we put it in as lay language or plain language as possible and we summarize it.

Next slide. And then we work to develop a series of visual scores or meters from low to high to help people understand this science, this article, this peer reviewed journal research, and the media coverage. How relevant is this to medical decision-making right now? Because people read, read about science and read about health, because science is cool and there's nothing wrong with that. But we've heard from our community that most people who come to FORCE want to know what does the science mean to me, and especially people who are having to make medical decisions about their care right now. So that's the score we give. So in this case you can see that we gave this article a relevant score of low because there were no medical decisions. This doesn't help medical decision making yet. It could in five to 10 years. But right now, it doesn't affect decision making.

Next slide. We also look at strength of science and part of that is looking at how the research was conducted and how strong the research design was. Was it a large study? Was it a small study? Was it early research in test tubes or in animals or in people? And that's also the purpose of the research timeline where we tell people where this is at in that whole cycle of research. So you can see from this that the strength of science was medium. These were well conducted studies, but they were small studies and you can see that these are animal studies and that's really important because research in animals may be years away from affecting medical decision making.

Next slide. And then we rate how the media did, you know, did they accurately portray the science? And in this case, the bunk this veggie, this green is responsible for spreading cancer cells to other organs, that media outlet did not do a good job in covering the science so we gave it one star versus other coverage, which did a better job and did a little bit more accurate journalistic reporting of what the science said.

Next slide. We also provide information about what the expert guidelines say now, because one of the things that we heard from patients was they wanted to know "what does this mean for me?" And so, you know, or "it's not guideline changing, but what do the guidelines say?" So we include the guidelines and we include question prompts for people.

Next slide. The other thing that we heard feedback about when we did some focus groups on this program, and especially from people with advanced cancers, they would say to us what if I read this article and it was about new and really promising science, but the, you know, the drug that they're looking at isn't available yet? How might I get my hands on it? Well, that would be through clinical trials. So depending on what the topic of the XRAY review is about, we also fold in any relevant clinical trial so that we can connect people to clinical trials and opportunities that may be relevant to them related to whatever topic we're covering. And then we also provide related resources, other advocacy groups, resources at FORCE, so that people can find other reliable forms of information on that topic.

Next slide. And we make it all searchable by cancer type, by category. So there's a whole host of different categories people can search for, prevention, treatment, side effects, menopause and clinical trials. And so they can search and find the studies that they're most interested in. And, at the moment, we have about 300 articles in our XRAY database so that you know, people don't have to sort through each and every one if they're interested in one cancer type and one topic associated with it.

Next slide. And then we, you know, work with partners and also internally at FORCE to disseminate the reviews because each of these reviews takes us about 40 hours to go through to get it in plain language, to find clinical trials, the guidelines, make sure that our scientific Advisory Board has reviewed it, we invest a lot into developing each one and we want them spread as widely as possible.

Next slide. So we have our own internal multi-channel promotion through FORCE, through our e-mail list. And you know we share each review, and on social media we also do social media ads. Next slide. But we also make them available through our partners website through something called syndicated content where our partners get to choose which XRAY reviews they want to share. It gets shared on their website, not on FORCE's, and it pulls through with the colors and the font and the look of the partner's website that's sharing it.

Next slide. So you can see, depending on what the colors are, what you know shapes are used for images, it pulls it in directly and so people are looking at the content, but it's on your site, they don't have to go to the FORCE site and it allows people to get more traffic through their website but also share this important information.

Next slide. And then coming soon we have been translating XRAY reviews into Spanish, and developing a fully functional site and syndicated content in Spanish, and are always going to be and are soon going to be looking for partners to share it via syndicated content in Spanish. So you can reach out to me if you're interested in syndicated content in either English or Spanish. Thank you. I think that's it. You can go to the next slide. Yep. OK.

Renate Haidinger: Thank you very, very much, Sue. It's amazing work you're doing there and we'll talk about it once again after Reagan's presentation. So that's about digital empowerment, I'd say. So Reagan please, the floor is yours.

PATIENT EMPOWERMENT NETWORK – DIGITAL EMPOWERMENT

Reagan LaBor, *Patient Empowerment Network*: Thank you so much and hi, my name is Reagan LaBor. I am the partnerships and programs coordinator with the Patient Empowerment Network also known as PEN. And before I start, really just wanted to say thank you so much for having me here today and for allowing us to really speak about the importance of this program and digital literacy as a whole.

So I'll start with a little bit about PEN. We are a virtual nonprofit organization, and we have a mission and a real dedication to improving health literacy, health equity and overall treatment outcomes for individuals who have been impacted by cancer. PEN is a pan cancer organization and currently we represent 18 different disease areas. What something that makes PEN unique is that we focus on providing programs for every step of an individual's cancer journey, and we do this through a model called our path to empowerment model. And within this model, it really allows the patient to take the information given and really kind of put emphasis on what needs to be done when. So we are able to provide resources all the way from time of diagnosis, up through survivorship as well.

Next slide please. So within our path to empowerment model, PEN really takes a focus on health literacy within all of the programming that we provide, we really make sure that the program that-- or the programs that we present make sense and are kind of more into lay language. So that way program participants, no matter how medically trained they might be or apt to medical language, that they are still able to take away valuable information from all of the programs that we provide. One of the ways that we enhance health literacy is through actually enhancing digital literacy skills. As many of us know, technology is growing quite literally every single day. New things are being created, new resources are produced, and it has become more imperative than ever that individuals be able to utilize technology in order for them to fully understand their diagnosis and successfully navigate their health care journey. And one of the ways that PEN really enhances or aims to enhance digital literacy is through our digital sherpa™ train the trainer and Digitally Empowered™ programs. Our digital sherpa™ train the trainer program really enables organizations as well as other healthcare institutions to provide digital literacy skills training to their community members as well as underrepresented communities. We do this through giving our program partners access to a comprehensive toolkit that has been created by Team PEN that consists of best practices for implementing the digital sherpa™ program as well as personalized training and support in order for them to successfully deliver these educational digital literacy workshops. Because we realize that each partner is implementing a new program into their already established programming, we are luckily, and thankfully, in a position to be able to provide all of our program partners with a small $2,500 startup grant that each partner organization can use how they see fit in order to administer the program. We've had partners utilize this money in the past, for example, for providing Chromebooks for their patient or for their community members who need access to technology and this grant has really helped them to put that in the hands of individuals, so that way they can be more digitally empowered. The great thing about the digital sherpa™ train the trainer program is its program's flexibility. There are different ways that you can implement the program. There's really no one true way of implementing it. And this really speaks to its flexibility for meeting the needs of communities all over, whether your community needs a virtual versus an in person, for example, this program can accommodate that. And we're here to help you with that as well. And we also have one of the format options for the train the trainer program, but it is also available completely free to utilize outside of train the trainer, is our Digitally Empowered™ program, and this was a Pfizer collaboration for it with for helping to fund this program, and it is a 10 module course that is designed to walk participants through the basics of technology. This course is great because it is completely free to access, and it is accessible directly from our website, and it is available in both English and in Spanish. This is also great because it is a completely on demand program, so all you really need to do is just send the link that is available on our website directly to the participants and they're able to complete the ten modules on their own time and when they best see fit. The programs have been amazing to see the growth so far, we've had the opportunity to implement and work with individuals from 40 different

nonprofits and health institutions, and the program has been able to have been reached over 10,000 times since the program began back in 2016.

Next slide, please. So this is a brief video. If you just hit play, it'll kind of play a couple times through, but this is kind of where you can access the Digitally Empowered™ program. You just click the link from our website, it'll take you to the home page that you see here and all you have to do is click get started and you will immediately have access to all 10 modules in order to complete on your own time. I know it kind of scrolls kind of quickly through here, but you can see it really does a great job of going through those technology basics, whether it be just the importance of utilizing technology when navigating your care, how to utilize applications or social media, and how to access those social community groups in order to feel empowered in your care, this program really does a great job on that and has really been able to help a lot of people, which has been amazing.

Next slide please. So some challenges that we've overcome since the program began. So as I said, the program began in 2016 and when the program began, it was originally an all in-person format model. So team PEN, we would actually help completely plan and travel to each of our partner locations in order to implement the program. However, over time, especially as the program has continued to grow, we've really tried to problem solve how to really get this program into as many hands as possible. This has led us to those format flexibilities that I mentioned earlier. We're now able to bend and flex each of the programs whether you want it to be in person or on demand or online. There is a way for us to implement the program in your communities and also in order to meet the community needs as well. Also, we've been able to enhance the program for a wider population through implementing a train the trainer model. As I mentioned when we were previously doing most of the planning, as well as implementation, it proved to be challenging at times because we knew we weren't able to meet to get the program to as many people as we would like. So with this train the trainer model that really alleviates that barrier and we are now able to give the toolkit as well as training to any organization for them to be able to implement their own programming and their own digital sherpa™ workshops to their community members whenever their community needs it. What's next with the program? The program has just been continuing to grow and we only plan to further that growth as well. One of the ways that we want to do this is just increase the number of community partners that we have for the program and really just wanting to get the program into the hands of as many people as possible. So our call to action for you today, we would love it if you would share the Digitally Empowered™ program link with your community. I've included the link here but as I said, it's also available on our website. Just getting this in the hands of as many people as possible in order to help them become more tech savvy is just an amazing tool to have. Also, if you're interested in bringing the digital sherpa™ train the trainer program to your community with the grant as well as the personalized training and support from us, we would love to hear from you. I've included my e-mail down below and I love to speak with you more about that. So thank you so much.

QUESTION & ANSWER SESSION

Renate Haidinger: Thank you very much, Reagan. Very impressive so, we'll talk about it in a minute. I think we have some questions already, so. Let's see what they are – just a moment. So maybe we start with back to Ranjit. Ranjit, how was it with the physicians, with the doctors? And what was the reason for getting the different doctors to do the narration? And read the script in the health literacy tool. Was it difficult?

Ranjit Kaur: That's a good question, Renate. I think we did have a few discussions regarding who should be reading the script and presenting it to the public. We came up with this decision that it should be the physicians themselves because people recognize them. The patients will recognize them and they feel that they can trust them and the information from them. And the other thing was also it was a good way to expose our physicians to lay language so that they could continue to use the same words they were using in the script that we had already revised and edited. And it was like I would say a learning experience for them as well as for us. So I we actually were very successful on that because when

the patients later on in the pilot project looked at the screen and they saw doctors that they could identify with and they could recognize, they felt reassured, they felt they could trust the information and they could understand what they were saying to them in a language that the patients themselves relate to. So I think that was the reason. Did I answer your question?

Renate Haidinger: Yeah, I think I mean for example, I imagine that it's not so easy to get the doctors to do it at all.

Ranjit Kaur: Yes. It wasn't easy. It was a bit of a revolutionary thing and as a patient advocate, I could put my foot down and say, look, you guys have got to speak you, you know, we'll make it easy for you because we had to put up the placards for them to read, because otherwise they sort of look everywhere else. So those were some of the things: getting their attention span, making sure they had the time to read and also to speak as though they're speaking to the patient. So there were a few sessions of rehearsal that we had to do, that was what we were doing when we were doing the screen testing with them. So we had to go through that and for them it was, in a way, they welcomed it after a while because it was getting away from their clinical work and doing something totally different, and I think everybody learned from it. So, yes, it was difficult, but it was not impossible. And we made it happen and they were so happy when they saw the end product because of course during the session it is like you know you're just taking in everything and then after that you do the cuts and you do the editing and then they when they saw the final product they found it very satisfying that they were participants in it.

Renate Haidinger: OK. Thank you. I mean, I like the idea to transform it to all or in a general manner, you know, so that patients might, in 10 minutes or something, get a basic idea of what is happening and coming up and what is – talk to them and to support them. So maybe we all can think about it. If we could create a video that helps all patients wherever they are. Thank you very much.

Ranjit Kaur: Yeah and also I would like to add a little bit Renate, because there was a patient's point of view because I – being a survivor – I could actually relate to that as to what the patient should wear when they come to the hospital or when they're going back home so that they don't, they don't have to worry about the arm where they're carrying the bag and things like that. You know how you know whether you wear pants or you wear a sarong or what is it that you wear to make it easier for them? Say for example a front open blouse you know which is easy to take off for them, for the doctor to examine. So there was some very practical issues that the doctors were looking at me and saying, oh, really, is that true? Is that what we're supposed to be saying? That they didn't know about that many of them. So there was some practical issues that were brought in and put into the footage so that the patient had the total perspective, not just from the doctors, but also while the doctors were saying that, they realized that, OK, I should be doing that.

Renate Haidinger: OK. Thank you. I think that's very, very helpful for patients and we as advocates can learn from that to give this advice to the patients. So thank you, Ranjit. So Sue, I come back to you. How do you select the articles you are looking at XRAY?

Sue Friedman: That's a great question and we keep a running calendar and we have a very active calendar. So you know we're always prioritizing and reprioritizing what we cover. We like to focus on, we do a lot of social media listening both in our channels, but also that unmoderated space, especially in social media and Facebook groups, to listen to what people are talking about, what they're confused about because you know the articles come out and the media coverage comes out and then it gets to the people who are using it to make decisions and many of them are part of support groups and some are moderated and some are not. So we listen to see who's talking about what, what's confusing to people, what's controversial, what's challenging. And so we like to cover those and we always add those to our calendar. The other is what's relevant right now. Is this something that's going to affect medical decision making? That's something that we want to prioritize. So if there is, you know, a new FDA approval, or the National Comprehensive

Cancer Network, or some other professional society just releases new updated guidelines, we definitely want to cover that as well. We take requests. And you know, we'll choose articles, too, that if the media, we feel the media didn't cover it well or they covered it in a way that could be dangerous to people if, you know, they're misunderstanding what the article said. Those are ones that we prioritize as well. And like I said, we take requests from our community and really from anyone and then just keep prioritizing and reprioritizing depending on what may be more urgent or important.

Renate Haidinger: Very exciting. And so how do patients learn that you are there and that you are providing this information?

Sue Friedman: Well, you know we do our own promotion internally, but we really rely on partners and a partner network. And so that's where everybody on the call, you can help us by letting people know, by sharing XRAY reviews through syndicated content and amplifying our message so that more people can see it because we do invest a lot in each XRAY review when we update them, they update for all our partners at the same time in real time which is one of the benefits of syndicated content as well. So we're, you know, we're still growing it. A lot of healthcare professionals promote it for us. They really like the ease by which you know someone may come to them with an article that they read in the media, which was very different. You know, like that media piece that said, bunk this veggie stop eating asparagus and it can save time for them to say, oh, you know, this was covered by right here. And here's a link to it. So we're really trying to make XRAY a time saving device for healthcare professionals and a health literacy tool to help people understand what new research means for them.

Renate Haidinger: Thank you very much, Sue. Now come to Reagan. I think it's, not everybody probably understood exactly what you have in your program, but everybody can look at it. But how, or what does it need to become a program partner or how to use it then?

Reagan LaBor: Yeah. So great question. If you are interested in providing digital literacy training to your communities, all you have to do is just e-mail me. We love to work with partners all over, so as you said, kind of the basics of it is that we provide you with a comprehensive toolkit that gives best practices as well as different templates, spreadsheets, et cetera that are there to assist you in planning a digital sherpa™ program for your community members. You also get personalized training on that toolkit. So that way you really we really make sure that you understand what material is there and kind of what we have done in the past to implement a successful program. Once you have that training, then you are really able to go and plan and implement different digital literacy workshops across your community. But like I said, we really we would love to work with any and all partners. All you have to do is just contact us.

Renate Haidinger: Now it's an international webinar we are having. Is it also possible to implement your sherpa and Digitally Empowered™ programs outside the US?

Reagan LaBor: Yeah. So in terms of the support and things of that sort, obviously we are, we are a completely virtual organization. So that support is able to be there with anyone all across the world. At the moment, our toolkits are available in English only, but because the toolkits are meant to be more used internally, so if you have internal staff that can speak English or read English then they can still utilize the toolkit. I think in the future we definitely want to eventually get it translated to other languages as well, but we also and then the Digitally Empowered™ program is available in both English and in Spanish as well for you to access.

Renate Haidinger: Thank you very much, Reagan. Now I have a two more questions actually to all of you, but please answer very brief because we are running out of time. So could you please tell us one thing to do and one thing to avoid when working with health literacy, maybe we start with Ranjit again. Short answer.

Ranjit Kaur: I think you need to make sure that you get different people to understand, to read and give you their version of what they have listened or watched so that you know that it meets everybody's needs, so it has to be something that everybody can understand, whatever their level of understanding is, whether it is they're academically highly qualified or low academic qualifications or no schooling, and if they can understand, then you know that it applies to everyone.

Renate Haidinger: And what should be avoided?

Ranjit Kaur: What should be avoided is, uh, only information that is being doled out by people who are from one section of society, like if they are just medical practitioners and they're going to give you information, then they may lose the perspective that patients don't understand because their level of understanding is different and they think that the patients understand. So it should not be skewed, it should not be coming from only one sector.

Renate Haidinger: OK. Thank you. Sue.

Sue Friedman: Yeah, I would say the thing to do if you can is really conduct focus groups or get feedback from your users. And, to the best of your ability, implement those within the program and you know, I mean I think that's part of meeting people where they are. So some of the enhancements that we put in XRAY, including adding information about current guidelines and adding information about clinical trials, and developing what we call an explainer video on how to use the program. Those really came through listening to users and getting feedback. I think the thing to avoid, and this can be really hard and we're constantly like struggling with this and thinking about it, is that there's a tendency - we want as many people as possible to read our reviews. And there's a tendency -- and this is why the media does it -- to you know, again sensationalize it because that makes it, it makes people more likely to click on it. I mean, there's a reason why you put, you know, media outlets use titles like "Bunk this veggie" But you know, really trying to figure out ways to get people to read it because it's relevant to them and, you know, not sensationalizing and getting people to read something that may or may not be relevant. So helping them at a glance know this is for you because you know, there's only so many hours in the day and we all have a lot of things being thrown at us. So people really appreciate it if you share with them information that really matters to them in their situation.

Renate Haidinger: Yes, I totally agree. I mean, it's always tempting to do something sensational, a headline everybody really sticks to. But I tell you, after 20 years in advocacy and my work, it works out if you keep good work, reliable work, and spread the news as far as you can and it will multiply at one day. So thank you. Reagan, what would you suggest and avoid?

Reagan LaBor: Yeah. So when it comes to health literacy, and especially on our side with digital literacy, we've really come to realize the importance of meeting patients where they are. With learning technology, we've seen everything possible. Some people need more advanced care or more advanced assistance, or if they already kind of have somewhat of a knowledge, whereas some people literally are starting at the beginning. So I think it's really important to make sure that individuals realize that and really making sure that people can have that individualized help when needed. And I would say something to avoid is really just to avoid being one-sided in the way that you're offering your program. I think it's really easy to kind of get into a certain rhythm once you find something that works for you, and you can kind of get into that rhythm, but I think especially with things such as tech literacy or health literacy, even as things grow and things change, I think it's important that you should maneuver with that and make sure that you are allowing your community to learn as much as they can.

Renate Haidinger: Thank you. Patti, I have to ask you, are we already running out of time or?

Patti Fine Jewell: We are running out of time, Renate. Your masterful leadership, go ahead.

Renate Haidinger: So I just want to thank all of you who contributed to this webinar. It was wonderful. I think all of us learned something and I thank Patti for your continuous commitment to these webinars and to our work. And certainly Pfizer for giving us the chance to exchange so much information. So thank you very much everybody and I give it back to Patti.

Patti Fine Jewel: Thank you so much, Renate. I would love to add my thanks as well to you, Renate, for leading this discussion, to Ranjit, Sue and Reagan. Your presentations were really insightful, and I love hearing you talk about it because I always learn something new in hearing your presentations, and I hope that everybody listening did as well. So thank you so very much. And if you would just advance the next slide. This is our website, breastcancervision.com, where we will post the recording of this webinar. We have three other webinars posted here in addition to some ideas generated in a summit that we held in October of 2020 about different ways that advocates can work with their communities to support patients in all different ways from research to patient support to public policy advocacy. So if you haven't visited the website already, we encourage you to do so. And lastly, if you go to the last slide, we welcome any feedback. I can be reached through, e-mail is probably the best way, and we welcome any comments, questions, feedback, ideas. But thank you so very much to everybody participating and especially to our speakers and moderator. And I hope you all have a great day. Take care of everyone. Bye bye.