INTERVIEW WITH

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Reflecting on your involvement in patient engagement, what are you most proud of?

I'm proud of a lot of different things, but a couple of things come to my mind right now. First, I want to say that I'm most proud of the influence and transformative power of patient and public partners. In terms of how we understand our research, how we understand community needs, patient needs, public needs.

For example, I liken research to a painting, a painting of a house with kids in front of it playing, it's within the wilderness. This is science, but it has little context. When you talk to public members, when you work with public and patient partners, their stories make these paintings alive. All of a sudden, you understand what the names of these kids are, what they are talking about, what they are playing, what is in the house, what's happening in the surroundings. They have this incredible ability to make the problems we are working on real problems, not just a problem written on paper. It gives a different approach, in my experience, to research.

I'm also really very impressed by their influence on us through their transformative power. For example, when I listen to them, I realize there are issues that I don't know, but I can actually have the privilege to speak up about their issues, even though they are not heard or they are not speaking up, but I can speak up. That is how I started to advocate for patients and public members, and they turned me into a fearless advocate. And I sometimes say to them (and they don't believe it, but it is the truth) I'm a chicken as a person. But when I advocate for patients and public members, I am fearless. They give me this incredible strength—they transformed me, and I'm very impressed and amazed by their ability. I think they need to know what valuable skill set and influence they have on us (researchers).

I would like to say that I'm very proud of everyone who made a change in our understanding and abilities.

Patient and public partners also personally impacted me because I have family members affected by cancer. My mom died of cancer. My sister is a long-term cancer survivor. But I wasn't really processing my feelings about their cancer experiences. It kind of helped me to face my own family's history with cancer and start my healing. I'm still in that process, but I would like to thank everyone who actually initiated this in me.

How does cancer research benefit from the inclusion of patient partners?

How does cancer research benefit when we include patient partners? A lot!

In research, we have a lot of blind spots. Research, to me, is like a nice painting. We have a research question, we have a scope, we have methods and so on. But it doesn't really have the full context; it doesn't have the ability to really understand the question. For example, let's assume I want to make a research project about life on a mountain, which I have never been to. I have no idea about the territory; I have no idea about the environment; I have no idea about the conditions, plants, animals, and risks. But people with lived or living experience, those people who live on this mountain, they know these. Therefore, as a researcher, what I don't have is what they have, and this is where I think there is a missing link. That's why we have a lot of blind spots. And I have experienced this in my research as well.

I thank again all the patient and public partners for giving us this much-needed guidance on what we want to do.

The other impact or influence of including patient and public partners in our research is ***humanizing the research process***. It really did humanize my research, how I approached research.

I'll try to explain it a little bit...

It's like a very sweet feeling. It's not just one question on paper, it's just something that you live and you feel, and it gives you a different kind of meaning in addressing your research question. It makes your research question more real and more approachable, more understandable. And I think it also gives us the much-needed recognition of the very people we want to benefit with our research.

I'm a cancer researcher. My long-term aim has been to improve the survival outcomes and lived experiences of cancer patients. Prior to partnering with patients, I was working on a very specific area. But now by working together with patient partners, hearing their issues, experiences and perspectives, and needs or recommendations, I realized that there are some other things to do for me. I also feel connected with them. This gives a different level of meaning to my research. I would recommend it to everyone!

If I need to summarize the impact of inclusion of patient partners in cancer research or in other research areas, I would say that it really gives life to the research that we want to do. It

humanizes the process. It brings us back to the big picture. As mentioned earlier, I was working on a very specific area, but my aim has been really big and there were other things that I could do. They helped me to shift my focus and develop new research areas, and that was very, very valuable.

Also it expands not only our abilities but also understanding, and these are really what we are looking for in an academic environment as well. So, it's win-win-win in so many different ways.

What approaches are needed to ensure diverse voices are included?

Well, we need diverse voices at the table: whatever we are doing, whatever we are working on, whenever we are educating, we need diverse voices. But it's not easy. We are still in the process of implementing equity, diversity, inclusion and belonging policies, practices. But there's quite an interest, which is amazing.

For our public and patient engagement and partnership activities, we really try to be purposeful about including diverse voices. For example, for our patient advisory committees, we gave priority to those coming from minority groups, whether they are racialized individuals, individuals with disabilities or members of the 2SLGBTQIA+ or the Indigenous Peoples. We really need to be purposeful about sharing the table with those whose voices are not well heard. Everybody has and should have space at the table. This increases the effort, and it takes a little bit more time, but is well worth it.

We also need to be aware of the fact that individuals that we really would like to integrate into our activities, work with, etc., are usually limited in numbers. So that means a lot of people are trying to work with them, which may actually tax them. I don't know how to solve this problem, but we really need to be mindful when we reach out to members coming from these groups; mindful of their other commitments and make sure that we are not taxing them. I don't have a practical solution for that, but we can talk about it.

Also, recruitment is one thing, but retention is another thing. You can recruit a patient partner or public partner to your research advisory board or other committees. That's great. But then retention is another part of this process. I found that relationship forming is really important. The relationship with the partners: public partners, patient partners. It's very important before even going into the project, details or expectations.

I find sometimes that the paperwork and policies may prevent the retention process. I'll give you one example. Now I am a very vocal advocate for transgender individuals with cancer because I had a wonderful patient partner who was a transgender individual also affected by cancer. They were like anyone else eligible for compensation—very little compensation—a token of appreciation for their involvement in our public events or activities. But we weren't able to give them the honorarium because their current name did not match the name that was associated with their CRA records. That happened with two projects. In one case, we went to the funder, we

said, okay we can't do the honorarium so we would like to give a gift card and they allowed us to do that. Hence, we were able to give this individual a gift card, after months of trying to solve the problem. But in the other case, we were not allowed to change from an honorarium to a gift card. So, we weren't able to compensate this individual through our funding. To me, this is a great example of federal government, university or funder policies that actually create barriers for certain public members to work with us. We don't need research on this - I'm increasing awareness about it right now. Please let's remove those barriers in compensation and others for individuals, especially transgender individuals that are our partners.

In summary, recruitment should be purposeful — we need to have space for everyone or diverse voices, this is one thing. But in terms of retention, there are a couple of things we still need to fix for keeping our members who are providing us very valuable diverse voices. There may be barriers such as a policy or other barriers that I just gave an example of that can prevent them from continuing to work with us. We don't want this to happen.

We need to be purposeful in recruitment and retention, and we also need to advocate for change to remove those barriers.

What advice would you give to researchers interested but anxious about working with patient partners?

I'll tell you something. I was very afraid of doing it.

I started public-patient engagement six years ago. Prior to that, I was a lab scientist. I'm not a local. I'm an immigrant to Canada as well. So, my social circle or community wasn't big at that time either, so I was very scared. I was unsure whether I could communicate and also being a lab scientist means that my language is mostly scientific as well, so I was very insecure about it.

But there was one opportunity. One of my colleagues, for example, introduced me to a patient partner and everything changed after that because that partnership is still ongoing and it really changed my abilities. And of course, I should mention Memorial University's interest in community involvement. It's historically been a very successful university in terms of community involvement, community work, partnerships, and so on. These all gave me some extra advantage to get into it.

So, folks do not wait. Get into it. You can do it. You will do it!

I still fail in doing certain things to the satisfaction of our patient and public partners. I'm very sad about this, but these are really great learning opportunities for me. There is a learning curve: the earlier you start, the faster you will climb up this learning phase. So please don't worry about it. It's okay. You are not the only one. I was very scared of initiating public partnerships myself. I wasn't sure that I could do it, whether they would accept me. But they did, and it’s amazing.

As patient engagement evolves and expands in Canada, what are your aspirations for the future?

I'm very excited about the future of patient and public engagement in Canada, whether it's in cancer or otherwise.

Almost every day, I see a patient advocate or an organization led or initiated by patients, or a conference that is organized by them. I think we are going to see more public and patient leaders, more initiatives by them, especially in terms of research and other areas.

I really hope that we will also see more advisory boards formed by public members in every single organization, including governments, not just as a token, “Oh, we have a patient advisor, committee or a patient member here,” but no seriously, an advisory board that is going to recommend their input into organizations’ activities. I know there are a lot of committees around, but I really am not sure whether their opinions are taken into consideration in every organization. I really would like to see them more empowered. I would like to see them having the barriers removed by organizations’ policies or power structures or whatever that is.

Thus, in my opinion, we are going to see a lot more patient and public initiated and led initiatives in Canada. And it's going to be well worth it folks, so don't be scared. Please do that. Listen to them. Humanize your processes, and hopefully you are going to address your aims far better and much faster.