

Transcript

Matters of Engagement podcast

Episode: "Advocacy and Health Equity, featuring Biba Tinga of the Sickle Cell Disease Association of Canada"

<https://mattersofengagement.com>

SPEAKERS

Jennifer Johannesen, Emily Nicholas Angl, Biba Tinga

**Jennifer** 00:07

Hello and welcome to Matters of Engagement, a podcast exploring the complex world of patient engagement and partnership. I'm Jennifer Johannesen.

**Emily** 00:16

And I'm Emily Nicholas Angl.

**Jennifer** 00:19

In this special feature, we're bringing you a conversation with Biba Tinga. Biba is parent and caregiver to her son, a young adult with sickle cell disease. Biba is also President and Executive Director of the Sickle Cell Disease Association of Canada.

**Emily** 00:34

For just a little bit of context, sickle cell disease is an inherited blood disorder. And according to Health Canada, it can shorten the life of affected individuals by more than 30 years. It's caused by abnormally shaped red blood cells that can impair blood flow, causing strokes, lung disease and organ damage. In Canada, around 5000 people live with sickle cell disease, and it most commonly affects people of African descent, as well as Caribbean, Latin or South American, Middle Eastern and South Asian descent.

**Jennifer** 01:07

We initially spoke with Biba to ask for her reflections on the Equity and Diversity episode with Nav Persaud. But once we started talking, we realized that Biba's experience as an advocate was almost a perfect case study of what we've been talking about - the importance of focusing on health equity, as opposed to comparatively simple notions of diversity. So even though this episode is an extension of the Patient Partner Reflections segment in the previous episode, it also gets into some of the realities of advocating for policy change to support the health needs of a racialized group - one that is disproportionately affected by a rare disease, and is not well supported by our Canadian health care system.

**Emily** 01:48

Biba's work as an advocate is of course directly informed by her lived experience. We'll put a link in the show notes to an interview with Biba on the Innovative Medicines blog. We encourage you to take a look as it's a good overview of Biba's personal experience, her work, and some of the policy changes her Association is advocating for.

**Jennifer 02:07**

And a quick note, Biba refers to the Sickle Cell Disease Association of Canada by its acronym, SCDAC. Okay, here's our conversation with Biba.

**Jennifer 02:22**

... It sounds like just being invited to have conversations isn't quite enough, is it?

**Biba 02:26**

Exactly, exactly, absolutely. Because as I said, we are not a source of information. We are equal stakeholders in this process, right? So we need to be at the table when the program has been developed when, when the resources are being put together, when the research project.... like, everything that is being done at every step. We have to be part of the conversation, not called in to just come and you know, provide input and then leave. And how does that work?

**Jennifer 02:57**

So that raises a question that comes up a lot in patient engagement. People want to be involved in projects or research from the very beginning, even before the funding application is submitted. But of course, there's no money for compensation yet, so people will be asked for free labour. Have you encountered this issue in your advocacy work?

**Biba 03:17**

Of course, and you know, as you rightfully said, that, we're going to have to ask people for the free labour, and it's very difficult, specifically in certain communities where, you know, people have to work. But here is the thing. Personally, for example, we are all volunteers. So imagine how hard it is for us, you know? But at the same time, it's very important that when I said like, you know, when I talk about patient, and I talk about the patient group, per se, or patient advocacy group, if a research program is going to be developed, they have to be stakeholders, they have to be co-applicants, they have to be partners. And we sit together, and we work and we determine what we are looking for, which information are we going to seek for. And right away this, this notion of, oh, they have to be paid so we're going to use them... I don't think that's the first goal here, when we are all advocating - we are advocating for something bigger than that. We are advocating for our quality of life, we are advocating for access to care, equal access to care, you know, to all services. So I don't want that to be used against the patient community. No. I don't want it to be a reason for us not being called at the table. No, no. I think... give us the opportunity to make our own decisions, bring us to the table, let's have the conversation. And we will tell you what we can or cannot.

**Biba 04:52**

But, anyway, I do not see how, for instance, let's take a real example - we are working on a project now. And we are collaborating with Canadian Blood Services for the need of blood, right. And the SCDAC is a collaborator and we are working with the researchers hand to hand - we put together this research project together. And we are going to the community and collect the data that's... you know, we can work on this project. So we feel like here we are stakeholders in this project. We are working together. And most of us are not being paid on this project. Yes, I know, now, people are going to talk about fairness. But to us, you know, the goal is bigger. The result that

we're going to get out of it for our community is more important than anything. So, I would like to leave these financial aspects out for now. And let us focus about bringing effective change. And that can happen only if we are able to work.

**Biba** 05:50

And why is it that a researcher or anybody can put a program, a research program together and get paid right away and not the patient community? Not the patient groups? Because the definition of an expert has to change at some point. The expert is not only the person who is able to come and do the research and do the work, but the person who is living with the disease, who has been affected directly, is providing all the information - should also be at the table sitting and represented equally as the person also who is coming and getting the information and analyzing it. So how do we change things, you know, to work together effectively? How do we do that? There must be a way. It's just about being willing to sit at the same table and work on it.

**Jennifer** 06:41

Yeah, I don't think this has occurred to me before - that asking for money or not participating because there's no money...? It's actually a pretty privileged point of view.

**Biba** 06:50

Because they're already at the table! They're already at the table. They are part of the conversation, they are being listened to and they are being considered. And we are working towards that. So make no mistake, I'm not saying that we shouldn't be compensated. I'm not saying that. What I'm saying is that, let's put that conversation aside for now. For now, it's about efficient and sustained policy against you know, everything that has been preventing us from being at that table, from having access to equitable care, you know, in the system. So for us to reach that, I don't think our concerns are there yet. Because and again, that's why we're having the conversation about equity, right? So the needs are different. And this is where we need to actually analyze, what are we trying to do here, right? So we're trying to treat everyone equitably according to their circumstances. So you cannot take those orders and apply it to a specific community, you see that it doesn't work. Right there, you are understanding that it is not the same level of, how do I say, implication for us.

**Biba** 08:03

So remember when I was telling you about blood donation, and iron difference? So as a Caucasian person your level of iron is, you know, higher than mine has a Black person. So when we are trying to donate blood, you and I, I would be deferred automatically, because of what is considered has the normal - as the norm comes from a Caucasian woman, not from a Black woman, right? So for instance, that has to be changed. So policies have to be changed for us to be able to be treated, you know, the same way, and then be able to participate the same way in any kind of research program first. So that's when... you see when the conversation comes to implementation details, you know, how do we compensate people? And how do we do this, and I'm saying that the change has to come from higher than that. For even us to be able to start sitting at the same table and having the same conversation. So we were bringing our chairs and sitting and we are starting a conversation. And already the conversation is at some point that we have to say, let's look at everything in general first - all the policies that are here at this time are preventing us from having access to the same opportunities as others.

Can we talk about that to remove them first, and then there will be no issues of saying how to compensate or not.

**Emily 09:30**

So then, when your organization or when you as an individual come to these so-called tables... ? What level do you find your conversations are happening at? Are they mostly talking about how people should be compensated? Or how to improve engagement? Or what you I guess called implementation details? Or are you asking more about changes that you're actually looking for at the structural or, like policy level?

**Biba 09:55**

So it depends, you know, where you are. For example, when I am in a network, like, where I meet with other rare disease groups, you know - of course, we have the same challenges, you know, we are all trying to have access with limited treatment options. So there, I feel like we fit and we can have a conversation about you know... because we're facing the same issues, dealing with a disease that has, you know, not a large population, limited resources. There the conversation I understand, that can be something that we can all relate to. And we can all work together and support each other in finding a solution.

**Biba 10:30**

Where I think that is different is where I have... where you're invited by these decision-makers, you know, maybe a hospital or anywhere and you're sitting there and trying to tell them that "well, our specific problem... we need more programs for our patient community, or we need more staff to be able to achieve comprehensive care" and then they are at another level of conversation telling you about, you know, but how do we do this? You know, can we have volunteers? Or can we... or for us to hire staff, you know, to come in and serve this particular population, we don't have a budget for it. So that's when I think like, "Okay, we have conflicting priorities." We have conflicting ... so we cannot have a discussion that will benefit us. And I feel like, okay, the priorities are different, right? So when you bring the hospital staff people talking to a patient group, we know what we need to serve us, we know what we want to see implemented in that clinic. But they have to work with a budget, they have to work with them on policies that are not made for us. So on that point, I'm like, okay, what I'm talking about and what they're talking about is just not... we are not having the... we are having the same conversation but we don't have the same priorities. And if we don't align them, then we cannot work effectively together.

**Biba 11:53**

I don't know if I'm making sense but I'm trying to give you an example for you to understand clearly why. So when I'm having a conversation with Maureen Smith, of course we understand this and we are patient advocates, even if it's for different diseases with different disorders we all have the same goals. We can sit at the table and say for sickle cell we need it, for any other disease this is what we need. We can come together and say okay, we're going to advocate. When we go to Canadian Blood Services we advocate for the same - the need for plasma, the need for blood. We are looking for solutions for our community. But now when we talk about the policymakers and the decision makers, for any institution, then it's different. So that's when you have to know as a patient advocate, what do you bring to the table and make it so that the conversation is about you. Your needs. And how they can understand them and meet them.

**Emily** 12:42

Do you find that the conversation is different depending on whether you're there to advocate for the sickle cell community specifically, versus, say, when you're part of a larger patient group or part of the broader rare disease community?

**Biba** 12:57

Yeah, of course, because the minute you step in, like, you know, when you... when you are standing on your own as an organization just for sickle cell, right away, people see the community that you represent with what, you know, what you represent, and then it shifts, it changes, right? Versus when you come has an advocate with a group of people. I'll give you an example. We were able to go to health committee at the Senate and talk about against a bill that was put forward about plasma donation, paid plasma donations, right? So we went as a group of rare blood disorders, and we were able to get the change. And we said that we were... anyway...so we were able to work efficiently and achieve our goals. But Sickle Cell has been standing on its own for how many years now? And advocating in Canada. For simple things such as a patient registry, where we know how the patient registry can help, you know, in health research, you know. And can address inequities, of course, because we're going to address the disease burden treatment and everything, and we've not been able to get a single champion, single healthcare provider to champion the program, or even get resources allocated from public funds to start it. While you look at other diseases who are here with less patients, and they've had this registry for 40 years. So that is... there is a difference, you know, when also even within advocacy, I can say there are, there are differences. So I wonder why? That's the question.

**Emily** 14:36

So what do you think, why do you think that is?

**Biba** 14:40

Um, you know, who sickle cell affects, right? The majority of people affected are African, Caribbean, Latin or South American, Middle Eastern, South Asians, you know, so we're visible minorities. So, to me, these are underserved communities, right? So the minute you come into that... wait a minute, there are no resources allocated to that. So now, when you want to know how to change things for those community? When you advocate for these communities for a long time, you know that nothing is easy. Compared to if you are seen as just somebody bringing... it was a very interesting experience for me to see that once we tried to move any other issue that is not specifically attached to our community, it moves faster than if it is for sickle cell. So we wonder why? You asked me why, right? Underserved communities, [...] communities, and there are those policies... policies that are implemented that are not for us, not made for us, and that are building a real disadvantage to our community.

**Jennifer** 15:57

So just to clarify, did you say that you felt you could move the needle faster or better when you aligned with other rare disease organizations?

**Biba** 16:07

I think yeah, I think so. I think, even though we've made a lot of effort in Canada as Sickle Cell on our own, right? We've achieved a lot since 2012, when the national organization was formed. But at the same time, I've noticed that effective change...? Like changes are coming faster with not only... not always causes that really benefit our community, but we do align with other groups to push for something that totally does not really change anything for our treatment. But we see it's just being carried, you know, quickly, faster than when we bring one specific issue that only addresses sickle cell.

**Jennifer 16:47**

Do you think there's a longer term benefit for you to be kind of associated with a larger group? And maybe some of that group is going to see benefits before you do, but maybe if you hang in there long enough, you'll eventually start to get some benefits or....?

**Biba 17:01**

...It shouldn't be. It shouldn't be like that. I don't think it's fair, right? It shouldn't be - we don't have to do that. I think we have to... we should be able to stand because and again, I'm creating an environment where everyone is being treated equitably according to their circumstances. And ours are different than other groups. So it has to be taken into consideration when it's on so that we can achieve the equity we are looking for right? So if we are doing that, and Sickle Cell has to be just considered to say okay, what are the challenges? What are the barriers to access to care for this population - we need to address them to bring them to the same level has any other disorder, cancer, any other one... any other cancer or any other red blood disorder, and then we can start having a conversation.

**Emily 17:55**

So one of the questions we obviously got into with Nav was whether increasing diversity and patient engagement has an impact on health equity... So what do you think about that?

**Biba 18:07**

You know, I think having those different voices and as many voices as we can, is important, because it raises, it's going to raise awareness, and it's going to start the conversation. But for effective change to happen, we need action. We need action. So looking at it really, from our perspective, the only way that we can bring as many voices as we can. If we don't put efficient and sustained policy against sickle cell disease, it's not going to do anything. So we need public support, we need to develop, you know, public support, and then remove all the policies that are creating a barrier for us. Bring the resources that are necessary, you know, for our circumstances to bring effective change. And again, as I said, before we change the staff, you know, we need to allow those staff when they're going to be hired to bring the diversity, whatever - we're going to have to bring them to put together in place the policies that can allow them to work and treat every single group, you know, the same way. With the same resources. And we don't have that now. So we have to affect the resources to the right place first, rather than doing anything else.

**Emily 19:27**

Yeah, what you're saying seems to align with some of what Nav said - not relying on small changes to have ripple effects, but to put the energy and resources into the big stuff first. So Nav also talked about how diversity isn't

always the goal, but when... when you center equity, or if you're centering equity, you might need to prioritize certain groups, right?

**Biba 19:50**

Yeah. Well, that's maybe that's one of the things where I totally agree with him that, you know, we need to make those [changes] before, to get any effective change, we need to. So if we don't put a priority on those community that has been, you know, misrepresented, underserved all these years? How are you going to bring equity in the healthcare system? How?

**Emily 20:17**

Biba - I wonder, given your position, what issues you and your organization want raised? Whether it's related to what we've been discussing already today, or something completely separate?

**Biba 20:29**

Well, it's clear that, you know, because of the community that is affected by sickle cell disease, as I said that... you know, as I mentioned earlier... that there is a clear gap to be filled, you know. We have to close this gap, you know, to achieve equity. So, it's why we are advocating what we're advocating for. If you look at sickle cell disease, for the treatment of sickle cell disease in Canada, for the past 40 years we've only been left with supportive care. What is supportive care? The only drug use for sickle cell disease is a cancer drug, okay? And then we have the blood products, blood transfusions. So that's the only thing that we have. But now, nowadays, since 2017, and at the end of 2019, we've had three new drugs, specifically targeting sickle cell treatment approved in the US, by the USFDA. They are not available in Canada yet. And we don't even know when, we are not even, you know, they're going to come to Canada.

**Biba 21:29**

So when a population is left with short life expectancy, many complications, you know, coming like kidney failure, heart failure, leg ulcers, you know, strokes at very young age, you know, under 10 years old kids are having strokes. And then, even though there is a cure for sickle cell which is the bone marrow transplant, but it's only being offered to less than 10% of the population, because of the eligibility criteria that are put there are so difficult, you know. And the decision is not given to the patient community but to the healthcare providers to decide who gets you know... who is... who can be eligible or not. So, when all that, with everything that we are facing, we fall right in the group of... disease group... that should be talking about health equity all the time. Because there is nothing, like.... we don't understand why all those barriers are there, if not policies that are not made for us, that did not take us into consideration, that did not take us in account. At even the decision level, you know, at our government level first, to start with the government, federal, provincial, you know. We are not being heard, we are not being considered, we are not being taken into consideration. And that's why when you come to the institution providing the care, resources are not there to treat our patient community. So, that's why we formed SCDAC in 2012, when we realized that the federal and the provincial patient group were there, they were working, offering support doing good in their provinces. But then we needed to do more, we needed to go to the federal level, and get things, you know, implemented from there. So that we come all the way down to the person standing in their province for them to receive care. So yeah, we need to continue this equity conversation, we need to talk about it, we need to continue to raise our voices. We need to continue to share

our experiences until we are heard. Until we are brought at the table to be listened to. And our government needs to step up and close the gap in the care for sickle cell disease in Canada.

**Jennifer 23:47**

So Biba last time you were telling me about some of the challenges around donation and blood products... can you talk about those again?

**Biba 23:56**

Yeah. So when you have only like a blood transfusion has a treatment option for you to stay alive and have a quality of life. So we look closely into that. So at SCDAC we have a blood strategy. The minute you know, we started working, we said we need to focus on that, because that's the only treatment option for our community. So when you receive frequent blood transfusion, it's very important that the blood you receive comes from the people from the same ethnic group as yourself. And in the case of sickle cell, the majority of people affected are African, Caribbean, or South American or Middle Eastern. So it's important that we get blood from this specific community, right? To support them. And there are some specific policies like the malaria deferral - if you've ever had malaria in your life, you can never donate blood in Canada, or if you even travel to a malaria-endemic region, when you come back, you are deferred for a few months before you can donate blood. And also I mentioned iron overload earlier, right? So most black women get deferred because of the level of iron in their body, which is how we are genetically, is not going to change. So for those, we consider them as simple barriers to our community to be able to support the treatment for sickle cell. So these are the type of issues that we advocate for that we try to work on.

**Biba 25:21**

So you know, when I was talking about the, the implementation details, right? So it won't make any change for us to put all the work in the community to educate them, or raise awareness about the need for blood to support sickle cell treatment, if when they come to effectively donate blood, they are being turned down. So the policies have to change first, to allow us, you know, to do the work, and bring good treatment for people living with sickle cell disease in Canada.

**Jennifer 25:54**

And in order for those policies to actually be meaningful, then you also still need that registry, right? Is that correct?

**Biba 26:00**

Exactly. So now, the registry that, as you all know... every patient group needs a registry, Why? First of all, it's the first tool to make you visible and counted in the healthcare system. So when you don't even know how many patients who are, where they live, how can you count them in the programs that you put in place to support people? So that's one of the first reason when every time I talk about reasons..., I'm like, it's a simple database to know that you exist in the healthcare system. And then you're going to be counted when it comes time to create, to put the... to allocate resources to every disease, and sickle cell doesn't have one. So unless we start by that, we address that, we are not.... we can have 10,000 panel discussions, we can bring sickle cell patients, caregivers, advocates, physicians to talk and talk. But that's one of the first tools we need to have to

implement change. Because we're going to be able to address you know, the disease burden, the treatment option, all the complications... it's going to change everything, you know, for us, for our community. And we've been asking for this in 2015.

**Biba 27:19**

And the first time we went to advocate in Ottawa, on Parliament Hill, that was one of the first thing we took, we said, we need a national registry for sickle cell. We need to count, to know. And also those who have the sickle cell trait, because many diseases have been able to be... I would say maybe reduce the number, the incidence of the disease and also reduce the number of births with sickle cell... if people knew about the sickle cell trait, that is, right? So if we do a registry, we are not only going to identify those who have the disease, but also those who have the trait because it takes both parents who have the trait for the child to have the sickle cell disease. So if we get the registry, we are also going to be able to educate our community, and make sure that when it comes time to have children, people can take, you know, decisions with the right information. Because it doesn't make sense that in 2021 people are still having kids and saying I didn't know I had the trait. Right? So that also is something that when we look at it for our community, if we are not given the opportunity to get the information that will help us make the right decision - how is that equitable for us in this system?

**Emily 28:32**

Yeah, it sounds like your experience would be quite frustrating in that, you know, it's like we've been at this table many times before, and we've told you what we need. So then how do you approach things? Do you still see a benefit in being invited to those tables, kind of "fresh" with people wanting to learn about your community and what you need...? After you've been doing this for so long?

**Biba 28:56**

Of course, I think it's just, we have to continue to raise awareness, right? That's how you create partnership, that's how you educate people around you who might be able to be part of the, you know, the change process. We are a community, right, so first of all, we need to know each other. And so if you don't know about my challenges, or my needs, how, you know, how are you going to be able to support in any way? So yes, I think we still have to continue to talk, to share, you know, to share our frustration, and our need to express them. And, but at the same time, we have to advocate for them at the right place. Because you can talk 10,000 times at those panel discussions - if the goal is just to listen to your experience and not, and no, and nothing comes out of it, you know, no change, no effective action then - it's not going to go anywhere. So we have to pick wisely where we appear from now on and, and how we do you know, effective, how we can bring effective change.

**Jennifer 30:12**

So, from your perspective, do you feel like most of the barriers, I guess if we want to call them that - are they more on the side of like, who's listening? And what tables you're sitting at? Or do you feel like it's more that your organization is under resourced? Like, what do you need? What does your organization need to advocate better or more effectively?

**Biba 30:35**

Yes, we need resources, as I told you, you know, SCDAC is run by volunteers, is a volunteer based organization. Everybody's a volunteer. And that makes it you know, difficult for people to stay committed, you know, and work effectively. So, I think at this point, every sickle cell organization should have a patient coordinator program that has full staff, you know, paid. So those resources should be allocated by our public system. You know, it has to be. We have to be funded, because otherwise there is no way that that patient voice that we are talking about - that patient engagement is going to happen has equal stakeholders. Every time we're going to come with you know, not being able to sit at the table and bring our opinion, you know, equally. So if we are funded, if we have resources, if we have well established organization where people are able to do the work, then there is no need for anybody to be worried to say, "At what stage do I bring them into the conversation? And how can I pay them?" Personally, I had to take a leave of absence for my own work just to do sickle cell - just to work, just to run the organization. Because there was it was not possible to do it part time, you know?

**Biba 32:03**

if you've noticed from the beginning of our conversation, I've been telling you about public funding. I've been insisting on the fact that, to me, it is the responsibility of our government, you know, to fund our programs, project, organization, whatever they can do so that you know we remain sustainable and we support our community. So my own strategy is to just say that, you know, we need multiple partners. I consider the pharma as partners, because they are the one who developed the drug that we need to treat the patient community. But for me, I don't necessarily rely only on them, you know, to fund everything. That's why, for the registry, for example, we've been sending letters to the Prime Minister, to Health Canada, to tell them, you know, to start to look for funding to say that this should be supported by our system, because it's about bettering the quality of life of Canadians, so it shouldn't be something that is being controlled by any, you know, private institution or anybody. So, yes, we know about it. And I could have maybe find the support I'm looking for to staff, you know, our organization if I wanted to do that. But to me, exactly what we say, it's not the responsibility of a pharma. They can do it if we do ask or if we agree, because now sickle cell is the new... because there is research happening. And this is one of the largest populations with, you know, this disease. But we keep standing as sickle cell community and as long as I am a leader that our strategy is to say that we need to be funded by our government. We need to be taken care of by our government, and not anybody else.

**Emily 33:49**

Thanks to Biba Tinga for participating in this episode. If you have any questions or comments, please get in touch through our website at [mattersofengagement.com](http://mattersofengagement.com).

**Jennifer 33:59**

This episode was written and produced by Jennifer Johannesen and Emily Nicholas Angl, with generous financial contribution from the Ontario SPOR SUPPORT Unit, or OSSU, which is jointly funded by the government of Ontario and the Canadian Institutes of Health Research, or CIHR. The views and opinions expressed in this episode belong solely to the producers or their guests, and are not to be considered endorsed by OSSU, the Government of Ontario or CIHR.