

Matters of Engagement podcast

Episode "Democratic patient-led councils, the rise of patient engagement, and the erosion of advocacy - with Lucy Costa"

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Jennifer: Hello, and welcome to Matters of Engagement, a podcast exploring the complex world of patient engagement and partnership. This is Jennifer Johannesen.

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Emily: And this is Emily Nicholas Angl.

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Jennifer: In this episode, we continue to dive into the topic of representation. We draw on some of the ideas presented in the previous episode called "Dilemmas of Representation with Paula Rowland." It's not a prerequisite at all, but you might find it handy to go back and listen to that episode if you haven't already.

Our next guest is Lucy Costa. She's Deputy Executive Director of the empowerment Council, a patient council run by and for mental health service users. The Empowerment Council is funded by the Centre for Addiction and Mental Health (CAMH) in Toronto. Now, you might think it's an unusual choice to include someone from the mental health sector. When Emily and I have spoken to people about engagement, one thing that most people seem to agree on is that there's this kind of solid impenetrable line dividing mental health and the rest of healthcare. During the course of at least three other conversations we had in the making of this podcast, people at one point or another said something like, "... except in mental health! That's different!" And perhaps this is true in many respects. But when it comes to talking about engagement, it's especially pronounced. But even so, we think speaking to Lucy was an inspired choice. Both of us have encountered her work on a number of occasions, and have been so struck by not only the parallels we see with our own work, but there's also a way Lucy is able to just see through the fog. She challenges assumptions that we take for granted and distills really difficult and messy concepts down to something quite accessible. She's been an advocate for mental health service users for a very long time, which I think is work that requires a lot of persistence and patience and political will, and a capacity for optimism that change is possible. In order to get into our discussion about engagement, we needed to better understand the history of the Empowerment Council and find out more about the origins of patient councils in general. So, here's Lucy:

02:17

Lucy: So patient councils emerged in the early 90s. And I would say it was a coalescing of various social movements activities that were happening in community and simultaneously, things that were actually happening in the hospitals. There had been an increase in deaths, there had been complaints about over-use of medication, over-use of restraints, and there was a report commissioned by the Ontario government called the Peat Marwick report that spoke to that. It was around that time that the government decided to pilot patient councils in mental health facilities. The first one was at Kingston,

the second one was at Queen Street, which is now CAMH. And then a couple of other patient councils were proliferated to act as independent advocacy patient-run organizations within hospitals. It's also important to note that there was social movement organizing before that. So it's not suddenly that the government decided, "Hey, we're going to fund patient councils!" There had been a lot of work and protest and engaging with the government through writing reports, and doing depositions, and so by the time the 1990s come around... I would say that the government had to do something in response.

Jennifer: So this was in response to pressure?

Lucy: I think it was a quite complex coalescing of different things that, you know, yes. So they were supposed to... they were funded by the hospital and they were meant to be independent and autonomous, speaking on behalf of patients...

Emily: But funded by the...

Lucy: Yes. There was always tension, the funding and the independence and that has remained until today, but it did happen. I think different councils were doing different kinds of work. And most of those councils have been dismantled — divested. There are only two left: ours, the Empowerment Council where I work, and there's a council in Waypoint which [...] used to be Oakridge, but that particular council is not just patient perspective, it's patients and families, whereas ours is solely patient perspective, and it's independent and has its... we have our own board and we're accountable to our constituency, which is like other patients. There was an "Ontario Patient Councils" formed, like a provincial kind of organization in 1993. I think that too has been... they've disbanded, and the work is different: so the councils... they were divested, or they had to change their work, and to begin to doing other kinds of work, either peer work or recovery and mental health work, not advocacy. The councils were meant to act as sort of "watchdogs for the patients." Again, that would have varied depending on the different sites and the different kinds of people that were involved in the councils I guess, but that's what they were meant to do.

05:05

Emily: When we spoke to Lucy, she described how patient councils in the mental health space in Ontario were set up by the government to function as independent patient-run advocacy groups, which were meant to hold their sponsoring or host institutions to account, as well as the wider system. Here, patient councils resulted from the work of an organized and focused grassroots community movement, combined with what we might call exposure through reports and inquiries about the unacceptable conditions and practices in the system which absolutely needed addressing. What we're familiar with more recently in other areas of healthcare, are councils more focused on sharing perspectives and experiences, working collaboratively... or usually, we say "co-designing" with the institution. In some cases, these councils are still mandated by the government, but they're not set up to be independent advocacy groups. In fact, in my experience, advocacy is actively discouraged in favour of advising. So thinking back to our conversation with Paula, you may recall the whole discussion about forms of representation and the question of who gets to speak on behalf of whom. We asked Lucy how the leadership of the Empowerment Council is determined.

06:16

Lucy: Board members are elected through their peers, i.e. other people who had experienced the mental health system. So every year at an AGM, if there are vacancies on the board, we say how many vacancies there are, and people who want to run — who are people with mental health or addiction backgrounds — who want to run, have to speak to the constituency and argue why they would be a good representative on the board, and then there's a vote by the constituency which are members which are current or former patients and then they elect the board members.

06:49

Emily: In the Dilemmas of Representation paper, the authors described engagement in health professions as having a weak form of democratic representation. But here, talking about the Empowerment Council, it's a much stronger form, as the structure to support democratic representation is actually in place. There are nominations, elections and even campaigning. So that's a bit of background on where the council came from. But what exactly does it do? We asked Lucy to describe the work of the council and also to share how that work is decided on.

07:20

Lucy: The work that we do is systemic advocacy, education, and then outreach and connection to other clients of the system, both in inside the Centre for Addiction and Mental Health, and outside. My role... my title is "Deputy Executive Director"... and again, I do systemic advocacy, education and outreach, and I also tend to pick up all the gaps that are not being picked up in other areas of engagement. Certainly, we talk about raising the concerns and issues of patients in the system, and historically, we've done that by doing focus groups, checking in at the AGM, doing research. So through that, we try to consolidate what is the particular work that we need to do. But there's always been a continuation of the work of addressing issues that we already have information about, like the saturation of data that we already know, [where] we don't have to consult people again to ask them. An example of that would be access to fresh air. Access to fresh air off an inpatient unit has historically been an issue that we tackle decade after decade, and we're not going to consult people endlessly about that, because we already know, so they are, like, large streams of work that are ongoing irrespective of consulting with people.

08:39

Jennifer: Lucy describes ongoing advocacy work that has never really done. In another part of the conversation, we talked about how policy and practice are always changing, and those working in advocacy have to just keep at it to ensure the needs of the service users don't keep falling even further behind. In addition to that ongoing advocacy work are specific mandates developed in consultation with their community. There might be timely issues brought up in focus groups or via survey or at their annual general meeting, but there are also these more evergreen issues that have persisted since the council began and haven't been adequately addressed. Their stance is that these things still matter, and that the push to resolve them continues, irrespective of whether people were consulted recently.

Emily: I find this interesting because in other healthcare spaces — certainly ones that I've worked in — it's framed differently, and assumes the healthcare system doesn't already have knowledge of patient priorities and preferences. This means we need to continually consult or engage in order to find these

things out. Of course, this may be necessary to answer new questions or address evolving situations. But surely there are many things we know could significantly improve patient and client experiences, which we're still not doing anything about. Lucy seems to be saying that a lot of her work isn't about trying to find new insights, but to constantly advocate for what is already clearly needed in order to improve the care of clients. Her term "saturation of data" is pretty thought-provoking because it implies that there's a lot of knowledge available from years of patient and client advocacy work and engagement that the system could be changing without more consultation. That said, Lucy points out that this advocacy work doesn't happen in a bubble. There's a wider context and changes over time that have to be taken into account.

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Lucy: How one chooses what the advocacy issues are, I think does matter and does have to be grounded in what is happening in the world outside of institutions. And again, I'll use racism, sexual orientation, and all the sort of kinds of go-to kind of identity categories or categories of marginalization that you have to attend to. I think we try to do that — and other organizations try to do that as best they can within the scope of their work.

10:55

Jennifer: I think Lucy is making an argument here for intersectionality where the advocacy work has to take into account both historical and current societal and political contexts, and that that must impact how decisions get made. Reading between the lines, though, I'm picking up that that's not always an easy task to do. So at this point, you may be wondering why we're talking about advocacy, when the focus of this podcast is patient engagement? We do realize they're not the same thing. And this point was brought home quite poignantly when we spoke with Lucy about engagement and advocacy, and the extent to which there may be differences or similarities, or maybe some overlap. Lucy has actually given quite a lot of thought to this issue as she can feel that there's a change in the air. There's a shift happening from advocacy to engagement:

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Lucy: In this climate, there's like, probably a misunderstanding of what advocacy is, and there's more of a reaction to it. And I think the reason why I was saying earlier that it's hard at some moments to make sense of what is happening in the system now is because there's so much of this that's driven by affect. It's driven by people being nice, emotions, people telling their stories, affecting hearts and minds, and less so on trying to do the hard work of challenging power and blocks in the structure of how services and the system is operating.

12:19

Emily: Lucy's language here is closely related to what Paula said about mismatches in forms of representation. Lucy is describing a trend towards including patients or service users for their affect — the emotions they provoke by telling their stories and sharing experiences — and she observes that this is not the same as pushing for system change to improve care for others. Paula mentioned this exact scenario as an example of a mismatch where we run into trouble if symbolic patient representation is expected to work in decision making spaces. We asked Lucy why she thinks this is occurring. Why is engagement more appealing than advocacy?

12:56

Lucy: I think I'm hearing the message that advocacy is too "confrontational," perhaps not productive, and that we want to "engage" people and, and problem-solve and hear from "lived experience," hear from lived experience, hear from lived experience.

13:14

Jennifer: In the course of our conversation, this was not the first time Lucy's tone changed when it came to talking about "lived experience" and the high value that we place on it, especially in patient engagement. So we asked her to elaborate: What's the issue with the focus on lived experience?

13:30

Lucy: I see the individualization and the singular narrative trumping systemic change, because you will only get particular kinds of individualized stories which the article attends to, and then you get this kind of symbolic representation and engagement, as the authors speak about. I think it's dangerous for the person doing that sharing [of] their story, because there's an ethics around that that I don't always think that people are aware of when they're doing that engagement, depending to the degree of how it gets used or leveraged in the system. But it also erases the need to look at things from a collective perspective.

14:09

Jennifer: So again, here with Lucy, we're confronted with the tension that Paula spoke about using democratic principles to justify patient engagement, when in reality, we tend to draw on patient stories and the emotional currency of lived experience. Lucy also raises the ethical question of whether patients have a full enough sense of how their narratives, or even just their presence, is being utilized in the system. As the conversation progressed, we started to wonder, "So what should this all look like?" I know for myself, I've often wondered about a parallel patient-led research institute that would seek support from interested researchers instead of the other way around. But of course, Lucy is way ahead of us and has explored this avenue already:

14:51

Lucy: Some colleagues and I a couple years ago did put in a proposal to the Ministry to have an independent research institute run by service users, so that we could develop, in partnership with people who had skills and with other service users, what we even define as a good health outcome. That proposal didn't go through, and we didn't get our independent research institute to do the research that we wanted to do. I think what's happening now in the system is that the knowledge is... the expertise is drawn out of the patients. And of course, I'm not saying like people don't have expertise, about their experience, but this is the problem with a phrase like "lived experience," it's always assumed that there's like this kind of benign expertise that's coming forward, that's going to make these kinds of monumental shifts in the system. It's not that I don't believe in, you know, people's experiences, but not for the kinds of systemic change. It's like it's too individualized and it's not grounded in any kind of like, theory.

Jennifer: Lucy's making a connection here that this tendency towards symbolic engagement. explains at least in part, why we just don't have a lot of patient-led initiatives. If patients participate and engage and collaborate within the system, it's presumed that that's enough or sufficient for system transformation, just by virtue of including a number of individuals with lived experience. The idea that Lucy puts forward, of rooting system change in theory, I think, is a really compelling one. And I'm glad she brought this up, because often patient engagement is discussed as a conduit for system change. And no doubt, patients often influence change in the system, especially when institutions and organizations create the opportunities for that. System change in an advocacy context, though, looks quite a bit different.

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Lucy: In order to make system change — which is what these engagement regimes are supposedly aiming to do — you absolutely, in my view, have to tie to some kind of theoretical framework because the work, the knowledge, the scholarship, the literature, already exists, and we have to do draw from it, reflect on it, go back to it, and also share it with people who might not know. And the people that I do see that sort of work from that expertise in interesting ways also do it in a very politicized manner. Like while I'm often sitting in these kinds of useless meetings where we're talking about, you know, what pink color we're going to choose for a new institution, there are activists who are marginalized people, or people with disabilities who are actively trying to work with the government to improve the state of disability support. So sometimes, when I'm sitting in meeting and I'm thinking about how much money is spent around the table, and then I think about this other group that's protesting on Parliament Hill, it kind of brings engagement to like a whole kind of landscape for me because I think about... what do we... "Shouldn't we be there?" You know? Supporting... supporting those people.

18:00

Emily: So Lucy is referring here to a kind of inner conflict, one which I've certainly experienced as someone who works in engagement professionally, about just where and how to best direct efforts to effect change. While there may be exciting things that happen from engagement, there are, of course, also limitations and constraints and they may be frustrating ones. These can come in the form of budgets or scopes of practice, or in the capacity of patients or service users to push for system change.

18:29

Lucy: I'm part of the machine that has to do engagement work and bring people together sometimes against my better judgment, and where I can, I will try to offer opportunities where I do some community capacity building, so that people that are supposed to be informing a process — and again, the article talks about this as well — people are supposed to be informing, often very complex medical processes, they don't have any previous knowledge, but somehow there's this presumption that they're going to bring all this like, magical lived experience and expertise to dismantle a very complex system... You have to do the real engagement work, which is [to] make information accessible, make it relevant to people's lives. If they're going to be informing a process like a lack of housing or something, you don't ask people how they feel about the lack of housing, you inform them: "This is what we know about the housing situation. This is what we've heard about." Based on that, what might be a useful process of conversation and dialogue here? But even that process of doing the real engagement work is fraught. So I don't know what institutions are doing — or what they think they're doing, right? Because I don't

find most of what they're doing accessible anyway to people. Having done this work for a long time, one of my limitations and barriers in the work now is actually not people who are providing services that I'm trying to reach, it's actual other engaged service users because they have become extensions of the system and they will sometimes react to the critical inquiry that I think is required to call the system to account.

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Jennifer: So Paula spoke about the “Catch-22” of patient engagement, where patients may be deemed to be too knowledgeable to be effective. What Lucy is describing here is maybe the other side of the coin, where service users become insiders working in accordance with institutional agendas, rather than — in this case — working on behalf of a collective. Service users integrate into the institution in a number of ways, and Lucy described the various roles for people with lived experience. I thought her descriptions very closely resemble what I've seen in other hospital or institutional settings.

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Lucy: So you have people who are hired to do like work within the system, which is work that might have been traditionally done by nurses or occupational therapists. There's now a para-professional designation of people with lived experience doing work, and that has seemed to be part and parcel of representing. Then you have people hired to do patient engagement work. Then you have these people who are not hired who'd sit on advisory committees and receive [a] honorarium. I think some people are critical, but I would say, generally, I see the engagement phenomenon eroding advocacy. And I don't think the people that are doing engagement work are aware of that. I think collective work has been replaced with something else — or collective concern, or collective outrage has been replaced with “engaged participants.”

21:35

Emily: Okay, so here we've circled back to Lucy's earlier comments that engagement is eroding or replacing the work of advocacy, and that this integration of patients directly into the system in a number of roles seems to smooth over or even avoid any friction that would have been caused by advocacy. Again, Lucy recognizes the inherent tensions that can be experienced by those involved.

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Lucy: I do think engagement alleviates a lot of guilt for the actors of a system, and I have no doubt that some of these actors in positions of power are fully aware of the limitations of these engagement models, but within their own, I guess, “status” have no power to speak up against it because it really is kind of a Zeitgeist that we can push against right now. It's everywhere. It's becoming more popular. People want to do engagement all the time. So it's really hard to... it's blasphemous to speak against engagement. So I don't think it's like conscious intentionality.

22:39

Jennifer: I've definitely felt the same energy, when I've questioned the motives of institutions that foster engagement. There's so much forward momentum and increasingly, organizations are committing more and more resources to it. And to some extent, it's understandable because patient engagement often

looks quite productive. And good things often come from a collaborative mindset. Lucy fully understands this and sees how this complicates the discussion.

23:05

Lucy: And this is what makes the engagement stuff and ideas tricky now, because I do think we do influence practice and how people work and who gets hired to work in an institution. So I go back to my... my thing is, "What is my problem? Like, "What am I complaining about?" You know? Because it feels murky, we don't know where we are. And there's something about the engagement process right now, where it kind of, in my view, masks a whole bunch of things that we can't exactly know what's going on and where we are. I don't know if that's because there's not that many... there's nothing to complain about and, you know, things are fine, or if because this is implicit in part of the obfuscating, that happens with all the engagement — if everybody's engaged and giving feedback, then everything's fine and there's nothing to look at here. Except every now and then you get a clue: Somebody dies, you know, in a hospital. Or there's the... like, black men and Middle Eastern men are being like restrained twice as much, or there's particular kinds of ways of being in these spaces that are allowed.

24:10

Jennifer: So before we go on, I just want to mention here that earlier in the discussion, we talked more in depth about recent research revealing that indeed, black and Middle Eastern men are much more likely to be restrained than white men. Lucy used this as an example of the kind of knowledge that would not likely be extracted from a patient engagement process. And here, she's pointing out that it's work like this that reminds her of what's at stake if we replace advocacy with engagement.

Lucy: We don't need to engage. We need to address the things that people have said previously. But these are the kinds of issues that I think we should be talking about, but I don't see anybody talking about that in a kind of political way. I do think there are small things that happen in the day-to-day running of a hospital unit, that — if you asked people — might be helpful to get that information. I guess the question for me is: were those conversations happening before? And again, if I look back... if I go back to the 1958 example of the archives, I look at the Patient Council minutes, the things that they were talking about in those minutes are the same thing that patients are talking about now. "We don't like the food, we want to be able to go smoke when we want to be able to go and smoke." I'm not suggesting that's all that people are raising because I do think there are new issues that, you know, maybe engagement, you know, serves a purpose. But conceptually, you can't look at the engagement phenomena without in and of itself thinking about... needing to think critically about: what do the engagement regimes... who do they serve? What is the purpose of them? Why now? What are they dependent on? And those are the things that I think about, and those are the questions that I guess I feel like I need to ask from my standpoint.

26:07

Jennifer: Lucy's obviously bringing a critical perspective to this discussion. She calls patient engagement a "regime." She's asking: Who is served? What is the purpose? And: Why now? These can be immensely challenging questions that threaten some of our idealized notions of engagement. So where does the theme of representation fit in? We think, actually, it's one of the cornerstones of the justification for engagement altogether. And so it's important to investigate assumptions around

representation, to pick apart the language and challenge the boundaries and definitions, and see where we net out.

26:40

Emily: Even though we knew just from her body of work that Lucy would have insightful things to say about representation, we didn't at all anticipate just how much her experience parallels our conversation with Paula. Lucy's observations are strikingly similar, and she notes that organizations will discount what service users or patients say by suggesting that they don't actually represent everyone.

Lucy: I think it's very difficult to assume any organization can do representation justice. It's sometimes an argument used against us, to prevent us from bringing forward an advocacy issue, i.e. "You do not represent everybody; therefore, we're not going to attend to the advocacy issue that you're bringing forward." I usually respond to that by talking about how in the literature, many service user organizations talk about how arguments against representation are used to silence them. So there's that aspect where representation can be used against a service user organization that's actually trying to do decent advocacy and representation work.

27:58

Emily: We spoke to both Paula and Lucy at length and of course did a close reading of the Dilemmas of Representation paper. But it actually wasn't until we were putting this episode together that it became clear what they had both been saying, but in different ways, and it's this: The dialogue about representation must include consideration of power dynamics, the political environment in which the dialogue is happening, and the ways in which patient voices can be instrumentalized for purposes both stated and unstated. We knew going into this episode that the world of patient engagement and the world of mental health advocacy are distinct and separate and different. Many engaged patients would say they're not advocates, and that they are not speaking on behalf of others. And that's entirely fair. But I'll also say that that view is not necessarily consistent across the board. It's not a unified stance, it's not a collective stance — it's an individual take.

28:34

Jennifer: And this is perhaps the central operating mechanism of patient engagement. Individuals are recruited by institutions to support their work of quality improvement, and in the case of health research, to bring voices of lived experience into a scientific process. Much of the existing literature about patient engagement looks at it from a particular vantage point, and it's through a lens that considers things like effectiveness and collaboration. What we don't see through that lens is what Lucy is pointing out, that engagement is potentially eroding, or even replacing advocacy, which means that long-standing gaps in the system in which people are suffering, or their needs continue to be ignored, may never be addressed. So where do we go from here? Obviously, we don't have the answers. Our goal for this episode and frankly, every episode, is to bring some of these trickier issues into the light and see what comes of the discussions.

Jennifer: If you have a comment about this episode, you can visit us at mattersofengagement.com. Big thank you to Lucy Costa of the Empowerment Council at the Centre for Addiction and Mental Health.

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