

Matters of Engagement podcast

Episode "Patient Engagement During a Pandemic – with Julie Drury and Christa Haanstra"

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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.

Emily: And I'm Emily Nicholas Angl.

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Jennifer: Well, Season 2! It's kind of amazing we made it here, given the state of, well, everything. We've been talking about this podcast project for a while, and really appreciate OSSU's financial support and helping to bring the podcast to life. OSSU is the Ontario SPOR SUPPORT Unit, which is jointly funded by the Government of Ontario and the Canadian Institutes of Health Research.

We began planning our episodes in the fall of 2019. But it wasn't really until early 2020 that we got rolling. And then the pandemic slowed us right down. Honestly, my own day-to-day life didn't change all that much since I already work from home, and I don't have any kids living at home. But Emily, that was not the case for you!

Emily: No, we went to visit my parents in the beginning stages of the pandemic. And then we stayed for four months. So that was a bit of a different way of life. But now we're back in the city and my son's restarted daycare. And that's included some challenges. But we're sort of figuring out a routine now.

Jennifer: Well, it was a good thing we managed to get most of our interviews done before we had to start working remotely. And I think as new producers, it was kind of good for us to have all this audio material before we even started editing. And it allowed us to develop a sense of where we wanted things to go overall. As we were making each episode, we kind of knew what was going to come next.

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Emily: That's right. And this season is a bit different, because we don't have that luxury of time anymore! We're making each episode as they come out, so things feel a bit more organic. But one thing we knew for sure, was that we wanted to make an episode that spoke to some of the things happening related to COVID-19 and the impact it's had on engagement and partnership.

Jennifer: For many of our listeners, I think it will come as no surprise to learn that when COVID-19 hit a lot of engagement or partnership projects were simply abandoned, or postponed indefinitely. Some of the structures in place for engagement aren't utilized in key decision-making spaces. And this led to a lot of soul searching by patient partners who had a lot of questions, and at least at first, didn't know how to even think about what was happening.

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Emily: I was following a number of friends and colleagues online and saw that this was happening across all areas of healthcare, research, clinical settings, organizational quality improvement, policy development... Existing initiatives - especially those that were primarily conducted in person - those are dropped. I think some groups and organizations were able to pivot to online in fairly short order. But those are the ones who'd already established a deep commitment to engagement and had already devoted time and resources to it.

03:12

Jennifer: In the past few weeks, we've seen more and more discussion about all of this - articles and commentary, webinars, podcasts - some great content from our friends at BC SUPPORT out west and also here in Ontario from OSSU. People interested in patient partnership have been discussing just how precarious engagement has turned out to be, and also have been thinking about ways to move forward. We'll put some links in the show notes to some of these resources. Anyway, given all of the content we knew already existed, we wanted to add to the discussion and not simply repeat it. So we picked an angle that, for me at least hits a little closer to home.

Most listeners might already know that I had a son with multiple severe disabilities, who died about 10 years ago. And I simply cannot imagine what we would have been facing now, with Owen as a young adult, requiring full time caregiving support, and with a severely compromised respiratory system. My feelings about caring for Owen have always been complex, but now experiencing COVID-19 as well as learning about all the hugely consequential policy decisions that would have affected us? Well, I'm appalled. I'm worried for my friends. And I'm relieved. I'm relieved that Owen isn't having to live through this and that I'm not faced with managing his care.

But, of course, there are lots of people who are having to live through this. Not just parents of kids with complex needs, but anyone who is a caregiver for a family member or someone important in their lives, particularly those living in long term care or residential homes.

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Emily: In the early days, we saw an almost instant shutout of visitors from those facilities. And for the most part that included any family or caregiver who might have been an integral part of the person's care team. We saw all kinds of heartbreaking stories of people visiting through closed windows or over FaceTime, or who even had to attend the death of their loved ones over the phone. There was a lot of pain and loneliness and suffering as a result of those shutdowns. At least at the beginning, I think many people saw this as an unfortunate consequence of necessary actions to address dangerous and evolving conditions.

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Jennifer: Where these shutdown policies have had significant impact includes clinical settings, emergency rooms, intensive care units, long term care facilities, and at home or in residences where people need ongoing caregiver support. And these are areas where we often hear the term patient and family-centered care, where the focus is not on the medical system, or even on the person's specific condition or disease, but rather on the person's goals and their priorities and their relationships, including with their families and caregivers. And often the notion patient and family-centered care

includes the idea that unpaid family caregivers are an integral part of the care team that makes decisions with or for the patient, with the patient's own interests at the center.

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Jennifer: And this is where patient engagement and partnership comes into focus. This ideal of patient and family-centered care includes partnership with patients and families, especially in terms of co-developing policies. Now, that might apply to clinical or medical decisions but it also applies all the way up through various levels of the healthcare system. If organizations and institutions want to claim to be patient and family centered, then the expectation is that their policies and activities should be created in partnership with patients and families.

Emily: Right. And so that brings us back to COVID-19 and its impact on engagement and partnership. COVID-19 arrives, all visitors including caregivers are restricted from seeing their loved ones. And there was very little partnership with families to create or revisit those visitor policies.

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Jennifer: So in this episode, you'll hear our guests talking about engaging with patients and family caregivers. In some cases, they're referring to engaging in care, as in patient-centered care, which often includes family members as part of the patient's care team. And in other cases, they may be talking about engaging as partners in broader decision-making spaces. There's a lot of crossover. And we decided not to attempt to separate these out. Because the truth is, especially for people living this reality, they're probably not experiencing them as separate things. Our guests do a great job of illustrating how patient-centeredness in their view, includes patient and family partnership.

08:14

Emily: We have two guests who have been living these realities themselves, and who have also been observing and commenting on how policymaking has unfolded during the pandemic. They have insightful observations about what happened, how to think about moving forward, and what successes and failures we should learn from. Let's meet Julie Drury.

08:37

Julie: My background is in strategic policy and strategic planning with the federal government. But I've been in this patient engagement/family caregiver engagement space now for well over a decade going into 12 or 13 years, and came to it because of my lived experience with my daughter, Kate, who died five years ago, after a lifelong illness with a rare and complex disease. And so the interest that I have in engagement and partnership really came from lived experience - first of all sharing my story and wanting to affect change for families like ours - but now it's really evolved into really interesting conversations about what does engagement partnership look like? How can it be effective? How can organizations do this? As well, creating safe space is really important to me.

Jennifer: So that was Julie Drury. And here's Christa Haanstra.

09:27

Christa: I've been a communicator in the healthcare space for over 20 years and many of the organizations I've worked with have had a very strong foundation in engagement and more recently in co-design, so my time at CAMH and my time at Holland Bloorview Kids Rehabilitation Hospital, and then more recently at the Change Foundation where I really spent five years with my sleeves rolled up deeply in the engagement and co-design space and even just really pushing the envelope on how we use that within healthcare to truly shape, change and improvement to the patient and caregiver experience.

Jennifer: Like Julie, Christa also has personal experience, seeing up close the realities of family caregivers, which has given her an added perspective.

Christa: I have a father who has a chronic illness. And so, you know, just the idea of isolation with him, and my mom was a really big issue. My mom was his primary caregiver. And I also was living with the reality of my brother in law being in a palliative situation. And so really understanding that personal experience of the caregiver in moving through systems and trying to deal with in those very early days, a lot of restrictions. We thought, "Oh, it's gonna be a couple of weeks" and here we are months later, still dealing with it.

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Emily: We asked our guests to reflect on the early days when the first shutdown started to happen. We wondered if they could recall, at any time, "Even if you knew that certain actions had to be taken, were there any alarm bells that something wasn't quite right with the process?" You'll hear Julie, then Christa. And then Julie again.

Julie: The early warning signal for me was the command and control approach. We actually were literally calling some of these strategic tables where we were going to discuss how we're going to handle COVID – we were calling them command tables. And they became very singular in their focus, they became very singular and who was around those tables. They weren't super transparent. They weren't super collaborative. They were only specific types of people at those tables, the highest levels of leadership.

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Christa: Yeah, I definitely didn't question the quick shut down at the very front end of COVID. I mean, it was such an unknown and we were just really trying to figure out what it meant for everybody. I think what disappointed me as the weeks went on is that there was no official pressure or in none of the directives were healthcare organizations asked to revisit the role of essential family caregivers, and how to bring them in safely. And we know that there were organizations that said, okay, no visitors allowed but family caregivers aren't defined as visitors. And so they were brought in safely. And so, you know, again, the timelines and the crunch, and the pressure didn't allow for this. But those examples really need to be considered as we go into 'wave 2' of how some organizations just simply pivoted, and recognize that there was a safe way to bring family caregivers in. And I really wish that from the official directives that were coming out from the government for different areas of health care that there had been pressure or directives earlier on to revisit the role of caregivers

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Julie: ...and what it demonstrated to me not at the time, but now upon reflection six months later, is a massive gap. Because the decisions that were being taken were being taken with no type of lived experience being included, there was very little patient engagement/patient partnership. Some of the patient engagement partnership tables that did exist, were just set aside, and the common phrase was, "we just don't have time, we don't have the time to consult with you or work with you." And I find that really interesting. You had time to bring the other types of people to the table, but you didn't have time to engage and partner with lived experience to make sure that what was being framed around policy to address COVID, particularly that would significantly impact patients and families. There was no time to consult with those people who are going to have to live the policy.

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Jennifer: We're hearing a few things here. Neither Julie nor Christa are questioning the decisions to stop everything and put safety procedures in place. What Julie's pointing out is that it happened behind closed doors and without collaboration. And she's also saying that the claim of there not being enough time? It just doesn't really hold up for her because there was time to bring in others. Christa has a slightly different view on this. She comes from a culture of engagement that invests a lot of time and resources into cultivating relationships, which is in her view, what partnership is built on. We'll be hearing more about this later. But Christa thinks that, indeed, there just wasn't enough time to establish the kind of engagement that would have been required.

So while Julie has an entirely fair point, so does Christa. For good partnership to happen, at least how many people define it? It does take time, not just to develop the approach but to implement it and to build the required relationships. Now, in the absence of that, it would certainly have been reasonable for the government to have given some directives as to how to bring caregivers back. It sounds like what they're both saying is that without engagement or partnership, that priority got lost. And the government didn't provide any guidance, which for many signaled a real lack of leadership.

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Emily: I think it's generally accepted as true that engagement supports better or more appropriate policy development. We asked Christa whether engagement during the pandemic would have made a difference to developing a more patient-centered visitor policy that included recognition of family caregivers.

Christa: You know, I think that there are places in which, and situations in which, engagement would have made a difference. And I think there's situations in which engagement wouldn't have made a difference. You know, it really all has to do with the, you know, the willingness of the organization or partner to engage, and truly engage, in order for it to make a difference. Probably engagement at the local level, at the community level at the organizational level would have had way more impact than trying to figure out how to influence policy at a provincial level. I also think that... you're always going to have that spectrum of commitment to engagement. So there's people who really believe in it and who are passionate about it and want to make it work. And they're going to bring them to the table as equal partners. And then there's people on the other end, who are going to just look for the voices that are

going to bring forward what they want to hear, or they're just going to hear what they want to hear anyway. And it's not going to change anything.

Engagement would have worked where engagement existed already, and where people were ready to take that and really make the most of it. Engagement wouldn't have worked if it was starting from from the ground up during a pandemic. First of all, there was absolutely no time to do it. You cannot build engagement and rapport in two days or less. There wasn't going to be the commitment. In the end, the approach wouldn't have been effective. And how do you even recruit people and build that rapport in a digital format? So I don't think it would have made a difference in that case. I do think where engagement was already embraced and where there were already existing platforms and ways to do that, yes I think it would have made a difference. And I think in some cases, it did. Like when we look at Huron Perth Healthcare Alliance - that's exactly how they built their program. And they did it in partnership with families and patients.

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Jennifer: Christa mentioned the Huron Perth Healthcare Alliance. And coming up, you'll hear Julie also mentioned a couple of organizations that she thought did a good job of pivoting or responding quickly. We'll include links to these organizations in the show notes. But for this episode, we don't elaborate on their programs. Anyway, what Christa was saying definitely makes sense. In the face of a crisis, pre-existing solid engagement relationships were more likely to continue, and weaker commitments to engagement were more likely to fracture under pressure. Julie mentioned this as well, and spoke about the impact of patients and families being embedded already.

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Julie: I will also say that in some instances, and what I've heard from patient partnerships, or quote unquote, on the ground working at the provincial level, or at an organizational level, some of them did have continuity of engaging. So some of them who are really embedded. I'll give the example of the BC Patients for Quality and Safety [BC Patient Safety & Quality Council] - they had a table that they constructed very, very quickly, in parallel with their command tables. That was patients, families and caregivers with a lived experience that were offering input and insight into the work of their quote, unquote, command table. That happened almost immediately as the same time as the other sort of tables are being pulled together to address COVID. We saw that there were some cases (very, very few and far between, let me be really clear) where engagement and partnership was continuing. We also saw it at some hospital levels. So I always give a call out to Janice Kaffer at Hôtel-Dieu Grace Hospital in southwestern Ontario. And she always has maintained as a hospital CEO a robust presence of her patients, families and caregivers, advising and collaborating partnering with them. And she'd continue that in a time of COVID. And I think it helped them navigate this much better. But it was few and far between and I was hopeful that that was happening behind the scenes or on bigger point of view.

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Emily: Unfortunately, Julie was hoping for something that didn't turn out to be the case. As Christa mentioned, there was very little support or mandate from the government requiring that organizations

bring caregivers back in. But, and this goes back to Julie's point, Christa saw organizations on the front lines working very hard to care for their patients as best they could, especially given the lack of support and communications from upstream channels.

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Christa: Interestingly, like I sat with not that long ago, a group of long term care providers and I was absolutely blown away by the thoughtful and compassionate approach that they were taking to communications and you know, that's certainly not the piece that we've heard in the media throughout this pandemic. But again, it's a bit to the point of: they didn't just take the template that was given to them through the directive. They took the the meaning behind it, and were obviously going to meet the requirements of it. But they created their own version that was very much reflective of their commitment to the residents first and to that resident experience and to really making it meaningful in their settings.

That was actually almost emotional in that, you know, you've just heard so much in the news about how bad everything was, but to see these people who've been working day in and day out, since this hit, to really make it as meaningful as they could – it was really impressive. The engagement and the approach, again, doesn't get built during a pandemic. It has to be embedded and truly rooted in the organization before and then you see how they interpret the directives in a way that reflects that. Which is very different than organizations where that's not a culture yet.

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Jennifer: One thing we were curious about was whether Julie thought there was some kind of magic formula that should have been in place for every organization. Was there a common element that defines successful engagement of partnership, as the pandemic carried on?

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Julie: I think it really came from a place of leadership, and people in positions of authority and decision-making who were calling the shots, recognizing that we need to have patients, family and caregivers at the table, if we're really going to do this well, and make sure that it's going to work well, for organizations. Maybe hospitals, some hospitals, were better poised for that, because they might have had long-standing engagement practices with their patients, families and caregivers and good structures in place. They continued that and could pivot easily to things like online and virtual rather than in-person meetings. I think, you know, but again, I think it depends on the leadership to be able to bring those structures to the new tables that were forming, like, quote, unquote, the command tables provincially.

Emily: Right. So leadership proved to be important. But here, Julie's referring to leadership at the organizational level, where she thinks the more successful responses happened. It's at the government policy level where Julie questions how things went.

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Julie: We did lose one of the best-practice markers of policy by making sure that we had strong representation from many different sectors around those tables. That's what we missed. And so it's a missed opportunity to maybe have done this a little bit better out of the gate. Some of the people

around the table have a stronger voice than others, and they have more authority and more decision-making, and so it might have come out the same way anyway. But we missed an opportunity to have more voices on the table.

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Jennifer: This sort of language about voice and representation... it's something we've explored a bit in other episodes. It leads to questions about: whose voice? who represents whom? questions of power dynamics and authority, which Julie is referencing here. Julie acknowledges the possibility that engagement wouldn't have affected the outcome, but remains committed to the principles of engagement. As we know, engagement and partnership are based on certain moral imperatives, and as such, are really compelling. Christa also argues for the inclusion of patient partners, even when conditions are less than ideal.

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Christa: I do think it's incredibly important to have the representation of all the different players who are going to, at the end of the day, have to live with the decisions that are made. And I do think having 1, 2, 3, 4 patients at the table is going to make a better outcome no matter how you cut it. Is it going to be representative? Is it going to work for everyone? No. But it's going to be further ahead than a system-oriented or system-minded solution. And I think some of the other things we've talked about before, sometimes if you don't bring patients and caregivers to the table you're solving, you're solving a problem that doesn't exist in the patient and caregivers experience. You're solving a system problem, not an experience problem. And I think that's incredibly important. Often by the time people are engaged, the thing that you're going to solve for is already been defined.

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Emily: This is a really interesting point Christa's making. If your mandate is to be patient-centered, then it would be important to you to have a means of validating what you're doing. And one way is to actually have patients and caregivers tell you or even direct you. Partnership provides an inside connection to at least with some patients and caregivers think

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Jennifer: I think that all of these points about the importance of engagement and partnership that both Julie and Christa are making are applicable regardless of whether there's a pandemic. But it's been pointed out that the pandemic has revealed just how deep or shallow our commitments really are. And it's been a hard lesson. Julie has been investing her time and energy in developing patient and family partnership for a very long time and found this realization to be difficult.

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Julie: It was a gut punch, let me be really, really clear - for myself personally, as well as I know some of the people who lead in this space. And it gave me real pause of what was our perception of reality and what we had gained in this engagement and partnership... in the space of community where patients families and caregivers are becoming more part of the healthcare system... this whole patient-centered care movement, you know, the 'quadruple aim' that patients were very much part of the system, and that partnership in care was, you know, gaining more of a foothold... that family caregiver presence and

partnership in care, you know, had increased in our country from 30% in 2015, to, you know, fairly flexible family presence policies. Close to 70% of hospitals had open family presence policies just before the pandemic hit - we pulled data in February 2020 that was demonstrating how we were really, I thought, solid in this area.

And so that reflection was really... it took a lot of energy to think about, okay, how do we move forward from here? How do we regroup? How do we take the next steps to get ourselves back into the game and back into these conversations? Because we know it's so valuable and so important. And a real concern that the shift in policies that we saw, the dramatic shift in policies that we saw, were going to become entrenched. And that we were going to have great difficulty walking it back. That engagement was going to go back to advisory and feedback, and less about collaboration and partnering and working together, you know, and sharing, sharing some power at least at some of these tables, and influencing some decisions. It was going to go back to more, "Here's what we've done, what do you think?" It's really challenging for me as someone who's been in this space for a long time to think of how far we had come and how quickly it disintegrated.

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Emily: And Julie has legitimate concerns thinking about what happens now, and struggles thinking about all the lost ground. Christa agrees, but also is aware that things could have been even worse. She spoke about the Ontario Caregiver Organization, or OCO. I'll just read from the website. They "work to amplify and spread existing caregiver support programs, as well as build new programs and supports where gaps are identified." They have a help line, publications, a lot of resources for caregivers. They essentially represent the caregiver voice in Ontario. And they've done quite a lot to amplify the needs of family caregivers. Christa thinks they've laid some important groundwork which has been beneficial during the pandemic.

By the way, in this next section, Christa mentions Caregiver ID, which we'll describe after, she also uses the term 'PFAC', which stands for Patient and Family Advisory Council.

28:07

Christa: Had the pandemic happened five years ago, caregivers would have been in 10 times a worse scenario, because there would have been absolutely no way to get that collective voice into any kind of policy or directive making. But what's missing is, who's the collective patient voice? There isn't a collective patient voice in the same way that the Ontario Caregiver Organization exists. We have witnessed that gap and experienced it a couple of times as we've gone through the Caregiver ID process because there isn't one organization that you say, "Oh, you just come to the table. Now we have the fulsome picture here." It doesn't... exist. So to me, that's a huge gap. And I don't think that a PFAC at the Minister or Ministry level is going to fill that gap, because that's a very different and distinct role.

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Jennifer: The key thing Christa wanted to get across here about the PFAC, is that while she thinks that while it plays a very important role in contributing to policy development, it doesn't fill this very specific gap she's talking about: representing a collective patient voice. Christa mentioned Caregiver ID. This is

an initiative that was developed even before the pandemic, by the Change Foundation and other partners. It gives organizations a way to visually identify caregivers and acknowledge their unique role when they're inside the hospital or healthcare facility. It includes an ID badge, but that's just one part of a wider family presence policy, which includes co-developing mutual agreements and commitments. Christa's saying that in the development of that Caregiver ID policy, they could draw on caregiver representation - but there wasn't an additional organization that they could turn to that would contribute on behalf of patients themselves as a collective voice.

Christa went on to describe the value of the OCO having an ongoing caregiver panel, which was originally convened by The Change Foundation and later transitioned to the OCO, which gave them a solid foundation from which to carry on, even during a crisis.

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Christa: When COVID hit, there was this existing panel of virtual panel of caregivers that the OCO, the Ontario Caregiver Organization could turn to and get 24-hour turnaround feedback on any of the materials they were putting out for caregivers. So there was this existing panel that ultimately became this, like incredibly important voice of caregivers feeding into every resource that the Ontario Caregiver Organization was putting out for caregivers during COVID. People across the country, were saying, "Oh, we see what you're putting out. It's really high quality, can we adapt this? Can we use this?" and I think a good piece of that is because there was actual caregiver input.

Jennifer: And one of those resources that's being more widely adopted now is the Caregiver ID policy. Some organizations like the one Christa referenced earlier, Huron Perth Healthcare Alliance, they were able to utilize it as a kind of ready-to-go package they could adapt to their needs to support staff, patients and families through all the uncertainty. In Christa's view, they really embraced the essence of it. But we also talked about the risk of developing tools like this. Organizations without the same commitment to the spirit of partnership might in fact, treat something like Caregiver ID as a way not to support caregivers, but to control them.

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Christa: And if you're coming into it with a mindset that families are a challenge or add to your workload, you're going to look at a Caregiver ID and say, "Okay, yeah, you can we can introduce a Caregiver ID, that's great. And then here are the terms under which we'll issue a Caregiver ID. We will abide by these rules, and the caregiver will abide by these rules." Well, that works when it's thought about as a partnership, but it can also be used as a tool of control, which is to say, "Okay, great, yeah, family caregivers are gonna have to sign a contract. And if they don't abide by that contract, we're not going to let them in anymore." Well, that's a very different approach to the very same tool. And to me, that comes back to the culture of the organization, the very specific community and commitment that there is to the patient and caregiver as true partners. And that doesn't exist everywhere yet. We're definitely getting there. But it doesn't exist everywhere.

You know, there's an element of trust and an element of partnership that either exists beforehand, or it doesn't. I'd say for the most part, the people who came to the table early on in these discussions absolutely are committed for the right reasons and are going to implement it with those principles

behind it. But I think that you could see it becoming, as we often say, a checkbox exercise rather than something that people embrace or that the organization embraces and

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Jennifer: Christa is reflecting on early planning discussions about Caregiver ID, with the Learning Collaborative, a group organized by the OCO, in collaboration with The Change Foundation. Now, there's a lot here to reflect on ideas about intention and control and checkboxes. Let's pick this up again at the end?

Emily: Oh, yes. But for now, we'll give the last word to Julie, who connects the exclusion of family caregivers during COVID-19 to a lack of patient-centeredness, possibly caused by a lack of patient and caregiver representation at decision-making tables.

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Julie: I think where I've landed is that there seems to be a lack of appreciation or understanding of the difference between visitors and family caregivers at the policymaker level. So at the government level, where guidance was being delivered to provinces about how you're going to address this. So there was definitely a lack of understanding and appreciation there. And I think that might go to that we really haven't infiltrated those rooms, those conversations, as patient family and caregiver partners. But I would put forward that the biggest challenge was at the government level and the misunderstanding or the misappreciation of the role that caregivers play formally in the healthcare system, and the incredible value that they have. And, you know, we've talked a lot about the unpaid multibillion-dollar healthcare workforce in this country - and that's caregivers. And it was just a slap in the face for them to be restricted so quickly and so unabashedly. But also for us not, now six months in, to be thinking about "How do we do this better?"

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Jennifer: Hey Emily.

Emily: Hi Jen.

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Jennifer: Our focus in this episode was not on the effects of COVID-19 or even on caregiver or visitor policies, but rather on engagement and partnership and on some of the related issues that have come into focus because of the pandemic. So with that in mind, let's recap some of the highlights of our guests' views, and then get to some of the issues that we wanted to talk about.

Emily: Sure, I'll start. So both guests felt that the organizations that were more effective in navigating through the pandemic were ones where a strong patient partnership was already in place. And also, government directives did not include a plan for bringing family caregivers back into health care facilities, which has been very hard for both patients and caregivers. Julie and Christa suggest the outcome of this may have been different if patients and caregivers were included in decision-making at the provincial level. And not just to have their interests included - but actual patients and caregivers with a seat at the table.

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Jennifer: Yep, and I have a couple more. So regardless of the pandemic, and regardless of any hoped-for outcome of engagement, patient engagement and partnership is still seen as a 'given' by our guests. A requirement, in fact, for good leadership. And we could say it another way: a strong healthcare leader is someone who engages patients and caregivers and fosters a culture of engagement.

And the last highlight I noted: Julie and Christa had different takes on whether there was enough time, especially in the early days for provincial level policy development, to include engagement from patients and caregivers. But I also think those different takes were really just a matter of which perspective they're coming from. I actually think they mostly agree that there was a failure of leadership at the provincial level to get the caregiver situation sorted out more quickly. And they attributed this to two things: one was that patient-centered care wasn't made a priority. And the other is that patients and caregivers weren't part of the policymaking. I think that's it...

Emily: I think that captures the key points. So where do we want to start?

37:01

Jennifer: Well, here's something that stood out for me. I assume you notice that both Julie and Christa have personal experience when it comes to understanding challenges for family caregivers. I actually think it's what makes them even more credible as commentators in this space, as they have a first-hand understanding of the possible consequences of decisions. And they've also likely developed a more sensitive ear when it comes to hearing the concerns of other patients and caregivers. So great. And here's the point I want to make: I think it's reasonable to assume that they're not the only ones who are in positions of influence, or who might have a seat at policymaking tables, who also have related personal experience.

Emily: True. This is the case throughout healthcare. I mean, everyone is a human being with a body and mind that doesn't always act the way we want! Psychiatrists might need mental health support. Surgeons might need surgery. Policymakers might have elderly parents or children with exceptional medical needs. I'm interested where you're headed with this...

38:06

Jennifer: Well, we take for granted that this is the case. I mean, of course. We're all people with experiences. But when it comes to discussions about 'engagement', we separate 'professional' from 'someone with lived experience'. Sure, in specific circumstances, this may be the case that there's no overlap, like if a physician is treating someone with a rare disease. But in relation to this specific conversation, what is the likelihood that no one at those command tables had experience as a family caregiver? No one had an elderly parent? And no one had a relative in a long-term care facility? I doubt that's true. Now certainly Julie and Christa were not specifically arguing with that. But their main points were based on not having the so-called 'patient voice' at the table. Now let's imagine that at least some of the leaders at the command tables have personal experience. Why do they not count as patient

voice? Well, we can guess why: it's because that's not their assigned role. We explicitly set up these discussions that require people to play certain parts. I'll be the policy-maker, you be the patient.

39:27

Emily: Right. It does seem that personal experience is only valid if it comes from someone who's been assigned to play the role of patient. We often talk about wearing hats. When professionals have personal experience, they're in most cases expected to take off their patient hats. Their experience may make them better at their jobs and sometimes that's an accepted use of experience. But professionals are not typically allowed to simultaneously act as the 'patient voice'. Someone else who exclusively puts on their patient hat is assigned to do it.

40:02

Jennifer: Right. So both Julie and Christa, and probably everyone else who supports engagement, want there to be lived experience in some form at decision making tables. Well, in this case, there probably were people with lived experience at those tables. But because of their assigned roles, their experience somehow doesn't count.

This raises all kinds of other questions for me, like: why is it important that the role of patient be played only by certain, let's say, types of people? How does maintaining this false narrative of 'us vs them' help to perpetuate the status quo? These will have to be questions for another time... for the purposes of this conversation, I'll simply ask: Who should play the patient? And this goes to a question, Emily, that you had raised while we were making this episode, which is, what should engagement have actually looked like at those command tables? Who should play that role of patient, and what exactly are they there for? And I would ask, is engagement or partnership really the best approach?

41:09

Emily: So, I'm kind of uncomfortable with the idea that including a couple of people with lived experience is sufficient to represent public interest just because they're part of the conversation. To me, this is misrepresentation and it isn't benign, for all kinds of reasons. I know Julie and Christa didn't say that patient partnership was the only thing missing. But it did seem they thought it was a key missing piece. I suppose I could imagine some constructive ways that patient partnership might have been helpful for ironing out details. But I'm increasingly doubtful that any two or three engaged patients or caregivers would have appropriately or effectively represented our collective interests. It's often said that patient partners aren't there to speak for all patients. They provide input and perspective informed by their personal experiences, which is fine in certain contexts. But for policymaking at the provincial level? They don't have a mandate from, well, anyone to make specific recommendations that address broader needs - which means they're also not accountable to anyone.

42:15

Jennifer: Patients and caregivers might have fared better with more robust advocacy, not engagement, which means it would have been more negotiation, not collaboration. Also, if there had been pre-existing patient representation in a collective sense, things might have turned out differently. There might have been clearer, more consistent pressure on the government to meet the needs of patients and caregivers. In this current culture of engagement, patients and caregivers individually wait for

opportunities or invitations to come and collaborate. That's how engagement works. Collective representation is very different.

Emily: Yes. And it's also how good leadership is defined currently, by the extent to which a leader creates those opportunities for engagement. In some cases, patients and caregivers may be waiting a very long time for an invitation. With advocacy, the terms and agendas would be set by patients, not institutions or governments.

43:18

Jennifer: Well, let's speculate a bit as to why we keep pushing for engagement rather than advocacy. Certainly, it's a whole lot easier for healthcare organizations and governments if patients aren't organized, making demands applying pressure. Lucy Costa talked about advocacy being seen as too confrontational, which, you know, in my opinion, is as it should be. Holding institutions to account is inherently adversarial.

But I also imagine that resistance to advocacy comes from patients too. Zal Press, in the episode about Compensation? He talked about the lack of an organized patient collective that could push for things like payment for engagement. And at the time, in that conversation, I remember thinking, "sure, okay, but who's going to organize that?" I would love to be proved wrong. But I'm not convinced there's enough interest for patients to organize and make collective demands in that way. And besides, being a patient isn't really an identity that bonds people together. It's a role we individually play in the context of a healthcare encounter. I think individually we more strongly identify perhaps with particular illness experiences, and less so as customers of our healthcare system.

So I think there's something mutually pleasing about engagement with its open door to collaboration. It's an effective way to absorb or defuse potentially disruptive energies. And it's a safe place where individuals can go and participate in something bigger than themselves. Like you Emily, I'm not convinced it's effective at influencing policy development in a way that addresses collective concerns, in the same way pressure through advocacy would.

45:15

Emily: So we have one more thing we want to address before we finish up. Christa's comments about Caregiver ID and the potential for it to be seen as a tool for control rather than for support. It's an interesting point, if not exactly surprising.

Jennifer: ...and probably more common than we'd like to think. I don't mean to say that most people are necessarily ill-intentioned - just that people are busy and distracted, and they want to get their jobs done. Why not use a packaged resource or program that both makes the organization look good and helps to ease some operational stress...? If it comes with a visible checkmark or seal of approval, even better.

Some people may find Caregiver ID convenient, and therefore implement it without actually buying in to the principles of patient engagement. I can also imagine some organizations seizing the opportunity to use something like Caregiver ID explicitly to keep caregivers out, and maybe use the pandemic as their

golden moment to do so. Earlier, Julie had expressed concern that the new visitor policies might become entrenched and there will be difficulty walking them back. And I think that's a legitimate concern – it's definitely easier to justify quickly bring in a new policy in a crisis – it's more difficult to convince leadership to drop that same policy, especially if it's proven useful somehow.

46:42

Emily: My impression throughout all of these conversations and interviews is that because engagement is dependent on relationships, there's, as Christa said, an element of mutual trust required. So yeah. Trying to convince others to adopt the spirit of patient partnership, especially if they're skeptical or resistant, can be a challenging task. And like a lot of aspects of engagement, it's hard to know if or when you've succeeded.

Jennifer: Thank you to our guests, Julie Drury and Christa Haanstra for their time and insights. We have a few resources and links to share related to this episode, so please be sure to check the show notes or website for links. As always, if you have any suggestions or comments, please get in touch at mattersofengagement.com.

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