



Patient Partner Working Group Webinar
A VIRTUAL DISCUSSION ABOUT PATIENT PARTNER CAPACITY BUILDING
Wednesday, January 19, 2022

Chat Summary

- 12:01:25 Greetings from very snowy Ottawa!
- 12:03:40 Hello from Saskatchewan.
- 12:04:10 Hello from beautiful Quebec City,
- 12:04:32 Hello from Ottawa!
- 12:04:49 Hello from Ontario.
- 12:04:57 Linda from Ottawa - Patient Engagement Research Ambassador with CIHR-IMHA, also patient advocacy for those living with dementia, and those living with ME.
- 12:06:10 Nope the poll is not visible.
- 12:06:27 no poll seen sorry.
- 12:06:28 I was able to see it and respond.
- 12:06:32 I saw it and responded.
- 12:06:34 Hello from New Brunswick! Glad to be here....
- 12:06:40 sorry, cannot respond. I am a patient partner.
- 12:07:05 yes.
- 12:07:16 Hello from Halifax NS.
- 12:07:16 Results are not visible either.
- 12:07:19 cannot see results is it possible to speak to the results?
- 12:07:28 Hi everyone, welcome! Thank you so much for attending the OSSU PPWG Webinar today, Please feel free to share where you are tuning in from and a little bit about yourself.
- 12:07:33 maybe verbally let us know what the questions are please?
- 12:07:34 Results not showing for all.
- 12:07:36 Can't respond or see the results either :-).
- 12:08:01 Hi, I'm Participant.
I'm Anishinaabekwe from Nipissing First Nation in Robinson-Huron Treaty territory in Northeastern Ontario.
- 12:08:18 How many responded? I saw neither results nor questions.
- 12:08:27 me neither.
- 12:08:36 From treaty 4 territory. PP on SCPOR.
- 12:08:46 Hello from chilly Saskatchewan.

12:09:33 Hello from Halifax , Nova Scotia.

12:11:05 Please everyone mute.

12:11:14 As a reminder, please mute yourselves.

12:11:17 Is anyone else getting an echo.

12:11:37 Host: Please mute everyone but the speaker.

12:11:38 someone is speaking and not muted.

12:13:58 For those on Twitter, please use #OSSUwebinar to share what you hear today for those who cannot join.

12:16:47 In the objectives I don't see patients specifically mentioned - mainly mentors and trainees. How is the NTE including patients?

12:19:59 Thank you for the question Annette! Please feel free to add questions to the chat for our presenters.

12:20:46 Annie, it is nice to see you. Our team is definitely interested in being involved.

12:21:59 Can someone copy Alexandre's email over here? I missed it and would like to reach out.

12:22:10 www.menti.com code: 8514 4996

12:22:50 Can you say more about how the SPOR NTE will work with existing training and capacity programs that have been implemented (e.g. by SPOR Support Units)?

12:22:52 How do individuals participate and collaborate, if not affiliated with a specific group?

12:23:36 Here are the emails Annie mentioned: Annie.LeBlanc@fmed.ulaval.ca
Alexandre.Parent.ciusscn@sss.gouv.qc.ca.

12:24:15 Can't reach menti - Would say Provide Opportunities.

12:25:14 Menti #2 - serious barriers to their participation.

12:25:58 Looking forward to engage with you! Typo in my email address. Please use this one:
alexandre.parent.ciusscn@sss.gouv.qc.ca.

12:26:57 Hi Participant, Patients are involved in all aspects of the NTE Governance and activities from key roles in the governance structure, participation in strategic decision making, providing guidance on patient and community engagement in activities, co-creating and co-delivering training, mentoring trainees and peers, to growing patient membership and participation in the NTE.

12:28:27 Our executive Director's email is: alexandre.parent.ciusscn@sss.gouv.qc.ca, mine is Annie.leblanc@fmed.ulaval.ca.

12:31:07 Thank you Annie. I saw that more in the slide after the objectives.

12:39:47 Hi Participant, there are a number of ways by which we will work with organizations regarding their training and capacity programs. First, the inventory will help promote what has been done and what is currently being offered. It will also shed light on redundancies in training and programs and where gaps remain. This should help with redundancy and help organizations in prioritizing their work. As per existing programs that are implemented, organizations have different needs, which many have already been shared with us, from

helping spread or scale their program, to adapt (ex. modality, language, context), to help promote. We work to adapt our support to the need of the organization. Hoping this help!

- 12:41:35 Amazing presentation, thank you Ambreen!!!
- 12:41:48 Agreed! A lot resonated with me as well!
- 12:42:01 Fully agree. Need to share this more widely
- 12:42:09 Hi Participant, looking forward to hearing from you. Key partners in PORCCH are members of the NTE, and the program will definitively be included :)
- 12:42:46 Great presentation. If I would add anything it would be to work with patient partners to determine patient priorities in research.
- 12:43:48 Agreed! Participant - patient priorities in research. Would move impact forward!
- 12:43:52 Great information and perspectives, thank you!
- 12:44:22 Will the NTE have any funding for specific POR projects?
- 12:44:44 I am curious to know what is the definition of patient partner? Who are they?
- 12:44:46 Question for Ambreen - are we making progress in EDI and how do you know?
- 12:45:20 Someone mentioned a patient partner registry - any thoughts on this? And, how would you recommend that we meet potential patient partners where they are?
- 12:45:44 thank you, very informative.
- 12:45:54 It seems like our community has remained stubbornly small over the years...
- 12:46:09 thank you; very informative.
- 12:46:41 Great points Participant!
- 12:46:52 Will the SPOR NTE have influence at CIHR itself? For example, ensuring that reviewers who review POR grants (e.g. the Priority announcement in the last Project Grant call) have a grounding in POR.
- 12:47:04 Ambreen -do you see your principles -model being integrated in training of new researchers?
- 12:53:30 Does anyone use an alternate term to "patient"?
- 12:53:30 I'm trying to answers as many questions as I can. If I don't get to yours, please reach out either on twitter or email :)
- 12:54:16 Thank you everyone for your questions. This may be the last one that we are ale to answer today.
- 12:54:59 That's a good point, Annie.
- 12:55:01 @Participant, sometimes we use the term "knowledge holders" to describe people that we think are experts in a particular area.
- 12:55:02 ...other than person with lived experience.
- 12:55:06 Thanks for your thoughts on these questions - very insightful....
- 12:55:43 A research project registry would be helpful to Patient partners.

12:55:57 Youth want to see and hear end results of their participations in a language they can understand.

12:56:01 Thank you for an informative and insightful presentation today Annie and Ambreen!!!

12:56:21 Some successful registries to match patient partners with researchers from UK could be looked at.

12:56:26 I agree Donna and to make sure you have a registry that is not missing those patients who are underserve you ensure that you have them on your registry.

12:56:34 Fabulous session today, more conversation and sharing needed ...

12:56:53 Agreed, amazing session! Thank you all so much! So many important conversations had today.

12:56:58 Capacity is a term that implies skills and knowledge is Western skills and knowledge. We should use it also mean skills and knowledge in another knowledge/skills systems.

12:56:59 Excellent session, thank you!

12:57:19 We need to define patient partner vs a person who wants to be engaged. There's a big difference in amount of time commitment and knowledge.

12:57:26 Thank you for a great session today! Excellent points - lots of food for thought.

12:57:30 Great points all around, thank you!

12:57:35 @Participant I agree.

12:57:37 Thank you!

12:57:58 thank you.

12:57:58 Thanks everyone!

12:58:04 Thank you!

12:58:09 That's why we need to focus on community engagement and partnering with community groups, we're guests in their space.

12:58:19 Thank you very much! Take care.