Chat Summary

12:13:54   Thank you for that reminder about tech restrictions. We tend to over-emphasize virtual spaces as a barrier-reduction tool.

> **Reacted to** "Thank you for that r..." with 👍
> **Reacted to** "Thank you for that r..." with 👍

12:14:09   All great points. We definitely need to go into communities to engage.

> **Reacted to** "All great points. We..." with 👍

12:15:08   Thanks Ron for giving a great presentation. Community sites/family doctors should be involved in research. Diverse providers will bring diverse trial patients.

> **Reacted to** "Thanks Ron for givin..." with 👍

12:16:48   besides patients' education, community health providers/physicians need to develop the trials importance. Very few physicians are involved in research trials. So we should work simultaneously on both groups.

> **Reacted to** "besides patients' ed..." with 👍

12:18:35   At the Arthritis Patient Advisory Board at Arthritis Research Canada - we have some very good steps in place for recruitment and new members.

> **Reacted to** "At the Arthritis Pat..." with 👍

12:19:08   good relationships work best with shared language and understanding. Patient/caregiver partners respond best to simple plain language communications. no jargon no acronyms.

> **Replying to** "good relationships w..." Fully agree with this.
> **Reacted to** "good relationships w..." with 👍

12:21:07   I am the Manager of Research Capacity Building with the Pulmonary Hypertension Association of Canada - one of the tools we have found useful in measuring and reporting the impact patient partner participation for both patients and clinicians are the McMaster University Patient and Public Engagement Evaluation Tools that includes indicators for patients about meaning and impact - the link is https://ppe.mcmaster.ca/resources/public-and-patient-engagement-evaluation-tool/ .

> **Reacted to** "I am the Manager of ..." with 👍
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> **Reacted to** "I am the Manager of ..." with 👍

12:23:01   Absolutely. Scheduling can exclude populations.

12:23:50 EMPaCT.

12:24:55 Onboarding with mentorship is a really great way assist someone new.

12:25:15 Making updates a visual as well and thinking about asl, adaptive, and inclusive communication.

> **Reacted to** "Making updates a vis..." with 👍
> **Replying to** "Making updates a vis..."   Yes to this.
> **Reacted to** "Making updates a vis..." with ❤️
> **Reacted to** Making updates a vis... with "👍"
> **Removed a** 👍 reaction from "Making updates a vis..."

12:25:48 Community centers would definitely be a great start. A lot of diversity in small communities and lost in the shuffle.

> **Reacted to** "Community centers wo..." with 👍
> **Reacted to** "Community centers wo..." with 👍

12:28:06 I was involved in the PIERS project with Clayon Hamilton and all the resources available are extremely helpful.

> **Reacted to** "I was involved in th..." with 👍

12:28:19 great point Ron. I have come across one Study coordinator going to her mom's restaurant with research site's name shirt on and end up in recruiting 5 patients the same day. 🙂 lol

> **Reacted to** "great point Ron. I h..." with 👍
> **Reacted to** "great point Ron. I h..." with 👍
> **Replying to** "great point Ron. I h..."   great idea.
> **Replying to** "great point Ron. I h..."   That's cool... having shirts to help brand and promote the research. Creative.
> **Replying to** "great point Ron. I h..."   😊
> **Reacted to** "great point Ron. I h..." with 👍

12:28:47 SORRY PEIRS - Patient Engagement in Research.

12:30:06 a simple filter that may be helpful is for researchers of today to think about how they want to be treated by the researchers of tomorrow when they become patient/caregiver partners.

> **Reacted to** "a simple filter that..." with 👍
> **Reacted to** "a simple filter that..." with 👍

12:31:01 It's very important for knowledge translation. Many times patient partners don't get access to the final publication of research they were involved with. Lay summaries and infographics on social media would be a good idea. We also need to move research into practice and share successes. This way other patients & caregivers might see it and want to be involved.

> **Reacted to** "It's very important ..." with 👍
> **Replying to** "It's very important ..."   Sandra I completely agree.
> **Replying to** "It's very important ..."   totally agree.
> **Reacted to** "It's very important ..." with 👍

> **Reacted to** "It's very important …" with 👍
>
> **Replying to** "It's very important ..."   trustworthy relationship between researcher and patient is the key for patients' involvement. Can you please emphasize how to develop this? why a community person should trust you? Their mindset is hard to change. How would you give them a feeling that they are not guinea pigs.
>
> **Reacted to** "trustworthy relation..." with 👍
>
> **Replying to** "It's very important ..."   Reciprocity in the relationship builds trust and increased engagement.
>
> **Reacted to** "Reciprocity in the r..." with 👍

12:32:02   Tokenism is unacceptable.

> **Reacted to** "Tokenism is unaccep..." with 👍
>
> **Reacted to** "Tokenism is unaccep..." with 👍
>
> **Reacted to** "Tokenism is unaccep... " with 👍

12:32:20   Very good insight Dr Nav. 100% agreed with you.

12:33:18   https://ossu.ca/resources/equity-framework-and-curriculum/

> **Reacted to** "https://ossu.ca/reso..." with 👍

12:33:58   Yes, Sharon thinking about and acknowledging inner bias and tokenism is very important.

> **Replying to** "Yes, Sharon thinking..."   true but subconscious bias are not easy to overcome.
>
> **Reacted to** "Yes, Sharon thinking..." with 👍

12:34:14   I've also heard feedback that equity means going beyond alignment with the census and having 'over-representation' of equity deserving groups in our work because we know they live with the greatest burdens of exclusion, discrimination, and barriers.

> **Reacted to** "I've also heard feed.. ". with 👍
>
> **Replying to** "I've also heard feed..."   These can be the most difficult populations to recruit and include.

12:34:36   Particularly IBPOC communities.

12:38:26   Perhaps tap into researchers that have experience with engaging patient partners and have an institutional belief and have invested in the process.

> **Reacted to** "Perhaps tap into res..." with 👍

12:38:50   Co-design is really important. As a patient partner before I join an organization I not only read their equity statements, I look up their staff make-up and the composition of their board. If it is predominantly homogeneous, I know not to apply.

> **Reacted to** "Co-design is really ..." with 👍

12:39:36   Ron, your point is well taken Just going back to the usual suspects each time does not address the deeper issues of inclusion.

> **Reacted to** "Ron, your point is w..." with 👍
>
> **Reacted to** "Ron, your point is w..." with 👍

Reacted to "Ron, your point is w…" with 👍
Replying to "Ron, your point is w…"   Love the idea of funding patient partners!
Replying to "Ron, your point is w…"   A challenge we're trying to tackle in a different context is somewhat related to this. We want to build relationships, and working with people we know and trust and have relationships well is something we value. Parachuting in and out (can you parachute out?) is not appropriate, so we want to keep engaging with our pre-existing groups. But, as you say, we also need to be mindful of how that repeat engagement with the same people can result in a lack of new or different perspectives. So how, in practical terms, do we balance the building of ongoing relations, with also making space and bringing in new perspectives?

    Reacted to "A challenge we're tr…" with ❤️
    Reacted to "A challenge we're tr…" with ❤️
    Reacted to "A challenge we're tr…" with ❤️

12:41:45   I a patient feels included - they will also feel free to open the conversation if support is needed.

    Reacted to "I a patient feels in…" with 👍
    Reacted to "I a patient feels in…" with 👍
    Removed a 👍 reaction from "I a patient feels in…".
    Reacted to "I a patient feels in…" with 👍
    Reacted to "I a patient feels …" with 👍
    Reacted to "I a patient feels in…" with 👍

12:44:48   For those that may not be aware yet, in collaboration with 18 SPOR-funded entities and PE organizations and PE researchers, the Centre of Excellence on Partnership with Patients and the Public created an Evaluation Framework for Patient and Public Engagement in Research in 2021 that is also a great PLANNING tool for researchers and all stakeholders that touches on many of these points brought up here by the great panelists. Many of these points on relationship-building, support and barrier removal, transparency and equity, diversity and inclusion, are generally addressed in the framework but this conversation adds more specific points brought up by the panelists that could be added in complement to the indicators in this framework. Here is the link to the project : https://ceppp.ca/en/resources/learning-together-evaluation-framework-for-patient-and-public-engagement-ppe-in-research/ .

    Reacted to "For those that may n…" with 👍
    Reacted to "For those that may n…" with 👍

12:45:11   And here is the link to the interactive Framework - CLICK ON THE ICONS to see the indicators : https://indd.adobe.com/view/8af4cb10-a621-4c0e-9ccd-21810c88ec1f .

    Reacted to "And here is the link…" with 👍
    Reacted to "And here is the link…" with 👍
    Reacted to "And here is the link…" with 👍

12:46:20   In a productive relationship patient/caregiver partners will help define what they feel is important to study and why. Research on something not relevant to the end users is simply an academic process not a meaningful way of moving thins forward.

    Reacted to "In a productive rela…" with 👍

12:46:24 Compensation / honoraria is also a really important piece of engagement. And finding ways of compensating without the patient partners experiencing a tax burden is essential - or impacting disability income etc.

> **Reacted to** "Compensation / honor..." with 👍
> **Reacted to** "Compensation / honor..." with 👍
> **Reacted to** "Compensation / honor..." with 👍
> **Reacted to** "Compensation / honor..." with 👍
> **Reacted to** "Compensation / hon..." with 👍
> **Reacted to** "Compensation / honor... " with 👍

12:48:13 love it Ron.

12:48:15 😃👍

> **Reacted to** "😃👍" with 👏

12:48:39 great suggestion, Ron.

12:48:42 Apologies.. need to step away for 5 min.

12:48:48 That's a great question, Stuart. I think about that a lot. Is it a combination of people with whom we've built relationships and adding new people on a regular basis?

12:49:06 @Ron Beleno (Toronto) - the example is one of Patient-Initiated Research (PIR). had a similar discussion this week about how funding eligibility criteria place barriers to that PIR approach.

> **Reacted to** "@Ron Beleno (Toronto..." with 👍

12:49:43 Love the idea of reimbursing patient partners. Of continuous concern is how much is 'appropriate reimbursement'

> **Replying to** "Love the idea of rei..."   SPOR Evidence Alliance has a great program in place already.
> **Replying to** "Love the idea of rei..."   Recognizing patient partner contributions to health research: a systematic review of reported practices
> https://link.springer.com/article/10.1186/s40900-023-00488-5 by Grace Fox (including @Maureen Smith) - OPEN ACCESS.
> **Replying to** "Love the idea of rei..."   Reimbursement for expenses should be a give. Compensation or honoraria for time should be determined in conversation with those who are being engaged. The Can-Solve CKD patient partners developed our model in collaboration with our team.
> > **Reacted to** "Reimbursement for ex..." with 👍
> > **Reacted to** "Reimbursement for ex..." with 👍

12:49:50 I love hearing thinking outside the box.

12:50:12 For researchers new to the process - being open is mandatory - being open to the patient input might in fact pivot the research topic to be more meaningful to the public.

> **Replying to** "For researchers new ..."   YES.

12:50:20 Patients/Caregivers should definitely determine research priorities. A Research question should also be viewed with PCPP to determine relevance.

Reacted to "Patients/Caregivers ..." with 👍

Reacted to "Patients/Caregivers ..." with 👍

Reacted to "For researchers new ..." with 👍

Reacted to "Patients/Caregivers ..." with 💌

Reacted to "Patients/Caregivers ..." with 👍

12:54:26   https://www.arthritisresearch.ca/peirs/ - there is a workbook available here to download and resource that answers a lot that has been mentioned here.

12:55:25   Here is the link for Patient Partner Appreciation Policy and Protocol which outlines compensation https://sporevidencealliance.ca/wp-content/uploads/2019/08/SPOR-EA_Patient-Partner-Appreciation-Policy-and-Procedure.pdf .

12:55:32   We will capture all of the links in comments on the OSSU website when we post the video.

Reacted to "We will capture all ..." with 👍

Reacted to "We will capture all ..." with 👍

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Reacted to "We will capture all ..." with 👍

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12:56:51   Is it possible to compile and share the links?

12:57:07   Click on the three dots and you can save the chat.

12:57:20   Breakfast on the west coast!

Reacted to "Breakfast on the wes..." with 😂

Reacted to "Breakfast on the wes..." with 😊

12:57:26   Great webinar 👏

Reacted to "Great webinar 👏" with 😃

Removed a 😃 reaction from "Great webinar 👏"

12:57:28   Many thanks to all the presenters and participants for the discussion today!

Reacted to "Many thanks to all t..." with 👍

12:57:39   time well spent.

12:57:40   Thanks so much everyone!

12:57:41   Awesome webinar, thanks!

12:57:41   Thank you so much to everyone today!

12:57:42   Thanks for a great convo! Great to see all the energy and how much things have nonetheless changed in the last years! Thanks OSSU and team!

12:57:47   Thank you!

12:57:47   thank you.

12:57:48   Thank you!!!

12:57:49   thank you.

12:57:51   thank you!

12:57:51   Thank you.