



Patient Partner Working Group Webinar
WHAT GETS COUNTED: PAYING ATTENTION TO SEX AND AGE IN HEALTH RESEARCH
Friday, November 25, 2022

Chat Summary

- 12:02:28 Welcome everyone! Bienvenue!
- 12:03:13 Hi, welcome to What Get Counted: Paying Attention to Sex and Age in Health Research. Please feel free to add in the chat where you're tuning in from, your pronouns, and why you are here!
- 12:03:57 Participant from Ottawa. Here to learn so that I can advocate!
- 12:07:27 Participant from Ottawa, land of the Algonquin.
- 12:07:42 I have the privilege of attending today as an uninvited settler on the traditional ancestral and unceded lands of the traditional ancestral and unceded territory of the x^wməθk^wəyəm (Musqueam), Skwxwú7mesh (Squamish) and Səlílwətaʔ (Tsleil-Watuth) Nations, now known as UBC's campus in Vancouver BC. I continue to unlearn and listen closely.
- 12:08:58 Participant living and benefitting from living in Toronto covered by Treaty 13. Here to learn and take away to better apply in my work.
- 12:09:28 I live & work on the traditional homeland of the Ojibway Nation and the Huron/Wendat Nation, and now includes communities from the Mohawk Nation, the Pottawatomi Nation and the Métis Nation of Ontario. Under the One Dish With One Spoon Treaty, the Haudenosaunee Confederacy and the Anishinaabe peoples agreed to share and care for this territory for the benefit of the future generations. I acknowledge their stewardship throughout the ages." The Odawa people were in the area between Gravenhurst and Orillia. The J. Collins purchase area is Gravenhurst and south into North Simcoe. The people of Rama are Chippewa. Here to learn.
- 12:09:30 I am joining from the unceded traditional lands of the Katzie, Kwantlen, Matsqui, and Semiahmoo First Nations in what is now referred to as Langley, BC
- 12:09:39 Participant from the traditional and unceded territory of the Musquem, Squamish, and Tsleil Waututh Nations (Vancouver). Executive Director at a patient organization, working on building capacity for patients to be drivers of research in our disease area.
- 12:11:04 There will be a Q & A period at the end. If you think of questions along the way, please insert here (with your name) and I'll collect them for the Q & A period. You can unmute and ask yourself or choose for the question to be read. If you could just say "To be read" that would be helpful too.
- 12:11:41 Participant from Treaty 1 territory, the traditional territory of the Anishinaabeg, Cree, Ojicree, Dakota and Dene peoples and on the homeland of the Metis Nation.

- 12:15:54 Participant from Hamilton (one Dish with One Spoon Treaty), Member of McMaster Collaborative for Health and Aging, Member. I'm interested participating in opportunities to improve inclusiveness in research. I've always liked the phrase for all participants "Nothing About Us, Without Us".
- 12:16:52 Great phrase, And in this case "Nothing about women, without women". 😊
- 12:17:32 They're closer to the steering wheel.
- 12:18:35 Exactly.
- 12:33:02 🙌🙌
- 12:36:14 It's always been important to me but I figured that there were experts on the research team who were "handling" that! Wrong assumption so now I'll ask more questions.
- 12:37:50 Regarding SGBA+ in research, I would add that there likely needs to also be consideration of training for research ethics boards and to support them in considering SGBA+ in the context of the TCPS2 principle of Justice. How to raise these issues with researchers without falling into the trap of 'the REB does not review the science, but the ethics'.
- 12:38:12 Question period coming up soon! Get your questions in or just indicate that you'd like to ask a question (and to whom).
- 12:41:38 I'm so impressed with today's presentation and this learning module. Is there a resource clearing house where all the SPOR SUPPORT Units can promote and post links to their learning resources? Thanks — from British Columbia.
- 12:43:44 Thank you to all speakers and organizers for an engaging and informative webinar! I am curious if you know of resources/guidelines to inform appropriate/inclusive language in survey demographic questions. For example, gender identities, categories for sex, etc.
- 12:44:01 I do have a question. It seems that these categories, sex, gender, ethnicity, age, etc.. aka more features are seen as more costly when it comes to research, because it requires more of the researcher when considering a project. I do not think all of the hesitancy is due to PI and security. A lot of times when I ask questions, I get the response that it is costly. I want to know if this is true.
- 12:44:13 Thank you for this great presentation!
- 12:44:32 Is there a growing movement to include patients on research ethics boards?
- 12:46:07 apologies for that on CIHR's behalf! We're still learning and trying to do better too.
- 12:47:23 I will relay your comments to the folks involved in the design of that module, Maureen.
- 12:47:36 For Computer Science programs, ethics classes are being considered and at some schools' ethics classes are being removed. Do you think that Computer Science, Data Science and

Machine Learning, Bioinformatics programs in universities should keep Ethics, and Research Basics as foundational programs in schools and not allow students to only take Technical programs?

- 12:47:40 The SPOR National Training Entity will be launched soon and will try to serve as a national clearing house. <https://cihr-irsc.gc.ca/e/51465.html>.
- 12:47:47 I've seen similar issues with the CIHR SGBA module in the past - patient partners were principal applicants on a grant application I was supporting. The module was very inaccessible to some of them, and one was unable to complete it.
- 12:48:01 I like this module. I hope it is open to people who are interested in learning and improving.
- 12:48:08 Carolyn - Great question for the National SPOR Training Entity launch next week!
- 12:48:15 I agree with the need for standardization.
- 12:50:08 sorry I can't speak at the moment.
- 12:50:12 Yes please!
- 12:50:38 And it is important for the National Training Entity to maintain and keep the resources up to date. So many platforms get stale, full of broken links and less relevant content.
- 12:50:39 This is a great question. Especially for those of us doing community-based research.
- 12:50:49 There is guidance developed by CIHI and StatCan
- 12:51:07 We used Stat Can in our last patient/community survey.
- 12:51:22 Good to know, thanks @Participant.
- 12:51:47 UBC has a resource:
<https://ethics.research.ubc.ca/sites/ore.ubc.ca/files/documents/Participant%20inclusivity.Gender%2C%20sex%20and%20sexual%20orientation.pdf>.
I expect there may be more comprehensive guides out there, but this is a starting point
- 12:51:49 <https://www.cihi.ca/sites/default/files/document/measuring-health-inequalities-toolkit-gender-stratifier-en.pdf>.
- 12:52:16 CIHI Measuring Health Inequalities Toolkit <https://www.cihi.ca/en/measuring-health-inequalities-a-toolkit>.
- 12:53:12 Very helpful, thanks so much.
- 12:53:22 PI = Personal information.
- 12:53:44 I have a question about surveys and gender options.

12:54:22 There is also work to develop new reporting guidance around the reporting of equity in observational research: <https://methods.cochrane.org/equity/projects/strobe-equity>.

12:54:34 CIHI also has a resource for race-based and indigenous identity data collection: <https://www.cihi.ca/sites/default/files/document/guidance-and-standards-for-race-based-and-indigenous-identity-data-en.pdf>.

12:54:51 Participant - you'll get the final question!

12:54:57 Led by Vivian Welch and on social media at: <https://twitter.com/EquityStrobe>.

12:56:34 Apologies I have to run to another meeting. Great session, thank you very much!

12:57:05 Webinar Experience Survey <https://www.surveymonkey.ca/r/SKYPFLZ>.

12:57:45 Wonderful presentations and presenters!

12:57:56 Excellent presentation. Thanks everyone for such an informative and accessible presentation. Super impactful.

12:58:01 Thanks everyone!

12:58:07 Thank you.

12:58:27 All of the slides will be posted!

12:58:29 Thanks Robin! Very helpful

12:58:44 Thank you!

12:58:49 Can we include the links that people shared in the chat as well, Maureen?

12:59:06 YEs please. I second Virtue's comment

12:59:35 Thank you!

12:59:35 Thank you! Great event!