



Bethany Kwan: Please feel free to engage with Dr. Perez Jolles in the chat!

Monica Perez Jolles: 2019!

Amy Huebschmann: Love this point about the dynamic and changing environment -- haven't we really appreciated how dynamically things can change in the times of the COVID pandemic? So much changed so fast in 2020...

Cole Hooley: What are the markers of successful stakeholder engagement? What sort of outcomes do you suggest newbies to stakeholder engagement focus on?

Monica Perez Jolles: This is an excellent point Amy. A context-dependent approach to engagement during and after COVID is relevant

Borsika Rabin (she/her): I appreciate Cole's question about how we assess the success of stakeholder engagement!! We have been tackling this in our own work.

Monica Perez Jolles: Success can be determined by the group itself but also I would see it in terms of whether your stakeholders were actively involved in the process from beginning to end. Funders also have their own guidelines (e.g, PCORI). Are you stakeholders identifying their own needs and preferences? we will go over concrete approaches in the 2:40 session

Bethany Kwan: I find it can be VERY difficult to bring in new stakeholders to a program or initiative that has been going on for a long time. But it's also necessary, as stakeholders with chronic and terminal disease may need to focus on other aspects of their lives - or unfortunately pass away - and can't necessarily be involved for many years.

Jess Indresano (they/them): Do you have recommendations for how to share findings with patient stakeholders? I'm thinking especially of cases when data analyses take a few months to years after the close of a study to complete. I've heard recommendations from others suggesting to direct people to the relevant publications. However, academic publications are often inaccessible due to pay walls and academic jargon. I also wonder about incorporating stakeholders into data analysis processes or more specifically analysis verification.

Amy Huebschmann: RE: engagement -- agree very much with Dr. Perez Jolles' comments on whether the community felt engaged. Re: how to measure this - we're also wrestling with this in our group. This is a review article of community engaged research contexts, processes and outcomes by Luger, Hamilton et al. on my reading list -- includes measures such as trust. <https://pubmed.ncbi.nlm.nih.gov/32428339/>

Monica Perez Jolles: This is such a challenge Bethany. Not only with patients but also with agency/organizational turn over. Our key champions leave for example. I have found helpful to include community leaders and diverse groups in ongoing meetings, where we allow rotation

Cole Hooley: Thanks @Amy Huebschmann for the article, looks very helpful!

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Implementation & Conduct of Pragmatic Research: Ensuring Rigor & Relevance in Practice

Monica Perez Jolles: Hi Jess. Good question. I do not rely on pubs for our community members. We visit their staff meetings at clinics or workgroup meetings to present ongoing progress on the project and we provide very short and visual reports to agencies on our findings. we have also created a video for community dissemination

Lisa: How and when do you deal with patient partner compensation or patient champion compensation / remuneration?

Bethany Kwan: Key champions leaving can really bring a project to a screeching halt, it's a huge challenge. What other implementation strategies need to be in place to mitigate the impact of turnover?

Monica Perez Jolles: Hi Lisa, I see patient time the same as expert time from a colleague or consultant. To the extent feasible based on funding, we provide incentives (gif card, bus passes, cash, help with childcare) every time they attend a meeting or data collection

Monica Perez Jolles: I strongly emphasize the strength of networks to face turn over, including the 'strength of weak ties'. I can expand on this during Q&A

Borsika Rabin (she/her): Incredible Monica, thank you ro including their perspective!!

Eugenia Weiss: Excellent presentation Dr. Perez Jolles!

Jess Indresano (they/them): Thank you for your presentation today!

Russell Glasgow: Can you talk about issues of logistics of scheduling- to get all SH at the table synchronously? Also I am wondering -longitudinally- if you need all SH for all activities or if engaging different SH for different purposes makes sense (of course with ways to keep all aware of what is going on)?

Bethany Kwan: I have a project with a stakeholder group that has two meetings per month, one is during the regular work day and one is during the evening. People join when they are able.

Amy Huebschmann: Thank you so much -- wonderful session!!

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