

Tokenism: Seeing it. Fixing it. Perspectives from IMHA Patient Partners

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The situation as a patient partner	What you might do as...	
	<i>A patient partner</i>	<i>Another member of the research team</i>
<p>You're asked to be part of a grant application only a few days before the deadline. Your role in the application is not well-defined, and it feels like you're being asked because the grant call requires a patient partner on the team.</p> <p>You're concerned that the invitation is not genuine – and instead is an opportunity to “check a box.”</p>	<p>It's ok to tell the team that you are not able to be part of the application team if you feel this situation isn't right and even if you feel the research is important.</p> <p>If you do feel you would like to be part of the team, you can make suggestions about your proposed role on the team and see if there is an openness to these.</p>	<p>Engage patient partners in the idea generation phase of a research project/grant application, well in advance of the application deadline. See how they wish to be meaningfully involved in the team. Otherwise, you may have to be prepared to learn that you're too close to the deadline for patient partners to accept your request to be part of a team.</p>

Scenario 2

The situation as a patient partner	What you might do as...	
	<i>A patient partner</i>	<i>Another member of the research team</i>
You're invited to research team meetings, but don't get a chance to often express opinions or ask questions.	Let someone on the research team know you feel this way. See if they can encourage or invite you to voice your opinions, questions, and ideas during the meetings. This may help you feel more comfortable about being assertive during the meetings.	Notice that this is happening or don't let it happen in the first place. If a team member is taking over a meeting or speaking too much, chime in and see if others have thoughts who haven't been able to express them.
	This short paper written by four patient partners to help guide the conversation about compensation might be a helpful resource: https://www.jospt.org/doi/full/10.2519/jospt.2020.0106	

Scenario 3

The situation as a patient partner	What you might do as...	
	<i>A patient partner</i>	<i>Another member of the research team</i>
<p>You provide input at meetings, but you feel it's not being taken into account or used thoughtfully by the team.</p> <p>You haven't seen good examples or had it pointed out to you how your ideas, opinions and experiences have made an impact on the research.</p>	<p>Let someone on the research team (whoever you are most comfortable with) about your concerns. Ask them where your feedback, experience, and insights have impacted the project so you can understand if or how they have or have not been incorporated into the research.</p> <p>Clarify your role on the team and what your expectations and theirs are.</p>	<p>Speak up about this if you notice it. If you're carrying out the research work of the team, make sure you circle back to patient partners so they know how their input and insights impact(ed) the project.</p>

Scenario 4

The situation as a patient partner	What you might do as...	
	<i>A patient partner</i>	<i>Another member of the research team</i>
There's little consideration put into resources or support that would help you engage with the team. For example, it's assumed you understand all of the acronyms the team uses, you're sent materials for meetings the evening before the meetings, meetings are during the day when you're not available, etc.	Share with a member of the team that this arrangement doesn't work for you, along with suggestions for what might help. For example: a list of acronyms and what they mean, training about the research process, accessing meeting materials a week or a few days in advance of the meetings, seeing meetings scheduled at times that work for you, or others we have not listed here.	Ask patient partners on your research team what resources or support will help them with their work on the team. Either support these requests, be realistic about how you are able to support them, or if you can't support them, explain why and see if there are some creative compromises that you can come up with together.

Scenario 5

The situation as a patient partner	What you might do as...	
	<i>A patient partner</i>	<i>Another member of the research team</i>
You're asked to be a patient partner on a research team without a discussion about compensation for your time and effort.	<p>This can be an awkward conversation to start, but if compensation for your commitment to the research team is important, ask about it.</p> <p>For some patient partners, compensation is important in helping their ability to participate, feel valued, and help them be accountable to the team; while for others, compensation is not of interest.</p>	<p>Be proactive and open with your patient partner about the possibility of compensation for their engagement on the research team. If you do have a budget for this, let them know what the possibilities are and what the logistics are related to this - be open and honest. If you are not able to provide compensation to them, be upfront about this and why. Work with your patient partner to determine compensation that is fair.</p>

Scenario 6

The situation as a patient partner	What you might do as...	
	<i>A patient partner</i>	<i>Another member of the research team</i>
<p>The possibility of authorship is important to you, but you're deep into the research project and no one has addressed this topic with you.</p>	<p>If this is important to you, ask for a conversation about authorship at the beginning of the project. Clarify how authorship is determined based on your contribution to the project. If you've contributed to writing before, you might share your comfort with the process and share some examples.</p>	<p>Authorship is an important part of being on a research team - and patient partners may have past experience with this or not. Talk to the whole team early in the project about authorship and how this is determined. Patient partners may contribute to publications in different ways than other members or the research team that will still lead to authorship.</p>
	<p>This paper about authorship and acknowledgement when patients are part of the research team might be helpful – it's written by and for patient partners and researchers - https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-020-00213-6</p>	