Status Quo BINGO: Busting Myths About Partnering with Patients

This BINGO was crowdsourced from Twitter, inspired by @Dr.MaryBlack 's BINGO for Manels, as shared in a tweet by André Picard (@PicardonHealth)

As you consider who needs to be involved in your project or initiative, you may hear reasons why engaging people with lived experience is not a good idea.

Know that each of the reasons listed in this BINGO was brought forward by passionate people that recognize the value of co-creation and believe these challenges are myths and and/or barriers that can be overcome.

Working in different ways means challenging the status quo. Calling BINGO on reasons not to engage people with lived experience will raise important questions, assumptions and might just lead you down a road to transformative change.

Thank you to all who have contributed!

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Patient stories are anecdotal	The project already started	We are already patient- centered (and have the survey to prove it)	If we paid them, it will seem like too much work	All of our meetings are in the day
It needs to be evidence-based	There isn't enough time	It's impossible for one patient to represent all patients	They would feel out of place	They will only complain
Can't they just come and tell their storywe only want stories	We are all patients	FREE	Senior Leadership doesn't want a patient/caregiver involved	They will ask for things that are unreasonable
We are the professionals	We will all eventually be patients	They're too young	We would have to pay them	We already have a community engagement team
Patients and caregivers will not understand this complicated information	We have real meetings to attend	They're too sick	If we pay them, they would become too biased to legitimately participate	Patients are too emotional

Commonly Perceived Barriers and Myths

- Patient stories are anecdotal
- It needs to be evidence-based
- Can't they just come and tell their story...we only want stories
- We are the professionals
- The project already started
- There isn't enough time
- We are all patients
- We will all eventually be patients
- We have real meetings to attend
- Patients and caregivers will not understand this complicated information
- We are already patients centered (and have the survey to prove it)
- It's impossible for one patient to represent all patients
- They're too young
- They're too sick
- If we paid them, it will seem like too much work
- They would feel out of place
- Senior Leadership doesn't want a patient/caregiver involved
- We would have to pay them
- If we pay them, they would become too biased to legitimately participate
- All of our meetings are in the day
- They will only complain
- They will ask for things that are unreasonable
- We already have a community engagement team
- Patients are too emotional
- They might say something that may embarrass the organization
- I listen to patient stories all day long
- No one wants to invest in patient engagement
- Where would we find them?
- I'm not sure it's a good use of their time
- It would take too much time/effort to educate them about the organization/the project
- This is a conference for healthcare professionals
- We need to come up with something strategically important with a defined scope and let them work on that
- patients will be bored
- patients and caregivers can't be objective
- further study is required
- there's no good evidence that involving patients will have a positive impact
- We can't pay them as speakers or we would have to pay everyone who speaks

- They'll only come with their own agenda
- They can't be objective
- They're too old
- They live in the wrong place
- They're not diverse enough. We need people:
 - Who are not white, wealthy women
 - We need the 6% with no smartphones
 - Who are new to the country
 - Whose first language is not English
- They won't maintain confidentiality
- They will change the agenda
- They can't afford to pay to come (no we will not give a reduced rate)
- They will ask too many questions
- The information we deal with is confidential
- We are only interested in feedback (not partnership)
- They don't understand our jargon/acronyms
- They will get up on their soapbox and be angry