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The Role of Patient Associations in the Person-Centered Care Movement

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Patient Organizations (POs) are essential contributors to decision & policy-making bodies



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Benefits of partnering?



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**Patient
Organizations are
your conduit to
patients:**



**Patient
Organizations are
the voice of
patients:**



Challenges



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Some *challenges* in bringing patient representatives to the table:

- PO leaders usually come with diverse skills and knowledge but because their focus is on patient values, they use a different lexicon than policy & decision makers.
 - Can we provide skills building to allow them to participate more fully?
 - Can we treat them like equals who bring valuable information?



Challenges

- Patient organizations lack validated data and are therefore seen as less credible.
 - Provide direct funding to organizations so that their staff are better equipped? (e.g. Sweden)
 - Bring POs into early research design for increased patient participation?
 - Support patient-initiated research (like GRIDD) by officially recognizing the invaluable contribution brought forward by research *for the people, by the people.*



Challenges



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- Patient organizations often depend upon pharma for funding, and thus their messages may be deemed to be influenced by others.
 - POs would welcome other sources of funding.
 - Most have clearly delineated *Codes of Conduct* which firmly keep pharma reps out of their policy and decision-making.



Next Steps...



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- How can the PCM movement involve POs?
 - Locally, **engage** them to sit on think tanks, on boards, etc.
 - **Invite and support** their participation in this conference and in any local PCM events or boards.
 - Provide them with **information** about the movement and stand back – they will run with it.
 - **Mentor, educate** and **support** PO leaders and their constituents.
 - Suggestions/examples from the audience?



Thank you



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