

Patient Voice/Patient-Focused Drug Development (PFDD)

Working Group Leader	BMS Champion	GRYT Health Leader
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Participants' Affiliate Organizations



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The importance of “open inclusion”

What do we mean by “open inclusion”—what is the vision for what this could deliver?

- More diversity of inputs into drug development
- Meeting the needs of more people
- Not constantly turning to the privileged few
- Balancing the need for inclusion with the need for a manageable approach (i.e., how to do this in a way that does not slow down the development of medicines)
- There was a recognition that this is not a one-time process but a series of engagements over time

What are the principles behind this “open inclusion?”

- Is it possible for this group to outline a set of principles that the stakeholders should be working towards (almost like an inclusion charter or something similar)

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What methods could be considered?

- More promotion/communication of involvement opportunities
- Different and more open ways of soliciting input from a wider group
 - Public calls to the patient community with relevant questions that will help drug development
 - The use of online tools and forums to gather the important information needed (ex. Imperial College London)
 - The need to ensure that the use of technology does not create/strengthen a digital divide
 - Need mixed methods approach that does not only rely on a technology platform
 - The need to choose platforms that are comfortable to those who we need to reach
- What can we learn from HIV in particular—this community shaped the regulatory environment we see today and has been constantly involved in the design of clinical studies since the 1980s. How did they do that? What could we learn from them?

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The advocacy organization level is best suited to help amplify patient voice

- Trust is likely the highest at the advocacy organization level from a patient perspective—these organizations are likely the highest trusted sources of disease area topics and resources
- Existing global coalitions means there are already established networks to tap into—no need to have to build a network from scratch
- Emphasize member advocacy training and support to ensure the confidence and conviction for patients to lend their voice

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How can patient organizations who have differing approaches work together more synergistically?

- Different patient organizations offer different patient perspectives—these differing points of view should be looked at holistically and not as differing viewpoints
- A portion of our discussion went away from drug development and more into prevention and programmatic needs in the time of COVID
 - Advocacy efforts are much more about driving to “establish the evidence base”
 - When the clinician and patient communities are learning about an issue at the same time, it makes it easier to work together in one voice

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The need for planning principles for good patient involvement in drug development

- How do we reach communities who have been locked out of this in the past?
- What different methods can we propose to help ensure diversity and inclusion in patient voice?
- How do we help amplify the need to get “more seats at the table” when it comes to impacting drug development?
- How can we ensure there’s a balance of the speed of which a drug maker wants to push their drug to the market vs. collecting experience data at a timeframe that is convenient for patients?
- What does “good” look like? What is our threshold for ensuring we have proper patient experience data (likely a mixture of qualitative and quantitative)?

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Suggested next steps

Focus on the principles of “open Inclusion”—exactly what are the principles/values behind this

- With the aim to see if this group could develop a set of principles or a charter

Share further examples/ideas/thoughts on methods

- To advance the group’s thinking on the different ways more diversity can be included in patient engagement around drug development

Share information between sessions

Join Us for the Next Working Group Session

Thursday, May 13, 2021
12:00-1:30pm ET