

Patient Voice/Patient-Focused Drug Development (PFDD)

Working Group Leader

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HTAi Patient and Citizen Involvement Group

Patient Focused Medicine Development (PFMD) board member

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Key Discussions from the Session

Support from the attendees on the development of general principles that all stakeholders in medicine development and research could aim for. Key areas identified included:

Education and training for all stakeholders

Diversity and inclusion

Flexibility in approaches

Allowance for multiple levels of involvement

Requires a culture change across stakeholders

Patient involvement criteria to release research funding

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Key Discussions from the Session

Diversity/Inclusion

- General agreement that for diversity in patient involvement, sources of input need to be reflective and representative of patient population
- Allow for a flexible approach to patient involvement, so they can get involved in different ways
- Not everyone can be an advocate and there should be “tiers of engagement” to include more patients, not just the medical expert advocates; not one size fits all
- Michael J Fox Foundation shared a framework for gaining input from patients that had many levels of engagement and a flexible approach (see slide 5)

Education and Support

- Support and education that is accessible is one of the principles identified
- Credible resources that are understandable are needed
- Leverage what exists and identify gaps
- EUPATI/PFMD, etc. have good resource already
- Need these not just for patients and advocates, but for all stakeholders including researchers, clinicians, industry, etc.
- Obligation to educate scientists. Many don't think patients can understand the scientific language. We should start in medical school and universities

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Key Discussions from the Session

Multi-stakeholder – 360-degree approach

- Need a cultural change so that all stakeholders are included in co-developing the path forward

Mechanisms

- Maybe research funding should be contingent on patient involvement, so patients are involved from the earliest point

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Next Steps and Action Items

Next Steps

- Consensus that we should draft principles and discuss with the group in future sessions
- Consensus that there should be a way to share ideas and resources between monthly meetings
- Find out when the “collaboration space” on the Advocacy Exchange is coming online
- Continue to map out systematic approach and identify principles of meaningful practices for patient involvement

Action Items

- GRYT Health should email participants in Working Group to ask for permission to share email addresses
- Email group members to connect and to share ideas and resources before next Working Group session

Join Us for the Next Working Group Session

Thursday, July 15, 2021
12:00-1:30pm ET