



PATIENT FOCUSED
MEDICINES DEVELOPMENT



Patient Engagement Quality Guidance

Public Consultation

[The PE Quality Guidance](#) is the outcome of extensive work initiated by PFMD and developed in collaboration with 76 professionals, representing 51 organisations active in patient engagement. It builds on existing frameworks, guidance, and standards published by or available as of June 2017. We are opening this work for a public consultation to ensure that all voices can be heard and expectations taken into account moving forward.

1. Which group or affiliation best describes you?

- Patients
- Patient advocate
- Patient organisation
- Research and academia
- Healthcare professional
- Pharmaceutical and biotech industry
- Policymaker or regulator
- Health technology assessment (HTA) agency
- Funder or payer
- Other (please specify)

2. Where are you located?

3. How much experience do you have in patient engagement?

- Advanced:** I am actively part of patient engagement projects
- Beginner:** Currently I have no previous experience, but I am planning to do patient engagement projects within the next year
- None:** I have no experience in working with patients, but would like to do more



4. Please read the following statements and choose the option that fits best to your opinion.

	Strongly disagree	Disagree	Not decided/ No opinion	Agree	Strongly Agree
Overall, the 7 Quality Criteria are useful for achieving qualitative patient engagement practice.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The language used to describe the Quality Criteria is comprehensive and easy to understand.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The format of the Quality Criteria is clear and easy to understand.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. I can use the PE Quality Guidance Tool

	Strongly disagree	Disagree	Not decided/ No opinion	Agree	Strongly Agree
To improve the quality and consistency of my PE activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
To better plan and develop my PE activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
To better assess the quality and impact of my initiatives	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
To identify gaps and opportunities for patient engagement activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
To capture and share learnings beyond the project or project team, throughout my organisation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
To structure our work together with partnering organisations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. Would you need help in understanding how to use the guidance?

- No
- Yes (Please specify)

7. In the context of your role or your work, it is important to have a practical patient engagement guidance.

Strongly disagree

Disagree

Not decided/
No opinion

Agree

Strongly Agree

8. In the context of your role or your work, would you use a patient engagement guidance?

- Yes
- No (Please specify why not)



9. Should other stakeholder groups use (a) patient engagement guidance? (e.g. patients, industry, payers, etc.)

- No
- Yes (Please specify wich groups)

10. Do you already use some guidance in your patient engagement work (e.g. internal guidances, or others)?

- No
- Yes (Please specify wich one)

Section 2

Detailed feedback for 7 Quality Criteria (optional)



PATIENT FOCUSED
MEDICINES DEVELOPMENT

If you have specific comments for the 7 Quality Criteria, please share them here (suggestions / amendments on the current criteria, structure, language, examples, etc.). These questions are optional.

11. Detailed feedback and comments for the 7 Quality Criteria

1. Shared purpose

2. Respect and accessibility

3. Responsibility and accountability

Section 2

Detailed feedback for 7 Quality Criteria (optional)



PATIENT FOCUSED
MEDICINES DEVELOPMENT

4. Representativeness of stakeholders

5. Capacity and capability for engagement

6. Documentation and transparency in communication

7. Continuity and sustainability



All responses will be treated anonymously.

However, if you wish to be kept updated on the PE Quality Guidance work, please provide your email address below. Your contact details will be used only for the purpose of updating you about the PE Quality Guidance work and will not be given to any third party. You may change this preference at any time by sending the PFMD team an email to be removed from the update list.

Please email us at pfmd@thesynergist.org if you have any comments or questions. And feel free to refer your colleagues and network to this survey!

12. Please choose from the options below if you wish to be kept informed of this work.

- Yes, I wish to be kept informed on the results of this survey (optional)
- Yes, I wish to be kept informed of the PE Quality Guidance work (optional)

Your name and e-mail address