



What do Stakeholders expect from Patient Engagement: Are these expectations being met?

Boudes M, Robinson P, Bertelsen N, et al. Health Expectations. 2018; 1 June: <https://doi.org/10.1111/hex.12797>.



What we did

- We performed a qualitative survey to understand stakeholder expectations from patient engagement (PE).
- 59 interviews** were conducted across a range of geographies, PE experience and job seniority/role.
 - Survey participants covered **7 categories**: policymakers/regulators; healthcare professionals (HCPs); research funders; payers/purchasers/HTA; patients/patient representatives; pharmaceutical/life sciences industry; academic researchers.
- The survey explored 4 themes from the perspective of each stakeholder group: meaning, views, expectations and priorities for PE.



1. Meaning

Definition:	What does patient-focused medicines development mean?
Language:	Does 'patient engagement' or 'patient involvement' best capture patients' needs at the heart of medicines development?

2. Views

Importance:	What is the importance of patient engagement to stakeholder groups now and what should it be?
Industry perceptions:	What are stakeholders' perceptions on the industry involving patients in medicines development?

4. Next Steps

Priorities:	What are the priorities for all stakeholder groups?
Skills gaps:	Are there any skills or knowledge that would help stakeholders involve patients more meaningfully?
Relationships:	What are the current and desired relationships between stakeholders?
Roles:	What do stakeholders think their own role and others' in patient engagement is?
Goals:	Do stakeholders have different goals from patient engagement?

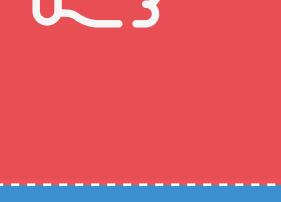
What we found



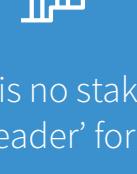
There was consensus across stakeholders on: meaning of PE; importance of promoting PE to a higher level than currently; and need for a more structured process and guidance.

Conversely, there was little consensus on stakeholder expectations and roles.

- Policymakers/regulators were expected by others to drive PE, create a framework and facilitate PE, provide guidelines of good practice and connect stakeholders, but this expectation was not shared by the policymakers/regulators group.
- HCPs were seen by others as the link between patients and other stakeholders, but HCPs did not necessarily share this view.



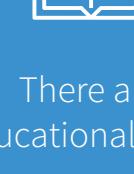
What our findings indicate



There is no stakeholder 'leader' for PE.



No stakeholder has a clear view on how to meaningfully engage with patients.



There are educational gaps.



Structure and guidance for PE is urgently required



There is a need for multi-stakeholder collaborative leadership in PE with consensus on roles, responsibilities, and expectations to synergise efforts to deliver meaningful PE in medicines lifecycle.