



# 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

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

### 2. Views

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

### 4. Next Steps

<b>Priorities:</b>	What are the priorities for all stakeholder groups?
<b>Skills gaps:</b>	Are there any skills or knowledge that would help stakeholders involve patients more meaningfully?

### 3. Expectations

<b>Relationships:</b>	What are the current and desired relationships between stakeholders?
<b>Roles:</b>	What do stakeholders think their own role and others' in patient engagement is?
<b>Goals:</b>	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.