



THE PHARMACEUTICAL MARKETING SOCIETY  
Patient Engagement Interest Group  
Sept 2015 Priorities Meeting - Summary

# PM Society Patient Engagement Working Group – Prioritization Meeting

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- In September 2015 the Patient Engagement Working Group held a discussion session to identify the priorities for the group going forward
- This was attended by representatives from across the industry, alongside individuals representing the patient voice
- The meeting objectives were to:
  - Share perspectives on the opportunities and challenges to achieving better engagement between patients and Pharma / Commercial healthcare industries
  - Identify potential immediate objectives for the working group
  - Prioritise specific issues and topics to be explored in greater detail during future working group activities in 2016 and beyond
- **The following report provides a summary of this discussion**

# What is the current status of engagement between industry and patients in the UK?

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- There is still a great deal of variation across the industry
- Some companies seem to be engaging deeply with patients on both a population and 1-to-1 level; however other companies still seem to be keeping their distance
- The history of the disease and the general engagement levels of the patient population can play a role in engagement levels
- Past experiences between the industry and patient advocacy groups can also be a key factor
- There is clearly increasing recognition of the importance of patient engagement, evident in the creation of new 'patient-specific' job roles and patient focussed departments and initiatives
- In reality, time and budget constraints, lack-of confidence / experience and inability to demonstrate benefit often impede effective implementation of many initiatives

# What are the biggest challenge(s) to effective interaction between patients and industry? (Page 1)

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*The group identified the following challenges within pharmaceutical/biotech organisations:*

- Lack of confidence or experience among internal stakeholders can be a barrier, even where they are supported at a senior level
  - This often manifests as an overall ‘fear’ of engagement due to caution over how to act in compliance with industry codes
- Difficulty defining metrics that can demonstrate tangible benefits of patient engagement for the company
- Lack of commitment to long-term follow-up and reporting of data/outcomes collected from patient programmes
- Budgets are usually short-term and subject to regular scrutiny. Long-term viewpoints and investments can therefore be difficult

# What are the biggest challenge(s) to effective interaction between patients and industry? (Page 2)

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*The group identified the following challenges within patient groups:*

- Lack of awareness of the potential benefits of partnering with industry (other than as a source of sponsorship or funding)
  - Lack of clarity about how to engage with industry, or how to propose projects that will be compliant with industry codes
  - Previous negative experiences of working with industry. For example, relationships that have been damaged by short-term projects without well communicated exit strategies. (It was noted that this is a particular issue with innovative projects that are often initiated as pilot schemes.)
  - Lack of resources available for the administration of projects, which may have long lead times or complex approval processes.
  - Variation between the objectives of different patient groups (e.g. advocacy vs support vs education), leading to differences in how they want to engage
  - Nature of patient engagement varies depending on the disease and its stage.
- No 'one-size-fits-all' solutions

# What are the biggest challenge(s) to effective interaction between patients and industry? (Page 3)

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*The group identified additional barriers to better engagement between patient groups and industry:*

- Lack of skilful reading of insight gathered from patient research and the ability to put insights into action. Concerns that we may currently only be paying ‘lip service’ to the insights we collect
- Healthcare professionals are crucial stakeholders in the interaction between patients and industry. Their role as potential advisors and facilitators is sometimes clouded by preconceptions about the motivations of industry, and barriers between the industry and patients can often be raised

# What do patients want from greater engagement with industry?

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- Honesty, transparency and sustained relationships with industry partners
- Empowerment to improve their experience of healthcare
- Feedback from projects that they have supported
- However, the attendees felt that this is an area where we need to hear more from patients and patient representatives themselves, asking the questions:

**“What does better engagement with industry look like from the patient viewpoint?”**

**“What is in it for them?”**

# What does industry want from greater engagement with patients?

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- Improved corporate/industry reputation
- Tangible/measurable change (improvements) in outcomes for patients taking their medications
- Improved patient access to available medications that could improve patient outcomes
- Insights that enable the design and delivery of a pipeline of products that better meets patient needs

# What are the biggest opportunities for the industry to add value to patients?

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- Commercial companies can provide a depth of data, research and insights that are often under-appreciated by other stakeholders, and the value that they can play in sharing and interpreting this information is often over looked
- The increasing focus of Pharma on personalised medicine and avoiding wasted medicines is a shared agenda with many other stakeholders, which could be more strongly communicated and acted upon
- There is a need for Pharma to seek out ways of adding value above and beyond the role of the NHS, rather than looking to compensate or reinforce what the NHS itself should be offering to patients
- True 'joint working' remain a key opportunity in the UK, and these are not currently being acted upon to their full potential by both industry or patient groups

# Identified priorities

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1. Listen to patients directly to gain a less 'industry-centric' view and keep the patient perspective constantly in mind; always asking "What's in it for them?"
2. Share success stories and demonstrate new models or facilitators of engagement
3. Educate pharmaceutical/biotech stakeholders to increase their confidence with implementing patient programmes (and overcome the 'fear factor')
4. Help key industry stakeholders to understand how to build a business case for patient engagement
5. Help key patient representative and stakeholders to understand how to put forward projects to industry
6. Build a network of stakeholders to identify key barriers and take an incubator approach to identifying ways to address them
7. Ensure that all activities are additive to what other organisations are offering (e.g. ABPI, AMRC)