

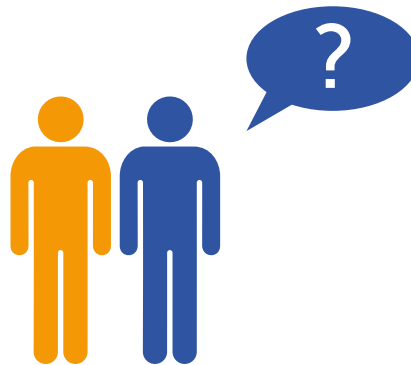


PM Society Patient Engagement Interest Group

Patient Online Forum

When we set our objectives for the Patient Engagement Group, we decided that one of our priorities was to find ways to listen to patients directly so that we could hear what engagement between patients (patient advocacy groups and charities) and the healthcare industry means to them. This helps us gain a less ‘industry-centric’ view; it also allows us to ask a really important question from the patient perspective:

“What’s in it for them?”



An online forum, supported by a short information webinar

Supported by Deborah Wyatt from Talkhealth Partnership Ltd, we used the talkhealth platform to reach out to patient members from across the UK. We invited them to participate in a private online discussion to share their thoughts on engagement between patients and commercial healthcare companies, to help shape the future of patient care. We were keen to hear from patients directly to capture their unique individual viewpoints and experiences. We also invited a small number of patient advocacy groups to participate.

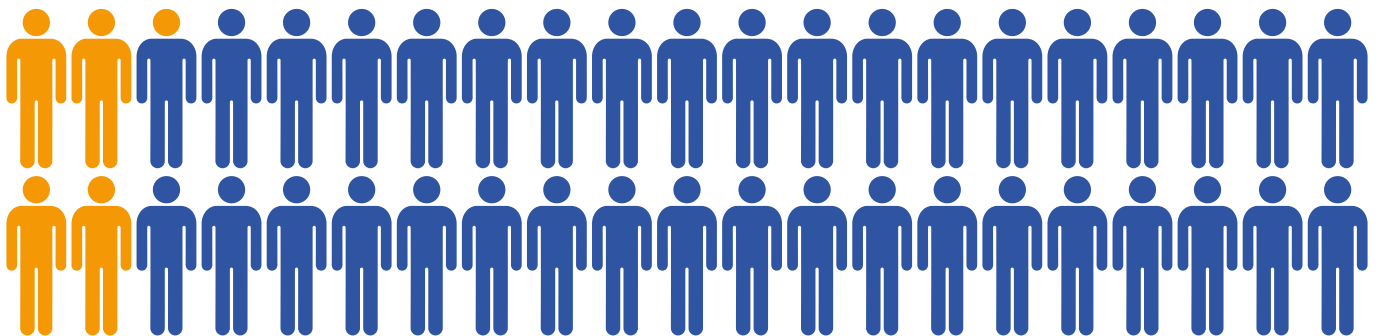
The online discussion was supported by a short webinar where we gave patients the opportunity to hear more about the industry view on the benefits of engaging with patients and provided an overview of the rules and regulations that govern this interaction. Over the course of a week we posted 10 discussion questions about their experiences engaging with healthcare companies and patient advocacy groups, what they would like from these interactions, and how we can improve engagement between healthcare companies and patients.

Feedback from the forum

42 patients registered to participate in the forum, and two patient groups also attended the webinar and responded online. Over the course of the week we received 116 responses to our 10 questions. [Click here](#) for the full slide deck report summarising the online discussion.

While this discussion represents a small population of patients in relative terms, we found it very helpful as our first listening exercise. We heard many things to keep us thinking and re-evaluating how we approach this important topic of patient engagement. Here are just a few key take homes from the discussion (see the slides for the full report):

- Although the majority of our respondents had not previously taken part in medical research many of them indicated that they would be interested to know about opportunities to do so in the future



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- Very few (only 10%) had received education or support for the medical treatments they were receiving. There was a specific comment about a desire to receive support and information for managing multiple co-morbidities

- When we asked about experience with patient support groups or charities, many of the participants shared a range of extremely positive stories and experiences. However, 60% indicated that they had never used patient support, and 87% expressed concerns about whether the patient group would be able to fully represent their healthcare experiences. One attendee particularly highlighted concerns that “Everyone seems to focus on the negativity of a health problem.”



60% indicated that they had never used patient support

- We received feedback on a range of ways in which patients would like to interact with commercial healthcare companies: from receiving more specific information on medicines and drug research, particularly allergies, contra-indications and expected outcomes, to support with interacting with their GP and finding ways in which the industry and patients could have more opportunities to exchange experiences
- When it comes to current interactions between patients and the industry, the attendees asked questions about how a company decides which patients to speak with? A number of attendees wondered if companies might be able to use online forums more effectively to speak with patients? The importance of trust was highlighted and ultimately the need for “as much communication as possible.”
- Interestingly the patients we heard from felt that they understand the regulations governing how the industry engages with patients, and this did not affect their expectations of a high level of interaction and communication between patients and the healthcare industry
- Ultimately, when asked about how engagement could be improved the attendees suggested broader access to patients (rather than a limited ‘sample’ of patients), more two-way discussion and interesting educational events, and more opportunities to directly input into research and innovation.



What this listening exercise showed us is that patients have some very clear opinions on what engagement with the healthcare industry could look like. Many of them had not experienced much contact with healthcare companies, but this did not reduce their opinion of its value. Moreover, even with a clear understanding that patient communications is very strongly regulated in Europe, they felt that there is an opportunity for broader, more inclusive, two-way communications between patients and the industry. So that the input that companies are receiving is not coming from just a small group of patients.

The collaboration between the industry and patient charities

Following the online forum, we asked the two patient groups that participated in our forum, what value they felt that working with the industry could bring. Here is what they said:

“Working in partnership with commercial healthcare organisations has offered far better opportunities for patient engagement. The resources available to the pharmaceutical industry and their readiness to absorb some of the costs that charities incur in their patient facing activities is a boon to all health related third sector organisations.

The BSF have been fortunate to partner with commercial healthcare on several campaigns, producing high quality support materials and resources for sufferers of skin disease. As well as being spared the costs of producing these campaigns, the BSF was able to draw on valuable scientific as well as marketing expertise made freely available by those partners.”

British Skin Foundation

What next?

We believe it is important for the working group to continue hearing what patients have to say about engagement with the industry. We are planning our next listening exercise, and hope to create a forum with more opportunity for two-way communications, just as our attendees suggested.

If you would like to get involved in this PM Society Interest Group or have any perspectives that you would like to share with us, please contact

helen@pmsociety.org.uk or carolinebenson@cuttsyandcuttsy.com