

# Patient Engagement

## A real world snapshot beyond the talk

An audience of agencies, charities, patients, pharma companies and others passionate about elevating the importance and value of patient engagement within healthcare gathered at The Royal Society of Medicine for the first PM Society Patient Engagement Event on 25th January 2018.

Opening the event, Caroline Benson, Co-chair of the PM Society Patient Engagement Interest Group (PEIG) and Co-founder of [Cuttsy+Cuttsy](#), shared key findings from a recent survey the group carried out investigating current perceptions and challenges the industry are facing. The survey revealed 100% of respondents believe that there is more pharma could be doing to engage with patients, especially earlier in a product's lifecycle.

“Product development should take patient need into consideration from day one, rather than thought about once the approval criteria have been addressed,” she said.

The [full report](#) is available on the PM Society website.

A series of presentations and case studies followed from different perspectives within the industry. The event was packed with best practice examples and ideas for improving patient engagement as well as advice on how to engage with patients in ways that are compliant with the ABPI code.



The PM Society PEIG recently created and published their [guide](#) on practical steps to move beyond the talk, many of which were reinforced in the presentations.

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## Engaging patients with their condition

The first case study, **Understanding the Patient Journey**, was led by Deborah Wyatt from [talkhealth](#) and [Mölnlycke Health Care's](#) Toby Cobbledick. The aim of their initiative was to gain a true understanding of the patient journey and the impact on patients of regularly engaging with their condition.

A representative sample of 200 parents of children with eczema was recruited from the **talkhealth** community. Once recruited, the patient engagement project included monthly surveys throughout a 12-month tracker programme covering aspects such as severity of the condition, dermatology referrals, emotional impact and quality of life factors. Parents were also crucially asked to record the daily condition, triggers and treatment given on an 'Eczema Tracker'.

The core insight gained through the patient engagement was that parent support to self-manage was key. Engagement with the initiative led to improvements in compliance and skin condition as well as fewer visits to the GP, resulting in savings for the NHS. The insights were fed back into Mölnlycke Health Care's brand plan throughout, allowing adaptations and change according to findings.

An online resource was also developed for GPs (identified as the first point of contact for most eczema patients) to help speed up the diagnosis of skin conditions and outline treatment options – commonly a minimal knowledge area for GPs.



“The one key benefit is that the Tracker has contributed a lot better understanding of eczema.”

A key strength of the programme was the end-to-end approach that involved patients throughout the journey and offered them an open two-way communication channel with **talkhealth** throughout. Mölnlycke Health Care were also open to adapting their plans according to findings and did so after each monthly survey.

**talkhealth** and Mölnlycke Health Care are continuing their support to this community on a longer-term basis.

## A framework for patient engagement

Guy Yeoman's session further emphasised the need to complete the cycle of patient engagement. After a 10-year career at AstraZeneca, where he built a patient centred framework, Guy is now Founder of MediPaCe and remains committed to making patient engagement deliver value for healthcare.

His engaging presentation outlined his '3i Model' of patient engagement.

- 1. Insights** - Start with patient insights
- 2. Involve** - Co-create solutions with patients
- 3. Impact** - Measure results and impact with patients

By involving patients at each stage, the patient engagement loop is completed. As well as offering learnings at every stage, a main benefit of the approach is patients actively engaging with their treatment and increasing the likelihood of them receiving the results they deserve.

Guy described what he called 'The Burning Platforms' of patients who fail to properly engage with the research agenda and who stop taking their medicine as prescribed. The health implications are huge for patients and also financially for pharma. By encouraging patients to want to participate in patient programmes and research, they are more likely to engage with their illness, and benefit from the research programs and the appropriate use of their medicines that they can help shape. Guy argued that if payors started paying by outcome and results, rather than for medicine only, the industry would by default quickly become more consumer-centric.



The 3i Model offers pharma a framework in which to operate and implement patient engagement within their organisation. Guy highlighted that we cannot take patient insight in isolation though, and stakeholders need to be brought together to develop whole company adoption of the approach.

Clarification was also brought to the definition of 'Patient Engagement' and Guy outlined the 3 elements as follows:

- 1. Provide an open and sustained relationship**
- 2. Engage with respect and compassion**
- 3. Deliver experiences and outcomes that patients actually want**

Positive steps are beginning to appear, such as the FDA expressing an interest in seeing patient engagement as part of the R&D process. This could lead to a significant change in the research and development of our medicines of the future.

## Taking a positive approach to compliance

Jayne Packham, Founder of [Jayne Packham Consultancy](#), encouraged pharma to focus on what can be done to engage with patients, rather than on compliance hurdles and restrictions. Jayne highlighted that the ABPI appreciate that pharma can work with patient groups and individual patients, so it is definitely not something to be avoided.

Jayne shared some tips for engaging with patients:

- There is little about disease awareness campaigns specifically within the ABPI code so it is also worthwhile reviewing the [MHRA blue guide](#), which summarises legislation on what can and can't be done in promotion
- Make sure all third parties know their compliance responsibilities
- Provide clear signposting of patient information on corporate websites, away from healthcare professional information. The patient specific pages are a great opportunity for pharma to engage with patients
- Ensure that campaigns include a clear declaration of sponsorship and that sponsorship of patient organisations is listed on the pharma website
- Check social media campaigns and discussion forums – these must be compliant too.



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## Turning patient insights into action

Audrey Liechti ([Takeda UK](#)) and Andy McGuinness ([Crohn's and Colitis UK](#)) joined together to tackle a shared goal.

A single IBD patient insight related to travelling uncovered a much bigger problem amongst IBD patients. A research study followed and findings included that 70% of IBD patients were worried about toilet facilities whilst travelling and 28% had deferred, changed or cancelled a trip abroad because of IBD-related issues. Read the full study [here](#).

To meet the needs that had been uncovered, Takeda UK and Crohn's and Colitis UK developed practical, actionable steps to campaign, gather support and put in place signage that made disabled toilets accessible to a wider group, including those with invisible disabilities such as IBD. Supporters included all the major UK supermarkets and multiple travel hubs across the UK.

The 'Travel with IBD' campaign coincided with Takeda's 'Fly with IBD' campaign to improve travel experiences and make toilets more accessible to patients while travelling abroad.

Partnering with patient organisations who hold a shared vision is a powerful way in which pharma can engage with patients to make a real impact, as well as enhancing brand perception of the companies championing the initiative.



## Question Time

The afternoon concluded with a panel discussion covering a range of diverse topics. Some of the key learnings were:

- Andy McGuinness explained that while there was a compliance learning curve when working with pharma industry partners, working with any new partner involves an education.
- Mark Duman, Patient and NW Service Champion, Diabetes UK, commented that we have two ears and one mouth for a reason. We need to learn to listen first and talk second. We need to ask questions such as 'How do you see your disease?' and 'What do you believe about your treatment?' Mark went on to state that we should be embarrassed that we have a 50% failure rate on products. We need to address effectiveness and start this process by listening.



- Guy Yeoman suggested that agencies can bring patient centricity into client briefs more readily by demonstrating its value simply and easily, and covering the compliance perspective.
- Deborah Wyatt highlighted the need to listen carefully to the client and to be firm with your views when necessary.

## Working together in pharma

A lasting insight from the day came from Guy Yeoman, who explained that pharma often use their resources in competitive isolation. As a result, patient solutions generated by individual companies are often difficult to scale and unsustainable. He highlighted that we need to start bringing pharma together to solve patient pathway problems. This approach would also make it less confusing for HCPs and patients who are overwhelmed by all the options and channels of communication open to them.