

Patient collaboration uncut!

The beautiful British Academy in London hosted the 2019 PM Society patient engagement event. An audience of over 70 representatives from the pharmaceutical industry, healthcare communications agencies and patients convened to hear the latest thinking on patient collaborations between pharma, agencies, patient advocates and charities.

Caroline Benson, Chair of the PM Society Patient Engagement Interest Group (PEIG), opened the meeting setting out the objectives of the event:

- to provide practical tips for delegates to take away and use and
- to encourage involvement of patients in healthcare communications and pharma initiatives for the benefit of all parties.

This meeting report summarises each of the sessions and key messages, as well as questions and answers from the audience and speakers, respectively.



ABPI Sourcebook: Your questions answered – Jill Pearcy (ABPI)

Coming fresh to the pharmaceutical industry just two years ago, Jill Pearcy observed that the ABPI Code of Practice was largely seen as an obstacle to collaborations between industry and patient groups; its dense language created uncertainty and inaction.

'The Code is being used as a scapegoat for not doing the things we want to do'.

Independent research was conducted with a variety of stakeholders to delve deeper into perceptions of the Code. Responses revealed that a desire for more engagement between industry and patients is hampered in practice by perceived compliance issues.

The Sourcebook was created to meet the clear need for interpretation of the ABPI Code. It does not replace the Code, but explains in practical terms how it, and other existing resources, can be interpreted to encourage compliant patient collaboration.

One of the six chapters in the Sourcebook focuses on an issue that many parties find tricky to navigate – payment. Jill highlighted that many companies struggle to balance the need to reward patients for their time financially, while maintaining independence and neutrality of the patient representatives. Patient remuneration is permissible as long as it upholds respect, trust and the reputation of all parties involved. The right balance must be decided in the context of each individual partnership and situation.

The next steps are likely to focus on case studies of how patient engagement has worked well in practice. The next edition of the Code is currently being developed, with a public consultation planned for Easter 2020 and release in early 2021.



Q&A with Jill Pearcy

Q. Are there plans for ABPI to support companies in refreshing their own Standard Operating Procedures (SOPs)?

A. The ABPI can't impose rules on companies. But producing a clearer Code will hopefully be a catalyst for companies to update their ways of working.

Q. The Sourcebook focuses on engaging patient organisations. But this is different to working with individual patient advocates who are not representing a patient organisation. Do you have any views on this?

A. The ABPI is working within current industry laws, which state that pharmaceutical companies cannot work with individuals on promotional activities. The lines are blurry, so different guidance may be considered for the future.

Q. How can carers be included in working with industry?

A. There is currently no specific guidance on engaging with carers, although they can support patient representatives with their activities. It's a really good time to put forward such requests to fill gaps in the current Code. I encourage anyone to approach the working group with their thoughts and ideas.

Q. Patient organisations are often apprehensive about collaborating with pharma. Is there any training for these groups to reassure them how collaborations can work compliantly?

A. The Prescription Medicines Code Of Practice Authority (PMPCA) runs introductions to the ABPI Code which give a useful overview. There could be more – again please bring these recommendations to the working group.

Q. Patients now have access to a lot of online information that is promotional, and it is difficult for companies to engage with patients online in the right way.

A. We are currently developing fresh digital guidance to ensure the Code is relevant for these modern-day issues. It seems that better clarity is needed rather than a change to the Code.

Q. Many people in the audience come from agencies, and we're often asked to interpret the Code. Are there plans to engage agencies in the public consultation?

A. It is important for agencies to be part of the process and some agency representatives are already involved in the Code update.



Patient engagement: Blazing a trail through uncharted territory – Dr Liz Clark (Norgine)

A passionate, ambitious advocate for bringing the patient into the centre of designing and developing healthcare, Liz took the audience on her journey as VP of Medical Affairs at Norgine.

Liz's aim was simple: Bring the patient into Norgine. From finance to manufacturing, office based to field-based colleagues, everyone should be able to recognise a patient and understand why Norgine is committed to delivering for them.

Norgine's journey was founded in Liz's recognition of key shifts in societal and behavioural factors – namely, the dawn of “the social age”, which brings new technology together with social needs, and the continued rise of digital amongst healthcare stakeholders.

Over a 3-year period, Liz oversaw steering groups, working sessions, manifestos and initiatives across the UK organisation to bring the patient into Norgine. Moving the initiatives out of affiliate and into Global was a key pivot, seeing the accelerated uptake of the values and ethos across other markets. Liz convened a working group of enthusiastic volunteers to explore how they could positively engage patients and at the same time affect positive change within the company.

Some notable company initiatives now include the fact that patients visit the headquarters to observe how drugs are made and question the drug makers themselves. Patients also give input into the development of patient materials. Patients are given the opportunity to receive reimbursement for their contributions, but they can decline if they feel it is inappropriate.

The relatively small size of Norgine, Liz believes, contributed to buy-in to the patient engagement ethos at every level of the company. Patient awareness became a way of being, and employees' sense of purpose increased once they observed the real impact of their work on patients' lives. Everyone in the audience was touched by the closing video, in which a delighted 8-year-old girl suffering from a gastrointestinal condition thanked the people who make her 'chocolate drink'.



Q&A with Liz

Q. What was the lowest point in the patient engagement journey for you?

A We had to work hard to engage affiliates outside the UK and help them interpret compliance regulations. This is a tricky thing for many people, and in hindsight, clear messaging from the very start of the initiative would have helped to smooth this process.

Q. Many companies will not compensate patients for travel costs for fear of being seen to influence the patient in some way. How did you approach this issue?

A I have always held the view that no-one should be out of pocket because they have contributed to one of our projects, and this includes patients. I talk to patients to find out about their situation and how we can help to make it okay for them to contribute.

Q. You chose to work with individual patients as well as patient organisations. How did you approach individuals initially?

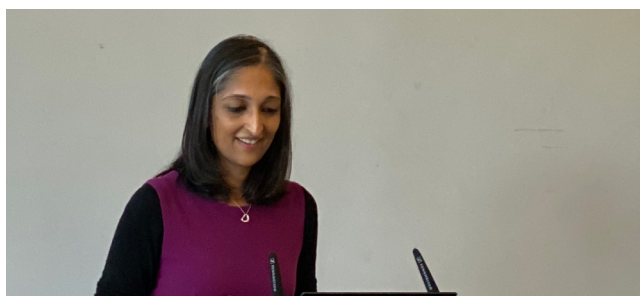
A I found that the more I spoke about what we wanted to do, the more people would help. As an example, I might put the word out that we're looking for patients who have had a colonoscopy and would be willing to attend an event at the company headquarters – I'd find patients via healthcare professionals, patient organisations, and patient experts' own networks. The next step is to understand more about how we can engage with patients through social media communities.



A practical view: Collaboration from a patient perspective – Trishna Bharadia (multiple sclerosis patient advocate)

Trishna is an award-winning patient advocate who has worked in partnership with many different stakeholders in healthcare for over 10 years. She gave the audience a fresh perspective on what individual patients need from industry partners in order to create long-lasting and trusting partnerships.

As a pro-patient with a high level of knowledge beyond her own condition, Trishna provides industry partners a wide variety of business services. She cited a case study in which she partnered with Merck to plan, run and co-host a congress event for people with multiple sclerosis (MS). Being involved throughout the project, she was able to shape the event so that patients got the most from it. Her involvement helped to steer the content, the choice of speakers, and even the food and drink at the event.



She noted the importance of explaining clearly to the patients in the audience that they could not discuss any treatments, since this would be viewed as non-compliant promotional content.

The partnership with Merck was a success, but more needs to be done to get the finer details of patient collaborations right. Issues such as underpayment for services rendered by patients, and un-thought-out, token gestures towards patient involvement still contribute to lack of trust and respect among patients working with industry.

Trishna argued that as a highly-skilled service provider working with a commercial entity, people in her position should be paid fairly for their services – the fair market value should not be assumed to be lower simply because the service provider is a ‘patient’.

Patients do of course vary widely in their own experiences, knowledge levels and skills sets. As with any other partnership, it’s important to select the most appropriate person for each project. At the broadest level, “Patients by experience” are those who are aware of how their condition affects their own life. “Expert patients” have a wider viewpoint and a more active role, being well informed and aware of the experiences of others with their condition. “Pro-patients” are the most well-informed and connected, possessing knowledge not only about their condition but also about surrounding issues such as healthcare systems and drug approval processes. Pro-patients often offer key business skills that are highly valuable to industry partners.

Returning to the issue of remuneration, Trishna posed some pertinent ethical considerations for working with patients:

- Ask if someone should be remunerated as an expert provider of a business service, or as a ‘patient’. Are they the most suitable patient to fulfil the service needed?
- Ask whether the patient collaboration is based on perceived added value, or is a ‘box-ticking’ effort
- Ask patients WHY they refuse compensation, to help understand each individual patient partner
- Ask the patients for feedback on how partnerships are working, to create positive, sustainable relationships.



Q&A with Trishna

Q. Are you ever offended by being called a ‘patient’?

A. I’m not offended, but I don’t like it when the word patient is used as an excuse not to work with people in a fair and collaborative way. I like to use the term ‘someone affected by MS’, as this can include carers and family members too.

Q. What are companies doing well?

A. When companies see patients as people, everything else seems to fall into place.

Breaking boundaries: Sharing a cross-sector collaboration to connect pharma with patients – Dr Lucy Major and Claire Myerson (CRUK)

Dr Lucy Major and Claire Myerson from Cancer Research UK (CRUK) reported on a ground-breaking project for the patient organisation; the development of an effective collaboration between CRUK, patients and pharma.

CRUK has developed an extensive network of over 1,000 patients whose role is to improve CRUK's informed decisions, increase CRUK staff's awareness of patients' experience, and strengthen the relationship between people affected by cancer and the organisation. There has been increasing demand for collaborations between large charities like CRUK and industry partners. Patients also now want to get involved more with the drug development process, from R&D to medical education. However, the ethical question for CRUK was whether they should share details of their patient network with commercial entities.

CRUK explored many questions to assess the feasibility of such collaborations. They wanted to clarify the intentions of the industry partners, the need for and scope of patient contracting, and what types of partnerships would be most appropriate for the charity to engage with.

Feedback from all stakeholders was positive: CRUK staff broadly supported the idea and flagged the need for transparency; other charities enthusiastically approved the idea and recognised legal discussions as the most arduous challenge within such a partnership; other pharma companies and contract research organisations recognised that patient involvement is becoming a priority in the pharmaceutical industry.

Claire reported on research into how patients in the CRUK networks viewed potential collaboration with the pharma industry. Again, the overall results were positive, with many patients (like Claire herself), expressing enthusiasm to get involved with drug-makers, if certain considerations were upheld. These included:

- Genuine interest from industry partners in involving patients in their activities
- Transparency of the partnership, confidentiality and reimbursement, clarity of roles and agreed evaluation criteria
- Openness and willingness to listen and to deliver real life impact for patients
- Clarity on patients' commitment, including considerations on logistics concerns, subsistence and emotional support



“Overall, people affected by cancer in the CRUK network ... feel that pharma companies are a key part of the solution that drives towards progress and the advancement of healthcare.”

CRUK is now piloting a collaboration with a pharma company and discussions are ongoing about the details of the partnership. This pilot will act as a test for future collaborations and with CRUK being such a major patient organisation in the UK, other charities may choose to follow their lead.



Collaboration in action: Working with patient organisations in scleroderma – Annie Gilbert (Boehringer Ingelheim (BI) International GmbH)

Boehringer Ingelheim (BI) have bold made steps to incorporate patients in all manner of projects and Annie Gilbert, Global Patient Advocacy Relations Manager, presented a successful case study. Annie guided the audience through her own experience in developing a fruitful collaboration with scleroderma patient organisations.

The project started four years ago with the development of a Memorandum of Understanding (MoU) in collaboration with the European Organisation for Rare Diseases (EURORDIS), a non-governmental patient-driven alliance of patient organisations and individuals active in the field of rare diseases. The document outlined a clear and transparent way of working and helped BI establish a trusted collaboration with scleroderma patient organisations across the globe. The MoU allowed BI to develop scleroderma advisory boards based on a robust legal and compliance framework that considered regulations from all countries.

Annie shared a project example relating to a clinical trial on the efficacy and safety of a treatment in interstitial lung disease (ILD) associated with scleroderma. The clinical trial protocol was shared with patient organisations, advising BI to modify the trial exclusion criteria and adjust trial logistics to better fit with patients' needs. This helped towards the high 94% participant retention rate in the trial. A clinical trial lay summary was co-created with patients and was developed in both written and video formats to ensure it was highly accessible.



“The changes implemented through the patient organisations’ feedback, not only improved the accuracy of the data collected but also improved the comfort of the participant which resulted in increased retention, an overall benefit to the trial sponsor.”

The “More than scleroderma” campaign was developed to raise awareness about this rare disease and educate the scleroderma community. BI developed disease awareness brochures and a website and submitted them to patient organisations for review and approval. The feedback was described as ‘brutal’! BI put the feedback into action in a continuous transparent collaboration that is still ongoing.

Key take away messages shared by Annie are summarised as follows:

- Patient collaboration is critical in clinical development
- Early engagement in clinical trial design and communication leads to a more effective and efficient trial
- Collaboration in communications leads to engagement and insight



Q&A with Annie

Q. What were the challenges that you experienced in the project?

A. Making sure that the right patient organisations and patients were involved so that their feedback was relevant.

Harnessing virtual reality technology: Empowering patients to make informed choices about their care – Dr Juhi Tandon (Cognitant)

Dr Juhi Tandon, GP and Clinical Director of Cognitant described an immersive educational project developed in partnership with patients and pharma, using virtual reality technology at the core.

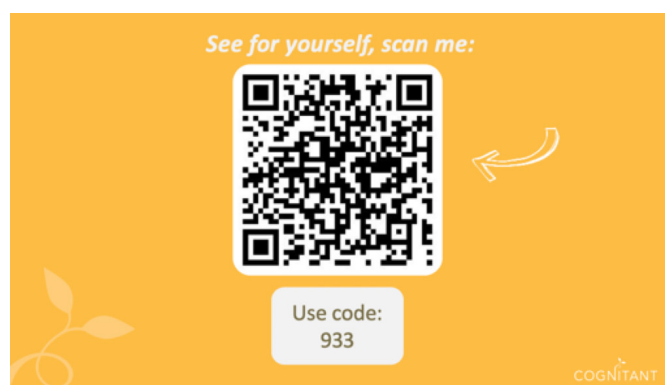
The project set out to address the lack of education around contraceptives, including long-acting reversible contraceptives (LARCs), for women. Juhi conducted a small survey with women from her practice who were seeking contraception advice. The survey results reported key challenges:

- Significant misconceptions about LARCs among patients
- Lack of HCP time to educate patients
- Lack of investment in LARC services
- Poor patient health literacy and lack of clear written health information

To overcome these challenges, Cognitant developed a new avatar-based immersive patient education programme at no extra cost to the NHS. Alongside this immersive experience, Cognitant are developing the Healthinote app, a platform that includes relevant information about contraception and a growing number of disease areas via a QR code.

Feedback results from patients is still being collected but results so far indicate 100% of users would recommend the programme to others. Key messages delivered by Juhi about this case study are as follows:

- Patient engagement and empowerment is essential to the delivery of optimal health outcomes
- Collaboration has helped to harness immersive technology to build an interactive LARC health module, overcoming health literacy and language barriers
- This encourages efficient patient and HCP consultations whilst educating patients about their options, enabling an informed decision to be made by patients



The QR code of Cognitant "Healthinote" app

The event drew to a close with an engaging panel discussion. The speaker panel comprised a variety of stakeholders, from the ABPI, patient charities, med comms agencies and the pharmaceutical industry, as well as patients. Questions and answers from the final panel discussions can be found in Appendix A.

Overall, the sessions and panel discussions highlighted patients' willingness to move forward by establishing collaborations with pharma industry. In their view, this has nothing to do with money, it is seen as an altruistic engagement which has a social value alongside satisfying curiosity in science. Within the engagement process, pharma companies may need to step out of their comfort zone. Sometimes the regulations lack a definitive answer. At that stage, it may be important to evaluate what specific aspect or clause of the code may drive the final decision. The right question to ask could simply be: Would it be ethical to do that?

Successful case studies throughout the event emphasised that truth and trust are key in the engagement process.

Panel discussion: What are the key ingredients for successful collaboration?

The last session of the Patient Collaboration: Uncut event included a panel discussion, chaired by Dr Liz Clark. The panel discussed and expanded key messages from the event's discussions:

Q: How can we accurately understand patients' different levels of experience?

A: Patients by experience can be reached through patient advocacy groups, who can reach out to the whole patient population. To access Expert and Pro-patients, the panel recommended using LinkedIn hashtags: #patientengagement, #patientcentricity, #patientadvocates, #patientadvocacy, #healthadvocates.

Q: What are the do's and don'ts in terms of establishing a cross-sectional collaboration?

A: It is key to be clear on the project proposition. When choosing a pharma partner, it is fundamental to share the same values, which means being genuinely aligned on goals.

Q: Are there any mentoring programmes to support patients who get involved with the pharma industry?

A: The European Patients' Academy (EUPATI) offers a thorough fellowship programme to educate expert patients, and the WEGO Health Network is a large online community of patient advocates across the globe. It is also important to highlight that support from charities is extremely valuable.

Q: What are the realistic timelines and top tips for organising a patient advisory board?

A: Start engaging with local advisors 13 weeks ahead of a meeting. The approval of materials takes on average two working weeks.

Q: What are the top tips for the co-creation of video materials with patients?

A: Engage at an early stage and include different ages and different professions. The project content can change based on feedback received. Process testing is continuous, and the content should be continually updated.

Q: What are the top tips for collaborating with hard-to-reach groups (e.g. patients with different levels of educations, or minorities)?

A: Leveraging patient advocates' network and experience is important. Sometimes it is necessary to think out of the box and focus outside of the specific target audience or community. For example, to engage with paediatric patients, you must reach patients, their parents, and clinicians.

Q: How do you quantify the cost/benefit of patient engagement?

A: Many of the benefits are intangible and there is no immediate return. However, the end customer of pharma industry is the patient and benefits for patients create a win-win for all stakeholders.



If you would like to find out more, please go to:
<https://pmsociety.org.uk/category/patient-engagement>