Pharma’s response to the patient voice

Summary: This report looks at the reaction to date, citing information gathered from eyeforpharma in Barcelona, Envision Pharma Groups on-going research activities in this space and our unique Patient Forum in London earlier this year. Ultimately, it asks what does the future look like for pharma and patients alike?

Patient centricity - trend or truth?

“Isn’t patient centricity the latest ‘fad’...with some orgs just using it as the latest marketing opportunity...the opportunity to say something new/different...how genuine are the intentions of some?”

This was an objection raised recently on Twitter in response to Envision’s Professor Karen Woolley speaking about the need for patient involvement in publications. Although quite a common reservation or objection, it is one quite easily answered. Patient ‘centricity’ - I personally prefer the term involvement - is a movement being driven by the patients themselves. It is not an initiative invented by pharmaceutical companies, rather a much-needed response by pharma to the growing influence of the patient voice.

“Working with patients is not promoting to patients.”

Prof. Karen Woolley

It is true that there are certain cases that may be damaging the reputation of the “patient centric” approach. Examples where patient involvement is no more than a token effort or the intention is not truly focused on improving patient outcomes. However, isn’t this where regulations come into play? As Prof. Karen Woolley said, “working with patients is not promoting to patients”, a sentiment backed by the FDA in their impending guidelines. Anyone with the wrong intentions will inevitably be in breach of industry regulations and therefore won’t be able to use it as their “latest marketing opportunity” for long.

On a positive note, we are continuing to see inspiring examples, testament to a growing response from pharma and a genuine belief in the value of patient involvement. At eyeforpharma in Barcelona this year we saw just this.

The impact of technology

The conference explored the disruption of both the patient voice and technology on the healthcare sector. Multiple presenters stressed that pharma as an industry needs to respond to these influences and be prepared for change in order to maintain its position as a key player. Noticeably the two are closely linked, with the increase of technological innovation giving rise to a more connected, health literate and influential patient. We can pretty much find information on any subject (the credibility of which is still a problem that remains to be resolved). We can seek out the advice and opinions of others with the same conditions and experiences and many of us have access to tools to monitor...
and understand our own health much better than ever before. The paternalistic approach, where a particular medicine is prescribed for a particular problem and the patient merely informed, is long out of date. Patients now play a much bigger part in their diagnosis and the decision-making process. A patient’s health is assessed holistically and we are seeing a strong shift of focus from medicines to healthcare, including non-drug related initiatives. Perhaps this is the result of a combination of tech disruption, economic pressures and a rise in chronic conditions with multiple comorbidities. However, without a doubt, technology has played its part in challenging medical paternalism, encouraging patient advocacy and providing the patient with more control.

The patients’ call for knowledge and involvement is something we have seen at both our recent Envision the Patient Forum in London in January and the patient-focused workshops at eyeforpharma. Both events were attended by highly respected patient advocates, all campaigning for change in the way patient expertise is realised in medicine development.

As the patient starts to evolve to being more akin to that of a consumer, it is no wonder certain big technology giants are responding. Using their extensive experience, they are starting to introduce effective solutions for the new holistic and patient focused healthcare industry, pulling it further and further away from the traditional model.

Solutions such as Artificial Intelligence are providing the ability to navigate big data and help identify and treat patients in a new way. Elena Bonfigliolo, Managing Director of Health and Life Sciences EMEA at Microsoft referenced a doctor-patient appointment system which can listen to and log a patient’s symptoms, recognise intent and offer appropriate treatment solutions. Such a system would mean the doctor could concentrate on human interaction with the patient, whilst the machine searched large data banks for evidence for the right solution for that patient and did the laborious task of note taking.

As solutions like these become reality, patient expectation will increase. Patients will demand that the healthcare industry (pharma included) innovate in similar ways on their behalf. Improving the speed and quality of care, whilst they remain firmly in control.

Pharma’s response

So where does this leave pharma and how should they respond? A rhetorical question posed at the conference was “does pharma want to be just a provider of low-cost drugs or an integral part of a technology driven, value-based healthcare system?”. The consensus was that in order to achieve the latter, pharma need to embrace technology as a solution to healthcare problems (not just medicines), collaborate with key players (including other pharma companies and tech giants) but most importantly, as Sebastian Guth from Bayer Pharmaceuticals said, they must “never lose sight of the person/patient they are serving”.

“They must never lose sight of the person/patient they are serving.”

Sebastian Guth, Bayer Pharmaceuticals

All of this is further support for the idea that patient centricity is not a fad or disingenuous marketing opportunity. It is an industry shift that will not only improve health for all in the long term but will help cement pharma’s true place in the evolving world of healthcare. And the good news is it is happening.

This year we saw plenty of tangible examples of true patient involvement and collaboration. Examples where the patient is considered from the very beginning and consulted even before medicine development begins. Lars Joensson spoke fervently about Grunenthal’s commitment to pain and including patients when setting research priorities and throughout clinical trial development. Using a process consisting of questionnaires, face-to-face interviews and patient journey development they were able to understand the psychological
and social influences on pain more deeply. This understanding has led to the development of a new way to measure pain impact and disease specific patient reported outcome tools for their trials.

“...bring patient involvement out of the nice to have space and build it into the core of their R and D strategy.”

**Steve Hildeman, Merck Group**

Steven Hildeman also gave an inspiring talk about how he was championing patient involvement through systemic change at Merck Group. He believes that pharma should “actively look for successes to bring patient involvement out of the nice to have space and build it into the core of their R and D strategy”. He spoke about the case of Mavenclad, in which patient interaction and demand resulted in the drug, whose marketing authorisation had been previously rejected, being investigated for another 5 years until it was finally approved - giving MS patients an important treatment option.

It wasn’t just industry examples that hit home. I met an inspirational patient advocate who, through his experience, saw the detrimental effects of the way food was provided in a cancer unit in the Netherlands. He developed the ‘FoodforCare’ concept (www.foodforcare.nl) to adapt the type of food, its nutritional value and the way it was consumed for cancer patients. Initially it took him 7 years to change the menu in a hospital. Now he has the evidence to support the impact of his approach on patient outcomes, both clinically and emotionally.

**What next?**

Despite some fantastic examples, the conference also highlighted that pharma still have quite a way to go. Patient involvement is inconsistent throughout the drug development continuum and across therapy areas. In publications in particular, patient involvement is still relatively low. At Envision Pharma Group our Envision the Patient team have recently presented a series of evidence-based research posters at ISMPP looking at the status and potential benefits and harms of patient involvement in publications. In the poster Who engages with patient-centered, peer-reviewed publications? Tweeting of JAMA Patient Pages. ISMPP 2017 we were able to conclude that the public is interested in credible, peer-reviewed, patient-centric publications and that they may amplify awareness of both patient-centric and scientific publications as well as peer-reviewed publications, even more than HCPs. Patients have a growing appetite for evidence and this shouldn’t be dismissed.

The key to patient involvement is respect for the patients’ experience, whether that is in publications, clinical development or the creation of patient support programmes. It should be likened to any other key skill that needs to be brought to the table when developing medicines or solutions for patient benefit. Only they can tell you what truly matters to them in that particular situation and this quite often needs to be the focus.

Which leads us back to the question, can pharma break out of a medicine focused model to become a patient focused, technology driven, value-based healthcare provider? One that never loses sight of the patient and their needs? The answer is of course yes. With inspirational figures like Lode Dewulf, Steven Hildemann, Lars Joensenn, Sebastian Guth, Julian Noij and many more leading the way, we just have to take it one step at a time.

Pharma have an advantage over new industry entrants in that they know medicine and they have a huge (mostly untapped) data resource – they just need to make it their mission to improve the way they use this data and to get to know patients better than anyone else. Pharma have to be prepared for change and consider collaboration at all times. Collaboration with other service providers and collaboration with patients. They need to treat patients like partners who will help them develop services to improve health in general. When they behave like this, with the patient at the centre, then the value will follow.

Not because that is what pharma are striving for, but because they are staying true to their purpose – to improve the health of those around the world. Or as Kris Sterkens from Janssen, poignantly put it “to help those live young for as long as possible”.

For any remaining sceptics who may ask whether this is sustainable in terms of a business model for pharma, I would argue that we have moved on from that objection. The benefits of patient involvement continue to be proven, in clinical development where costly protocol amendments have been prevented, in the validity of HTA submissions and quite frankly in the development of medicines that meet actual patient need. We are now in a place where we should be asking what if pharma doesn’t work in this way? Will there even be a pharma industry to speak of? Or will tech giants who know what the people want take their place?

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