

The value of the patient voice

The patient voice is hugely important and it's vital that charities and industry obtain a thorough understanding of patient needs and concerns. From an Industry perspective there is an increasing focus on improving the understanding of patient needs as this has a direct influence on the adoption of new drugs. For instance, if industry developed a drug that was biologically ground-breaking, but did not address the fundamental patient need, it would unlikely be approved by regulators (like the MHRA) and payers (like NICE or a Clinical Commissioning Group).

Charities can provide a valuable source of information representing the patient voice as well as carers, clinicians and academic researchers. In many cases, charities encourage patients and carers to provide input to their research strategy, and many also involve lay reviewers on peer review panels. Such links provide the charity with valuable insights into research, current treatments, the experiences and aspirations of both patients and medical professionals, and the ability to identify where treatment gaps exist. Industry recognises this and is increasingly looking to foster collaborations with charities to gain access to this valuable information.

The Association of the British Pharmaceutical Industry (ABPI) also recognises the value of the patient voice and has established a Patient Organisation Forum (POF) that brings together industry and patient organisations. The POF is a useful vehicle for industry and patient representatives to discuss each other's needs and perspectives, promoting engagement and information sharing.

The regulators and payers – why is the patient voice important to them?

In order for a drug to be successfully approved, brought to market and adopted by the NHS there needs to be sufficient patient need and a justifiable cost. Patient need varies depending on many factors, including how many people are affected by disease, the severity of the disease and symptoms, the extent and severity of adverse effects related to the new treatment and whether other drugs currently available on the market can address the unmet need. The patient voice is at the heart of all these considerations. In the future, patients will become increasingly focussed on self care with greater awareness of their condition and treatment options available.

The National Institute for Health and Care Excellence which advises on the use and cost-effectiveness of new medicines is broadening the scope of its assessments to include the value to patients and society. It proposes to include a measure of the 'burden of illness' and 'wider societal impact' into appraisals. Therefore, engagement between industry and patients is a key part of the successful uptake of new drugs in the NHS.

What else are pharmaceutical companies doing?

Recognising the need for pharmaceutical companies need to interact with patients, some companies are taking extra steps increase public engagement activities. For instance, GlaxoSmithKline has developed a [patient advocacy initiative](#) to bring the company closer to patients to improve the company's understanding of patient needs and enhance its reputation as a patient centred company. It also holds regular webcasts to strengthen the patient voice and inform employees about specific health conditions to help the organisation better understand the patient needs.

Where can I find out more information

- MHRA: <http://www.mhra.gov.uk/Howweregulate/index.htm>
- ABPI – Patient Organisation Forum: <http://www.abpi.org.uk/our-work/patient-organisation-forum/Pages/default.aspx>
- GlaxoSmithKline: www.gsk.com/responsibility/our-behaviour/public-policy-and-patient-advocacy.html