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Patient Engagement: How Soon Do You Start?



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► By Lucie Ellis, November 30, 2016

JULIE ADRIAN, EUROPEAN MANAGING DIRECTOR OF inVentiv Health Communications, outlines the greatest barriers preventing companies from engaging patients earlier in drug development and highlights the greatest benefits on offer to those that can successfully implement patient-centric drug discovery models.

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The pharmaceutical industry has got a handle on new patient engagement models when it comes to marketed drugs, but the sector has more work to do prior to drug approval according to healthcare marketing communications veteran, Julie Adrian, European managing director of inVentiv Health Communications.

According to an Oct. 2015 survey conducted by Accenture Life Sciences and cited by inVentiv Health, which included responses from 200 pharma executives, 85% of those asked have piloted “patient-centric” models within their businesses. 51% said their companies have since widely adopted a patient-centric approach and more than 80% noted that they are continuing to develop their commercial models in this area and are increasing investment in patients services, including new staff hires, investment in analytic services and establishing more partnerships with customers.

InVentiv Health, a global provider of healthcare and pharma consulting to biopharmaceutical clients, believes that patient-centric models will help to bridge the historical gap in biopharma companies between their clinical and commercial activities; and enhance pharma’s reputation among the general public.

However, Adrian told Scrip in a recent interview that biopharma companies still need to increase their levels



Source: inVentiv Health Communications

of patient engagement during clinical development – instead of focusing just on patient-centric commercialization models for new drugs. “We are seeing a tectonic shift in thinking within big and small pharma towards getting the patient voice into development, even as early as product discovery,” Adrian said. She noted this push was coming from clinical teams within biopharma companies: “It’s not the marketing guys, the communications people or the commercialization teams: we are hearing more and more from preclinical people. This is a change in thinking for these teams, they are now talking about involving patient voices very early in drug discovery and development,” Adrian said.

The Clinical Trials Transformation Initiative, a public-private partnership that includes international government and industry representatives, estimates that 80% of biopharma companies are already engaging with patient groups during the later stages of drug development, Phase III and Phase IV. However, this percentage drops significantly as you move back up the development chain. Approximately 62% of biopharma companies covered by CTTI’s data are engaging with patient groups in the Phase II setting and only 35% of companies consult with patient groups at the Phase I/proof-of-concept stage for drug development. For drug discovery only 15% of companies analyzed by the CTTI are deemed to be working with patient groups.



CTTI highlights that the top five major barriers for pharma companies not pursuing patient-centric models are:

- Insufficient tools
- Wariness on how to engage with patient groups
- Internal resistance
- Lack of funding
- Absence of sophisticated patient groups

Adrian believes the wider healthcare system is evolving to replicate the business models of companies like Amazon and Zappos – which she says are very transparent and treat their customers like partners. Traditionally, she noted, the patient voice hadn't been heard by pharma groups until the later stages of drug development, when these companies were focusing on commercialization strategies. "While the industry is getting better at being more interactive and transparent, patients are still demanding involvement earlier," Adrian said, noting that concerns around access to novel therapies was driving this evolution.

Adrian highlighted some of the key benefits of involving patient groups during drug discovery and earlier stages of development as:

- The ability to build long-standing relationships, which she noted was particularly important in the rare disease space where patient numbers are small
- The opportunity to plan along the continuum for a drug from development into commercialization, which helps to connect clinical insights with commercial models
- A chance to break down internal silos that have historically divided clinical and commercial activities
- The ability to develop an early understanding of patient needs within a disease space
- The opportunity to relay these insights to regulators

Adrian believes that patient engagement in the clinical setting has been promoted in recent years by companies and patient groups in the rare disease field. "There are a number of things we have taken from a lot of our work in the rare disease space that we have translated to things like diabetes or Alzheimer's disease. Advocacy groups are absolutely critical, especially in rare diseases," she said.

In this early drug development setting Adrian noted there is a stronger focus on just the disease and the unmet needs, rather than a specific compound. "You're talking about what's missing in terms of care and options," she said. "The idea of patient engagement in the early drug discovery and development setting is still at its infancy but successful companies – those that have started with an early, better relationship and moved it all the way through the drug development lifecycle – these businesses are seeing new ways to enhance the experience of engaging with patients in a disease setting that aren't just focused on one drug program. It's really about creating patient experiences," Adrian said.

Adrian noted that flexibility is critical to working with patients in the early drug development setting. She highlighted one example of a company inVentiv Health worked with that found, through working with patient groups, that its drug program was not addressing the concerns of a rare disease community. "If the community said, 'You know what, that's not going to serve our needs the best right now,' the organization involved would adapt. The company had the cultural flexibility and the corporate courage to say, 'Okay, fine. We're not going to do what we originally planned.'"

Adrian said this is still one key reason why patient engagement in drug development is growing more in the smaller and mid-sized biopharma companies, because of their ability to adapt quickly. "It's not for lack of wanting at the bigger organizations, but a lack of flexibility," she said. However, she noted that the increasing trend of creating micro-organizations within big companies is starting to address this problem. Adrian also noted that a number of big pharma companies have introduced chief patient officers and patient engagement leaders to propel these micro-organizations and patient engagement teams within big pharma firms. (Also see "Rise of the patient affairs officer; Sanofi makes appointment" - Scrip, 1 Apr, 2014.)

Adrian gave one example of a big pharma company working with inVentiv Health that changed the course of its drug development plans within the diabetes space based on patient feedback in the discovery setting. "Patient engagement at that early stage literally changed the course of drug development within that organization. That was a big one," she said. "Change is happening across the biopharma sector, it is just at varying levels because this is really a cultural shift."