Patients Involved – Patient expert on external Bioethics Advisory Panel

Introduction

A case report on the inclusion of a patient expert on a pharmaceutical company's external Bioethics Advisory Panel. The patient expert was proposed to the existing panel so a patient view would be included in topics brought to the panel such as patients' rights in conducting clinical trials in developing areas; informed consent or the use of biological data and material in research.



Where in the process? – Strategic framework to launch

When does it happen? – Strategic framework to Launch

Description of the case

Pfizer's External Bioethics Advisory Panel (BAP) is a small group of global ethics experts convened to provide insights on emerging medical, scientific and ethical issues globally, to help inform the company's clinical research planning and policies and ensure that the clinical trials Pfizer sponsors are conducted according to the highest ethical standards. The lens of a patient expert may provide a more inclusive

perspective on these issues.

Meetings of the Bioethics Advisory Panel cover topics such as ethical considerations and patients' rights in conducting clinical trials in developing areas; the role of accreditation in positioning research sites to conduct clinical trial; and how informed consent should be structured in an environment of broader clinical data sharing and access, including the use of biological data and material in research. As our aim is to advance patient centricity more systematically in everything we do at Pfizer, in 2015 we proposed to the existing panel adding a patient expert to serve as a standing member so that a representative patient view would be included in consideration of all topics brought to the panel. There was unanimous agreement to include a patient expert.

Type(s) of patient (advocates) involved

Expert patient / patient advocate with good expertise on disease and good R&D experience

Benefits of patient involvement

Schmitt's participation has been an invaluable enhancement to the conversations during the first three meetings she participated in. Her contributions as a patient, a Board member of a tissue bank, an advocacy group and as an expert in communications among health care professionals and the patient community regularly highlight nuances that others on the panel and among Pfizer attendees had not considered or voiced.

In addition to enhancing these discussions that help inform our R&D and policies, Pfizer leaders who attend as standing or agenda-driven meeting participants have seen the added richness of the discussion from involving a patient expert. This helps address the question some may have about whether

patients have the appropriate expertise for involvement in complex scientific discussions. The example demonstrated on this panel supports leaders as they are catalysing the culture shift at Pfizer to have more systematic patient involvement across the lifecycle of development.

Challenges and barriers

A challenge is that one patient expert cannot comprehensively represent every patient or patient experience. Including more panel members would enhance the diversity of representation but may reduce the conversational and interactive nature of the meetings.

It was useful that we already had expectations of the panelists and expertise outlined. When we proposed possible patient experts to the existing panel they and we were able to look to that outline to help ensure alignment with the experience of the patient expert who was selected.

Learnings

Next time we might include patient expert representation in a committee such as this from the outset. There should be recognition of the enhancement of outcomes of advisory committees when patients are involved. There should be an understanding of processes in place and that may need to be developed for engaging patients who are experts in an appropriate manner (consistent with law, regulation and culture).

A3-Patient-expert-on-bioethics-panel-V1.0

Attachments

- Patients Involved Case Report: Patients

organisations’ access to information

Size: 860,621 bytes, Format: .pdf

An infographic describing a case of collaboration between a breast cancer patient’s organisation and a pharmaceutical company to share information on conducted clinical trials making it accessible for patients.