

# Patients Involved – Patient Input Forum

## Introduction

A Patient Input Forum organised by Merck & Co to expose the company's workforce to patients and caregivers and hear their perspective on living with Alzheimer's disease.



Where in the process? – Phase II

When does it happen? – Phase II

## Description of the case

Consistent with the corporate strategy to enhance human health and focus on the patient, the primary objective of the Patient Input Forum (PIF) is to expose the company's workforce to 'real world' patients and hear their perspective on living with a disease in a key therapeutic area where we are working. The patient (and caregiver) input will provide meaningful insight for company employees as they work to optimise, develop, and launch innovative products and services with a focus on the patient.

The company engages with doctors facilitators based in the US who in turn will identify patients who are willing to share their experiences with their illness, including their overall

treatment experience and systems of care, and to respond to questions submitted in advance, and from the audience of Merck employees. The doctor will serve as the patient interviewer. The meeting lasts approximately one hour and will be conducted at a company site as a webcast (with a live audience of employees). The doctor, patient and caregiver also participated in an informal meeting with invited members of the company team to gain deeper understanding on the disease burden from PIF participants.

## **Type(s) of patient (advocates) involved**

- Patients and caregivers with personal disease experience.

## **Benefits of patient involvement**

This event happened very recently. Feedback from employees highlighted value to hear first-hand the impact of an AD diagnosis and about living day to day with the difficult challenges of the disease. Also the clinical team heard important input related to clinical protocol / trial design and aspects of trial conduct that could be more patient friendly. The consideration of whether or not to participate in clinical trials was especially insightful as well as how the caregivers obtain the information they use to make such decisions. The caregiver's sense of responsibility for the patient was quite powerful and the importance of trust and good communication with the treating doctor was evident. The R&D team was left with a feeling of the significance and urgency for the work that they do as well as the gratitude from the patient and family for all the ongoing work to advance novel treatments.

# Challenges and barriers

Evaluation of the appropriate policies and development of guidance documents to define process and procedures for an event involving patients. Identification of patient and caregiver who were willing to participate and had the courage and communication skills to engage in meaningful dialog.

## Learnings

Given the internal feedback from this event, one outcome is that we will consider to doing more of these across various therapeutic areas and perhaps stages of disease as it really catalysed discussion and energy for the work ongoing in R&D organisation. Also feedback from the doctor and caregiver were that it was a meaningful experience, including meeting the people within the company who are working to 'make a significant impact in the fight against AD'. Sharing of best practices and various approaches to obtain patient input should continue to be supported externally.

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## Attachments

- Patients Involved Case Report: Patient Input Forum  
Size: 472,807 bytes, Format: .pdf  
An infographic describing a patients involved case report on a Patient Input Forum organised to expose the company's workforce to patients and caregivers and hear their perspective on living with Alzheimer's disease.