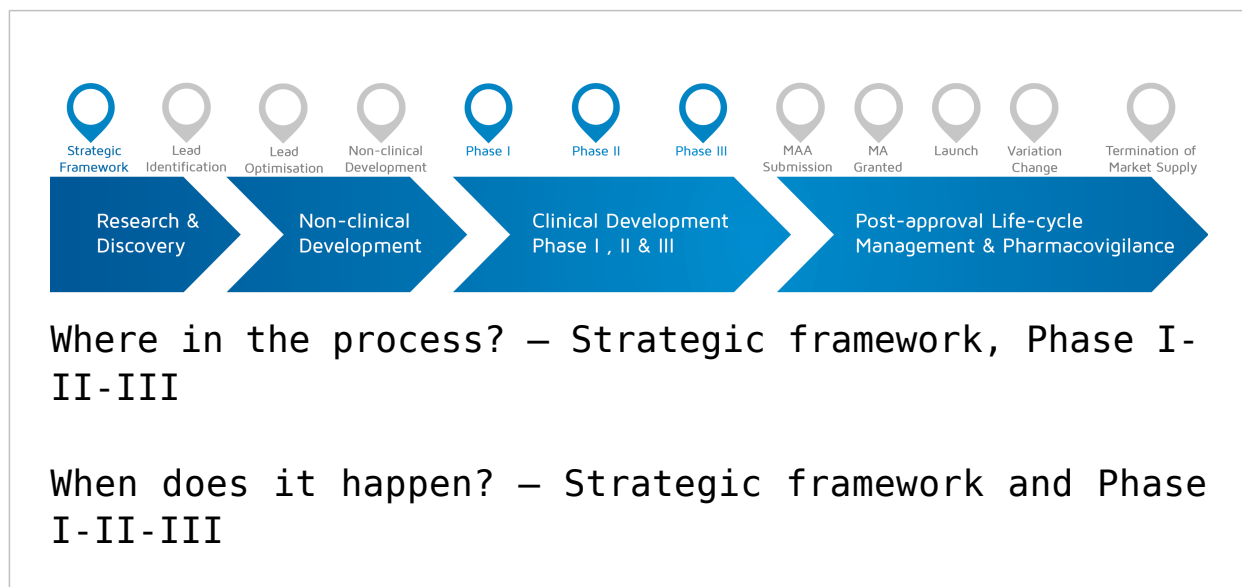


Patients Involved – Patient sounding board

Introduction

Collaboration between the International Alliance of Patient's Organisations and local patient organisations with pharmaceutical company Novo Nordisk A/S to facilitate dialogue between them and develop learnings for future use.



Description of the case

Objectives:

- To ensure that patient perspectives on Novo Nordisk's work are explored and acted upon, so the company can better address patient needs as expressed by patients and patient representatives and facilitate ongoing dialogue between patients, patient organisations and Novo Nordisk.
- To apply a full cycle involvement approach (scoping, strategy, implementation and evaluation) and develop learnings for future use.

Methodology:

A framework for the patient sounding board with aims, guidelines and principles were developed together with the International Alliance of Patients' Organisations.

From 10 to 16 board members consisting of people with diabetes and haemophilia, family members of people with diabetes or haemophilia and patient organisations from different regions and continents were invited.

Implementation:

- Meetings of 1 to 2 days duration were held.
- Representatives from R&D and other parts of the organisation were engaged in advance to propose priority questions / topics of interest. Topics of particular relevance and interest to the sounding board were covered.
- Minutes outlined the conclusions and implications.

Type(s) of patient (advocates) involved

- Patients with personal disease experience.
- Expert patient / patient advocate with good expertise on disease but little R&D experience.
- Expert patient / patient advocate with good expertise on disease and good R&D experience.

Benefits of patient involvement

New important perspectives related to patient-centricity were identified by the various representatives from different parts of the organisation who took part in different sessions.

Specific global projects were concretely adjusted to optimise particular aspects from a patient's perspective in accordance

with detailed inputs from the sounding board.

There was improved understanding that it is possible and of great value to obtain the patients perspective on a range of issues.

Challenges and barriers

Challenge:

It is resource demanding:

- Human resources (preparations, delegate involvement, telephone meetings, contracts, administrative work).
- Travel and venue costs (due to global geographical reach).

Solution:

- Do meetings less frequently, use fewer persons tailored for the specific questions.
- Consider electronic communication opportunities.

Legal and contractual paper work could not be diminished.

Challenge:

- Expectation management.

Solution:

- Clarify upfront how potential use of any advice offered by the sounding board would be fed back.

Learnings

'Everyone is different'

Every patient advocate is different and offers a different mix of personal and professional interests, insights and skills.

It is essential to:

Understand each person's interests and unique contribution areas.

Carefully ensure that the profile of the patient expert matches the specific requirements for input in each case, e.g. considering age, professional experience background, patient advocacy experience, specialisation in certain topics, geography, etc.

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Attachments

- Patients Involved Case Report: Patient sounding board

Size: 905,531 bytes, Format: .pdf

An infographic describing a case of collaboration between two patient organisations with a pharmaceutical company to facilitate dialogue between them and develop learnings for future use.