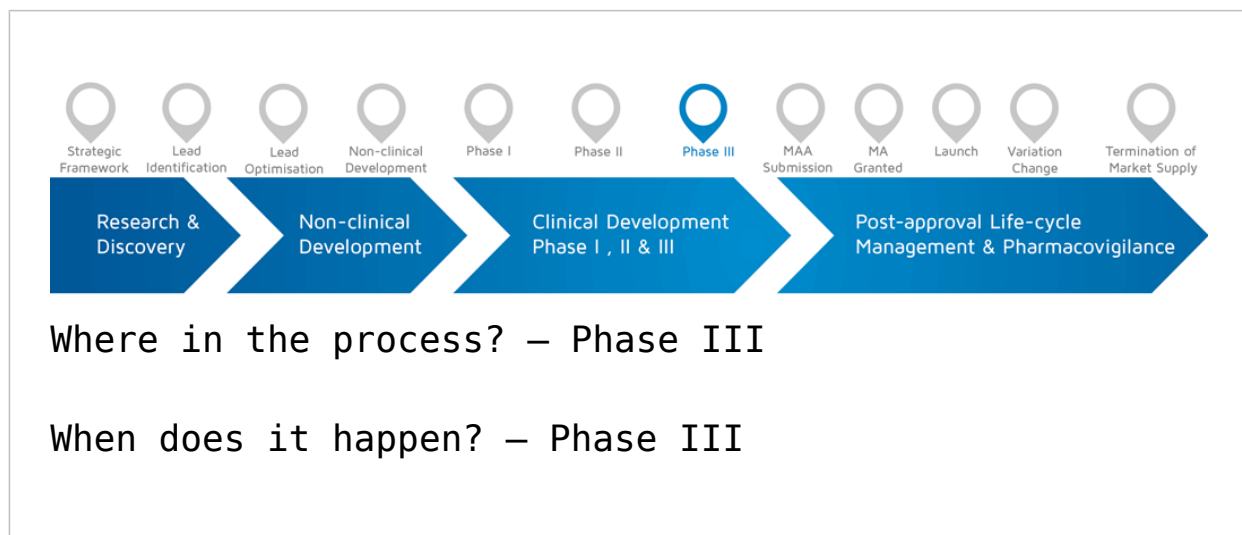


Patients Involved – Ovarian Cancer

Introduction

An example of patient involvement looking at a case report on Phase III patient involvement in an advisory board comprising six expert GYN oncology nurses from across Europe and four ovarian cancer patient group representatives to advise Amgen.



Description of the case

An Advisory Board meeting of nurse experts and advocacy group experts was held to explore perceptions about novel treatments used in the management of ovarian cancer to gain insight into the advanced ovarian cancer patient journey from a nursing and patient perspective, and to define gaps in meeting ovarian cancer patient needs.

The meeting included discussions about the ovarian cancer patient journey, a presentation from a clinical trials specialist nurse and discussion of the patient experience in that trial as well as a presentation about novel agents in the management of ovarian cancer in current Phase II and Phase III

trials. The meeting enabled clear identification and outline of patient informational needs as well as nurses' informational needs and areas of collaboration were identified.

Type(s) of patient (advocates) involved

- Expert GYN Oncology nurses with expertise in R&D/Clinical Trials from across Europe.
- Patients with personal disease experience.
- Expert patients / patient advocates with good expertise on disease, but little R&D experience.

Benefits of patient involvement

The practical and very 'real world' experiences highlighted in such a meeting cannot be replaced by market research or other more remote or non-personal ways of collecting information. Internal team members were able to share these insights directly back to key individuals and decision-makers within the company to assure these voices were heard and the feedback was taken into consideration.

The meeting minutes and outcomes were shared internally with regulatory and R&D Leads within the company. Key insights about management and treatment realities and hurdles as well as opportunities were identified in various countries. Varying management and treatment plans exist in country and region. Nursing and advocacy leads internally advocated for plans and resources to meet these stakeholder needs and will act as advisors to continue the dialogue and engage with these experts throughout the development process.

The outcomes triggered R&D to be aware of patient needs, and acknowledged practical realities in the clinic / hospital setting. Opinion leader thinking about patient experience or

perceived patient needs was debunked.

Challenges and barriers

Challenge: mapping and identifying expert nurses in GYN oncology nurses, as well as ovarian cancer groups or expert ovarian cancer patient advocates.

Overcoming this: speaking with many experienced advocates in broader cancer patient groups and gaining insights about how and with whom other industry sponsors in the ovarian space are engaging.

Surmountable hurdles: managing expectations and understanding of country-level medical and compliance leads to appropriately engage and invite the participants.

Working through SOPs and interactions with the assigned agency to make the appropriate arrangements as well as directly with the advocates about the processes and agreements.

Learnings

Principles agreed upon generally across the company at global, regional and local levels about:

- Why and how to engage with expert nurses and patients.
- Clearly outlined process for all to find/read on the above two points.
- Action plans and formats-not to reinvent the wheel each time one wants to conduct such a meeting.
- Establishing more systematic and regular meetings of such key external stakeholders and agree and maintain budgets, and responsible functions/persons to manage ongoing engagement and relationships.

Attachments

- Patients Involved Case Report – Ovarian cancer

Size: 451,586 bytes, Format: .pdf

An infographic describing an Advisory Board meeting of Nurse experts and Advocacy group experts to explore perceptions about novel treatments used in the management of ovarian cancer as well as areas of collaboration between groups.