

Patients Involved – Melanoma board

Introduction

Expert melanoma nurses and advocacy group experts held a Melanoma board meeting to explore perceptions about novel treatments and scientific developments in the management of melanoma.



When does it happen? – Phase III

Description of the case

Advisory Board meeting of Nurse experts and Advocacy group experts held to explore perceptions about novel treatments and scientific developments in the management of melanoma, discussion of oncolytic immunologic therapies; gain insight into the melanoma patient journey from a nursing and patient perspective, and define informational and supportive need of persons with melanoma.

The meeting included discussions about the melanoma patient journey, a presentation on TVEC by the Medical director (legally approved), presentation from experienced clinical trials specialist nurse and their view of the patient experience in that trial. Considerable discussion focussed on

the diagnostic journey and access to clinical trials across Europe.

Clear identification and outline of patient informational needs as well as nurse's informational needs and areas of collaboration were identified.

Type(s) of patient (advocates) involved

- Patients with personal experience disease.
- 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

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.

Meeting participants truly highlighted the challenges faced in the clinic setting with fatalistic attitudes toward the disease, reluctance to conduct biomarker tests, and often updated knowledge about where and what trials might be available.

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 stakeholders and will act as advisors to continue the dialogue and engage with these experts throughout the development process.

Triggered R&D to be aware of patient needs, and also acknowledge practical realities in the clinic/hospital setting. Debunk opinion leader thinking about patient experience or perceived patient needs.

Challenges and barriers

Tasks (partly challenging):

- Mapping and identifying expert nurses in melanoma and melanoma trials.
- Contacting, partnering and engaging with some melanoma advocate experts only due to time, work and family related constraints (part-time advocates who are full time employees and or caregivers). 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.
- Surmountable hurdles: managing expectations and understanding of country level medical and compliance leads to appropriately engage and invite the participants.

Learnings

General agreed upon principles across the company at Global, Regional, and Local levels about:

- Why to engage with expert nurses and patients.
- 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.
- For global and regional support to establish 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.

A3-Melanoma-V1.0

Attachments

- case-report-Melanoma-board-v1-EN

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An infographic describing a patients involved case report of a meeting with expert nurses to explore management of melanoma.