

Research Priorities in Metastatic Breast Cancer: A James Lind Alliance Priority Setting Partnership

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For which topic were research priorities identified?

metastatic breast cancer

In which location was the research priority setting conducted?

North America - Canada

Why was it conducted at all?

Breast cancer is the most commonly diagnosed malignancy among Canadian women and is the second most common cause of cancer-related mortality, which is ultimately a result of developing metastatic disease. While metastatic breast cancer (MBC) remains incurable, new therapies have led to meaningful improvements in survival. Women living with MBC experience many physical and psychological consequences from both their disease and its treatment, leaving opportunities for further research to improve patient outcomes. Incorporating the views of patients and caregivers into setting research priorities improves the relevance and uptake of the research.

What was the objective?

to identify the top 10 research priorities relating to metastatic breast cancer from patients, caregivers, and health care professionals

What was the outcome?

a ranking list of 10 research questions

How long did the research prioritization take?

No information provided.

Which methods were used to identify research priorities?

JLA method

How were the priorities for research identified exactly?

Step 1: setting up PSP: establishing protocol and drafting survey. Step 2: collecting research questions: survey asking respondents: "What questions do you have about metastatic breast cancer (i.e. about the diagnosis, treatment, monitoring, and consequences of the disease)?" 1194 responses. Step 3: data processing: out-of-scope questions removed, grouped into 62 unique questions. Step 4: interim ranking: survey with 62 unique questions, top 27 questions taken forward. Step 5: final prioritization: workshop: small group discussions with nominal group technique and small group rankings using diamond nine ranking approach, followed by plenary discussions and plenary rankings

Which stakeholders took part?

MBC patients, caregivers, and healthcare professionals. Survey: 668 participants: 49% patients, 13% physicians, 9% caregivers, 4% allied HCPs, 2% patient organization representatives. Workshop: 7 physicians, 10 patients, 3 representatives from patient organizations.

How were stakeholders recruited?

The survey was distributed by e-blasts to the members of various clinical associations including the Canadian Association of Medical Oncologists (CAMO), Canadian Associations of Nurses in Oncology (CANO), and patient organizations (CBCN, Rethink Breast Cancer, and patient support networks).

Were stakeholders actively involved or did they just participate?

Stakeholders not only participated but were also actively involved in the research prioritization process: They were part of a steering group. The steering group consisted of 4 medical oncologists, 1 nurse, 3 patients with MBC, 1 family member of a patient with MBC, representatives from the Canadian Breast Cancer Network (CBCN) and Rethink Breast Cancer, and 1 JLA advisor.