

Dutch breast cancer patient driven research agenda developed for and by breast cancer patients

Patient Expert group Scientific Research:

Lidy Biekmann, Marlene Hoyneck, Ellen Kooijmans, Lucie Loman, Jessica Steglich, Cheryl Roumen

Eva Vroonland, PGOsupport, The Netherlands

Marjolein Scholten, Dominique Sprengers, Carol Richel, Breast Cancer Association (BVN), The Netherlands

Introduction

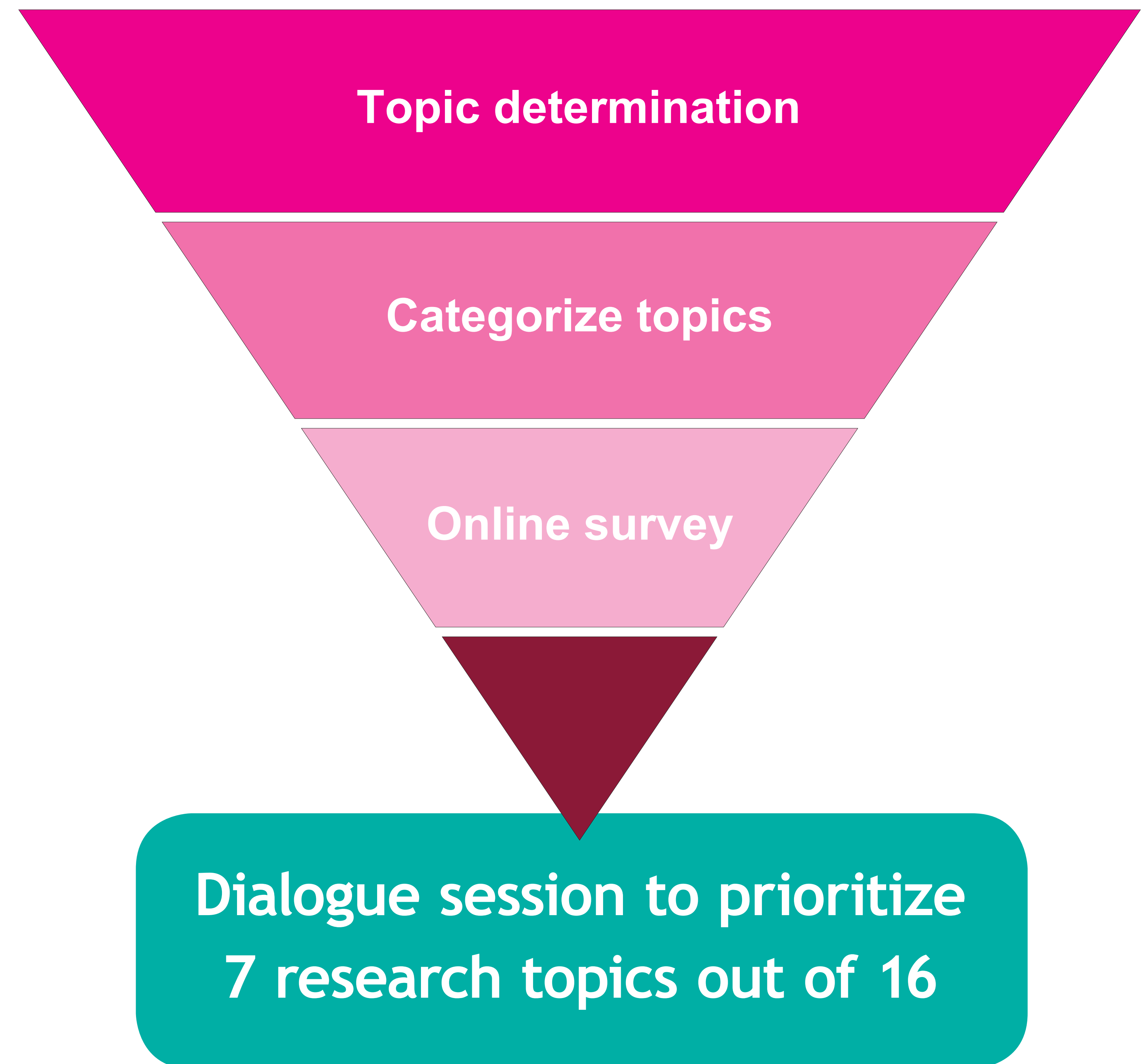
The survival rate of breast cancer has increased rapidly during the last decades, due to better treatment options. For example tumour specific treatments have brought great progress. Also early detection of breast cancer improved. However, according to patients, there are still topics that require additional research. Examples are: the higher suffering from side effects that occur with longer survival, integrating knowledge, clinical relevance, taking patients questions and perspectives into account. Addressing these areas in future breast cancer research will be of added value to innovate breast cancer care.

Aim

Developing a patient driven research agenda for breast cancer in The Netherlands; based on a thorough review and prioritization process of topics identified by patients. The research agenda aims to stimulate researchers to answer patients questions.

Methods

1. Topic determination: After review of prior surveys and consulting relevant working groups within BVN the Expert group Scientific Research of the Dutch Breast Cancer Patient Association (all type of breast cancer patients) determined a long list with a broad variety of topics.
2. Categorize topics: The items of the long list were categorized into 6 themes.
3. Online survey (664 respondents): Patients were asked to prioritize the 6 themes and the most relevant topics within each theme. Leading to 16 topics.
4. Dialogue session: In a live meeting 15 patient advocates and 15 breast cancer professionals discussed the 16 topics. The 7 most urgent research topics were identified through consensus. The method was inspired by the Dialogue Model (Abma & Broerse, 2010)



Results

Urgent research topics breast cancer patients in The Netherlands

1. Tailored treatments based on tumour and patient characteristics.
2. Long term effects of the various treatments (including fatigue, (nerve) pain, effects on organs).
3. Improve communication about the effects of treatments, side effects and long term consequences.
4. The best order, length and intensity of treatments in patients with metastatic breast cancer (aiming at living longer).
5. The best order, length and intensity of treatments for survival of breast cancer (targeted at cure).
6. Effectiveness of follow-up and self-monitoring in early detection of an initial occurrence or recurrence of breast cancer.
7. Psychological consequences of living with genetic predisposition, also for children and family members.

Quote patient:



“My needs changed during my journey”

Conclusion

A thorough process led by patients resulted in seven urgent topics requiring more research from a breast cancer patient perspective. Defining a breast cancer patient driven research agenda was a long and thorough process that is the basis for a valuable instrument to better influence the breast cancer research landscape in The Netherlands.

Discussion

Some of the 7 topics prioritized by patients are not included in the current research priorities of breast cancer researchers. Whilst tailored treatment based on tumour and patient characteristics are high on the agenda for both, e.g. long term effects are not very often studied. This might be caused by lack of funding.

Recommendation

While BC researchers are inclined to ask for patient input into research protocols, now time is ready to incorporate patient needs earlier in the process, e.g. when formulating the research questions. This agenda can be used, not only by researchers but also by funding organisations. BVN will promote the use of this research agenda by researchers and by funding organisations.