

Patient and Public Priorities for Breast Cancer Research: A Qualitative Study in the UK

Boundouki et al. (2021)

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For which topic were research priorities identified?

breast cancer

In which location was the research priority setting conducted?

Europe - United Kingdom

Why was it conducted at all?

In 2013, Breast Cancer Campaign (BCC) funded a gap analysis to determine areas of research need in breast cancer. This involved over 100 internationally recognised, specialist breast cancer scientists, clinicians and healthcare professionals but no PPI. Despite evidence emerging that patients and clinicians have different research priorities, in 2018, the Association of Breast Surgery (ABS) in the UK published a complementary gap analysis that focused on surgical research themes, which included only one patient representative.

What was the objective?

to determine the research priorities of the public in breast cancer care, particularly focusing on early (non-metastatic) breast cancer

What was the outcome?

a list of 24 research topics

How long did the research prioritization take?

No information provided.

Which methods were used to identify research priorities?

focus group

How were the priorities for research identified exactly?

Step 1: focus groups: designed as deliberative listening events, events started with brief introduction, followed by 45min free discussion, patients with breast cancer and public representatives used a patient's breast cancer journey to identify research themes, participants talked freely about breast cancer, treatment and research, participants were invited to discuss what they did and did not know about screening, diagnosis, treatment and survivorship relating to early (non-metastatic) breast cancer in women, in total four listening events were held, eight participants were invited to each listening group, 6, 4, 5 and 12 participants respectively participated. Step 2: data processing: thematic content analysis

Which stakeholders took part?

16 patients with breast cancer and 11 public representatives

How were stakeholders recruited?

Participants were sampled from attendees at four participating hospitals in the Northwest of England, including patients and their family and friends.

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; including 2 lay representatives.