

Research in Haematological Cancers: What Do Patients in the Netherlands Prioritise?

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For which topic were research priorities identified?

haematological cancer

In which location was the research priority setting conducted?

Europe - Netherlands

Why was it conducted at all?

The research priorities of people with haematological cancer have only sporadically been articulated. In both of these studies, the consulted patient community was relatively confined and people's everyday problems and concerns regarding the consequences of their disease were not investigated. It has been shown that enclave deliberation, namely the empowerment and development of a shared voice based on collective experiences, reduces the chance that patients are replicating media or healthcare professionals' priorities (Nierse & Abma, 2011). In this study, the everyday problems and concerns of people with haematological cancer were articulated prior to the formulation and prioritization of their research needs in order to formulate a research agenda from the patients' perspective.

What was the objective?

to identify and prioritize everyday problems and research needs of haematological cancer patients and people who have undergone a stem cell transplantation

What was the outcome?

a list of 5 research topics

How long did the research prioritization take?

January 2016 - October 2016

Which methods were used to identify research priorities?

focus group; interview; meeting; survey

How were the priorities for research identified exactly?

Step 1: 6 interviews with patient representatives providing insights into commonly discussed everyday problems and concerns. Step 2: 4 focus groups, 6 interviews: to further identify everyday problems, concerns and research needs. Step 3: survey with a list of 32 research topics categorized into six research areas, participants were asked to rank topics within each area and to rank overarching areas. Step 4: dialogue meeting: the nine highest prioritized research topics were discussed in two rounds of small group discussions focusing on three guiding questions: What are the unanswered scientific questions on this topic, or does it entail an implementation or communicative issue? What type of research is most relevant to solve this issue? What collaborations can be useful and who is responsible?

Which stakeholders took part?

Patient organizations, healthcare professionals, researchers, funding and policy experts, patients. Interviews: 19 participants. Focus groups: 27 participants. Survey: 146 participants. Meeting: 30 participants.

How were stakeholders recruited?

For the focus groups, participants were recruited via Hematon, several hospitals and social care meeting venues for people with cancer. For the questionnaire, recruitment of respondents took place via several communication channels of Hematon and all academic hospitals in the Netherlands.

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 an advisory board. The advisory board consisted of 7 leading experts in the field of haemato-oncology and funding agencies. The members met twice in plenary to provide advice on the progress of the study, to discuss the preliminary research findings and to assist in the implementation of the results.