

Engaging Patients in Setting a Patient-Centered Outcomes Research Agenda in Hematopoietic Cell Transplantation

Burns et al. (2018)

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For which topic were research priorities identified?

hematopoietic cell transplantation

In which location was the research priority setting conducted?

North America - USA

Why was it conducted at all?

The goal of patient-centered outcomes research (PCOR) is to help patients and those who care for them make informed decisions about healthcare. However, the clinical research enterprise has not involved patients, caregivers, and other non-providers routinely in the process of prioritizing, designing and conducting research in hematopoietic cell transplantation (HCT).

What was the objective?

to set a patient-centered outcomes research agenda for the hematopoietic cell transplantation community

What was the outcome?

a list of 3 research topics

How long did the research prioritization take?

2 years

Which methods were used to identify research priorities?

meeting; webinar

How were the priorities for research identified exactly?

Step 1: meeting 1: to set the stage, round table discussions identifying topic areas that merited assignment to a working group. Step 2: second and third meeting: presentations and refinement of research questions. Step 3: webinars: presentations of knowledge gaps and priority recommendations for critical research

Which stakeholders took part?

25 patients and 7 caregivers plus clinicians, researchers, social workers, policymakers, administrators, payers and NMDP staff liaisons.

How were stakeholders recruited?

No information provided.

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 patients and caregivers. The members provided input and oversaw all aspects of the project.