

Determining Research Priorities for Young People with Haematological Cancer: A Value-Weighting Approach

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For which topic were research priorities identified?

haematological cancer

In which location was the research priority setting conducted?

Australia - Australia

Why was it conducted at all?

Haematological malignancies account for a third of all cancers affecting adolescents and young adults (AYAs). Funding agencies are regularly faced with the dilemma of how to deploy resources in order to provide the greatest possible benefit to this patient group.

What was the objective?

to quantify the stakeholders' perceptions about how resources should be allocated to best improve outcomes for adolescents and young adults patients and their families

What was the outcome?

a ranking list of 5 research areas

How long did the research prioritization take?

No information provided.

Which methods were used to identify research priorities?

survey

How were the priorities for research identified exactly?

Step 1: collecting research areas: advisory group was asked to list areas of research which would have the greatest impact on improving outcomes for AYAs with haematological cancer and their families. Step 2: advisory group designed and tested survey. Step 3: survey: participants were asked to allocate 100 points of funding to the items they felt would best improve outcomes for AYAs with haematological cancer and their families, participants were asked to indicate how soon they felt research in each area needed to start.

Which stakeholders took part?

80 participants: 7 clinicians, 29 nurses, 17 allied healthcare professionals, 7 researchers, 10 young people, 10 carers.

How were stakeholders recruited?

AYAs with haematological cancer, and their parents, partners and siblings, were recruited from the client databases of either the Leukaemia Foundation, Australia or Canteen, Australia. Health care and other professionals (e.g. oncologists, nurses, allied health and teachers) working with young haematological cancer survivors were recruited from the Leukaemia Foundation's Support Services Staff database or via peer nomination. Members of the advisory group also invited peers and colleagues in their field to take part in the study. The number of health care professionals invited to participate was greater than that for the consumers to ensure that a wide range of specialties were represented.

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 1 pediatric oncologist, 1 pediatric haematologist, 1 cancer care coordinator, 1 cancer nurse coordinator, 1 clinical psychologist, 3 researchers and 2 AYA haematological cancer survivors. The members took part in the Delphi process.