

# Research Priorities for Young People with Cancer: A UK Priority Setting Partnership with the James Lind Alliance

Aldiss et al. (2019)

<https://bmjopen.bmj.com/content/9/8/e028119>

## For which topic were research priorities identified?

cancer

## In which location was the research priority setting conducted?

Europe - United Kingdom

## Why was it conducted at all?

Young people, broadly those aged 13-24 years at diagnosis, present with a spectrum of cancers distinct from children and older adults. The treatment and care they receive is complex, a consequence of a disparate range of cancer types occurring during a period of unique physical and psychological growth, superimposed on the social and cultural dimensions of teenage and young adult development. Working with young people and carers/significant others as equal partners to set research priorities for young people with cancer had not yet been explored.

## What was the objective?

to conduct a UK-wide survey of young people who have experienced cancer, carers and professionals, to identify and prioritize research questions, to inform decisions of research funders and support the case for research with this unique cancer population

## What was the outcome?

a ranking list of 10 research questions

## How long did the research prioritization take?

Survey: October 2016 - December 2016. Evidence searching: August 2017 - September 2017. Interim ranking: November 2017. Workshop: January 2018

## Which methods were used to identify research priorities?

JLA method

## How were the priorities for research identified exactly?

Step 1: setting up PSP: steering group established, stakeholders and partner organizations identified. Step 2: collecting research questions: via online survey participants were asked to submit up to five questions related to young people's cancer they considered unanswered: 855 questions submitted. Step 3: data processing: refining and grouping questions, searching for already existing evidence. Step 4: interim ranking: top 104 questions a-priori selected by steering group, participants were asked to rate each of the 104 questions. Step 5: final prioritization: workshop: prior to workshop participants were asked to rank 30 questions individually, during workshop: small group discussions and small group rankings, plenary discussion and plenary ranking

## Which stakeholders took part?

Young people diagnosed with cancer between 13-24 years, relatives/friends/partners/carers of someone with a cancer diagnosis between 13-24 years, healthcare providers working with young people. Survey: 292 participants: 108 (36%) young people, 101 (34%) family members/ partners/ friends and 83 professionals (30%); equal numbers of nurses and doctors (n=25, 30%), 24 (29%) allied health professionals, 9 (11%) other. Interim ranking: 174 participants: 58 (33%) young people, 45 (26%) family members/ partners/ friends and 71 professionals (41%): nurses (n=27, 38%), medical doctors (n=17, 24%), 14 (20%) allied health professionals, 11 (15%) other. Workshop: 25 participants: 7 young people, 4 parents and 14 multidisciplinary professionals from nursing, oncology, haematology, social work, youth-support, psychiatry and physiotherapy

## How were stakeholders recruited?

Survey: snowball sampling: Partners promoted the survey through websites, social media, newsletters and conferences including a young person's cancer conference. Self-selected survey participants participated in the interim ranking and the workshop.

## 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. The steering group consisted of 17 members: 5 young people with previous cancer diagnosis, 2 healthcare and health professionals, 1 youth support coordinator, 1 adult medical oncology, 1 adult clinical oncology, 1 pediatric haematology, 1 psychiatry, 1 general practitioner, 1 pediatric oncology, 2 funding partners and 1 JLA advisor. Members oversaw the project, approved aims/objectives, survey materials, cleaned data and provided expert opinions for evidence checking.

