

# Research priority setting exercise for teenage and young adult cancer: Reducing the mismatch and influencing the agenda from priority to funding

## Professor Faith Gibson

*On behalf of the TYA PSP Coordinating Team:  
Professor Faith Gibson,  
Mrs Susie Aldiss  
Dr Bob Phillips  
Dr Lorna Fern  
and the TYA PSP Steering Group*

### Teenage and Young Adult Cancer



Teenagers and young adults (TYA) aged 13 – 24 years old who develop a cancer, are said to inhabit a unique "no-man's land" placed between the healthcare systems mainly centred around children (paediatric oncology) or adults.

The conditions that this group of young people develop are often different to those of adults or children. Their physical, psychological and social responses to these life-threatening diagnoses are different, and the outcomes from the same malignancies are distinct; in some settings they have poorer survival than somewhat older adults and in some settings better outcomes.

We know that TYA with cancer are less likely to be involved in research than children, and that the specific aspects of the cancers they develop and the way common drugs are handled by their bodies is less well understood than for children or older adults.

To encourage more research, which is focussed on the priorities set by TYA with cancer, the clinicians that work with them and the academic teams that research these areas, three charities have combined to fund a PSP. These are Teenage Cancer Trust, Children with Cancer UK and CLIC Sargent.

The PSP's initial survey opened at the beginning of October 2016.

The Teenage and Young Adult Cancer PSP published its Top 10 in January 2018.



@TYAPSP @lornaAfern @ProfFaithG @AldissSusie @drbobphillips

# Why did we do this project?

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- To find out **what research questions are important to young people** who have experienced cancer, their **families/carers** and **professionals**.
- To **align research priorities** between young people, carers and professionals.
- To **raise awareness of research needs/gaps** within this field of cancer care.
- To **inform funders** of priority research areas for young people.



Final report of the  
James Lind Alliance  
Priority Setting Partnership



Teenage  
and Young  
Adult Cancer:  
research priorities



TYA PSP



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[Teenage and Young Adult Cancer | James Lind Alliance](http://www.jla.nihr.ac.uk/priority-setting-partnerships/teenage-and-young-adult-cancer/)

[www.jla.nihr.ac.uk/priority-setting-partnerships/teenage-and-young-adult-cancer/](http://www.jla.nihr.ac.uk/priority-setting-partnerships/teenage-and-young-adult-cancer/)

Teenagers and young adults (TYA) aged 13 – 24 years old who develop a ... The Teenage and Young Adult Cancer PSP published its Top 10 in January 2018.

[@TYAPSP](https://twitter.com/tyapsp) | Twitter

<https://twitter.com/tyapsp?lang=en>

The latest Tweets from TYA Research PSP (@TYAPSP). A research priority setting exercise with professionals, young people, and the public. What are the ...

<http://www.jla.nihr.ac.uk/priority-setting-partnerships/teenage-and-young-adult-cancer/downloads/Teenage-and-Young-Adult-Cancer-PSP-final-report.pdf>

# We experience things differently...

NOT Happy,  
Happy, Happy !!!





# We see different things...



# Informing funders and raising awareness

...Is this a priority area of research for young people with cancer?...



CANCER  
RESEARCH  
UK



National Institute for  
Health Research

...how have patients and the public been involved in identifying the research question?...



MACMILLAN  
CANCER SUPPORT



# The aim of the project

*“To identify gaps and unanswered questions in research, the answers to which may reduce the individual and societal burden of young peoples’ cancers.”*

Your questions can be about any aspect of Teenage and Young Adult Cancer during:

Pre-diagnosis  
Diagnosis  
Referral

Treatment

End of Treatment  
Follow-up  
Relapse

Survivorship

Palliative care  
and end of life

## Such as:

- Communication
- Care
- Education
- Health
- Long-term effects
- Relationships
- Family
- Work
- Social life
- Side effects

# Multi-Disciplinary Steering Group

## Youth Support Co-ordinators

Helen Veitch

JLA representative Sheela Upadhyaya

## Paediatric Oncology

Bob Phillips

## Medical Oncology

Jeremy Whelan

## Clinical Oncology

Karen Dyker

## Haematology

Rachel Hough

## Psychiatry

Mike Grozsmann

## Nursing

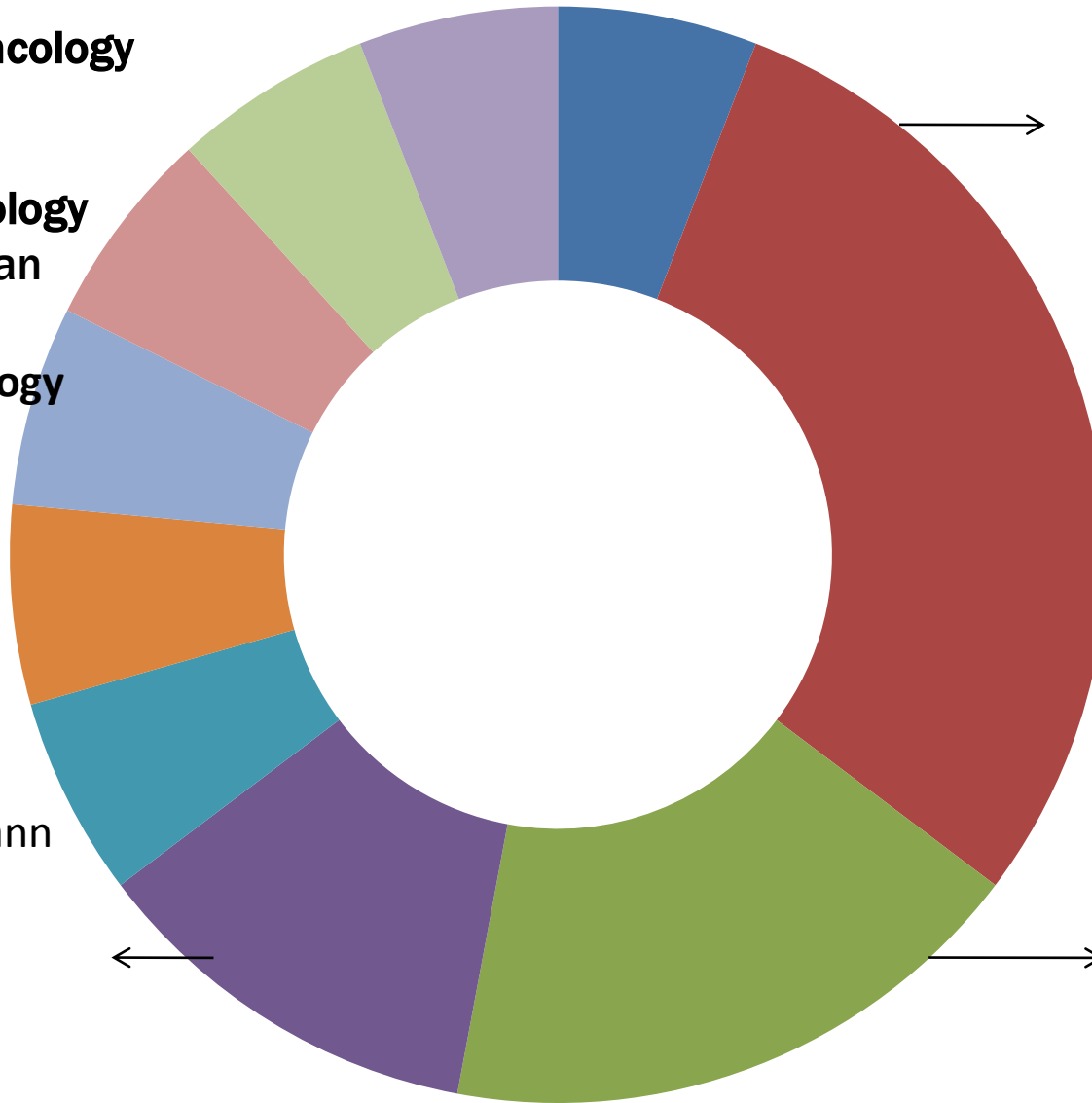
Sue Morgan  
Sam Smith

## Patient representatives

Leila Hamrang  
Amy Callaghan  
Demi McGeachy  
Max Williamson  
Lara Veitch

## Funders

Sam Smith  
Helen Gravestock/  
Caroline Weston/  
Anna Carnegie





# Project overview

Initial survey



Interim survey



Workshop

- Online survey.
- Questions collected from young people, families, friends, partners, professionals.
- 292 people sent in questions.
- 855 questions.

- Online survey.
- 104 questions.
- Rated from very high to very low priority.
- 174 people responded.

- Top 30 rated questions from interim survey discussed to decide Top 10.

# How did we reduce the 855 questions from the initial survey?

326 'out of scope questions' removed  
(e.g. about availability of services, personal questions, ambiguous questions)

Duplicates combined, questions worded into 'researchable questions'

**Evidence checking:**

- Has the question already been answered?
- Is there a study currently looking at this question?

**Found 7 questions already answered, 16 ongoing studies**

**= 185 unanswered questions**

# Out of scope questions, for example

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1. It did not fit the scope of reducing the individual and societal burden of young peoples' cancer or could not be answered by research.

*'Can a cancer sufferer become an organ donor?'*

2. It was a statement rather than question (and no specific question could be identified from the statement).

*'Can the late effects Drs stop telling us how BAD outcomes are and focus just a little on some of the POSITIVE outcomes'*

3. The question related to a specific person's situation/issue.

*'Who can I talk to about my worries for my child?'*

## Interim survey preparation

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- 185 questions – too many to ask people to vote on.
- Steering group decided to include all the questions asked by more than one person (64 questions).
- Steering group voted on the priority of remaining questions – top 40 added to survey.
  
- = 104 questions for interim survey.

# Interim survey

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- Rate each question - very high to very low priority.
- 174 people responded:
  - 58 young people (33%)
  - 45 parents/relatives/friends/partners (26%)
  - 71 professionals (41%).
- We worked out the rankings of each question for each of the 3 groups then averaged these rankings to come up with **Top 30 questions** for the workshop.



# Workshop

- 7 young people.
- 4 parents.
- 14 professionals.
- 3 James Lind Alliance Advisors.
- Homework, then group work to discuss, debate and order questions.
- Ensure everyone's voice was heard.



# Pre-workshop task for participants

- **Review** the Top 30 questions
- **Prioritise** the Top 10 and give reasons

**Please bring your ranking with you to the workshop. Thank you.**

Your name:

Question ID	Question	Your ranking 1 = most important 30 = least important	Your comments/notes
A	What are the best ways of supporting a young person who has incurable cancer?		

# Teenage and Young Adult PSP Top 10 questions

1. What psychological support package improves psychological well-being, social functioning and mental health during and after treatment?
2. What interventions, including **self-care**, can reduce or reverse adverse short and long-term effects of cancer treatment?
3. What are the best strategies to improve access to clinical trials?
4. What GP or young person strategies, such as awareness campaigns and education, improve early diagnosis for young people with suspected cancer?
5. What are the best ways of supporting a young person who has incurable cancer?
6. What are the most effective strategies to ensure that young people who are treated outside of a young person's **Principal Treatment Centre** receive appropriate practical and emotional support?
7. What interventions are most effective in supporting young people when returning to education or work?
8. How can parents/carers/siblings/partners be best supported following the death of a young person with cancer?
9. What is the best method of follow-up and timing which causes the least psychological and physical harm, while ensuring relapse/complications are detected early?
10. What targeted treatments are effective and have fewer short and long-term side-effects?

**This is what success looks like.....**

**JOB DONE.....NO.....**



# Promoting the TYA PSP

European Journal of

**Cancer Care**

A multidisciplinary journal for cancer research -  
from prevention to palliation



EDITORIAL |  [Free Access](#) |

## Transitioning adolescent and young adult cancer care research out of its adolescence

Dan Stark , Lorna A. Fern, Faith Gibson, Mike Hawkins, Rachael Hough, Martin G. McCabe, Rachel Taylor

**CANCER NURSING**

*An International Journal for Cancer Care*

## How Far Do Research Priority Setting Exercises Influence What Research Is Undertaken

### A Little, a Lot, or Not at All?

Gibson, Faith, PhD





## After the top 10: Bringing community priorities to life

It's been over a year since the final workshop of our neurodevelopmental disorder Priority Setting Partnership (PSP). This seminal moment marks the day when patients, family members, and front-line care providers came together and reached consensus on a top 10 list of research priorities for the research community. While all PSP initiatives culminate in a final workshop, we've been working hard to spread the word about the top 10 and address the community's priorities.

### Spreading the word

We've spent the past year promoting the top 10 priorities and ensuring that they reach the right audiences. This includes researchers studying neurodevelopmental disorders, organizations that fund research, the community, and general public.



Community Priorities for Research  
on Neurodevelopmental Disorders

### Final report

In August we released a report on the Community Priorities for Research on Neurodevelopmental Disorders. The report provides a step-by-step breakdown of the priority setting process and the resulting top 10 priorities. [Read the report.](#)

### SHAPING THE FUTURE OF NEURODEVELOPMENTAL DISORDER RESEARCH

We received 1200+ questions from individuals, families, carers, and health/education professionals about interventions for neurodevelopmental disorders. We then asked them to rank which questions were most important to them. Here are the top 10 research priorities from the neurodevelopmental disorder community.

#### TOP 10 RESEARCH PRIORITIES FOR NEURODEVELOPMENTAL DISORDERS

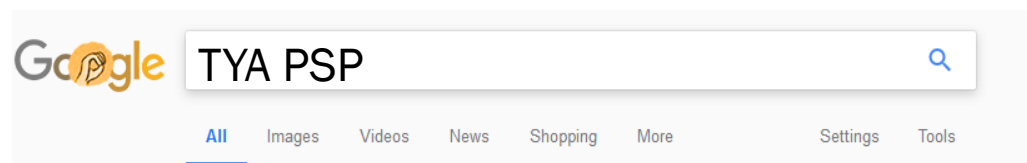
1. What are the most effective treatment options/plans (e.g. timing, frequency, duration, type, intensity or dosage) for individuals with neurodevelopmental disorders for both short and long-term benefits?
2. How can system navigation be organized in a manner that enables coordinated services and supports across the lifespan for individuals with neurodevelopmental disorders and their families?
3. Which biological treatments (including medications, gene therapy, stem cell therapy, etc.) are effective for neurodevelopmental disorders and associated symptoms?
4. Which child and family-centred
5. Which are the most effective
6. Which resources are needed to more effectively address the health, social and emotional needs of families or caregivers of individuals with neurodevelopmental disorders?
7. How can treatment decisions for individuals with neurodevelopmental disorders be more person (i.e. based on the diagnosis, age, functional need of the individual)?
8. Which are the most effective pharmacological and non-pharmacological treatments for aggressive and self-injurious behaviour in individuals with neurodevelopmental disorders?
9. Which are the most effective

### Infographic

After the final workshop we released an infographic of our top 10 research questions and shared it widely through our networks and social media channels. [Download and share](#) this with your network to help us continue the conversation.

# Spreading the word.....

- Dissemination, report, paper, conferences, we have a roadshow of presentations
- Ensure questions not in the Top 10 are not lost
- Out of scope questions to be published
- Active on social media
- Active engagement with research funders
- Collaborate with relevant Clinical Studies Groups
- Encourage researchers in as many ways as we can to consider these priorities when they are planning new studies.
- Support the networks by designing appropriate and acceptable studies to young people and professionals



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# BMJ Open Research priorities for young people with cancer: a UK priority setting partnership with the James Lind Alliance

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Susie Aldiss,<sup>1</sup> Lorna A Fern,<sup>2,3</sup> Robert S Phillips,<sup>4</sup> Amy Callaghan,<sup>5</sup> Karen Dyker,<sup>6</sup> Helen Gravestock,<sup>7</sup> Michael Groszmann,<sup>8</sup> Leila Hamrang,<sup>5</sup> Rachael Hough,<sup>9</sup> Demi McGeachy,<sup>5</sup> Sue Morgan,<sup>10</sup> Sam Smith,<sup>11</sup> Sheela Upadhyaya,<sup>12</sup> Helen Veitch,<sup>11</sup> Lara Veitch,<sup>3,5</sup> Max Williamson,<sup>3,5</sup> Jeremy S Whelan,<sup>2</sup> Faith Gibson<sup>1,13</sup>

Thank you to all the young people, carers, parents,  
siblings, friends, partners and professionals who  
completed the survey

Thank you for listening

Questions?



@TYAPSP