

NEWS RELEASE

Tuesday 23 January

Top research priorities for Teenage and Young Adult Cancer identified for the first time

“What psychological support package improves psychological well-being, social functioning and mental health during and after treatment?” has been rated the top priority for future research into teenage and young adult cancer, according to new research launched today.

The results from a national research prioritisation exercise were revealed at the Teenage and Young Adult Cancer Priority Setting Partnership workshop in London on Friday 19 January. Young people, parents and professionals with experience of cancer in young people, debated and agreed on the top ten research priorities for this area.

Teenage and Young Adult cancer patients have very different physical, psychological and social responses to their diagnoses, with distinct outcomes. Yet this patient group is less likely to be involved in research than children, which can lead to a knowledge gap. For the first time ever, the research agenda for young people with cancer has been set with those it affects most, young people, their carer's, and the healthcare professionals looking after them. The results will be critical in informing the funders of cancer research which priority areas need funding.

The Teenage and Young Adult Cancer Priority Setting Partnership was launched to tackle this issue with funding from Teenage Cancer Trust, Children with Cancer UK and CLIC Sargent, independently overseen by the James Lind Alliance and hosted by the National Institute for Health Research.

The group asked young people who had been diagnosed with cancer between the ages of 13 and 24, their families, friends, partners, carers and healthcare professionals to tell us what questions about teenage and young adult cancer they would like to see answered by research. Nearly 300 people replied, submitting 855 questions.

The top ten priorities were identified as:

- 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 harm, while ensuring relapse/complications are detected early?*

10. *What targeted treatments are effective and have fewer short and long-term side-effects*

Leilia Hamrang, a former cancer patient and member of the Priority Setting Partnership steering group, said: "If you have been affected by cancer, whether that's as a young person or have been involved in their care as a parent, carer or professional, you will know that there are a lot of unanswered questions. As a survivor, my main priority is around long-term effects from cancer treatment and I'm glad that this question made it in the top 10. It has been a privilege to be involved in this project, I'm looking forward to seeing change within the TYA services whether that's at the point of diagnosis, during treatment or survivorship."

Kate Collins, Interim Chief Executive at Teenage Cancer Trust, said: "It's essential that young people themselves make sure organisations like ours are focussed on the research priorities that matter to them. This vital top ten will drive the work of Teenage Cancer Trust going forwards – all ten areas are critical but and we're pleased to see effective psychological support at the top of the list. The effects of a cancer diagnosis can be devastating, long-lasting and wide-ranging for a young person and the psychological impact can be felt long after treatment. Teenage Cancer Trust Nurses and Youth Support Coordinators play a vital role in improving psychological wellbeing during and after treatment and we're working with researchers to develop the evidence in this important area – an area we know is at the heart of improving the lives of young people with cancer."

Kate Lee, Chief Executive, CLIC Sargent said: "Finding out what's most important to teenagers and young adults with cancer, and responding to this, is at the heart of what we do. We have heard the need for appropriate psychological support, help returning to education and work, access to clinical trials and early diagnosis being raised by many of the young people and families that we support, and we will work together with other charities to ensure that their voices are heard and responded to."

Cliff O'Gorman, CEO, Children with Cancer UK, said: "Cancer and its treatment can take an enormous toll on the young people and their families that go through it – so it is crucial that the voices of young people are at the heart of our research priorities.

"This research shows that patient well-being during and after treatment should be a top priority for research funders – both through psychological support, as well as cutting-edge, kinder treatments that reduce the long-term health effects on young patients."

-ENDS-

Patients from the steering group are available for interview upon request.

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Notes to Editors:

About the Teenage and Young Adult Cancer Priority Setting Partnership

The project is independently overseen by the [James Lind Alliance](#) (JLA), a non-profit making initiative, which is hosted by the National Institute of Health Research. Its aim is to bring patients, carers and health care professionals together to identify and prioritise research questions in order to influence the direction of future research in that area.

Three charities have combined to fund the Teenage and Young Adult (TYA) Cancer Priority Setting Partnership (PSP). These are [Teenage Cancer Trust](#), [Children with Cancer UK](#) and [CLIC Sargent](#).

The Steering Group

The project is managed by a Steering Group, led by an independent chair from JLA. The Steering Group includes patient representatives as well as clinicians and representatives from charities supporting teenagers and young adults with cancer.

Patient representatives:

Amy Callaghan
Leila Hamrang
Demi McGeachy
Lara Veitch
Max Williamson

Steering Group Professional representatives:

Bob Phillips (Clinical Lead of the TYA PSP; Paediatric Oncology Consultant)
Anna Christina Carnegie (Research Officer, CLIC Sargent)
Karen Dyker (Clinical Oncologist)
Mike Grozsmann (Consultant Child and Adolescent Psychiatrist)
Rachael Hough (Consultant Haematologist and Transplant Physician)
Sue Morgan (Nurse Consultant)
Sam Smith (Head of Nursing and Clinical Services, Teenage Cancer Trust)
Helen Veitch (Head of Youth Support Co-ordinators, Teenage Cancer Trust)
Caroline Weston (Research and Policy Manager, CLIC Sargent)
Jeremy Whelan (Consultant Medical Oncologist)

The Partnership and the priority setting process is being supported and guided by:

Sheela Upadhyaya (James Lind Alliance Adviser)
Susie Aldiss (Research Fellow)
Lorna Fern (NCRI TYA CSG Research Development Co-ordinator)
Faith Gibson (Professor of Child Health and Cancer Care)