

Teenagers and
Young
Adults with
Cancer

RESEARCH STRATEGY

Leading and funding research into teenage and young adult cancer treatment and care

November 2021



A key objective of TYAC is to lead and fund world-class research dedicated to teenage and young adult cancer.

We recognise the need for a well-defined research agenda that bridges the gap between the children's and adult oncology research worlds. TYAC is taking the lead on building a new focus on research that is dedicated to the very specific needs of teenage and young adult cancer treatment and care which will help change the future of teenage and young adult (TYA) cancer care and improve outcomes for young people with cancer.

This is TYAC's first research strategy which outlines our overall aims and objectives.

Over the next 3-5 years we aim to:

- Define and establish a comprehensive research strategy and portfolio
- Identify and fund research gaps to ensure the whole cancer experience is taken into account
- Promote and encourage TYA tumour banking with patients and hospital centres to increase samples for research within the Children's Cancer and Leukaemia Group (CCLG) Tissue Bank
- Strengthen national and international collaborations and partnerships within the cancer research community to drive improvements
- Encourage new types of partnerships and collaborative working to support the development of innovative ideas and novel approaches for TYA research
- Ensure patient involvement and experience is at the heart of our research
- Develop the next generation of TYA cancer researchers





Why is TYAC a research funder?

There are currently no major national funders who solely fund TYA cancer research, and no Association of Medical Research Charities (AMRC) members with a unique TYA focus. Proposals are either submitted to predominantly children's or adult research funders.

The James Lind Alliance TYA Cancer Priority Setting Partnership (TYA PSP) employed a rigorous process to identify the top ten research priorities for teenagers and young adults with cancer, their carers and the healthcare professionals treating them. The TYA PSP also identified that many of the top ten priorities are outside the scope of existing remits for research funders. A fresh focus is needed to help bridge the gap between children's and adult cancer research to address the priorities identified for TYA research. New collaborations and partnerships across different disciplines such as education, as well as clinical and health roles, can stimulate novel ways of working in research.

We are in a unique position in the arena of TYA cancer charities, as we are also the multidisciplinary professional body for those involved in the treatment and care of young people with cancer. As part of the Children's Cancer and Leukaemia Group, we also have considerable expertise in the funding of research projects and are a member of the Association of Medical Research Charities.

Our medical and scientific expertise, alongside the recent TYA PSP, puts us in a strong position to prioritise areas of unmet need and offer funding for specific research projects.

The TYAC Research Academy

We aim to expand our TYAC research community, encouraging professionals and researchers to develop expertise in TYA cancer research. **We will do this by:**

- Nurturing the careers of early-stage professionals and researchers to become TYA experts
- Facilitating national and international collaborative research
- Encourage new types of collaborations and partnerships bringing together expertise from across different disciplines and roles
- Providing training on topics such as writing abstracts, preparing a manuscript for submission or completing a grant application
- Provide training and support for Patient and Public Involvement (PPI) in research
- With the TYAC Professional Education Group, provide a pre-submission review process for new researchers submitting abstracts to the TYAC annual conference
- Continue to award The Lisa Thaxter Prize for research presentations
- Offer travel grants to support new investigators to attend conferences for oral presentations

What do we fund?

We are funding research that will reduce the individual and societal burden for teenagers and young adults with cancer.

We aim to fund world-class research across the TYA cancer timeline including prevention, diagnosis, treatment and consequences, short- and long-term effects. Interventions should aim to improve the physical, psychological, social and economic wellbeing for TYA and their carers/significant others. All aspects of research will be considered; however, priority will be given to questions identified in the recent James Lind Alliance Top 10 Research Priorities for TYA [see Appendix 1].

How do we fund?

TYAC is part of Children's Cancer and Leukaemia Group (CCLG), a member of the Association of Medical Research Charities. As such, our robust peer-review processes of proposals received in open competition ensures we only fund high-quality research.

The nature of grants we are able to offer will vary with our income and the wishes of our donors. Initially, we will aim to support research that is likely to inform studies which will then be funded by larger mainstream funders. Examples might include feasibility work and/or pilot studies or testing processes.

Small does not mean poor in research rigour. We will support high-quality study design with cohesive dissemination plans for peer reviewed publications and lay summary outputs.



How will we measure success?

Our impact will be measurable by:

IMPACT	EXAMPLES
New knowledge	Peer-reviewed publications
	Conference abstracts and presentations
	New research tools, methods, databases and models
Policy and practice influences	Research projects which influence policy
	Research which informs our 'best practice' guidelines
	Research which informs professional and patient education
Further investment	Subsequent funding leveraged from government, industry and charities
Awareness and engagement	Research studies with patient and public involvement embedded into methods
	Engagement and involvement approaches are transparent in publications
Enhanced skills and capacity	Funded projects allow individuals to secure subsequent positions in research
	Increased TYAC membership
	Awards and recognition from other societies and networks
Partnerships	National and international collaborations established
	New types of partnerships and collaborative working across roles and disciplines formed
New products and services	New medical products including drugs, diagnostic tools, software, artificial intelligence and technical products
	New interventions, tools and services for clinical use

Working in partnership

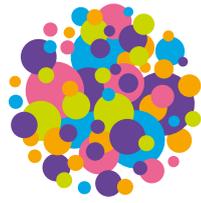
As an aspiring funder of TYA cancer research, we will meet our aims by working in partnership with key groups in the field, including:

- The National Cancer Research Institute TYA and Germ Cell Research Group, which generates a portfolio of research studies.
- The National Institute for Health Research Clinical Research Networks who support the delivery of research studies through a nationwide network and have a TYA group with a remit to increase recruitment of TYA to research

Appendix 1

The top 10 research questions identified by the TYA PSP

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?



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www.tyac.org.uk



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Children's
Cancer and
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Group

TYAC is part of Children's Cancer and Leukaemia Group (CCLG), registered charity in England and Wales [1182637] and Scotland [SC049948].



CCLG is a member of the Association of Medical Research Charities.