

ecmc

Experimental
Cancer
Medicine
Centres

Working together to improve access
to clinical trials and biobanking for
teenagers and young adults with cancer

Our journey towards a better future

Jointly
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Foreword

This roadmap sets out how we can improve access to clinical trials, and therefore outcomes, for teenagers and young adults. It has been developed with and for the cancer research community.

Patients, survivors, parents, and families were central in creating this roadmap, and will continue to be as we move forward. All future work that develops from this roadmap should be relevant, impactful, and truly serving the needs of people affected by cancer.

A big thank you to everyone for their time, support and for sharing personal stories and experiences to help us understand the challenges that teenagers and young adults (TYAs) with cancer experience.

Here is what we heard from people affected by TYA cancers.

- Targeted treatments are especially important for TYA patients to reduce the significant number of late effects often caused by aggressive non-specific treatment.
- Medical teams need to be aware of relevant trials and developments in cancer treatments, so patients feel confident about getting the best possible care.
- Clinical trials should be discussed very early on so patients and families are aware of the process should it arise, rather than resorting to googling clinical trials.
- Increased awareness and offering information and support throughout can help patients and families make informed decisions easier and sooner based on what is right for them as delaying treatment is something to avoid.
- Engaging and getting patients' point of view is crucial to make clinical trials feel accessible and something to be involved in.
- Sometimes TYAs cannot join clinical trials due to personal social and economic circumstances.
- There should be opportunities to conduct trials closer to the TYA patients' homes as young people are less likely to travel long distances for treatment including financial barriers and relying on parents and carers to take them.
- Raising awareness of biobanking and encouraging young patients to do this will help gather samples needed in research.
- The more sample collection we have and can store, the more we can learn about the many different types of cancers that are out there.



What is the take home message for people reading this?

Recruitment to clinical trials should be much easier for patients. The more obstacles we remove, the more likely people are to join trials. We need to involve TYAs in their treatment as soon as possible to get the best outcome for TYAs and the advancement of medicine.

"This is a roadmap developed by the community and for the community, with a shared vision and a way forward. It showcases the progress already being made which inspires some hope but reminds us how far there is still to go."

TYA patient and parent advocates





Kyle's and Max's perspectives : hear from two patient advocates involved in developing this roadmap

Kyle works for the University of Glasgow

"The TYA roadmap is such an important step in understanding and overcoming the under-representation of the teenage and young adult community within clinical trials and biobanking in particular. The impact of cancer is always enormous but as a teenager, you can really feel at the eye of the storm. Making access to trials easier and as inclusive as possible will reduce stress at an already stressful time and lay the foundations for a much smoother journey for the TYA community as a whole."

Max is studying medicine at Oxford

"Like most young people with cancer, I faced challenges throughout my treatment and follow up that are different from children and adults. One of the best ways to understand these problems better, and to improve treatments for cancers affecting young people, is through research. The Experimental Cancer Medicines Centre (ECMC) network are key to this. They manage much of the research into new treatments in the UK and run biobanks to store patient samples and help our scientific understanding of cancer. They are now focussing on giving young people more access to this research and developing a roadmap to make this more inclusive. As a cancer patient, being involved in research to help patients who come after me was really empowering, and the ECMC's new work will hope to extend this work to as many young people diagnosed with cancer as possible."

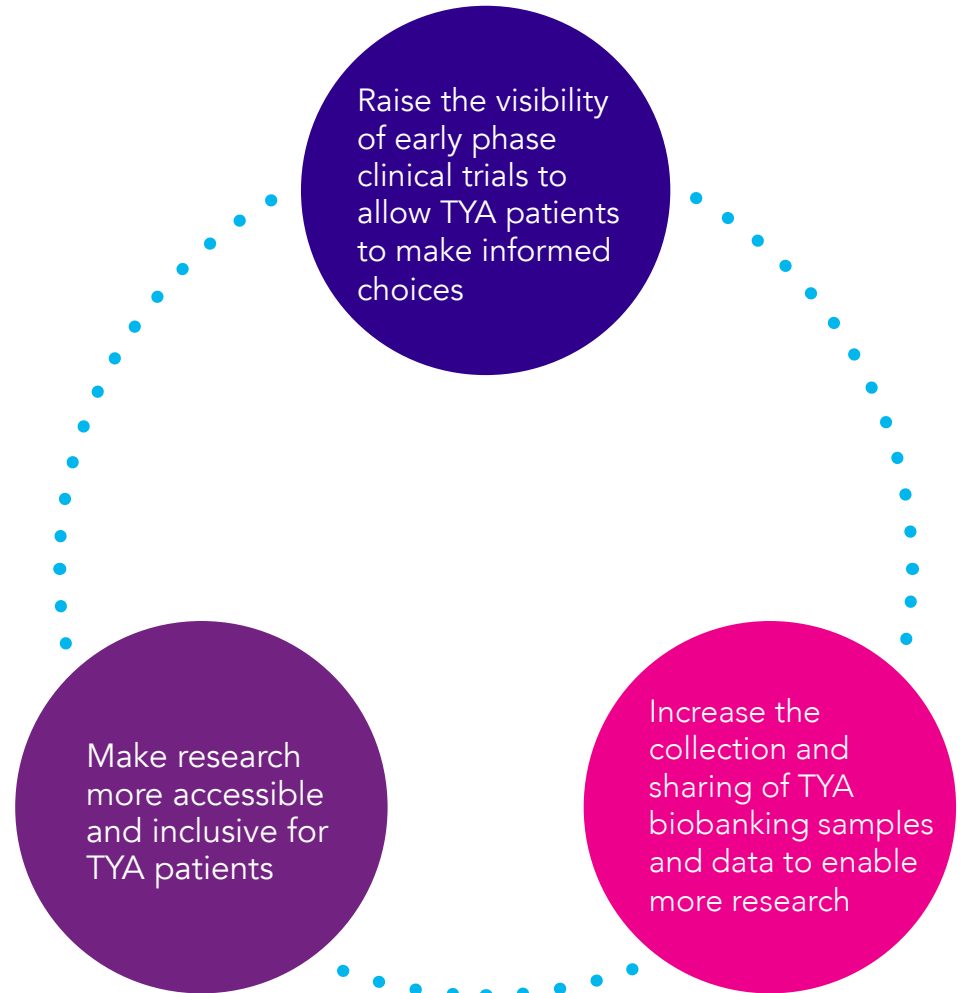


Executive summary

TYAs face many challenges in accessing clinical trials and biobanking, which are two of the key ways in which progress is made in research

This roadmap sets out how we can improve access to clinical trials and biobanking, and therefore outcomes, for TYAs. It sets out three key aims – as shown on the right. Taken together, these will help us to achieve our vision of TYAs having equal access across the UK to clinical trials and biobanking, compared to other age groups.

This roadmap has been developed with and for the cancer research community. We can't achieve any of it without that community working together, especially research groups and NHS organisations with expertise working with TYAs. It will also require research funders and industry to promote, prioritise and invest in dedicated research and clinical trials that will benefit TYA patients.





Introduction

Every year, 2,110 teenagers and young adults (TYAs) aged 15-24 are diagnosed with cancer in the UK.¹

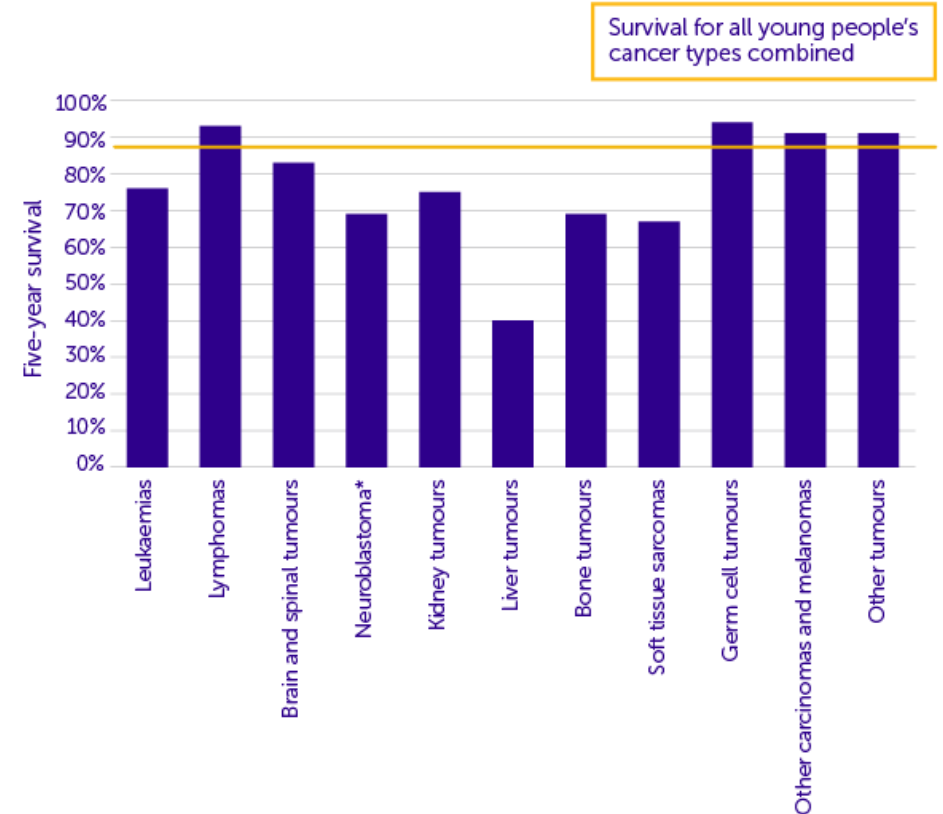
Cancer remains the most common disease-related cause of death for this age group. Overall survival is around 87%, which is similar to children aged 0–14 years old. However, this picture varies across cancer types, with survival far lower for certain cancer types than others (see figure 1). Long-term physical side effects of treatment and quality of life issues for survivors remain significant.

TYA cancer patients often experience lower survival compared to children or older adults for certain cancer types. This has been attributed to several factors, including low participation in clinical trials. There are a number of reasons for this, including the small numbers of potential participants, lack of accessibility in trial design and lack of trial visibility.

By addressing these issues, we can improve access to clinical trials and biobanking for teenagers and young adults with cancer. This is key to making progress in research into cancers affecting this group and therefore improving outcomes.

Differences in survival among young people’s cancers

There are 12 main groups of young people’s cancers, and survival varies considerably between them. Overall, almost 9 in 10 young people diagnosed with cancer in the UK survive for 5 years or more, but some cancer groups have much lower survival.



Source: Public Health England. Children, teenagers and young adults UK cancer statistics report 2021. Population-based 5-year survival, young people diagnosed 2012-2016 (or 1997-2016 for cancer types marked with asterisk), UK. No survival data for retinoblastoma due to low case numbers.

Together we will beat cancer



Figure 1. Differences in survival among young people’s cancers



What are clinical trials and why are they important?

Most advances that have been made in treating cancers affecting children and young people (aged 0–24) have been made because of clinical trials.

Cancer in children and young people is different to cancer in adults, from the types of cancers they develop to the impacts of treatment. The best way to treat every cancer type is not clear. This is where clinical trials come in.

Clinical trials find better ways to treat different cancer types. Before a new treatment becomes available to all patients, it must first be tested to make sure it is safe and effective.

The challenge of low TYA participation in clinical trials and its impact has been well recognised. The [NHS England Long Term Plan](#),² commits to “actively support children and young people to take part in clinical trials, so that participation in children remains high, and among teenagers and young adults rises to 50% by 2025.”



Potential benefits of clinical trial participation

- Receiving a new treatment that is only available on a clinical trial.
- There is considerable emphasis on patient safety and patients will be monitored closely.
- Results of clinical trials can help improve cancer treatments for future patients.



Things to consider before clinical trial participation

- More hospital visits may be required.
- Travelling to a specific hospital where the trial is open.
- Having more tests carried out.
- Experiencing side effects.
- The new treatment, although expected to be better, may not be better.

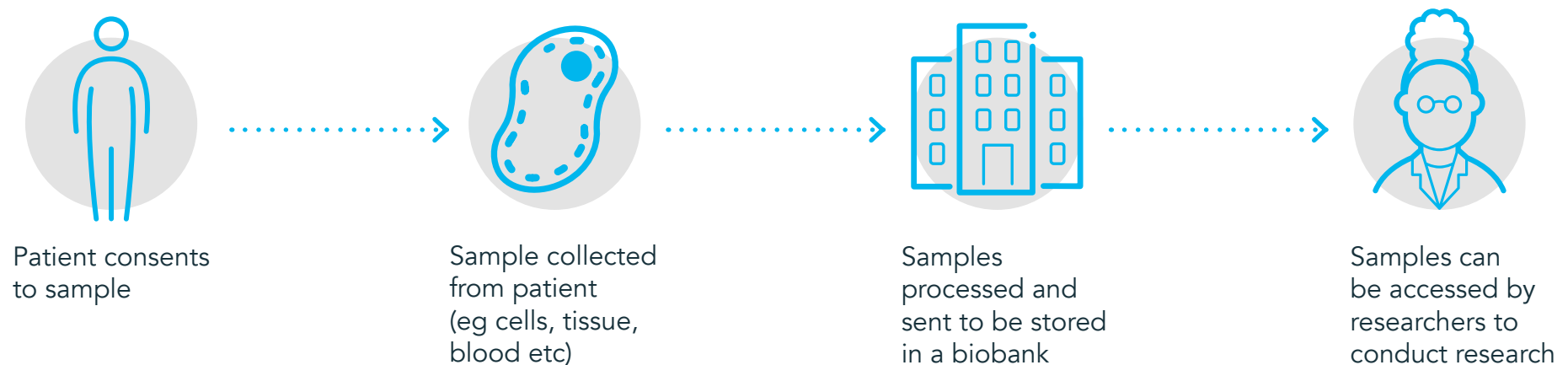


What is biobanking and why is it important?

Biobanking is the process of collecting samples for research use to improve understanding of disease, in this case cancer.

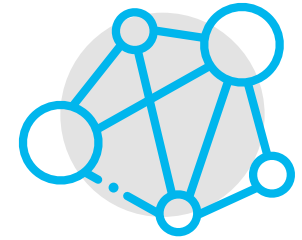
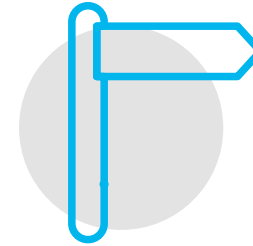
Researchers need tumour cells and normal tissue to carry out research that aims to better understand cancer. With a better understanding of cancer, researchers can then develop new tests and treatments that will lead to better outcomes for cancer patients.

Currently, the biobanking pathways for collecting and storing TYA patient samples are varied, resulting in inconsistency and low numbers of TYA biological material available for research. As well as improving clinical trial access, it's also important to improve access to biobanking for TYA patients to drive further progress.





How was this roadmap developed?



Feb 2021

Research identified challenges TYA patients experienced during diagnosis, care and follow-up

March–July 2021

Conducted 50 interviews to discuss key challenges in research (clinical trials and biobanking)

Sep–Oct 2021

Held four national workshops bringing together 200 people to tackle these challenges and offer solutions

Dec 2021– Mar 2022

Summarised the discussions of the workshops and prioritised the actions

Oct 2022

Developed a roadmap to outline how to make clinical trials and biobanking more accessible for TYA patients

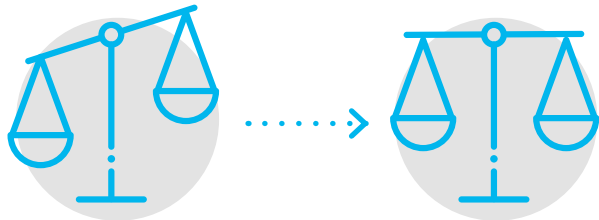
2023 onwards

Will create working groups who will lead on specific projects and will monitor and evaluate work



Our vision for a better future

To ensure TYAs across the UK have equal access to early-phase clinical trials compared to other age groups.



Current situation:
TYA patients less likely to participate in clinical trials and biobanking

Future situation:
TYA patients equally able to participate in clinical trials and biobanking





Our aims to improve access to clinical trials and biobanking

Aim 1: Raise visibility of early phase trials.

Share trial finding tools to easily search for open clinical trials.

Increase understanding of early phase clinical trials.

Encourage more discussions of clinical trial opportunities.

Aim 2: Make research more accessible and inclusive for TYA patients.

Better understand the barriers to accessing clinical trials.

Raise awareness of these barriers: eg age exclusion and placement.

Develop best practice and provide training on how to implement them.

Aim 3: Increase the collection and sharing of TYA biobanking samples and data to enable more research.

Determine how data will be collected, shared and used.

Apply a consistent approach for TYA biobanking across UK.

Create links between genomic, biobanking and clinical trial data.

Cross-cutting themes

Collaborate

Work together with internal and external stakeholders to drive progress and maximise impact

Community

Support the TYA cancer community and existing initiatives to avoid duplication and maximise resources

Influence

Be vocal about the challenges TYA patients experience to drive action

"This strategic roadmap has huge potential power for good for young people living with and after cancer, and scientific progress to benefit everyone affected by cancer."

Dan Stark, Professor of Teenage and Young Adult Cancer Research in Leeds



Aim 1: Raise the visibility of early phase clinical trials to allow TYA patients to make informed choices

The challenge

It is difficult for clinical teams treating TYA patients to have full visibility of all available clinical trials open in healthcare services for children, TYAs and adults. This can limit or delay TYA patients being offered and referred to clinical trials, leading to missed opportunities.

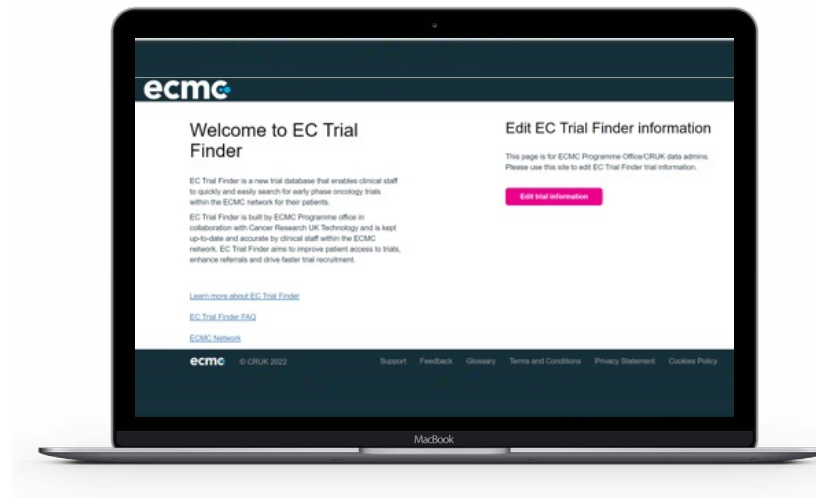
"I have found EC Trial Finder very useable and an intuitive platform. We will now be using trial finder in our MDT meetings to find the best opportunities for our TYA patients."

Bethan Ingram, Senior Teenage and Young Adult Nurse in Cardiff

What has been achieved so far?

The [ECMC EC Trial Finder \(ECTF\)](#) tool is now available for all clinical staff in the UK to use. The aim of the tool is to improve patient access to clinical trials, enhance referrals and speed up clinical trial recruitment by quickly and easily searching for open clinical trials. All TYA clinicians and nurses will have access, which should help raise the visibility of open early-phase clinical trials in the ECMC network to TYA clinical staff.

In addition, Cancer Research UK has a public facing [Find A Clinical Trial](#) webpage.





Aim 1: Raise the visibility of early phase clinical trials to allow TYA patients to make informed choices

What else do we need to do?



Share trial finding tools to help staff search for available clinical trials for their TYA patients



Encourage more discussions about clinical trial opportunities for TYA patients in the relevant forums



Increase awareness and understanding of early phase clinical trials through education training for clinical staff and healthcare professionals



Develop specific communication methods and tools to help staff have better discussions about early phase clinical trials with TYA



Increase understanding and visibility of clinical trials with TYA patients and their families



Determine what additional knowledge and information is required for NHS TYA teams and services to enhance TYA referral to early phase trials, eg decision support tools

If we achieve this, we will see greater clinical trial visibility with TYA staff, which should mean more clinical trial opportunities for TYA patients.

“Many clinicians don’t know what’s available for their TYA patients. EC Trial Finder evens the playing field and provides signposting for all.”

Joanne Zabkiewicz, Senior Fellow Cardiff ECMC



Aim 2: Make research more accessible and inclusive for TYA patients

The challenge

Teenage and young adult patients are less likely to participate in clinical trials compared to children and older adults. This is because TYA patients are often under-served in terms of trial opportunities due to lack of clinical referrals, reduced recruitment and the lack of inclusive eligibility criteria.

There are a number of reasons for this. Sometimes this is down to clinical trials not being carried out in cancer types affecting TYA patients. The small patient numbers also makes the development of TYA-specific trials less of a priority in the wider setting, due to recruitment challenges and the additional complexities of opening these trials. In turn, this makes trial viability and availability lower for TYA patients, who are often put in adult or paediatric trials, depending on their age and cancer type.

The specific needs of TYA patients are also not always considered within clinical trial design and delivery, which can create barriers to accessing clinical trials. Examples include age barriers and having to travel regularly and over long distances.





Aim 2: Make research more accessible and inclusive for TYA patients

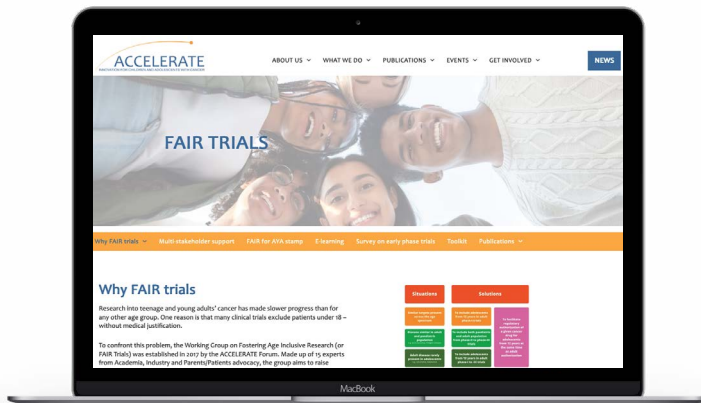
What has been achieved so far?

The ACCELERATE Fostering Age Inclusive Research (FAIR) Trials initiative proposes a six-point approach to improve access for TYA patients to new anti-cancer drugs. Here are some examples of what the working group have achieved to date:

- an e-learning tool to improve TYA access to innovative therapies
- a FAIR accreditation stamp for medical research that avoids unnecessary barriers based on age
- having a set of practical resources to assist in designing age-inclusive clinical trials
- scientific publications

The National Cancer Research Institute (NCRI) Teenage and Young Adult Clinical Studies Group published a paper outlining a strategy to improve participation of TYAs in cancer trials by focusing on five key criteria: available, accessible, aware, appropriate and acceptable (also known as the 5 A's).

DETERMINE is the first UK national precision-medicine trial in rare cancers. It's available for children, TYA and adult patients with rare cancers or cancers with rare genomic alterations. DETERMINE will open across the ECMC Network in early Summer 2022. The aim is to enable new treatment options approved by the Cancer Drugs Fund (CDF) for patients with rare cancers. TYA and adult cancer experts, as well as patients. The trial will be open in multiple centres across the UK, with the aim of having a good geographical spread.





Aim 2: Make research more accessible and inclusive for TYA patients

What else do we need to do?



Conduct more research and open more clinical trials in cancers affecting TYA patients to increase availability and recruitment



Work closely with TYA patient groups: to understand attitudes of clinical trials and using this evidence to recommend ways to improve clinical trial access and develop specific methods to involve TYA patients in designing clinical trials



Training, guidance and best practice on how to design and delivery accessible and inclusive research for TYA patients and ensure that this is implemented effectively



Work with researchers, funders and regulators to find solutions to clinical trial access and to raise awareness of the impact of age exclusion in clinical trials so it's considered in a meaningful way



Greater representation of TYA patient advocates in scientific discussions that design international academic and industry-sponsored early phase trials



Better consider clinical trial placement including how aspects can be brought closer to TYA patients, reducing unnecessary travel and financial burdens as well as enabling equitable geographical access



Highlight the importance of innovative approaches to research that harnesses digital applications to reduce travel and time for TYA patients eg remote consultations and monitoring

If we achieve this, we will see more accessible and inclusive research for TYA patients, which should make it easier for TYA patients to participate in research, including clinical trials.



Aim 3: Increase the collection and sharing of TYA biobanking samples and data to enable more research

The challenge

Research is critical for better understanding of TYA cancers and driving progress in TYA cancer research and improving patient outcomes. However, there are varied and complex pathways for collecting and storing TYA biological samples as well as collecting and sharing TYA health data. This leads to inconsistency and under-representation, which limits the amount of TYA samples and data available for future research.

What has been achieved so far?

VIVO Biobank is the UK's leading research resource dedicated to storing samples and associated data of cancers in children and young people (CYP). VIVO Biobank aims to increase tissue banking within the TYA community.



Uniting research
into cancers in the young

As a partnership between Cancer Research UK and Blood Cancer UK, VIVO provides a single point of access for people and organisations involved in researching blood, bone marrow and solid cancers in CYP.

By merging two existing biobanks – the CCLG Tissue Bank and BCUK's Cell Bank – VIVO is the widest collection of CYP cancer samples available, helping to advance high-quality research needed to develop new treatments faster.

"The main reason I see for patients not going into a trial within this age group is that there were no suitable trials available. I feel that researchers don't have enough information about where to focus trials for diseases within the TYA population. The information that can be gathered from biobanks regarding specific make up of TYA cancers, and the relatively unknown biology of the adolescent, should make it easier to develop trials specifically for TYA."

Kirsty Slater, TYA Research Nurse in Bristol



Aim 3: Increase the collection and sharing of TYA biobanking samples and data to enable more research

What else do we need to do?



Determine what TYA specific data is missing and lacking that is needed to better understand trial access and referral patterns



Increase clinical data being shared with existing specialist age-specific cancer registries and databases to improve completeness of TYA clinical data to study the relationship between eligible patients and early phase trial recruitment



Increase awareness of biobanks in UK open to receiving TYA samples and promote biobanking in adult cancer settings for TYA patient cohort – with support from specific TYA teams – so that samples can be made available for research



Work with pathologists (including national groups) to standardise practice and ensure they're committed to providing valuable tissue samples for this patient group



Agree what data should be collected, who and how it will be collected, shared and used so TYA data is included in local and national datasets (biobanks, NHS England, Genomics England and ECMC clinical trials) to develop future interventions



Work with patients and parents to raise awareness of the importance of biobanking and data collection for research



Design a consistent approach as a community for collecting and storing samples from TYA patients across the UK

If we achieve this, we will see more biobanking samples and data available for research, leading to a better understanding of TYA cancers and progress in TYA cancer research.



Moving forward

We've highlighted some amazing work and effort already being made in this space and the progress achieved that offers hope. However, we know that we're not where we want to be in achieving equal access for TYA patients. We cannot keep doing the same things and expecting different results. So it's up to all of us to take action and make the necessary changes to make research fairer, inclusive and accessible. We need to work together to enable a better future for teenagers and young adults with cancer.

This roadmap has been developed with and for the cancer research community. We have a shared vision of equal access to clinical trials and biobanking, and we have outlined a way to achieve this. We want you to use this as your foundation and want you to identify what you can do in your role and organisation to be more inclusive of TYA patients.

This is particularly important if you are someone who is involved in research, whether that's designing and delivering, reviewing and approving, and funding research. Research should include and benefit everyone, so join us in making that happen for young cancer patients.



"Bringing together NHS experts, scientific researchers, and rich information will overcome 30 years of slow progress for teenagers and young adults with cancer. Working in this way together, we can learn about the cancer, the young person, their current treatment and develop newer, kinder, better treatments, fast."

Dan Stark, Professor of Teenage and Young Adult Cancer Research in Leeds



Acknowledgements

None of this work would have been possible without the contributions of people affected by cancer and the wider cancer research community, NHS healthcare professionals, research organisations, cancer charities, industry and regulators. Thank you for providing your time, insights and perspectives to help shape this work.



Get in touch, we'd love to hear from you

Email caroline-may.huxley@cancer.org.uk to work together to improve TYA access to clinical trials and biobanking



Glossary

Short version	Full Version
<u>BCUK Cell Bank</u>	Blood Cancer UK Childhood Leukaemia Bank (Cell Bank)
<u>CDF</u>	Cancer Drugs Fund
<u>CRUK</u>	Cancer Research UK
<u>CRUK Find A Trial</u>	Cancer Research UK Find A Clinical Trial Webpage
<u>CCLG Tissue Bank</u>	Children’s Cancer and Leukaemia Group Tissue Bank
<u>DETERMINE</u>	aDvancing gEnomically maTchEd tReatMents IN rare cancErs
<u>ECMC Network</u>	Experimental Cancer Medicine Centre Network
<u>ECTF</u>	Experimental Cancer Trial Finder
<u>NHS</u>	National Health Service
<u>NIHR</u>	National Institute for Health and Care Research
<u>PPI</u>	Patient and Public Involvement
<u>TYA</u>	Teenagers and Young Adults
<u>WGS</u>	Whole Genome Sequencing
<u>CYP</u>	Children and young people

References

[1] “Public Health England Children, Teenagers and Young Adults UK Cancer Statistics Report 2021” [Online]. Available: http://www.ncin.org.uk/cancer_type_and_topic_specific_work/cancer_type_specific_work/cancer_in_children_teenagers_and_young_adults/. [Accessed March 2021]

[2] The NHS Long Term Plan 2019 [Online]. Available <https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/>. [Accessed June 2021]

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