



**James
Lind
Alliance**

Priority Setting Partnerships

Final report of the James Lind Alliance Priority Setting Partnership



Teenage and Young Adult Cancer: research priorities



Research Priorities for Teenage and Young Adult Cancer

Final report of the James Lind Alliance Teenage and Young Adult Cancer Priority Setting Partnership (TYA PSP)

Executive Summary

The Top 10 research priorities for teenage and young adult cancers as agreed at the final workshop of the Teenage and Young Adult Cancer Priority Setting Partnership are detailed here. Following the national consultation, fourteen professionals, seven patients and four parents prioritised the final 30 questions identified as unanswered research questions by young people, carers, significant others, and professionals. During the workshop, questions were considered, debated and deliberated throughout the day as the final list was named.

The final questions reflect the breadth of the cancer experience for young people, from early diagnosis through to targeted treatments based on the biology of disease; access to clinical trials, psychosocial care, and support after treatment; impact of cancer on the wider support networks for young people such as parents and siblings; and also recognise that not all cancers in young people are curable.



Top 10 research priorities

- 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 General Practitioner 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?

Foreword



Our philosophy is clear – young people with cancer should always be treated as young people first, cancer patient second. Teenage Cancer Trust is naturally delighted at how this partnership has given the opportunity to ensure that young people's priorities for research are heard loud and clear. Organisations like ours and decision makers across the country must always make sure that young people's voices are front and centre as we strive to improve their lives and experiences of care.

Young people here are saying that effective psychological support is top of the list. Every single one of these top ten areas are vital, but it is increasingly clear that young people are wanting more support to handle the devastating, long-lasting and wide-ranging psychological impact that can be felt long after treatment.

We know that Teenage Cancer Trust Nurses and Youth Support Coordinators play a vital role in improving psychological wellbeing during and after treatment – but right now they can't reach everyone. Going forward we will be working with researchers to develop evidence of the impact of this support, and making sure we can in helping every young person get back on track after cancer.

Kate Collins *Chief Executive*



Being part of the James Lind Alliance Teenage and Young Adult Cancer Priority Setting Partnership (TYA PSP) and helping to identify the top 10 research priorities for teenage and young adult cancers has been a privilege for CLIC Sargent.

Developing quality research and knowledge on the issues important to young cancer patients and their families is core to CLIC Sargent and what we do. The top 10 research priorities identified by young people, parents and professionals will absolutely provide valuable insight into how to shape the future evidence base on teenage and young adult cancers and make change for young cancer patients and their families.

Kate Lee *Chief Executive Officer*



Children with Cancer UK is delighted to have been involved in the James Lind Alliance Teenage and Young Adult Cancer Priority Setting Partnership (TYA PSP). We know very well through our own work the importance of being responsive to the needs and priorities of young people and their families.

At Children with Cancer UK we have a broad remit to investigate the cause, treatment, prevention and survival from cancer in children and young people. We hope that the top 10 research priorities established by the PSP will be used to shape future policy and research, for the benefit of all young people living with cancer.

Denis Henshaw *Scientific Director*



Amy Callaghan,
young person
on the steering
group said...

... 'I think it speaks volumes we have psychological support as our top research priority. Physical health is so important but the impact mental health issues can have is monumental so I'm delighted we agreed this as our upmost priority.

Having patient input in this process is fundamental - we have a different perspective of what works and what doesn't and where there's room for research and improvements to be made.

Having a priority that names ways to improve GPs knowledge of TYA cancer is essential in empowering young people to feel able to attend their GPs if they are noticing changes in their body.'

Table of Contents



Table of Contents

List of Figures	5
Abbreviations	5
Background	6
Management and scope	7-8
<i>Establishing the partnership</i>	7
<i>Steering group</i>	7
<i>The Scope</i>	8
<i>Partners</i>	8
Process	9-23
Stage 1 - Gathering the questions	9-12
• <i>First survey results</i>	9
Stage 2 - Refining the questions	13-14
• <i>Organising the questions</i>	13
• <i>Removing out of scope questions</i>	13
• <i>Formatting questions</i>	14
• <i>Searching for evidence</i>	14
Stage 3 - Prioritising the questions	15-19
• <i>Interim survey</i>	15
Stage 4 - Agreeing the Top 10	20-23
• <i>Decision making: prioritising the Top 10</i>	20
TOP 10 Research Priorities	23
The remaining 20 priorities	24
Next steps	25
<i>For research funders</i>	25
<i>For researchers</i>	25
<i>For Charities</i>	25
<i>For the TYA PSP</i>	25
Acknowledgements	25
Reference	25
Appendix 1: Partners	26
Appendix 2: Overview of TYA PSP methodology and results	27
Appendix 3: Initial survey	28-32
Appendix 4: Answered questions	33
Appendix 5: Ongoing studies	34-35
Appendix 6: Unanswered questions included in the interim survey	36-40
Appendix 7: Unanswered questions not included in the interim survey	41-43

List of Figures

Figure 1	Gender distribution of respondents (round 1)	9
Figure 2	Ethnicity of respondents (round 1)	10
Figure 3	Age, in years, of respondents (round 1)	10
Figure 4	Geographical distribution of respondents (round 1)	11
Figure 5	Cancer distribution in young people, carers and significant others (round 1)	11
Figure 6	Cancer timeline of respondents (round 1)	12
Figure 7	Distribution of carers/significant others (round 1)	12
Figure 8	Distribution of professionals (round 1)	12
Figure 9	Gender distribution of respondents (round 2)	16
Figure 10	Ethnicity of respondents (round 2)	16
Figure 11	Age of respondents (round 2)	17
Figure 12	Geographical distribution of respondents (round 2)	17
Figure 13	Cancer distribution in young people, carers and significant others (round 2)	18
Figure 14	Cancer timeline of respondents (round 2)	18
Figure 15	Distribution of carers/significant others (round 2)	19
Figure 16	Distribution of professionals (round 2)	19

Abbreviations

GP	General Practitioner
JLA	James Lind Alliance
NCRI	National Cancer Research Institute
PSP	Priority Setting Partnership
TYA	Teenage and Young Adult
TYAC	Teenage and Young Adults with Cancer Professional Organisation



The Teenage and Young Adult Cancer Priority Setting Partnership (TYA PSP) was established in 2014 and emerged from the National Cancer Research Institute's (NCRI) Teenage and Young Adult Health Services Research Subgroup and the Teenagers and Young Adults with Cancer (TYAC) Research and Registration Group, two independent but linked research groups.

The research agenda for young people with cancer, broadly those aged 13-24 years at diagnosis, has typically been set by professionals caring for young people with cancer and researchers. In the United Kingdom, we have previously asked young people to prioritise research themes identified by professionals as key areas for research however, we had not explored working with young people and carers/significant others in an equal partnership to undertake a research priority setting exercise in this field. This is an important step, as there is increasing evidence that research questions and outcomes identified by professionals as important may not be the same as those experiencing the disease, particularly for young people with

cancer who present with a number of rare diseases during a time of enormous physical and psychological growth (Chalmers et al. 2013).

Working with the James Lind Alliance (JLA), using an established methodology, we aimed to address this imbalance to generate a list of Top 10 research priorities for young people with cancer agreed by multiple stakeholders affected by the disease. Employing rigorous methodology we have been able to bring patients, carers/significant others and professionals together to prioritise unanswered research questions in teenage and young adult cancer research.

Establishing the partnership

The project was funded by Teenage Cancer Trust, CLIC Sargent and Children with Cancer UK, with support from the University of Surrey and the NCRI. The coordinating team oversaw and directed the project to completion.

In the first instance, we needed to identify the range of professionals involved in the treatment and care of young people with cancer. We aimed to reflect the breadth of professionals involved in the multidisciplinary care of young people in the steering group. We also contacted a number of specialist teenage and young adult cancer treatment centres and relevant charity partners asking for patient representatives. Due to the time commitment required to be part of the steering group, establishing one with the right mix of patients and professionals took longer than initially planned. We had aimed to have a GP (General Practitioner) as part of the group; a GP joined at the start but

unfortunately due to retirement was unable to continue their involvement and we were unable to recruit another GP to join us in the time given.

A number of young people who were involved at the start of the project left midway. This is expected for projects which are carried out over a number of years, as young people will leave as they transition back to their previous lives before their cancer diagnosis and move for education or employment purposes. Three young people remained with the project for the duration and they were joined by two who replaced those who had left and remained to project completion.

Steering group

The project was managed by a steering group, led by an independent chair from the JLA, Sheela Upadhyaya. The steering group included young people with a previous cancer diagnosis, healthcare and allied health professionals involved in treatment delivery as well psychosocial support.

Two of the funding partners were part of the steering group but were not involved in the final prioritisation exercise. The steering group approved the aims and objectives of the process, approved all decisions relating to the project, tested and ensured the surveys were accessible to a wide range of people and provided expert opinions on the evidence checking.

Patient representatives:



Amy Callaghan
Glasgow



Leila Hamrang
Manchester



Demi McGeachy
Glasgow



Lara Veitch
London



Max Williamson
London

The Partnership and the priority setting process coordinating team:



Sheela Upadhyaya
(JLA Adviser)



Susie Aldiss
(Research Fellow)



Lorna Fern
(NCRI TYA CSG Teenage and Young Adult Researcher and Patient/Public Involvement Lead)



Faith Gibson
(Professor of Child Health and Cancer Care)



Bob Phillips
(Clinical Lead of the TYA PSP; Paediatric Oncology Consultant)



Karen Dyker
(Consultant Clinical Oncologist)



Mike Groszmann
(Consultant Child and Adolescent Psychiatrist)



Rachael Hough
(Consultant Haematologist)



Sue Morgan MBE
(Teenage Cancer Trust Nurse Consultant)



Sam Smith
(Head of Nursing and Clinical Services, Teenage Cancer Trust)



Helen Veitch
(Head of Youth Support Co-ordinators, Teenage Cancer Trust)



Helen Gravestock
(Head of Research, Policy and Campaigning, CLIC Sargent)



Jeremy Whelan
(Consultant Medical Oncologist)



The Scope

The treatment and care of young people with cancer is complex, young people present with a 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.

This is further complicated by an extended network of significant others, such as parents, siblings, partners and peers. Consequently, the scope of the project was kept broad allowing participants to ask questions around prevention, causes of cancer, diagnosis, treatment, care, follow-up, survivorship, relapse and end of life care.

The final aim of the TYA PSP was:

‘To identify gaps and unanswered questions in research, the answers to which may reduce the individual and societal burden of young peoples cancer.’

Partners

The steering group identified potential partner organisations. This was achieved through peer knowledge, consultations and steering group member’s networks. Potential partners were contacted about the TYA PSP and asked to join the partnership and contribute to disseminating the surveys and results through their contacts and networks, the partner list can be seen in **Appendix 1**.

The TYA PSP followed the methodology described in the JLA Guidebook – <http://www.jla.nihr.ac.uk/jla-guidebook/>. The full protocol is available here <http://www.jla.nihr.ac.uk/priority-setting-partnerships/teenage-and-young-adult-cancer/>. An overview of the process is shown in **Appendix 2**.

Stage 1: Gathering the questions

Questions were gathered in an online public survey (Appendix 3) which was launched in October 2016 and remained open until 31st December 2016.

The following groups of people were invited to participate:

- People diagnosed or treated for cancer between the ages of 13 and 24 years old;
- Relatives/friends/partners/carers of someone who has been diagnosed or treated for cancer between the ages of 13 and 24 years old;
- Professionals working with teenagers/young adults with cancer.

The survey was built using Bristol Online Survey software. The wording and design of the survey was piloted with five young people, nine parents and five professionals outside the steering group and adapted to incorporate their feedback. On the day of the survey launch, a press release was issued and the partner organisations which had previously agreed to help to

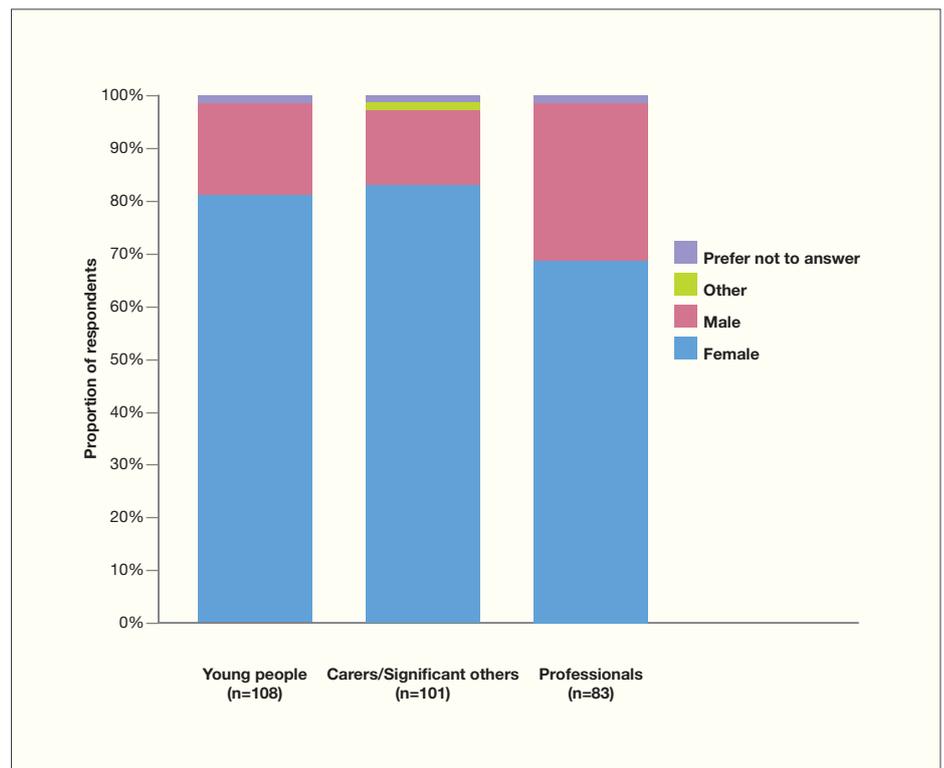
disseminate the survey were notified that the survey was open. Some of these partner organisations added a link to the survey on their website, mentioned the project in their newsletter or sent an email to their members to alert them. The survey was promoted at conferences, including a conference for young people with cancer. Social media was used throughout the three month period to promote the survey, including a bespoke twitter handle @TYAPSP.

Respondents were invited to submit up to five questions about any aspect of teenage and young adult cancer they considered to be unanswered. Basic demographic data were requested and a box was provided for any additional comments respondents wished to add.

First survey results

A total of 292 respondents answered the first survey submitting 855 potentially unanswered questions. The proportion of respondents was similar across the three groups, patients (n=108; 36%), carers (n=101; 34%) and professionals (n=83; 30%). Across all groups more females responded than males, as is often typical with survey research (**Figure 1**).

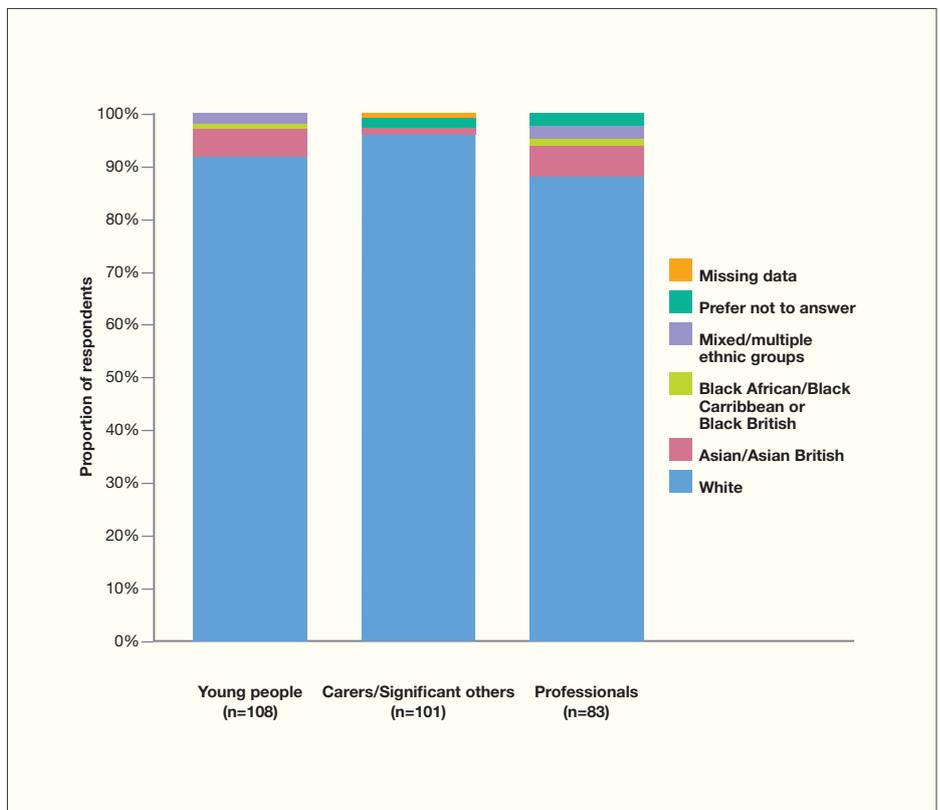
Figure 1: Gender distribution of respondents (round 1)



Process - Stage 1: Gathering the questions

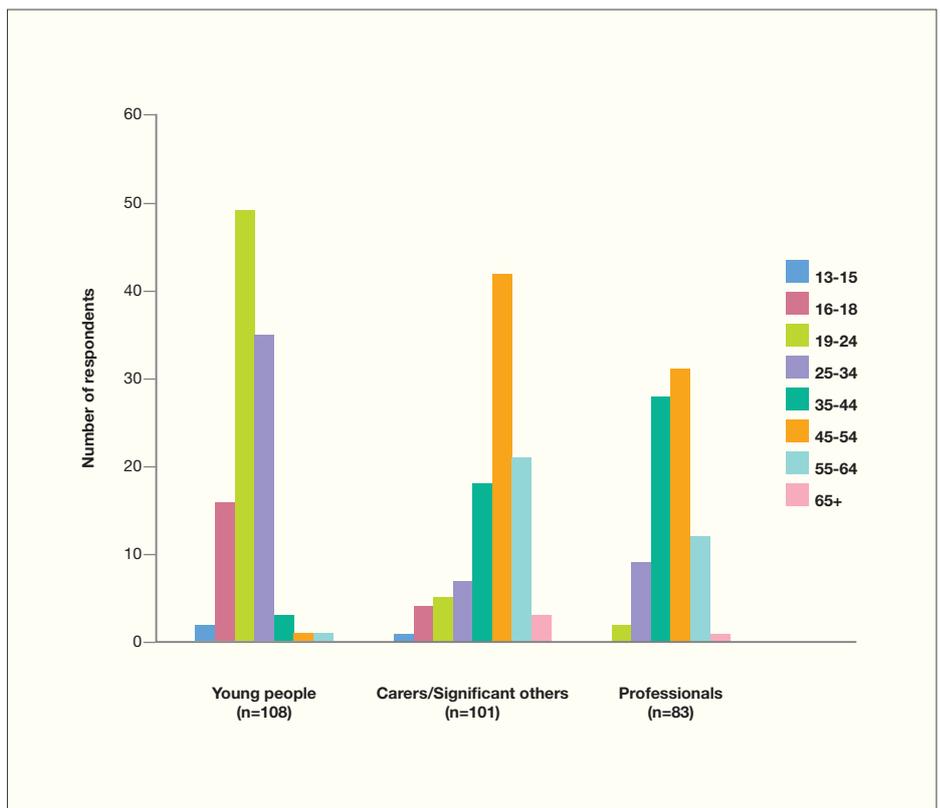
The majority of respondents across all groups described themselves as white, in particular parents/carers (**Figure 2**). For young people, the proportion of respondents from other ethnic groups was slightly less than the incidence cases reported by Public Health England (PHE), where approximately 84% of cancers occur in white European people compared to around 90% of respondents answering the survey (PHE Data: personal communication).

Figure 2: Ethnicity of respondents (round 1)



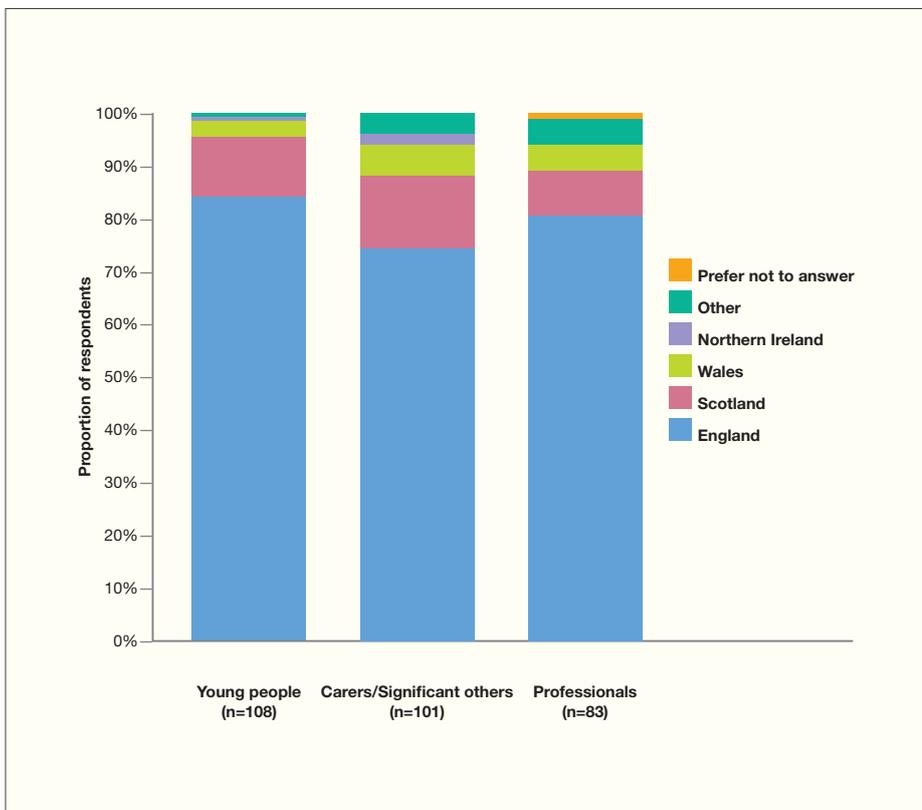
The majority of young people answering the survey were aged 19-24 years, followed by those aged 25-34 years and for parents/relatives/friends/partners the majority were aged 45-54 years, followed by 55-64 years, most professionals were aged 35-54 years (**Figure 3**).

Figure 3: Age, in years, of respondents (round 1)



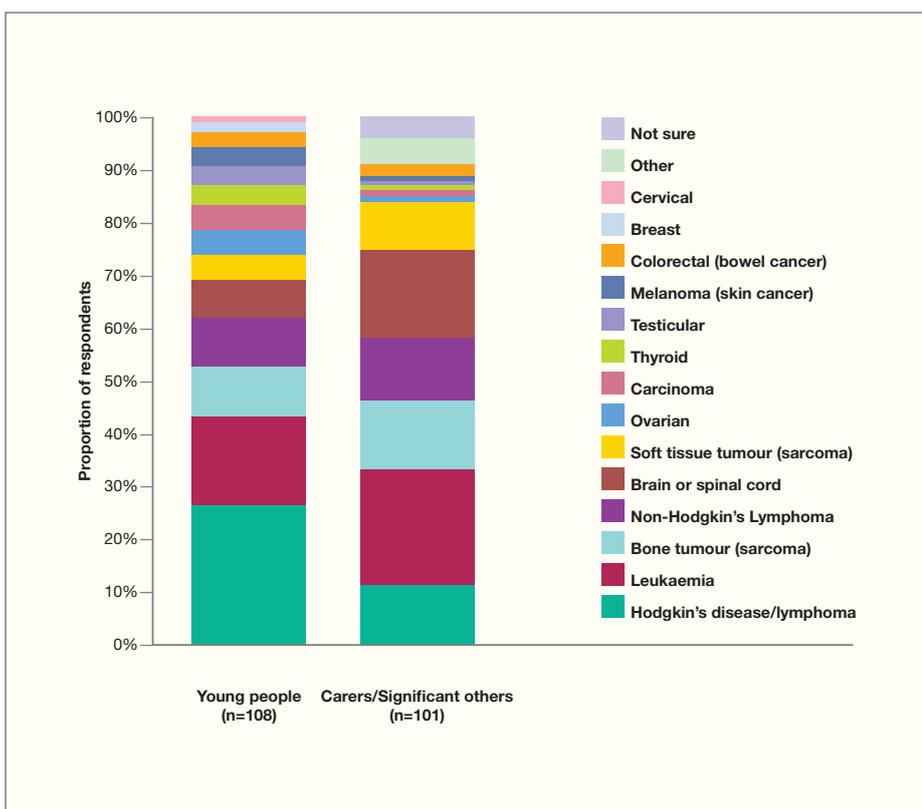
Process - Stage 1: Gathering the questions

Figure 4: Geographical distribution of respondents (round 1)



The geographical distribution of respondents was broadly similar to the proportion of incidence cases from the four devolved nations in the United Kingdom (Figure 4): the majority of young people are diagnosed in England, followed by Scotland, Wales and Northern Ireland.

Figure 5: Cancer distribution in young people, carers and significant others (round 1)



The representativeness of cancer types in young people responding was broadly similar to those occurring in the 13-24 age group (Figure 5). For young people, most of the respondents had been diagnosed with Hodgkin's Disease (27%); Hodgkin's Disease represents around a third of all newly diagnosed cases in this age group. This was followed by leukaemia (17%) and bone tumours (9%). Testicular cancers were underrepresented with only 4% of respondents despite this being the most common cancer in young males with around 27% of incidence cases (<http://www.cancerresearchuk.org/health-professional/cancer-statistics/teenagers-and-young-adults-cancers/incidence>). The reasons for this may be two fold, a) lower male participation in survey research in general and b) location of care for patients with testicular cancer as many do not receive their care in a specialist TYA centre and therefore may not be linked into the TYA networks the survey was circulated through.

Process - Stage 1: Gathering the questions

The cancer types of carers/significant others were also similar to the distribution of cancers expected. With the notable exception of brain tumours which were over represented in carer/significant other cohort and under-represented in the young people's group; this may be due to the lower survival rates of this group.

The young people on the steering group identified a number of timeline points that young people would consider themselves to be on (Figure 6). Respondents could select more than one timeline point. The majority of young people, 64%, described themselves as 'survivor/follow up care'. The majority of carers/significant others were bereaved. Differences were observed for those who described themselves as 'on treatment', only 5% of young people said they were on treatment compared to 19% of carers/significant others. We know from other research that during the treatment phase young people will approach their treatment team for answers to questions and also, it is when nearing the end of treatment that young people start to consider additional questions.

Figure 6: Cancer timeline of respondents (round 1)

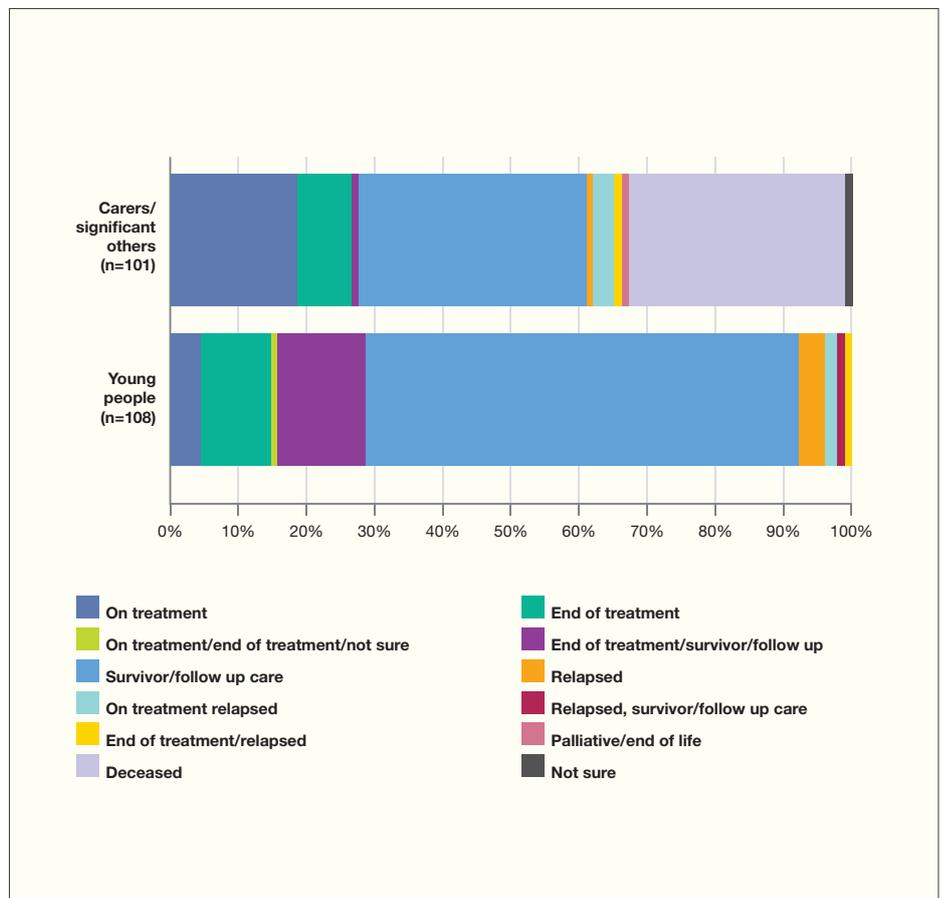


Figure 7: Distribution of carers/significant others (round 1)

The composition of the carer/significant other group can be seen in Figure 7 with the majority of respondents describing themselves as a parent/carer, and around 10% describing themselves as a relative or friend; a smaller proportion of partners responded (<5%).

A broad range of professionals responded to the first survey, as would be expected considering the multidisciplinary care of young people with cancer. Figure 8 illustrates the distribution between medical, nursing, allied health professionals and 'other'. 'Other' included a number of professionals such as people from the third sector and academic researchers.

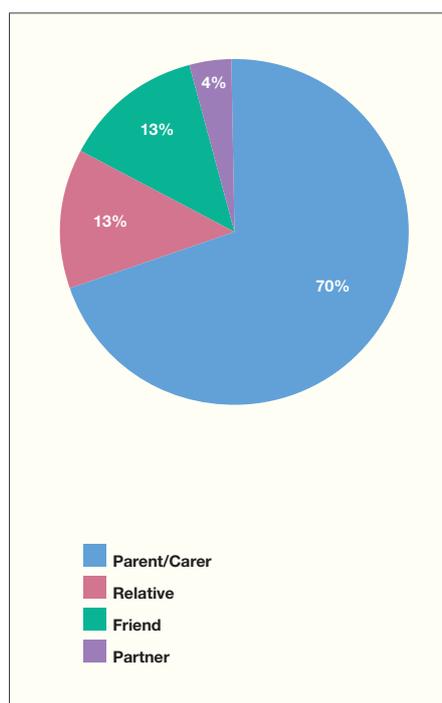
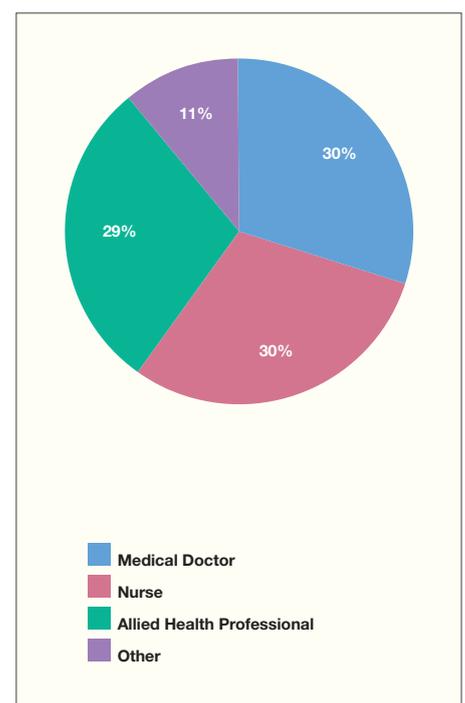


Figure 8: Distribution of professionals (round 1)



Stage 2: Refining the questions

All the submitted questions were extracted from Bristol Online Survey into an Excel spreadsheet. Multiple questions written in the same box were separated. The comments sections were checked for further questions. In total, 855 questions were submitted.

Organising the questions

An initial coding of the questions was carried out by coordinating team members LF, SA and FG using the International Cancer Research Partnership Common Scientific Outline (CSO, <https://www.icrpartnership.org/cso>): this served two purposes. Firstly, we were able to group the questions into themes to make them easier to review and discuss. Secondly, we will be able to compare research funding allocation to the priorities identified by young people, carers and healthcare professionals. The CSO is an internationally recognised classification system organised around six broad areas of scientific interest in cancer research:

CSO1: Biology;

CSO2: Etiology;

CSO3: Prevention;

CSO4: Early diagnosis, detection and prognosis;

CSO5: Treatment;

CSO6: Cancer control, survivorship, outcomes.

The six main categories contain numbered sub-categories and these sub-categories all have a number of points within them. The bullet points were numbered and used as sub-codes. For example:

CSO6: Cancer control, survivorship, outcomes

CSO6.1 Patient Care and Survivorship issues

1. Research into patient centred outcomes
2. Quality of life

When the question being coded did not fit into an already existing sub-code, additional sub-codes were created; this was mainly for questions specific to young

people such as getting back to education, or the role of youth support coordinators. Each question in the spreadsheet was assessed by the three coordinating team members, and coded one by one. Sometimes the bullet points (sub-codes) were not used and coding was at the sub-category level. This was for questions which seemed to fit all the sub-codes in that particular category.

For example, **'Why did a healthy young adult get cancer?'** was coded as:

CSO2: Etiology

CSO2.1 Exogenous Factors in the Origin and Cause of Cancer

CSO2.2 Endogenous Factors in the Origin and Cause of Cancer

CSO2.3 Interactions of Genes and/or Genetic Polymorphisms with Exogenous and/or Endogenous Factors.

As demonstrated by the above example, some questions were coded in more than one sub-category or category. Differences in opinion about which codes to use were resolved by discussion between FG, LF and SA. When consensus could not be reached, the question was added to a list of queries to be discussed by the steering group.

Once all the questions had been coded, questions in the same category were grouped together and categories separated into different tabs within the Excel spreadsheet to assist with data management.

Removing out of scope questions

During the coding, LF, SA and FG identified questions that were potentially 'out of scope'. Questions were out of scope if they were deemed not to be reducing the individual and societal burden of young peoples' cancer or could not be answered by research. The steering group agreed the following criteria to identify out of scope questions, an example is given under each criteria:

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 was ambiguous, was interpreted in different ways by steering group members and the meaning could not be resolved following discussion.

Supportive care

4. The focus was on research methods rather than a research topic.

How should we collect information about the late-onset side effects of cancer treatment in TYA?

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

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

6. It was a political statement.

Should medical professionals routinely explain to patients that there may be more up-to-date treatments available in other parts of the world, which may increase the patients' chances of survival?

Questions identified as out of scope were discussed face to face with the wider steering group. The steering group also reviewed the full list of submitted questions to identify any further out of scope questions.

Identification of out of scope questions was an iterative process. All out of scope questions were checked and agreed by the steering group. In total, 326 questions were identified as out of scope. There is commitment from the organisations represented on our steering group to review and consider how to make the best use of these questions.

Formatting questions

During two steering group meetings, members were grouped depending on their area of expertise and worked in small groups to review questions in a number of CSO categories. During this process, similar questions were merged and were then converted into an overarching research question. Five hundred and twenty nine questions were merged, resulting in 208 unique questions.

The submitted questions took a number of forms which had to be organised into the recognised research question structure of Population, Intervention/Exposure, Comparison and Outcomes (PICO). It was noted that most questions either stated or assumed two elements of this: the population was generally 'young people with cancer', the comparison was 'young people without cancer' or 'cancer in older or younger populations'. The intervention and outcome was varied, for example, interventions in the 'time to diagnosis' question below included 'education' and 'awareness campaigns'. Outcomes included cancer incidence, survival, relapse, psychological well-being, social functioning and mental health.

For example, 17 questions were submitted in the survey about improving time to diagnosis, including:

- ***How can we get earlier stage diagnosis for young patients?***
- ***How can we improve doctor diagnosis/early referral of cancer in young people?***
- ***How do we improve the diagnostic pathway for all young people to ensure they receive a timely diagnosis?***
- ***Do you think GPs require more training to raise awareness of the possibility of cancer when young people go to their Dr?***
- ***The early diagnosis I feel is difficult. How can the medical profession get better at this with young adults?***
- ***Should cancer awareness be taught in school and be a compulsory part of the curriculum- signs/symptoms, self-examination.***

These questions were all incorporated into the research question:

What GP or young person strategies, such as awareness campaigns and education, improve early diagnosis for young people with suspected cancer?

Searching for evidence

A data assessment group consisting of members of the steering group including young people and experts in evidence synthesis was established to oversee the evidence searches.

A search strategy was produced by the data group and discussed with the steering group. Searches were limited to evidence published in the last five years (since January 2012), to ensure evidence was up-to-date. Only publications which brought evidence from multiple studies together (such as systematic reviews and qualitative meta-synthesis) were considered. As the evidence was unlikely to be restricted to the 13 to 24 age range, evidence which included participants between these ages along with older/younger participants was also considered.

When reviewing the evidence, the data assessment group and steering group discussed whether further work focussing specifically on 13 to 24 year olds was needed. Searches were also carried out for ongoing studies. This involved personal communication with experts in the field and checking clinical trial databases.

Steering group members provided key words for the evidence searches within their area of expertise. Searches were carried out in August and September 2017 by LF and SA. For many questions, no reviews were identified. In some cases, the identified reviews only partly answered the question; these questions were recorded as unanswered. When any evidence was found, it was initially reviewed by SA/LF and BP. Seven questions were identified as already answered (**Appendix 4**). All were discussed with the steering group in order to ensure consensus that the question had been answered. Sixteen questions were the focus of studies currently underway (**Appendix 5**). One hundred and eighty five unanswered questions remained.

Stage 3: Prioritising the questions

A steering group meeting was held to discuss the prioritisation of the 185 unanswered questions. As this number of questions was too many to ask people to consider in the interim survey, the steering group decided that all questions which had been asked by more than one person should be included (64 questions) and the remaining 121 questions would be rated by the steering group in an online survey; the top scoring questions would be included.

When carrying out the rating, steering group members were asked to, 'identify the questions which would have the most impact if funded, on either the teenage and young adult cancer community as a whole or young people with that particular cancer type'. Questions were presented in a random order and rated as to whether answering them would have: high impact (score 4), moderate impact (score 3), low impact (score 2) or negligible impact (score 1). Total scores for each question were calculated and questions were ordered from highest to lowest score. It was originally intended that the 36 top rated questions would be included in the interim survey (to give a total of 100 questions in the survey). However, the steering group decided that the top 40 questions would go through to the survey as 13 questions at the cut-off point had scored the same, if these were excluded only 27 questions would go through and the steering group wanted to take as many questions as possible to the public vote.

A further preparation step which involved ensuring all questions were understandable to the public was carried out by LF and SA and checked by the young people on the steering group.

Interim survey

The interim survey was created using Qualtrics online survey software and launched in November 2017; it was open for three weeks. Responses were invited from the same groups of people as the first survey. The opportunity to take part was publicised through the same partner organisations as the first survey and on social media. Everyone who had requested to stay involved in the project and provided their email address in the first survey was sent the survey link directly.

Respondents were invited to rate the 104 questions (**Appendix 6**) according to how much of a priority they thought it was for research to be undertaken to answer that particular question. The options for rating were: very low priority (score 1), low priority (score 2), high priority (score 3), very high priority (score 4) and no opinion (no score). Respondents were asked to

select 'no opinion' if they were unsure about whether a question was a priority for research to answer or did not have an opinion about that question. Questions on similar topics were grouped into sections. Each respondent was presented with the sections in a random order to minimise the chance of survey fatigue:

1. **Causes of cancer, prevention and diagnosis**
2. **Treatments and therapies**
3. **Short and long term side effects**
4. **Information and support**
5. **Psychological support**
6. **How cancer impacts on daily life**
7. **Impact of cancer on families, friends and partners**
8. **End of treatment and follow up**
9. **Healthcare delivery**
10. **End of life care**

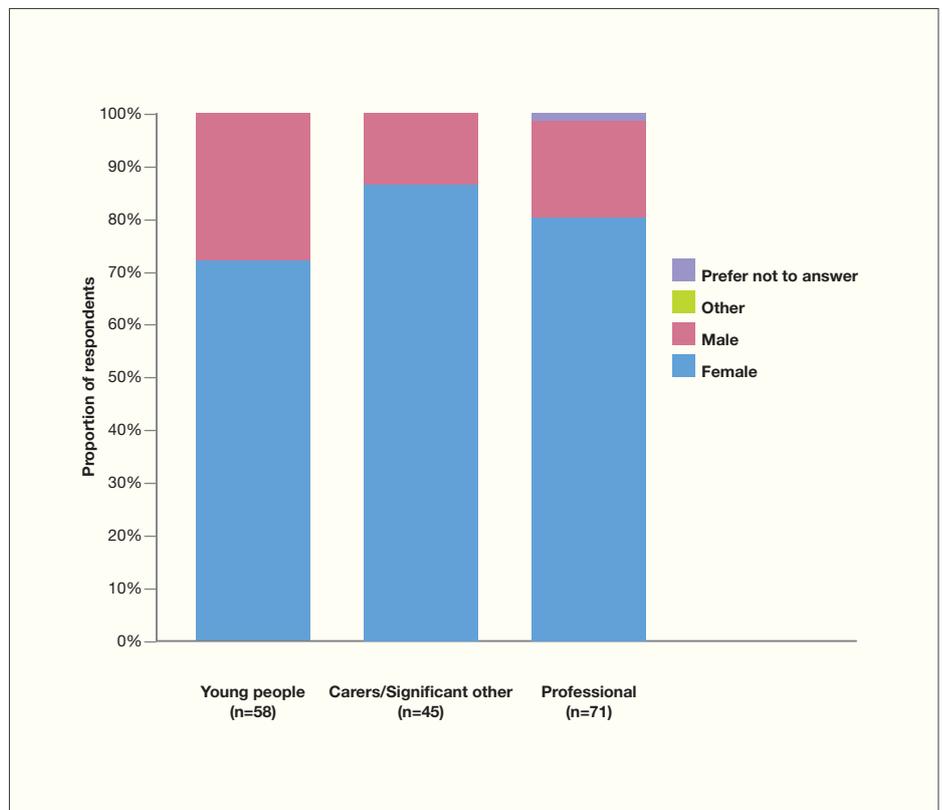
Ratings were submitted by 174 people. The demographics of those responding can be seen in **Figures 9 to 16**.

As there was some missing data, average scores for each question were calculated for the three groups of respondents: patients/former patients, family members/friends/partners and professionals. The questions were then ordered from highest to lowest score for each group.

The steering group reviewed how the ratings compared between respondent groups. As the distribution of respondents from the three groups was not equal, an overall ranking which combined scores would give more weight to professionals' views and so this method was discarded. Instead, the average ranks across the three groups were calculated to give a shared ranked order. The top 30 questions were shortlisted for prioritisation at the workshop. The 81 unanswered questions not included in interim survey are shown in **Appendix 7**.

A higher proportion of males responded for young people in the second round of the survey (28% compared to 18%), however taking into account the smaller number of respondents in the second round the actual number of males responding had decreased (**Figure 9**). A smaller proportion of male professionals responded in the second round, 18% compared to 30% in round 1.

Figure 9: Gender distribution of respondents (round 2)



The ethnic distribution of those answering the survey in round 2 was similar to round 1 (**Figure 10**).

Figure 10: Ethnicity of respondents (round 2)

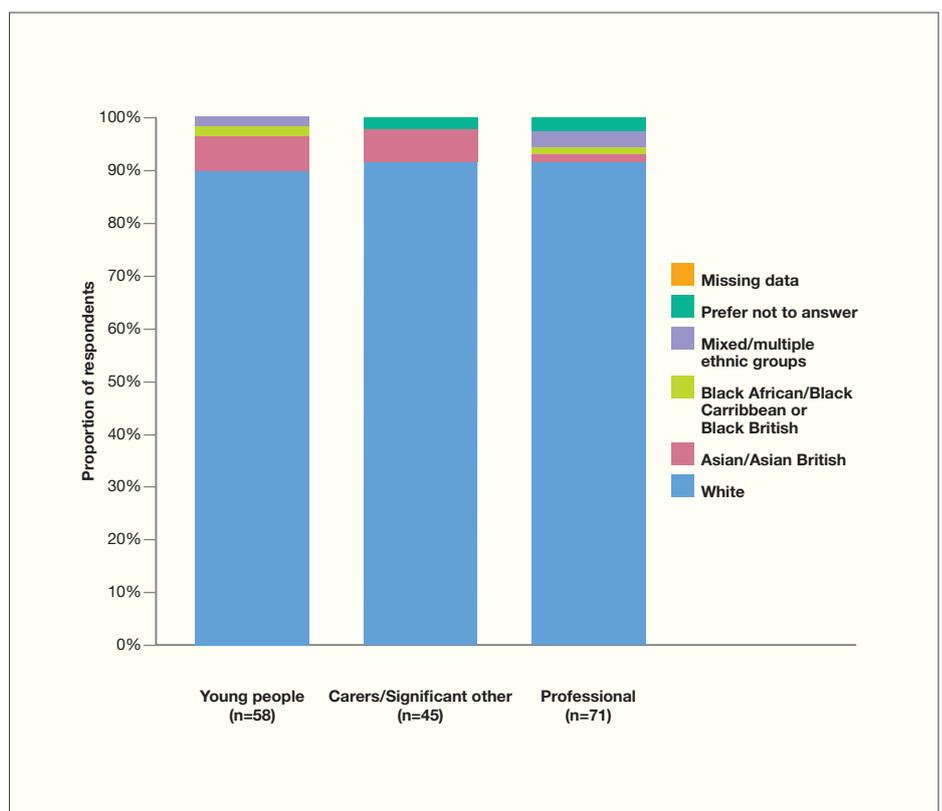
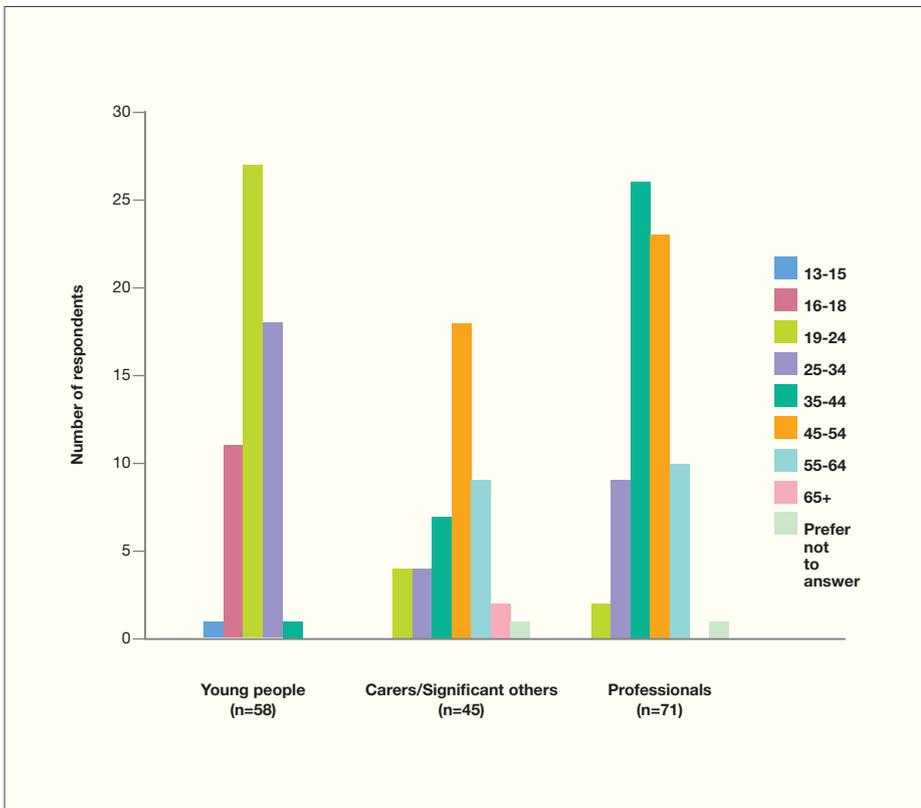
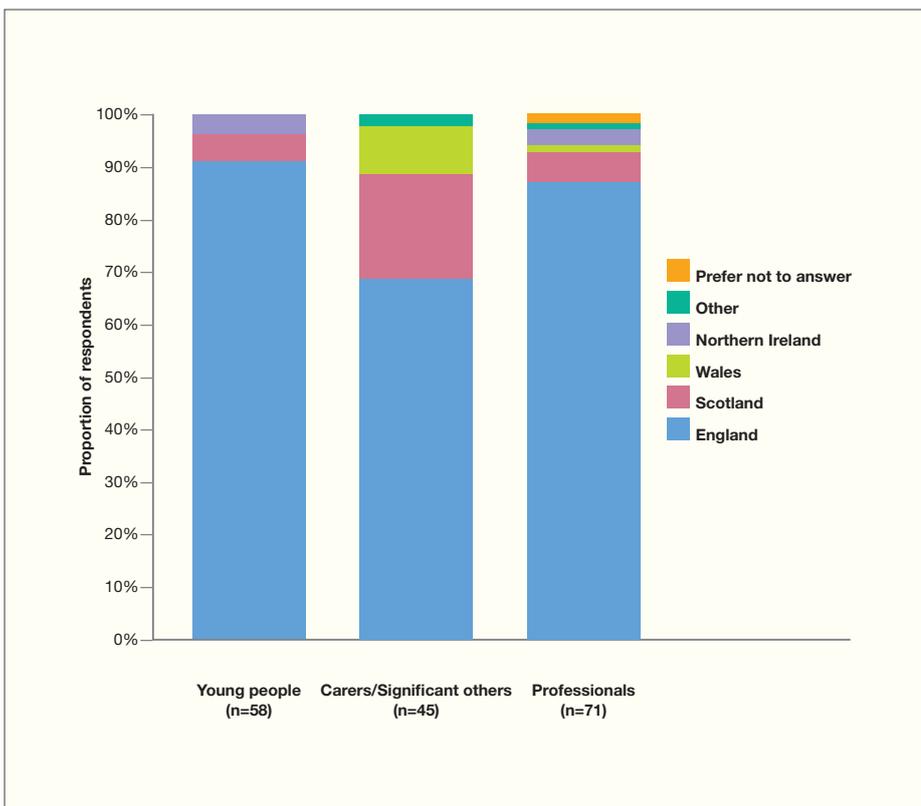


Figure 11: Age of respondents (round 2)



The age distribution of the young people answering the survey in round 2 was similar to that observed in round 1, the majority of respondents were aged 19-24 years, followed by 25-34 years (Figure 11). The age demographics of carers/significant others answering in round 2 was also similar with the majority of respondents aged 45-55 years.

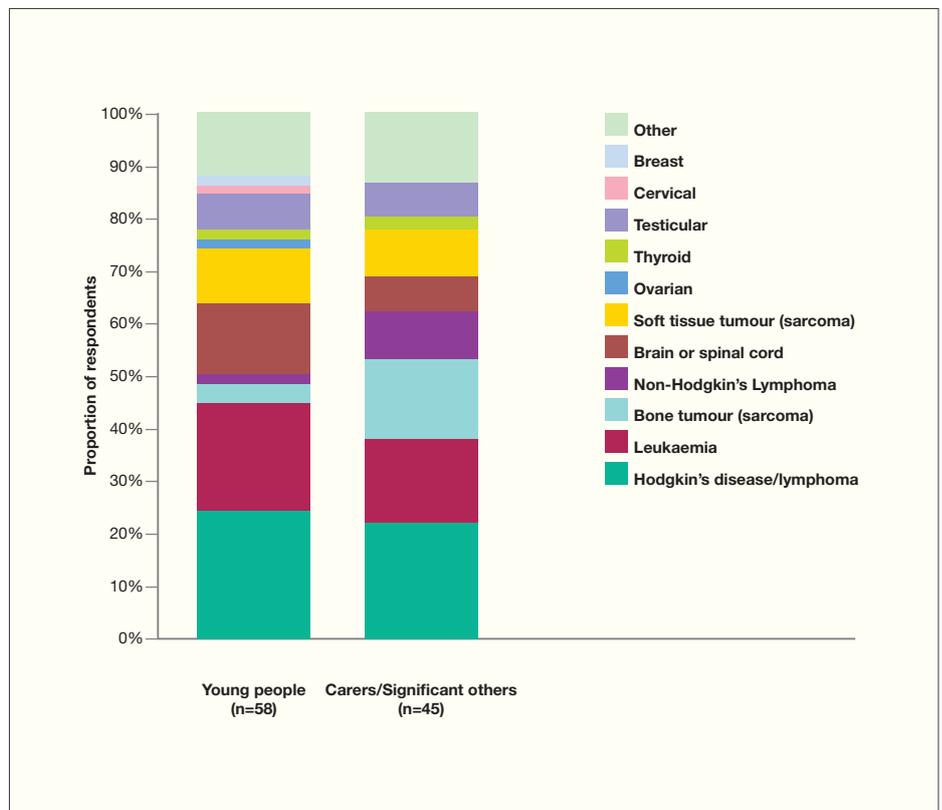
Figure 12: Geographical distribution of respondents (round 2)



The geographical distribution of respondents answering the survey in round 2 was similar to round 1 (Figure 12).

There were slight differences in the distribution of cancers in round 2 (Figure 13). Similar to round 1 the most frequently occurring cancer for young people was Hodgkin's disease/lymphoma, followed by leukaemia, however for carers/significant others this was slightly reversed with a higher proportion of Hodgkin's lymphoma compared to leukaemia respondents in round 1. Overall, a higher proportion of respondents had brain tumours, however given the lower numbers in round 2 the actual number of young people with a brain tumour responding was the same (n=8).

Figure 13: Cancer distribution in young people, carers and significant others (round 2)



Where young people considered themselves to be in their cancer timeline was similar to round 1, as were the responses of the carers/significant others (Figure 14).

Figure 14: Cancer timeline of respondents (round 2)

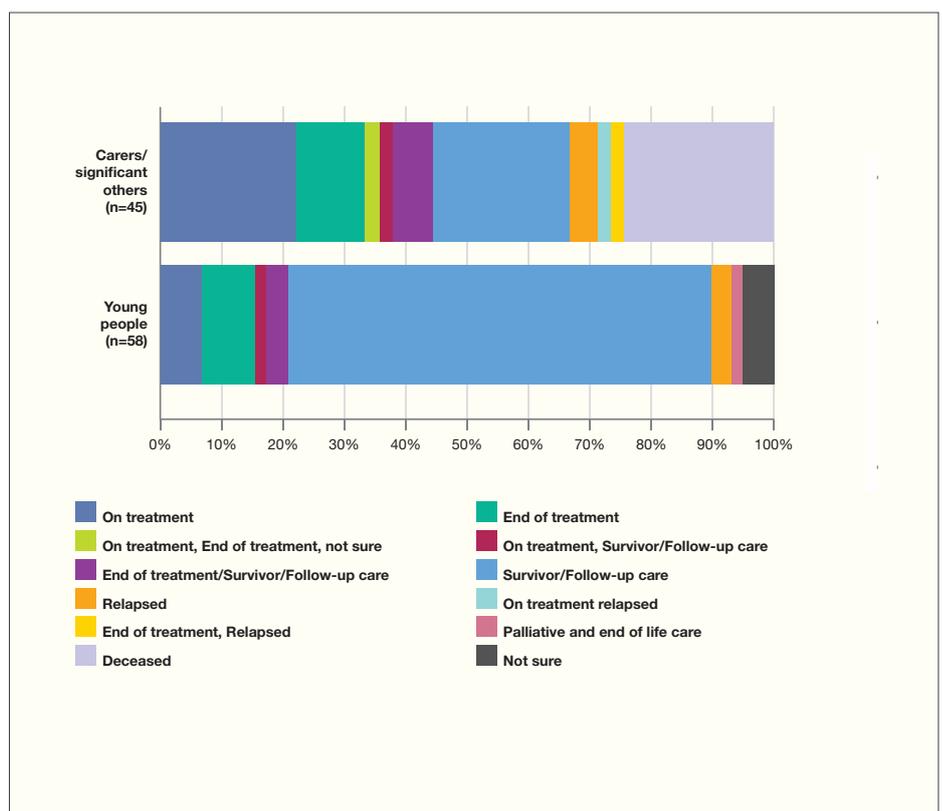


Figure 15: Distribution of carers/significant others (round 2)

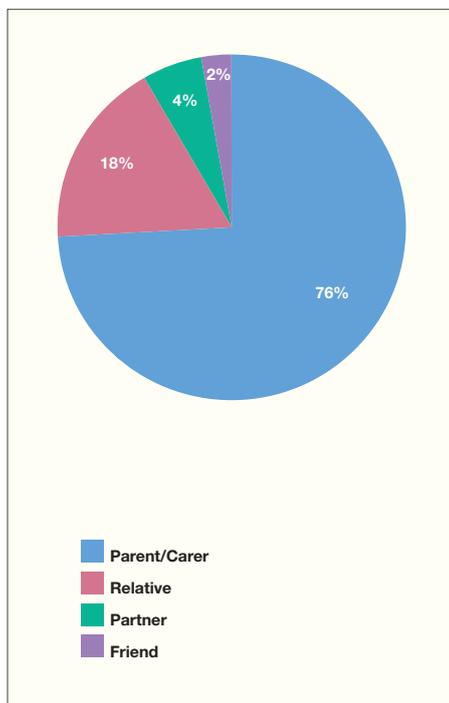
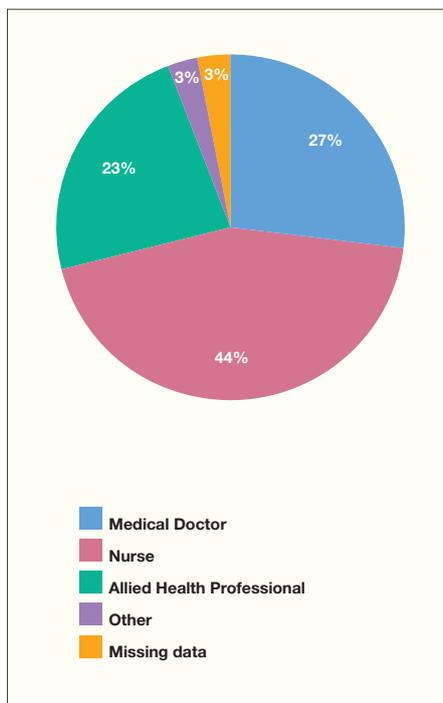


Figure 16: Distribution of professionals (round 2)



The majority of carers/significant others responding in round 2 were parents/carers which is similar to round 1 (**Figure 15**).

A greater proportion of nurses compared to doctors completed the round 2 survey, the actual number of nurses responding was similar to round 1 and the differences were due to lower numbers of doctors in round (**Figure 16**).

Stage 4: Agreeing the Top 10

A final prioritisation workshop took place in central London on 19th January 2018 to identify the Top 10 unanswered research questions for teenage and young adult cancer. The workshop was attended by 25 participants: seven young people who had experienced cancer, four parents of a young person with cancer and 14 professionals who work with young people who have cancer. The professionals were from a wide range of backgrounds including nurses, oncologists, a social worker, youth support coordinator, psychiatrist and physiotherapist.

Seven participants were members of the steering group. The other participants were invited as they had indicated they would like to attend when completing the interim survey or they were suggested by steering group members due to their professional role. Young people were also recruited through the BRIGHTLIGHT study Young Advisory Panel. The workshop was also advertised to parents through CLIC Sargent's parent Facebook page. Participants were asked to individually rank the 30 questions in order of importance prior to the workshop; this was used as a starting point for discussion. Biographies of participants were also circulated before the day.

The workshop was chaired and facilitated by Sheela Upadhyaya with support from two co-facilitators from the JLA, Katherine Cowan and Toto Gronlund. The participants were divided into three groups which had been pre-arranged to ensure

a balance of professionals from different disciplines, young people and parents. Each group was given a set of the 30 questions on A4 cards, which were laid out on a table. For the first step, each person was asked to tell their group the three questions they had ranked highest and lowest in their individual ranking. Discussion followed and the groups were asked to place the 30 questions in a collective order of importance. Each participant was encouraged to share their views and give consideration to other people's opinions. At lunchtime, the ranking of the 30 questions from the three groups were combined. In the afternoon session, in new group compositions, the consensus ranking was the starting point for discussion. Following this second round of discussion, the group rankings were again collated and the participants came together as one group to agree the Top 10 and debate their order.

Decision making: prioritising the Top 10

In this section we aim to give an overview of the discussions in the workshop and how the Top 10 were decided upon. What was striking was the similarities between the three groups within the workshop who independently developed very similar strategies to decide which questions should be in the Top 10. Their strategies involved:

Ensuring all parts of the pathway of care are covered

All three groups wanted to ensure the Top 10 questions covered topics relating to diagnosis and treatment, through to end of life care and reflected the range of experiences of young people with cancer.

Ensuring all the themes within the questions were represented

The groups tried to cluster the questions into similar themes, such as support, treatment or side effects, their aim being to include each 'theme' in the Top 10. For example, the groups wanted either, 'What GP or young person strategies, such as awareness campaigns and education, improve early diagnosis for young people with suspected cancer?' or, 'What are the most effective strategies for engaging primary care professionals (e.g. GPs) to listen to young people?' to be included in the Top 10, but not both as they felt

this would be a wasted opportunity for answering a question in a different area.

Opting for questions that could include other questions / overlap

Linked to the above point regarding themes, the groups considered which questions overlapped and could cover other questions. For example, they thought, 'What are the best ways of supporting a young person who has incurable cancer?' could include, 'For young people with incurable cancer, how should parents/carers communicate with them to improve quality of life and experience?' and 'For young people with incurable cancer, how should healthcare professionals communicate with them to improve quality of life and patient experience?' as good communication is part of providing support.

Opting for questions that could have a wide impact

Initially, the majority of participants selected their top three questions based on what was relevant to their personal experience or focused on the area they worked within. However, during the discussion that followed their opinions changed and the groups decided that the Top 10 questions should be generic and not focus on one type of cancer (e.g. 'What is the best treatment for brain cancers to increase survival and decrease toxicity?') or one type of treatment (e.g. 'What are the long-term physical effects of stem cell transplants, how long do they last and how could they be reduced?'). Reducing side effects was important and again the groups opted for a broad question, 'What interventions, including self-care, can reduce or reverse adverse short and long term effects of cancer treatment?' rather than the questions which focused on one side effect ('chemobrain' and fatigue). Their reasoning was that not enough is known about how to reduce all side effects to single out a particular side effect in the Top 10.

Including a question that is focused on support for families

Support for families was high priority for the participants; they wanted to ensure a question was included that focused on this. The gaps in support following the death of a young person were discussed and, 'How can parents/carers/siblings/partners be best supported following the death of a young person with cancer?' was included. Although the following question does not specifically mention families, 'What psychological support package improves psychological well-being, social functioning and mental health during and after treatment?' the participants thought research on this should include supporting families as part of the young person's support network.

Opting for questions focussed on intervention rather than description

The groups were clear that although it is useful to describe a problem, it is action through intervention that is required in

order to improve young people's and families' experiences. Therefore, 'What psychological support package improves psychological well-being, social functioning and mental health during and after treatment?' was chosen rather than, 'How common is psychological distress and/or mental health problems in young people following treatment?' Similarly, 'How can parents/carers/siblings/partners be best supported following the death of a young person with cancer?' was selected rather than, 'What are the support needs of the family following the death of a young person with cancer?'

Excluding questions considered to be too subjective to be answered by research

'What are the factors that should determine stopping treatment when the young person cannot be cured?' was considered to be difficult to research as it is too dependent on an individual's situation. 'For young people with incurable cancer, how should healthcare professionals communicate with them to improve quality of life and patient experience?' was also considered to be subjective, with participants feeling it is important but it is a difficult skill to teach to professionals and also was a wider social problem around our views on dying and death.

From the very start of the workshop when the participants were asked to give their top three questions, there were some questions that were clearly high priority for many and stayed high in the Top 10 throughout the workshop. The question ranked as top priority, 'What psychological support package improves psychological well-being, social functioning and mental health during and after treatment?' was the top priority for two groups after the first group discussion and in second place for the third group.

Following the second group discussion, it was top for all three groups. The young people present discussed the importance of support being available after treatment as this can be lacking and can be when young people need it the most. Reducing the burden of side effects of treatment was also fundamental. 'What interventions,

including self-care, can reduce or reverse adverse short and long term effects of cancer treatment?', was placed at number two in the final Top 10, it featured as number four for two groups after the first discussion and number five for the third group. After the second discussion, it was in second place for all three groups.

There were a few questions that featured in the groups' initial Top 10s which were not included in the final Top 10. One example being, 'What are the long term physical effects of a cancer diagnosis and treatment and how long do they last?' Following the group discussions, this question had an average ranking of number three across the groups. During the whole group discussion at the end of the workshop, the decision was made to move it out of the Top 10. The participants agreed that the long term effects are known in practice. There was consensus that it is more important to focus on interventions to reduce side effects and treatments that have fewer side effects. Moving the question out of the Top 10 made room for, 'What targeted treatments are effective and have fewer short and long term side-effects' to be included instead.

'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?' had only featured in one group's Top 10 however, during the whole group discussion, there was a push to include it in the final Top 10. Inclusion of this question meant there were questions across the pathway of care. Although it was recognised that this is a broad question to answer which is dependent on a young person's cancer and treatment, it was considered to be important that professionals get follow-up right for young people. As this population moves around more (e.g. for university), follow-up that is tailored to their needs is important.

Rewording of questions

The workshop participants requested that three questions be reworded:

- 1) 'What are the best ways to support young people getting back to a 'normal' life after treatment?' There was consensus that the word 'normal' should not be used as the participants

Process - Stage 4: Agreeing the Top 10

said that life does not go completely back to 'normal' and what is 'normal' is unclear. This question was reworded to, 'What are the best ways to support young people getting back to **an 'everyday' life** after treatment?'

- 2) 'What are the most effective strategies to ensure that young people who are treated in non-specialist hospitals receive appropriate practical and emotional support?' Non-specialist was changed to 'outside of a young person's Principal Treatment Centre',

'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?'

- 3) The young people at the workshop asked for 'including self-care' to be added to the following question, 'What interventions, **including self-care**, can reduce or reverse adverse short and long-term effects of cancer treatment?' They thought 'intervention'

referred to something that is 'done to' a person and were not aware that interventions could include self-care. They wanted this to be made clear as it was important to them to know what they could do to help their recovery and reduce side effects of treatment. By adding 'self-care' to the question, they felt it also encompassed, 'What can young people do to help their recovery after chemotherapy or radiotherapy?'



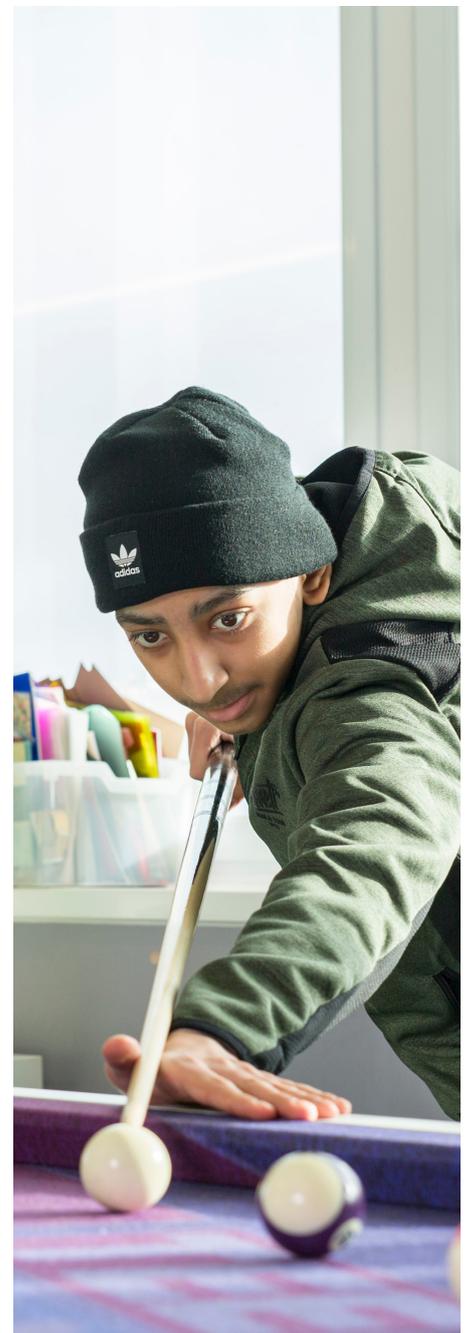
The Workshop Group

This photograph shows the people present at the workshop including: young people, parents, professionals and the coordinating team.

TOP 10 Research Priorities

The Top 10 priorities for teenage and young adult cancer research were agreed 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 General Practitioner 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?



The remaining 20 priorities

The following 20 questions were also discussed at the workshop but not placed in order of priority:

DIAGNOSIS

- What factors affect the time to diagnosis and what outcomes are affected?
- What are the most effective strategies for engaging primary care professionals (e.g. GPs) to listen to young people?

TREATMENT

- What key factors (both cancer and individual) determine whether a treatment plan for children or adults will give better outcomes?
- What is the best treatment for brain cancers to increase survival and decrease toxicity?
- What are the factors that predict life threatening chemotherapy side effects?

AFTER TREATMENT

- What can young people do to help their recovery after chemotherapy or radiotherapy?
- What are the long term physical effects of a cancer diagnosis and treatment and how long do they last?
- What are the long-term physical effects of stem cell transplants, how long do they last and how could they be reduced?
- How common is psychological distress and/or mental health problems in young people following treatment?
- What causes problems with cognitive functioning ('chemobrain'), how long do they last and what are the most effective treatments and strategies?
- At the end of treatment and during long term follow up, what support services improve psychological well-being, social functioning and mental health?
- What are the best ways to support young people getting back to 'everyday' life after treatment?
- What interventions are most effective in supporting young people who are experiencing fatigue/tiredness when returning to work or education?
- What are the best strategies for detecting and treating second primary cancers early?

RELAPSE

- What is the most effective way of supporting young people with relapsed cancer?

END OF LIFE

- What are the factors that should determine stopping treatment when the young person cannot be cured?
- For young people with incurable cancer, what methods, techniques or strategies for communication can help them to talk with their family and friends about their situation?
- For young people with incurable cancer, how should healthcare professionals communicate with them to improve quality of life and patient experience?
- For young people with incurable cancer, how should parents/carers communicate with them to improve quality of life and experience?
- What are the support needs of the family following the death of a young person with cancer?

For research funders	The Top 10 list provides major national research funders such as the National Institute for Health Research (NIHR), Medical Research Council (MRC) and Economic and Social Research Council (ESRC) with clear guidance on what questions are important to young people, carers/significant others and professionals. The findings will enable existing funders to target their funds to prioritise what matters most to those involved in the care of young people with cancer.
For researchers	A common question in reviewers' comments and applications for funding include whether it is a) an important question b) whether it has already been answered. This Top 10 will allow researchers to tailor their research questions and strategies to develop a portfolio of studies relevant to young people with cancer based on priorities agreed by multiple stakeholders. The long list of questions will be made publically available via the James Lind Alliance website.
For Charities	Charitable funders within their research and policy teams can refer to the TYA PSP to demonstrate need for research funding in priority areas for young people. The out of scope questions may be able to inform where more information resources are required describing services and service provision in local areas.
For the TYA PSP	The survey returned 855 potential research questions, many of which included comments and questions which did not fit within the scope of the TYA PSP. We will look at how these questions, statements and service enquiries can be best used to improve outcomes for young people, carers/significant others and the professionals who care for them.

Acknowledgements

This project was supported and funded by CLIC Sargent, Teenage Cancer Trust and Children with Cancer UK.

We would like to thank Dr Sabine Best, Marie Curie and Prof Helen Roberts, UCL Great Ormond Street Institute of Child Health, for their contribution to the data assessment group. We would also like to thank previous Steering Group member Dr Ken Lawton.

With thanks to the following people from CLIC Sargent for their contribution Caroline Weston, Anna Carnegie, Beccie Platt and Jane Darragh.

The TYA Cancer PSP would like to thank everyone who took the time to send in their questions and rate the importance of them. Thank you also to the young people, parents and professionals who attended the final workshop.

Reference

Chalmers I, Atkinson P, Fenton M, Firkins L, Crowe S, Cowan K.J (2013) Tackling treatment uncertainties together: the evolution of the James Lind Initiative, 2003-2013. *Journal of the Royal Society of Medicine*, 106(12):482-91.

Appendix 1

Partners

The TYA Cancer PSP is grateful for the support of all of our Partners who helped to distribute the surveys and Top 10 priorities:

- Antony Nolan
- Bloodwise
- Bone Cancer Research Trust
- Brain Tumour Charity
- Cancer Research UK
- Children's Cancer and Leukaemia Group (CCLG)
- Coppafeel!
- Ellen MacArthur Cancer Trust
- Find Your Sense of Tumour Steering Committee
- Guy Francis Bone Cancer Research Fund
- JTV Cancer Support
- Royal College of Nursing
- Marie Curie
- Macmillan Cancer Support
- National Cancer Research Institute (NCRI) - All relevant NCRI groups including: the Teenage, Young Adult and Germ Cell Tumour Clinical Study Group
- Sarcoma UK
- Target Ovarian Cancer
- Teens Unite
- Trekstock
- TYAC – Teenagers and Young Adults with Cancer Professional Organisation
- Young People's Health Special Interest Group (YPHSIG)

Overview of TYA PSP methodology and results



Initial survey



James
Lind
Alliance

Priority Setting Partnerships



James Lind Alliance

Teenage and Young Adult Cancer Priority Setting Partnership Survey

Do you have unanswered questions about Teenage and Young Adult Cancer?

We are aiming to identify questions that patients, families, friends, carers and professionals think are important about Teenage and Young Adult Cancer but which have not yet been answered by research. The questions will be made available to research funders to ensure that they are aware of what matters most to patients, their friends and families, and professionals.

We would like to invite you to complete this survey if you:

- ***have been diagnosed or treated for cancer when you were between the ages of 13 and 24 years old (it does not matter what age you are now)***
- ***are a relative/friend/partner/ carer of someone who has been diagnosed or treated for cancer between the ages of 13 and 24 years old***
- ***are a professional working with teenagers/young adults with cancer***

This survey is being overseen by the Teenage and Young Adult Priority Setting Partnership (TYA PSP) Steering Group; led by the James Lind Alliance in partnership with Teenage Cancer Trust, CLIC Sargent and Children with Cancer UK. You can find more information about the TYA PSP and this survey here (www.tyac.org.uk/News/

[have-you-or-someone-you-know-been-affected-by-cancer-as-a-teenager-or-young-adult](mailto:tyapsp@gmail.com)), by emailing tyapsp@gmail.com or by telephoning XXXXX. For further information about the James Lind Alliance please go to <http://www.jla.nihr.ac.uk/>.

Consent

As part of this process, the question(s) that you suggest when taking part in this survey may be published on the James Lind Alliance website. By participating in this survey you are agreeing to allow us to publish your question(s). Your name will not be published in association with your question(s). For more information, or to see what this will look like, please go to <http://www.jla.nihr.ac.uk/top-10-priorities/>.

Information about you

It would be really helpful to know some information about you; this will enable us to check whether we have responses from a wide range of people or whether any groups are missing.

If there are any questions you would prefer not to answer, please select 'prefer not to answer'.

Who are you?

- Patient or former patient
- Parent/carer of a teenager or young adult who has been diagnosed or treated for cancer
- Relative of someone who has been diagnosed or treated for Teenage and Young Adult Cancer
- Friend of someone who has been diagnosed or treated for Teenage and Young Adult Cancer
- Partner of someone who has been diagnosed or treated for Teenage and Young Adult Cancer
- Professional working with teenagers/young adults with cancer

What is your gender?

- Male
- Female
- Prefer not to answer
- Other

If you selected Other please specify:

What is your ethnic group?

- White
- Mixed/multiple ethnic groups
- Asian or Asian British
- Black African, Black Caribbean or Black British
- Prefer not to answer
- Other

If you selected Other please specify:

How old are you?

- Under 13
(option for family members/friends/partners/carers only)
- 13-15
(option for patients/former patients and family members/friends/partners/carers only)
- 16 – 18
- 19 – 24
- 25 – 34
- 35 – 44
- 45 – 54
- 55 – 64
- 65+
- Prefer not to answer

Please select the country you live in.

(Patients/former patients and family members/ friends/ partners/carers)

Please select the country you work in.

(Professionals)

- England
- Scotland
- Wales
- Northern Ireland
- Prefer not to answer
- Other

If you selected Other please specify:

Appendix 3 - Initial survey

Which cancer were you first diagnosed with?

(Patients/former patients)

Which cancer was your relative/friend/partner first diagnosed with?

(Family members/ friends/ partners/carers)

- Leukaemia
- Hodgkin's disease/lymphoma
- Brain or spinal cord
- Bone tumour (sarcoma)
- Soft tissue tumour (sarcoma)
- Non-Hodgkin's Lymphoma
- Testicular
- Ovarian
- Thyroid
- Colorectal (bowel cancer)
- Breast
- Cervical
- Melanoma (skin cancer)
- Prefer not to answer
- Not sure
- Other

If you selected Other please specify:

Which of the following best describes your current situation?

(Patients/former patients)

Which of the following best describes your relation/friend/partner's current situation?

(Family members/friends/partners/carers)

You can select more than one response if you wish.

- On treatment
- End of treatment
- Relapsed
- Survivor/Follow-up care
- Palliative and end of life care
- Deceased
(option for family members/friends/partners/carers only)
- Not sure
- Prefer not to answer

What is your profession?

(Professionals)

- Doctor
- Nurse
- Allied Health Professional
- Other

Please enter your job title:

Your questions

In your experience of Teenage and Young Adult Cancer, you may have had questions that you think have not yet been answered.

What questions would you like to see answered by research? To help you, here are some examples of the questions that have been submitted for other health conditions:

- What are the most effective ways of supporting carers of people with dementia living at home?
- Are counselling/psychological strategies (e.g. talking therapies) effective to promote the mental health of children and young people with neurodisability?
- What are the best ways to help people come to terms with the long-term consequences of stroke?
- Which treatment is more effective for vitiligo: steroid creams/ointments or light therapy?
- Is high-dose Loperamide safe and effective in the treatment of diarrhoea in Inflammatory Bowel Disease?
- What treatments are helpful for reducing balance problems and falls in people with Parkinson's?

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

Please suggest a maximum of five questions. Your questions can be written in any order of importance.

- 1 Please write your first question here:
...
- 2 What is your next question? *(Please leave blank if you do not have any further questions)*
...
- 3 What is your next question? *(Please leave blank if you do not have any further questions)*
...
- 4 What is your next question? *(Please leave blank if you do not have any further questions)*
...
- 5 What is your next question? *(Please leave blank if you do not have any further questions)*
...

Do you have any additional comments you would like to share with us?

...

Next steps

Would you like to be involved in the next stage of the project, which is to vote for the questions you think are most important of all those submitted? This may involve voting online or attending a workshop.

If you are 16 years old or over and would like to be involved please provide your details for your preferred method of contact:

.....

If you are under 16 years old please ask a parent/carer to contact us with your details. Please email tyasp@gmail.com and put 'TYA PSP Contact' in the subject line.

All contact details will be kept confidential and secure, in accordance with the Data Protection Act. We will not publish your details and they will not be linked to your responses on this form. We will not use your details for any purpose other than inviting you to take part in the next stage.

Name:

Email address:

Address:

Thank you for completing this survey.

These are our contact details:

Tel: XXXX

Email: tyasp@gmail.com

Completing this survey may have made you feel that you would like further support or information about cancer, if so, you could speak to a health professional involved in your care or you may find the following links helpful:

Teenage Cancer Trust:

<https://www.teenagecancertrust.org/get-help>

Macmillan Cancer Support:

<http://www.macmillan.org.uk/information-and-support/index.html>

CLIC Sargent:

<http://www.clicsargent.org.uk/content/help-and-support>



Answered questions

No	Question	Question submitted by	Evidence found	Evidence web link	Comments
1.	How can young people with osteosarcoma of the leg be successfully treated without amputation?	1 x patient	Salang K, Foocharoen T, Laopaiboon M, Jirattanaphochai K. Limb salvage for treating pathological fracture at diagnosis in children and adolescents with localized high grade osteosarcoma (Protocol). Cochrane Database of Systematic Reviews 2016, Issue 4. Art. No.: CD012146. DOI: 10.1002/14651858.CD012146; Yin K, Liao Q, Zhong D, Ding J, Niu B, Long Q, Ding D. Meta-analysis of limb salvage versus amputation for treating high-grade and localized osteosarcoma in patients with pathological fracture. Experimental and Therapeutic Medicine.2012;4(5):889-894.	http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD012146/full https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3493816/	Correspondence with Sarcoma expert - Most young people are treated successfully without amputation. Amputation rates ~ 10%
2.	Does the use of low-level laser therapy reduce the incidence of mucositis in highly mucositis provoking chemotherapy regimens for young people with cancer?	1 x professional	Oberoi S, Zamperini-Netto G, Beyene J, Treister NS, Sung L. Effect of prophylactic low level laser therapy on oral mucositis: a systematic review and meta-analysis. PLOS ONE.2014;9(9):e107418.	http://journals.plos.org/plosone/article/file?id=10.1371/journal.pone.0107418&type=printable	
3.	What are the side effects of chemotherapy in young people with cancer?	1 x patient	Ahmad S, Reinius M, Hatcher H, Ajithkumar T. Anticancer chemotherapy in teenagers and young adults: managing long term side effects. BMJ 2016; 354 doi: https://doi.org/10.1136/bmj.i4567 BMJ 2016;354:i4567 Bukowinski AJ, Burns KC, Parsons K, Perentesis JP, O'Brien MM.Semin Oncol Nurs. 2015 Toxicity of Cancer Therapy in Adolescents and Young Adults (AYAs). Aug;31(3):216-26. doi: 10.1016/j.soncn.2015.05.003. Epub 2015 May 7.	http://www.bmj.com/content/354/bmj.i4567.long https://www.ncbi.nlm.nih.gov/pubmed/26210200	
4.	What are the survival rates for young people with cancer?	1 x patient	Trends in five-year survival for teenagers and adults with cancer in the UK, Public Health England. Pattern of deaths in the year following diagnosis in cancer patients aged 15-24 years in England Authors: Tony Moran, Debasree Purkayastha, Catherine O'Hara Date: 15.4.2013.	http://www.ncin.org.uk/view?rid=2751 http://www.ncin.org.uk/view?rid=2134	
5.	What is the incidence of new primary and secondary cancers following cancer treatment as a young person?	2 x parent/carer 1 x patient	Second cancers among survivors of teenager and young adult cancer, National Cancer Intelligence Network Data Briefing. Franklin J, Eichenauer DA, Becker I, Monsef I, Engert A. Optimisation of chemotherapy and radiotherapy for untreated Hodgkin lymphoma patients with respect to second malignant neoplasms, overall and progression-free survival: individual participant data analysis. Cochrane Database of Systematic Reviews 2017, Issue 9. Art. No.: CD008814. DOI: 10.1002/14651858.CD008814.pub2. Ongoing study: Teenage and Young Adult Cancer Survivor Study	http://www.ncin.org.uk/view?rid=1606 http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD008814.pub2/epdf http://www.birmingham.ac.uk/research/activity/mds/projects/HaPS/PHEB/CCCSS/TYACSS/index.aspx	This question was discussed by the steering group and agreed that it was answered with more data collection underway from the ongoing Teenage and Young Adult Cancer Survivor Study. Specific to Hodgkin's disease – currently unanswered but should be answered by the Teenage and Young Adult Cancer Survivor Study.
6.	What are the outcomes associated with physical activity during treatment for young people with cancer on managing fatigue?	1 x professional	Tomlinson D1, Diorio C, Beyene J, Sung L. Am J Phys Med Rehabil. 2014 Aug;93(8):675-86. doi: 10.1097/PHM.000000000000083. Effect of exercise on cancer-related fatigue: a meta-analysis.	https://www.ncbi.nlm.nih.gov/pubmed/24743466	
7.	What are the barriers to clinical trials for young people with cancer?	1 x professional	Eric Tai, Natasha Buchanan, Lauren Westervelt, Dena Elimam, Silvana Lawvere Pediatrics June 2014, VOLUME 133 / ISSUE Supplement 3. Treatment Setting, Clinical Trial Enrollment, and Subsequent Outcomes Among Adolescents With Cancer: A Literature Review.	http://pediatrics.aappublications.org/content/133/Supplement_3/S91.long	

Ongoing studies

No	Question	Question submitted by	Evidence found	Evidence web link	Comments
1.	What is the genetic fingerprint of Ewing's Sarcoma?	1 x parent/carer			Correspondence with Sarcoma expert - work on this question is ongoing in several labs. Publications exist from Delattre/Ladhanyi.
2.	What targeted therapies are effective for young people with Ewing's Sarcoma?	1 x parent/carer			Correspondence with Sarcoma expert - early phase studies are currently under way.
3.	Do PD1 pathway affecting drugs have a role in the treatment of young people with bone and soft tissue sarcomas?	1 x professional			Correspondence with Sarcoma expert - work on this question is ongoing and some trials have reported in abstract.
4.	How do education outcomes for young people with cancer compare to young people without cancer?	3 x professional, 1 x patient	Review protocol: Andrew Thomas, Defne Saatchi, Alastair Sutcliffe. Educational progression of survivors of cancer diagnosed in childhood: a systematic review. PROSPERO 2017:CRD42017057501 Ongoing study: Study at University College London looking at this in children Educational Outcomes Following Childhood Cancer in England: A Population Based Linkage Study.	http://www.crd.york.ac.uk/PROSPERO/display_record.asp?ID=CRD42017057501	
5.	How does protocol adherence and toxicity impact prognosis for young people with cancer?	1 x parent/carer	Systematic review protocol in this area is in development.		Correspondence with pediatric expert - A protocol for a systematic review in this area is in development.
6.	Do specialist cancer services for young people improve outcomes and patient experience?	5 x professional	Ongoing study: BRIGHTLIGHT is the overarching name for a collection of research projects designed to answer a single question: Do specialist services for teenagers and young adults add value?	http://www.brightlightstudy.com/	
7.	Is the life expectancy of teenagers and young adults with cancer shorter compared to the general population?	3 x patient 1 x partner	Ongoing study: Teenage and Young Adult Cancer Survivor Study	http://www.birmingham.ac.uk/research/activity/mds/projects/HaPS/PHEB/CCCSS/TYACSS/index.aspx	Correspondence with Chief Investigator – confirmed this question will be answered by this ongoing study.
8.	Are young people with germ cell tumours more likely to develop leukaemia?	2 x parent/carer	Ongoing study: Teenage and Young Adult Cancer Survivor Study	http://www.birmingham.ac.uk/research/activity/mds/projects/HaPS/PHEB/CCCSS/TYACSS/index.aspx	Correspondence with Chief Investigator – confirmed this question will be answered by this ongoing study.
9.	What treatment is most effective for relapsed leukaemia in young people?	1 x professional	Search of clinicaltrials.gov database found 138 studies ongoing or set up (September 2017).	https://clinicaltrials.gov/ct2/results?term=relapse&type=Intr&slt=&recrs=b&recrs=a&recrs=f&recrs=e&age_v=&gndr=&cond=Leukemia&intr=&titles=&outc=&spons=&lead=&id=&cnyr 1=&state1=&cnyr2=&state2=&cnyr3=&state3=&locn=&phase=2&sfpd_s=&sfpd_e=&lupd_s=&lupd_e=	
10.	Do young people with Hodgkin's disease have a higher incidence of second cancers than young people with other cancers?	1 x patient	Second cancers among survivors of teenager and young adult cancer, National Cancer Intelligence Network Data Briefing Ongoing study: Teenage and Young Adult Cancer Survivor Study	http://www.ncin.org.uk/view?rid=1606 http://www.birmingham.ac.uk/research/activity/mds/projects/HaPS/PHEB/CCCSS/TYACSS/index.aspx	Correspondence with Chief Investigator – confirmed this question will be answered by this ongoing study.

Appendix 5 - Ongoing studies

No	Question	Question submitted by	Evidence found	Evidence web link	Comments
11.	For young people with incurable cancer, what are the barriers and facilitators to accessing hospice/specialist palliative care?	2 x professional	Review protocol: Johanna Taylor, Lorna Fraser, Bryony Beresford, Bob Phillips, Alison Booth, Kath Wright, Stuart Jarvis. Specialist paediatric palliative care for children and young people with malignancies: a mixed methods systematic review. PROSPERO 2017:CRD42017064874	http://www.crd.york.ac.uk/PROSPERO/display_record.asp?ID=CRD42017064874	
12.	What is the incidence of heart disease and second cancers in young people following ABVD?	1 x parent/carer	Henson KE, Reulen RC, Winter DL, et al. Cardiac Mortality Among 200000 Five-Year Survivors of Cancer Diagnosed at 15 to 39 Years of Age: The Teenage and Young Adult Cancer Survivor Study. <i>Circulation</i> . 2016;134(20):1519-1531. doi:10.1161/CIRCULATIONAHA.116.022514. (see Table 4) Ongoing study: Teenage and Young Adult Cancer Survivor Study	https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5106083/ http://www.birmingham.ac.uk/research/activity/mds/projects/HaPS/PHEB/CCCSS/TYACSS/index.aspx	
13.	What is the best model of survivorship care based on risk stratification and individual needs?	7 x professional 3 x patient 1 x relative	Guidelines on models of care for childhood and adolescent cancer survivors are in development.		Correspondence with expert - guidelines on models of care for childhood and adolescent cancer survivors are in development. We looked for evidence concerning survivors treated for cancer up until 25 years age.
14.	What fertility preservation techniques are effective for young women with cancer?	2 x patient 3 x professional 1 x parent/carer	British Fertility Society Policy and Practice Guideline is under development.		Correspondence with fertility expert - British Fertility Society Policy and Practice Guideline is under development.
15.	Is the use of Vincristine and Dexamethasone pulses required during maintenance treatment in young people with cancer?	1 x patient	Ongoing study: United Kingdom Trial for children and young adults with Acute lymphoblastic Leukaemia and Lymphoma 2011.		Correspondence with expert haematologist - This question is being studied as a randomised question in the current ALL trial which includes TYA patients up to 25th birthday, UKALL2011.
16.	Do the benefits outweigh the risks of continuing to use steroids in maintenance as part of the treatment protocol for young people with leukaemia?	1 x patient	Ongoing study: United Kingdom Trial for children and young adults with Acute lymphoblastic Leukaemia and Lymphoma 2011		Correspondence with expert haematologist - This question is being studied in the current ALL trial which includes TYA patients up to 25th birthday, UKALL2011.

Unanswered questions included in the interim survey

SECTION: CAUSES OF CANCER, PREVENTION AND DIAGNOSIS

Why do young people develop cancer? (This question was asked about all cancers and specifically: Hodgkin's disease/lymphoma, cancer of the appendix, bowel cancer, leukaemia and brain tumours)

Are the children of young people who have had cancer more likely to develop cancer compared to those whose parents have not had cancer?

How does cancer biology in young people differ from cancer biology in children and adults? (This question was asked about all cancers and specifically: brain tumours and Hodgkin's disease/lymphoma)

What GP or young person strategies, such as awareness campaigns and education, improve early diagnosis for young people with suspected cancer?

What factors affect the time to diagnosis and what outcomes are affected?

How can cancer awareness campaigns be used/adapted to address the needs of young people without creating alarm?

What written information do young people with cancer want at diagnosis in order to meet their needs without overloading them?

SECTION: TREATMENTS AND THERAPIES

What impact does eating well during treatment have on patient outcomes?

What targeted treatments are effective and have fewer short and long term side effects?

What is the role and how effective is cannabis oil in treatment for young people with cancer?

What is the best treatment for brain cancers to increase survival and decrease toxicity?

What are the best strategies to improve access to clinical trials?

What are the most effective ways to ensure that young people follow their treatment plan?

Are there effective less toxic treatments to corticosteroids for young people with cancer?

Is proton radiotherapy more effective than photon radiotherapy for young people with brain tumours?

What are the key factors that impact on outcomes in osteosarcoma / soft tissue tumours?

What key factors (both cancer and individual) determine whether a treatment plan for children or adults will give better outcomes?

What complementary or relaxation therapies improve quality of life?

SECTION: SHORT AND LONG TERM SIDE EFFECTS

What causes problems with cognitive functioning (chemobrain), how long do they last and what are the most effective treatments and strategies?

What are the long-term physical effects of stem cell transplants, how long do they last and how could they be reduced?

Appendix 6 – *Unanswered questions included in the interim survey*

What are the long term physical effects of a cancer diagnosis and treatment and how long do they last? (This question was asked about all cancers and specifically about leukaemia, thyroid cancer and brain tumours. It was also asked in relation to these treatments: spinal radiation, bone marrow transplant, mercaptopurine and methotrexate and in relation to pain conditions/nerve pain)

Following cancer treatment, do young people have different cognitive functioning ('chemobrain') compared to young people without cancer?

What factors influence poorer health and psychological outcomes?

What cancers and treatments cause avascular necrosis, how does it develop, how common is it, what are the physical and psychological effects and what can be done to improve early diagnosis and treatment?

What types of cancer and treatment lead to fatigue/tiredness, how long does it last and what are the most effective interventions (apart from exercise) for overcoming cancer related fatigue/tiredness?

What are the differences in outcomes when febrile neutropenia/neutropenia is managed as outpatient compared to inpatient?

What interventions can reduce or reverse adverse short and long term effects of cancer treatment?

What is the long term impact of different cancer treatments on the fertility of women who are treated as young adults?

What is the psychological impact for young people whose fertility has been affected by treatment?

How can the short and long term negative effects of radiotherapy be reduced?

What are the factors that predict life threatening chemotherapy side effects?

SECTION: INFORMATION AND SUPPORT

What is the best approach to prepare young people for treatment and long term side effects?

What are the best ways to provide information about services and treatment and when do young people want this information?

How are young people best supported to talk about their cancer diagnosis with families, friends and schools?

What is the most effective way of supporting young people with relapsed cancer?

What factors influence young people with a recent cancer diagnosis to decline first line treatment and how are they best supported?

What is the most effective way of providing peer support for young people during and after treatment? What outcomes are affected and how much does it cost?

What are the best ways of communicating information about treatment to young people with cancer who have learning difficulties or social communication disorders?

Do young people and parents who use a decision aid make more informed choices about treatment and side effects compared to people who do not use a decision aid?

What are the most effective approaches to communicating prognosis?

What prevents and helps young people access the support they need following a cancer diagnosis?

What information and support is required to improve patient experience and psychological wellbeing in young people with cancer exploring fertility preservation options?

SECTION: PSYCHOLOGICAL SUPPORT

What is the role of social media and/or online support in supporting young people during and after treatment?

What psychological support package improves psychological well-being, social functioning and mental health during and after treatment? (This question was asked about all cancers and specifically brain tumours and Hodgkin's disease/lymphoma)

Are the holistic care needs of young people with cancer being adequately assessed and met?

In young people with cancer, how does the quality of family relationships impact on acceptance of the diagnosis, adherence with therapies and health outcomes? What individual and family based interventions improve these outcomes?

Do internet-based psychological support programmes delivered to young people and families during and off-treatment improve their mental health and wellbeing?

What is the best intervention to support young women psychologically when their fertility has been affected by cancer?

Do young people receiving mental health therapies do better than those receiving physical treatment only?

SECTION: HOW CANCER IMPACTS ON DAILY LIFE

What interventions are most effective in supporting young people who are experiencing fatigue/tiredness when returning to education or work?

What interventions are most effective in supporting young people when returning to education or work?

What methods of support from education/school for young people improve wellbeing, participation and mental health? (This question was asked about all cancers and specifically about brain tumours)

What interventions are most effective in supporting young people to maintain their education whilst on treatment?

How are career choices and prospects affected by a cancer diagnosis and are some groups more at risk of encountering issues than others?

What interventions can reduce the potential negative impact of a cancer diagnosis on a young person's employment and career prospects?

How can schools and teachers better support young people with memory problems following cancer?

How are young people best supported to reintegrate with their peers when returning to school?

What interventions are most effective in supporting young people to maintain their social lives whilst on treatment?

How does cancer and its treatment impact a young person's friendships?

What interventions best support young people in developing and maintaining romantic and sexual relationships during and after treatment?

What are the best ways to support young people getting back to a 'normal' life after treatment? (This question was asked about all cancers and specifically about brain tumours)

How effective is rehabilitation in assisting recovery from cancer?

What are the barriers and motivators to exercise during and after treatment?

SECTION: IMPACT OF CANCER ON FAMILIES, FRIENDS AND PARTNERS

How are families and partners best included in communications and supported during and after treatment?

What is the most effective way of supporting families at relapse?

What is the impact of a cancer diagnosis in a young person on the family?

What are the best ways for families to re-establish normal life after treatment?

How can families best support young people through the emotional and social impact of a cancer diagnosis?

What type of psychological support do families and partners want during and after treatment?

What are the most effective interventions to improve mental health in families and friends of young people with cancer?

SECTION: END OF TREATMENT AND FOLLOW UP

What are the best strategies for detecting and treating second primary cancers early?

What are the health outcomes of long term follow up and screening?

Is long term follow up and screening cost effective?

What are the best strategies to help healthcare professionals to co-ordinate care to address survivorship needs raised by a young person?

What are the most effective approaches to communicating end of treatment information to young people?

What is the ideal period of psychological support after treatment?

What can young people do to help their recovery after chemotherapy or radiotherapy?

What are the most effective strategies for achieving long term health behaviour change with young people following cancer?

What impact does attending an end of treatment clinic have on the health behaviour of young people in the first 12 months after treatment has ended successfully compared to those who do not attend a clinic?

What are the best strategies to empower young people to get their survivorship needs discussed and addressed by healthcare professionals?

What are the survivorship needs of people diagnosed with cancer as a teenager or young adult compared with people who had cancer as a child or older adult?

How does having cancer as a teenager or young adult affect a person socially and emotionally in later life?

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?

At the end of treatment and during long term follow up, what support services improve psychological well-being, social functioning and mental health?

How common is psychological distress and/or mental health problems in young people following treatment? (This question was asked about all distress and specifically about post-traumatic stress disorder and depression)

What are the rates of relapse, predictive factors and survival outcomes?

SECTION: HEALTHCARE DELIVERY

What is the most effective model of care for the delivery of regional teenage and young adult cancer services?

How can patient-reported outcome measures be used to improve care for young people?

How can communication methods between healthcare professionals and young people be enhanced in the current age of digital communication?

What are the barriers for health professionals in engaging with the teenage and young adult multi-professional team and regional teenage and young adult service?

What is the structure of the ideal multi-professional team caring for young people at diagnosis, during treatment, end of treatment, long term survivorship and end of life?

What are the barriers for transition to adult services for young people and what are the most effective strategies to improve transition?

What are the most effective strategies to support nurses caring for young people with cancer?

What are the most effective strategies for engaging primary care professionals (e.g. GPs) to listen to young people?

How do socio-economic factors influence where a young person chooses to be cared for (for example choosing a local hospital versus a specialist hospital)?

When do young people want family present in consultations with healthcare professionals and when would they prefer family not to be present?

What are the most effective strategies to ensure that young people who are treated in non-specialist hospitals receive appropriate practical and emotional support?

SECTION: END OF LIFE CARE

What are the best ways of supporting a young person who has incurable cancer?

How can parents/carers/siblings/partners be best supported following the death of a young person with cancer?

For young people with incurable cancer, how should healthcare professionals communicate with them to improve quality of life and patient experience?

For young people with incurable cancer, how should parents/carers communicate with them to improve quality of life and experience?

What are the support needs of the family following the death of a young person with cancer?

What are the factors that should determine stopping treatment when the young person cannot be cured?

For young people with incurable disease, what methods, techniques or strategies for communication can help them to talk with their family and friends about their situation?

Unanswered questions not included in the interim survey

- In young people with cancer how do we enable new technologies (molecular profiling) to be integrated in standard management approaches to monitor, adapt and target treatment?
- What is the best treatment for young people with relapsed bone and soft tissue sarcomas?
- How should we investigate novel targeted therapies in rare cancers?
- How does having cancer as a young person shape identity across the life course?
- What is the best strategy for young people restarting fitness and exercise after treatment?
- How many young people return to their parent's home during treatment and how does this impact on their mental health and quality of life compared to those who continue independent living?
- What are the financial stresses on young people with cancer and their families?
- What are the long term effects on fertility for males who received high intensity chemotherapy?
- What is the most effective hormone support for post-transplant female survivors?
- What are the outcomes associated with physical activity during treatment for young people with cancer on the side effects of chemotherapy, including managing social isolation and returning to school, leisure, work?
- What are the best ways to provide peer support for families of young people with cancer?
- What is the most effective strategy to embed end of treatment summaries into routine cancer care for young people with cancer?
- What proportion of young people with recurrence are offered clinical trials?
- How can electronic health records empower young people with cancer?
- What factors contribute to poorer survival outcomes in young people with breast cancer compared to older women?
- In young people with cancer, would screening all patients for cancer predisposition syndromes impact upon the patient and family and their children to improve uptake of appropriate screening /early detection of related cancers?
- Does appropriate physical challenge improve confidence post treatment in young people with cancer?
- How do disease and treatment impact patient experience of symptoms for young people with cancer?
- In young people with cancer which 'holistic care assessment', best delineates baseline psychological functioning, social functioning and mental health?
- Does emergency admission to an adult ward impact on young people's compliance to treatment?
- What are the most effective strategies to empower young people to engage with follow up?
- Do clinical trial accrual rates vary across the UK for young people with cancer?
- How effective is pre-habilitation in assisting recovery from cancer?
- In young people with cancer, what information should be delivered and by whom to improve knowledge and satisfaction and wellbeing?
- In young people with cancer who are themselves parents, what emotional/social/psychological support services improve psychological functioning social functioning and mental health for the young person and their child(ren)?
- Are there regional differences in survival rates for acute myeloid leukaemia (AML) and acute lymphoblastic leukaemia (ALL)?

Appendix 7 - Unanswered questions not included in the interim survey

- What evidence is there of effective end of treatment transition on to community services?
- How do young people with incurable disease chose their preferred place of death?
- What are the most effective ways of supporting a friend with incurable disease?
- What is the psychological impact of hospital isolation (hospitalisation in single rooms) whether short term or long term when hospitalised?
- In young people on cancer treatment, what safety netting (information / support / education) can be given to improve the appropriate management and reduce toxic complications?
- What is the educational trajectory of young people with cancer from 6 months pre diagnosis up to age 18? (This question was asked about all cancers and specifically about brain tumours and leukaemia)
- What are the most effective ways of supporting young people with long term adverse psychosocial impact of cancer in addition to previous life events/trauma?
- Is there an association between early psychosocial adversity (individual and family) and cancer aetiology?
- What lifestyle changes can young people make to prevent cancer in young people?
- Why is Ewing's sarcoma drug resistant in some young people?
- Does a cancer diagnosis and treatment in young people during puberty affect survival?
- In young people who are cancer survivors, what is the prevalence of anxiety about their future children developing cancer and about dying early after having children?
- How can sleep be improved in young people undergoing cancer treatment?
- What are the most effective ways of supporting a friend undergoing treatment?
- How do young people manage their experience of their friend being diagnosed with cancer?
- What is the experience of parents of young people with cancer as their child transitions into adulthood and discussions about treatment and management are now directed at their child?
- What is the interaction between pre-existing immune system disorders and lymphoma?
- Is ABVD (adriamycin; bleomycin; vinblastine; dacarbazine) equally effective if bleomycin is omitted?
- What are the survival outcomes of second stem cell transplant for young people with cancer?
- How can GI (gastrointestinal) side effects be diagnosed and managed more effectively in young people with cancer?
- What is the impact of uncertainty and changes on a young person and their family following a brain tumour diagnosis?
- What are the barriers to accessing radiotherapy for young people with brain tumours?
- How does EBV (Epstein-Barr Virus) interact with T-cells and NK cells?
- How do young people describe the impact of a cancer diagnosis once treatment is completed at one year and two years?
- In young people exposed to ototoxic agents, how long should hearing tests/assessments be undertaken in follow-up?
- In young people who have anticancer treatments, are they at increased risk of autoimmune disease in later life?
- Does early detection and treatment of GVHD (graft-versus-host disease) impact on recovery time for young people with cancer?
- How can we minimise the vascular effects of cisplatin in young people with cancer?

Appendix 7 - *Unanswered questions not included in the interim survey*

- In young people with cancer who have an eating disorder, do interventions need to be modified to take account of factors that arise uniquely from the 'cancer journey'?
- Does participation in support activities for young people with cancer differ by gender?
- How does treatment for lymphoma affect outcomes for immune system diseases?
- What are the most effective treatments for rare cancers in young people such as Sertoli cell tumours?
- Is it safe to use NSAIDs (non-steroidal anti-inflammatory drugs) as an analgesic in young people undergoing chemotherapy treatment?
- How can hair growth be stimulated following radiotherapy in young people with cancer?
- How do the needs of lesbian, gay, bisexual or transgender (LGBT) young people with cancer differ from the general population of young people with cancer?
- Is cardiac screening post anthracyclines more effective if carried out by a cardiac specialist in late effects of cancer?
- Why is the incidence of brain cancer in young people high in comparison to older adults?
- Is there an association between young people's cancer and eating disorders?
- What alternatives are there to loperamide for treating chemotherapy-induced diarrhoea?
- What is the relationship between daunorubicin and cytarabine doses and bowel problems?
- How can grandparents who have a grandchild with cancer talk with them about their cancer?
- What are the most effective ways of offering psychological support to young people with lymphedema?
- What proportion of young people who have had leukaemia relapse more than once?
- What are the survival rates for young people with leukaemia who have Down syndrome?
- Are the early warning indicators of sepsis the same in children, young people and adults?
- What support do young people with cancer and their families want from Grandparents?
- What are the recurrence rates for melanoma?
- Do young people with posterior fossa tumours have higher rates of Autistic Spectrum Diagnoses than young people with other cancers/general population?
- How many liver cancers in young people are not related to lifestyle choices (diet, health, drinking)?
- Would taking T3 alongside T4 after a thyroidectomy help with tiredness even when bloods are normal when taking T4 alone?
- What are the recurrence rates of thyroid cancer after five years?
- What is the incidence of mixed leukaemia?
- Does taking blood thinners long-term cause health problems?
- Is there a link between HPV (human papilloma virus) vaccines and blood cancers?
- Would young people prefer their nurse specialist to wear a uniform or not?



**James
Lind
Alliance**

Priority Setting Partnerships



Teenage Cancer Trust: 1062559
(England & Wales), SC039757 (Scotland)



CLIC Sargent: 1107328
(England & Wales), SC039857 (Scotland)

**Children with
Cancer UK**
Keeping families together



Children with Cancer UK: 298405
(England & Wales)

This report should be cited as:

Aldiss S., Fern L.A., Phillips B., Gibson F, on behalf of the Teenage and Young Adult Cancer Priority Setting Partnership Steering Group (2018) Teenage and Young Adult Cancer: Research Priorities. Final Report of the James Lind Alliance Priority Setting Partnership. <http://www.jla.nihr.ac.uk/priority-setting-partnerships/teenage-and-young-adult-cancer/>

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