Teenage and Young Adult Cancer JLA PSP. Details of all questions discussed at the priority setting workshop, 19 January 2018

Uncertainty	**Explanatory note**	**Rank of the uncertainty at the final workshop.**	**Evidence at time of PSP**	**Comments on evidence**
What psychological support package improves psychological well-being, social functioning and mental health during and after treatment?	The top priority identified in this exercise reflects an increasing drive to focus on both physical and psychological health during and after cancer. It is increasingly recognised that a cancer diagnosis has serious implications for young people’s mental health but this has yet to be systematically investigated and how these young people are best supported is currently unknown. **Example submissions:** What is the most effective way to deliver psychological support to this patient group? ~ What are the most effective ways of looking after young people with cancer from a mental health standpoint? ~ What are the most effective strategies to limit the emotional/mental health consequences associated with lengthy cancer treatments? ~ Living and surviving cancer - what measures can be put into place to help people psychologically live a filled life ~ Why is life so psychologically hard to deal with after cancer? ~ What is the best way to support TYA during their treatment particularly in relation to social relationships, employment and education ~ At what point in the cancer journey is psychological support most helpful?	**1**	1) Muglia-Wechsler, A, Bragado-Alvarez, C, Hernandez-Lloreda, Maria J. Effectiveness of psychological interventions intended to promote adjustment of children with cancer and their parents: an overview. Anales de Psicologia.2014;30(1):94-104. http://revistas.um.es/analesps/article/view/149161 ; 2) Archer S, Buxton S, Sheffield D. The effect of creative psychological interventions on psychological outcomes for adult cancer patients: a systematic review of randomised controlled trials. Psycho-Oncology.2015;24:1-10. https://www.ncbi.nlm.nih.gov/pubmed/24953449 ; 3) Faller H, Schuler M, Richard M, Heckl U, Weis J, Kuffner R. Effects of psycho-oncologic interventions on emotional distress and quality of life in adult patients with cancer: systematic review and meta-analysis. Journal of Clinical Oncology.2013;31(6):782-793. http://ascopubs.org/doi/10.1200/JCO.2011.40.8922	These three reviews conclude that more research on psychological support interventions is needed.
What interventions, including self-care, can reduce or reverse adverse short and long term effects of cancer treatment?	It is well known that cancer treatments can have many side effects, some of which are long lasting and can be distressing for young people, having a huge impact on their lives. Reducing these side effects in the short and long term is high priority. The young people at the workshop asked for ‘including self-care’ to be added to this question. 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. **Example submissions:** What's the best way to avoid long-term complications from treatment? ~ Can some of the damage caused by the illness and treatment be reversed ? ~ What are the best ways to help people with long term effects after treatment.	**2**		Very broad area to search. Steering Group concluded that this question is unanswered.

What are the best strategies to improve access to clinical trials?	It is well documented in commentary papers, that young people are less likely to be involved in clinical trials than children or adults. This has an impact on outcome, we now need to describe and test strategies to improve access. **Example submissions:** How can we improve uptake of clinical trials in the TYAC population? ~ How do we improve access of TYA to investigative therapies ~ How can we ensure that new cancer drugs under trial do not exclude people's access by thoughtless use of age boundaries which are not related to the biology or social factors that determine the relevance of the research?	**3**	No reviews identified.	
What General Practitioner or young person strategies, such as awareness campaigns and education, improve early diagnosis for young people with suspected cancer?	Cancer in young people is hard to diagnose; it is rare and the signs are often mistaken for other more common illnesses. Raising awareness of the signs of cancer in young people is important as this could improve time to diagnosis. Delay in diagnosis in young people with cancer may be one factor contributing to the lower reduction in cancer mortality rates compared with children or older adults in recent years. **Example submissions:** 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 diagnositic pathway for all young people to ensure they recieve 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.	**4**	Schichtel M, Rose PW, Sellers C. Educational interventions for primary healthcare professionals to promote the early diagnosis of cancer: a systematic review. Education for Primary Care. 2013;24(4):274-290. https://www.ncbi.nlm.nih.gov/pubmed/23906171	The paper conludes: certain educational interventions delivered at a clinician as well as at a practice level may promote the early diagnosis of cancer in primary care. There is currently limited evidence for their long-term sustainability and effectiveness. This review is not young-person focused.
What are the best ways of supporting a young person who has incurable cancer?	Some young people have a poor diagnosis from the outset. There has been little previous research focusing on the experiences of young people with incurable cancer. How best to support these young people is currently unknown. **Example submissions:** What are the best ways of supporting a young person who has incurable disease? ~ How can you support someone when they've just been told 'theres nothing more we can do' what's the best words? ~ what do palliatve services look like for this population - what are the gaps, what do we know about how best to support patients	**5**	1) Barbara Gomes, Natalia Calanzani, Vito Curiale, Paul McCrone and Irene J Higginson (2013) Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. Cochrane Database of Systematic Reviews. https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD007760.pub2/full 2) Ngwenya N, Kenten C, Jones L, Gibson F, Pearce S, Flatley M, Hough R, Stirling LC, Taylor RM, Wong G, Whelan J. (2017) Experiences and Preferences for End-of-Life Care for Young Adults with Cancer and Their Informal Carers: A Narrative Synthesis. J Adolesc Young Adult Oncol. 6(2):200-212. https://www.liebertpub.com/doi/10.1089/jayao.2016.0055	1) Limited relevance for young people and does not fully answer the question. 23 studies (14 cancer, 6 mix of cancer/non-cancer patients, 3 non-cancer patients). Median/mean age ranged from 53 to 77. 2) Review states: there is little evidence focused on the end-of-life needs of young adults. Analysis of reports including some young adults does not explore experience or preferences by age; therefore, it is difficult to identify age-specific issues clearly. Further research is needed focusing on the experiences and preferences of young adults.

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?	A Principal Treatment Centre (PTC) is a centre that specialises in young people's cancer and in delivering care to this age group. Depending on where a young person lives or what type of cancer they have, they may be treated outside a PTC, such as at a local hospital. For some young people, this may be their choice, for example if they wish to be treated at a hospital closer to their home. Young people treated outside a PTC might not have the same access to support as young people treated in a PTC; this question seeks to find out the best strategies to ensure that they are supported. **Example submissions:** How do ensure young people who receive their treatment in hospitals other than principal treatment centres receive appropriate practical and emotional support? ~ What practical and emotional support do young people who are treated in hospitals other than principal treatment centres have access to? ~ Do young people who spend little or no time in hospital during treatment receive any appropriate practical or emotional support?	**6**	No reviews identified.	
What interventions are most effective in supporting young people when returning to education or work?	It can be difficult for young people to return to education or work following time off during treatment, they may feel anxious about returning and/or they might be experiencing tiredness or other physical effects of cancer and treatment. Finding out the best ways to help young people return to education or work is important to help them to live well during and after cancer. **Example submissions:** How has your diagnosis affect your education and what can we do to help ~ how do we support young people to return to education and work? ~ What forms of assistance are most useful for young	**7**	de Boer Angela; G E M; Taskila Tyna; K; Tamminga Sietske; J; Feuerstein Michael; Frings-Dresen Monique; H W; Verbeek Jos; H; (2015) Interventions to enhance return-to-work for cancer patients. Cochrane Database of Systematic Reviews. https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD007569.pub3/full	Limited relevance for young people: 15 studies, included 7 breast cancer, 2 prostate, 1 head and neck cancer. Particpants were 18 years+. 3 UK studies (all breast cancer). Review concludes: We found moderate quality evidence that multidisciplinary interventions enhance the return to work of patients with cancer.
How can parents/carers/siblings/partners be best supported following the death of a young person with cancer?	Families, friends and partners of young people with cancer have identified a lack of support after a young person dies. There is a need for support not to 'disappear' following the death of a young person; the best way to provide continued support is not known. **Example submissions:** What bereavement support is most acceptable to parents who have lost a young adult to cancer? ~ How can young people best be supported after the loss of a sibling?	**8**	No reviews identified.	

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?	Young people treated for cancer are at risk of late-effects. These can vary from physical health effects, such as second primary tumours, cardiovascular disease, effects on fertility and growth to educational, behavioural and social problems. Relatively little is known about the long-term consequences of treatment and the need for long-term surveillance has been identified in order to better characterise the late-effects specific to this group. There remains a lack of consensus regarding the optimal methods and timing of follow-up. Young people and families describe anxiety about waiting for scan results as well as worry about the physical effects of scans. **Example submissions:** How important are the check ups every 3 months? ~ What is the balance between scans for reassurance and the damage they might do?	**9**	1) Cochrane review protocol: Beverley Lim Høeg , Pernille Envold Bidstrup , Trine Allerslev Horsboel , Susanne Oksbjerg Dalton , Lena Saltbæk , Randi Valbjørn Karlsen , Klaus Kaae Andersen and Christoffer Johansen (2016) Follow-up strategies following completion of primary cancer treatment in adult cancer survivors https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD012425/full ; 2) Heirs M, Suekarran S, Slack R, Light K, Gibson F, Glaser A, Hawkins M, Phillips R. A systematic review of models of care for the follow-up of childhood cancer survivors. Pediatric Blood and Cancer. 2013;60(3):351-356. http://onlinelibrary.wiley.com/doi/10.1002/pbc.24253/abstract	The review protocol/review are not young person-focused. Review concluded more robust evidence is needed.
What targeted treatments are effective and have fewer short and long term side-effects?	Targeted treatment is a newer type of cancer treatment that uses drugs or other substances to more precisely identify and attack cancer cells. Cancer cells have changes in their genes (DNA) that make them different from normal cells. These changes mean that they behave differently. Cancer cells can grow faster than normal cells and sometimes spread. Targeted cancer treatments work by ‘targeting’ those differences that a cancer cell has. **Example submissions:** Are there more target treatment being developed that are better for the body's than chemo? ~ Is it possible to find agents which have fewer short and long term side effects?	**10**		Very broad area to search. Steering group concluded that this question is unanswered.
What are the long term physical effects of a cancer diagnosis and treatment and how long do they last?	Young people experience many long-term physical effects of cancer such as fatigue and pain which can have a huge impact on their lives. How long these effects last for in young people is unknown. **Example submissions:** Will my side effects go on forever? ~ When will my body get back to normal after treatment? ~ What issues are caused by chemotherapy/radiotherapy treatment after completing and how long do they last? ~ Will the treatment affect the patient in adulthood? ~ What is the late effects burden of treatment of TYA cancer? ~ Is there research being conducted to help people with long term effects of treatment to know what to expect?	**This was one of the 20 questions at the workshop that fell outside of the Top 10. These were not ranked in any order of priority**	Ahmad S, Reinius M, Hatcher H, Ajithkumar T. Anticancer chemotherapy in teenagers and young adults: managing long term side effects BMJ 2016; 354:i4567 http://www.bmj.com/content/354/bmj.i4567.long	Non-systematic review and does not address 'how long' the effects last.

What factors affect the time to diagnosis and what outcomes are affected?	Pathways to diagnosis have been well described in the adult population. Less clear are the pathways for young people. **Example submissions:** What signs and symptoms allow early recognition if sarcoma in young people? ~ What are the routes to diagnosis in TYA with cancer that are amenable to improvement? ~ Why are GPs not picking up signs of cancer in young people? ~ Have we concrete evidence delays impact on survival (worse stage disease more metastatic disease etc)	**This was one of the 20 questions at the workshop that fell outside of the Top 10. These were not ranked in any order of priority**	Lethaby CD, Picton S, Kinsey SE, et alA systematic review of time to diagnosis in children and young adults with cancerArchives of Disease in Childhood 2013;98:349-355. https://adc.bmj.com/content/98/5/349.long	The majority of reviewed articles included childhood and teenage populations, with seven papers including patients aged 20 years or over. The conclusions drawn from early diagnosis research in children and young adults to date are far from clear. This review highlights some limitations in this research area. The vast majority of publications lack a theoretical framework and consequently the definitions used for key time intervals and milestones are neither robust nor reproducible.
What can young people do to help their recovery after chemotherapy or radiotherapy?	Self-management has become a focus of care for young people who have a long-term condition. This question explores what young people can do to help their recovery, this might include maintaining a healthy weight, eating well and having regular exercise. Such behaviours can help improve a person's sense of well-being as well as lowering the risk of getting other illnesses and cancers. **Example submission:** How can a patient help their recovery after chemo/radiotherapy	**This was one of the 20 questions at the workshop that fell outside of the Top 10. These were not ranked in any order of priority**	1) Cohen JE, Wakefield CE, Cohn RJ. Nutritional interventions for survivors of childhood cancer. Cochrane Database of Systematic Reviews 2016, Issue 8. Art. No.: CD009678. DOI: 10.1002/14651858.CD009678.pub2. https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD009678.pub2/full ; 2) Braam KI, van der Torre P, Takken T, Veening MA, van Dulmen-den Broeder E, Kaspers GJL. Physical exercise training interventions for children and young adults during and after treatment for childhood cancer. Cochrane Database of Systematic Reviews 2016, Issue 3. Art. No.: CD008796. DOI: 10.1002/14651858.CD008796.pub3. https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD008796.pub3/full	1) The partipants had cancer under 18 years. Conclusion: Due to a paucity of studies, and the heterogeneity of the studies included in this review, we are unable to draw conclusions regarding the effectiveness of nutritional interventions for use with childhood cancer survivors. 2) The participants were under 19 years old, concluded effects of exercise not convincing.
What key factors (both cancer and individual) determine whether a treatment plan for children or adults will give better outcomes?	We have increasing knowledge about the role of genetics, personal characteristics, and tumour biology. We are beginning to understand more about therapies in relation to this, but there is much we still do not know. **Example submissions:** What are the clinically relevent differences in drug metabolism in TYA from children which can guide therapy choices? ~ My son was 14 and the question during treatment was whether to use child or adult doses as there was not much data on teensgers. Would like to see more research on this area ~ What is the best way of integrating the instances where the standard paediatric and adult management of the same cancer (e.g. Hodgkin lymphoma) differ? i.e. What is best for the TYA patient in this circumstance? ~ How do we ensure that treatment is suitable for the disease process/biology in a specific cancer in a TYA patient in order that they receive optimum treatment?	**This was one of the 20 questions at the workshop that fell outside of the Top 10. These were not ranked in any order of priority**	No reviews identified.	

What are the best ways to support young people getting back to 'everyday' life after treatment?	Finishing treatment can be a difficult time for young people, the routine, people and support suddenly fall away. Moving forward after cancer can be daunting and for young people experiencing ongoing side effects, such as fatigue, getting back to their 'everyday life' such as work or education can be challenging. The best ways to support young people following treatment are currently unknown. **Example submissions:** What is the most effective way of not having to think about the illness and just get on with life? ~ How can we best support AYAs in their integration back to "normality" after treatment ~ What are the best ways/techniques to help young people integrate back into their normal lives after cancer treatment? ~ What is the best way to help young people come to terms with what has happened to them and rebuild a life beyond cancer ~ How do I fit back into society post treatment ?	**This was one of the 20 questions at the workshop that fell outside of the Top 10. These were not ranked in any order of priority**	1) de Boer A; Taskila T; Tamminga S; Feuerstein M; Frings-Dresen M; Verbeek J (2015) Interventions to enhance return-to-work for cancer patients. Cochrane Database of Systematic Reviews. https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD007569.pub3/full ; 2) Ongoing study: CANTEEN- ReCaPTure LiFe (Resilience and Coping skills for young People To Live well Following cancer) is a new online support program for young cancer survivors which enables them to share their experiences with other young people and learn new ways to get back to 'normal' after cancer. https://www.canteen.org.au/research/recapture-life/	1) Limited relevance for young people: 15 studies, included 7 breast cancer, 2 prostate, 1 head and neck cancer. Particpants were over 18 years. 3 UK studies (all breast cancer). Review concludes: We found moderate quality evidence that multidisciplinary interventions enhance the return to work of patients with cancer. This review only considers return to work and not other aspects of returning to 'everyday' life.
How common is psychological distress and/or mental health problems in young people following treatment?	Across the general population of young people there is an increase in mental health issues. We might anticipate that a cancer diagnosis may further impact upon a young person's mental health; however, we do not know the extent of this problem. **Example submissions:** What are the risks mental adverse health outcomes among survivors of TYA cancer ~ What is the long term psychological impact of having cancer as a child/young person and what can be done to alleviate negative impact? ~ What are the common emotional needs during and following treatment? ~ How do we prevent the high levels of mental illness seen in cancer survivors treated in the TYA age group? What are the levels of mental illness in this group post treatment? ~ What is the prevalence of PTSD within cancer survivors? ~ is depression after cancer normal?	**This was one of the 20 questions at the workshop that fell outside of the Top 10. These were not ranked in any order of priority**	No reviews identified.	
What is the most effective way of supporting young people with relapsed cancer?	We anticipate that a number of young people will relapse from their primary disease. Although they have previous experience of therapies, we do not know enough to plan strategies of what might help them when facing more therapy and further decisions**. Example submissions:** How can TYA's and their families be best supported at the point of relapse ~ If relaps occurred how can we explain and support the patient and the family?	**This was one of the 20 questions at the workshop that fell outside of the Top 10. These were not ranked in any order of priority**	No reviews identified.	

What are the factors that should determine stopping treatment when the young person cannot be cured?	Open and honest communication at this time can be difficult; we know that early conversations between the young person, family members and professionals is crucial. A decision that involves all these parties is essential, but what initiates that conversation will be different for each young person: a young person needs to be enabled to voice their concerns. **Example submissions:** Appropriateness of treatment when patients not going to physically improve. ~ How to decide when enough treatment is enough?	**This was one of the 20 questions at the workshop that fell outside of the Top 10. These were not ranked in any order of priority**	No reviews identified.	
What are the factors that predict life threatening chemotherapy side effects?	Life threatening side effects from chemotherapy could be related to a specific diagnosis or treatment, but individual factors also have a role, and we know less about these. **Example submissions:** Why do some people react with life threatening side effects to chemotherapy. I.e. Kidney failure, swelling of brain, heart and lung damage	**This was one of the 20 questions at the workshop that fell outside of the Top 10. These were not ranked in any order of priority**	No reviews identified.	
At the end of treatment and during long term follow up, what support services improve psychological well-being, social functioning and mental health?	Late physical effects of therapies are well documented, but we know less about which young people might be left with psychological issues such as anxiety, Post-Traumatic Stress Disorder (PTSD), or depression. As a result we know less about how to support these young people. **Example submissions:** What sort of support do TYA's really benefit from at the End of Treatment ~ End of Treatment: what additional psycho social supports are needed to support young people following treatment? ~ How do we support young people in recovery in the long term? ~ What support would be useful for patients after cancer? ~ What are the three most important ways young people can be supported to integrate back into their peer group? ~ When should the formal cancer support structures end and when should they remain?	**This was one of the 20 questions at the workshop that fell outside of the Top 10. These were not ranked in any order of priority**	No reviews identified.	

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?	Sharing information about prognosis is complex and individual. It can be difficult for young people to talk with family and friends; we need to explore what might help them to do so. **Example submission:** How do I talk to family /friends if I am palliative?	**This was one of the 20 questions at the workshop that fell outside of the Top 10. These were not ranked in any order of priority**	No reviews identified.	
What are the most effective strategies for engaging primary care professionals (e.g. GPs) to listen to young people?	Young people describe how difficult these encounters are, in terms of how they talk with, and feel listened to by their GP. We are yet to really understand all the complexities of this, and therefore what would help and improve this experience is not known. **Example submission**: Is there any way as young people we can find a way for gp's to listen and not disregard our concerns?	**This was one of the 20 questions at the workshop that fell outside of the Top 10. These were not ranked in any order of priority**	No reviews identified.	
What interventions are most effective in supporting young people who are experiencing fatigue/tiredness when returning to work or education?	We know quite a bit about fatigue, and what young people describe as 'feeling fatigued', but what helps or makes it worse we really do not know. **Example submissions:** What can be done to support those going back to school/work when suffering from significant fatigue? ~ Cancer can make you change your life for the better. Is there any help for those who want to go back to uni? Working and studying isn't an option due to tiredness. ~ What is the best way to keep up with education after a major surgery or when constantly fatigued?	**This was one of the 20 questions at the workshop that fell outside of the Top 10. These were not ranked in any order of priority**	Chang CW, Mu PF, Jou ST, Wong TT, Chen YC. The effectiveness of non-pharmacological interventions on fatigue in children and adolescents with cancer: a systematic review. JBI Libr Syst Rev. 2012;10(10):574-614. https://www.ncbi.nlm.nih.gov/pubmed/27820554	Not young people focused - Participants up to 18 years. Suggests exercise is helpful in reducing fatigue but this review is not focused on fatigue and returning to education/work
What is the best treatment for brain cancers to increase survival and decrease toxicity?	There are some very specific short and long term effects from therapies for those with a brain tumour, which can have a big impact on how young people get to live their lives, for example, in terms of employment, and the 'job' they can do as opposed to what they wanted to do. More clinical trials, that consider quality of life and survival, are required. **Example submissions:** What is the best treatment protocol for relapsed mixed germ cell brain tumour ~ What is the recommended protocol for re-irradiation of the brain ? ~ Why can we not find better and safer ways for treating brain tumours without causing damage to young people? ~ What treatments will cure aninoperable brain tumour? ~ Is there a better way to deliver chemotherapy to brain tumours?	**This was one of the 20 questions at the workshop that fell outside of the Top 10. These were not ranked in any order of priority**	No reviews identified.	

What causes problems with cognitive functioning (chemobrain), how long do they last and what are the most effective treatments and strategies?	'Cognitive functioning' means brain activities such as memory and concentration. Problems with these things are often called 'chemobrain' which some people describe as feeling spaced out, dopey and sleepy, struggling to concentrate and remember things. The most effective ways of helping people experiencing such problems and how long they last are currently unknown. **Example submissions:** What is chemo brain and how is it caused ~ Why does 'chemo brain' happen and who is more likely to be susceptible to it? ~ How long do the affects of chemo brain last? ~ Chemo Brain - Is there any way of preventing it or treating it after main treatment? ~ Is there going to be research of combating the effects of chemo brain in young people to reduce side effects later in life? ~ Are there any treatments/things that can help with 'chemo-brain'?	**This was one of the 20 questions at the workshop that fell outside of the Top 10. These were not ranked in any order of priority**	1) Treanor CJ, McMenamin UC, O'Neill RF, Cardwell CR, Clarke MJ, Cantwell M, Donnelly M. Non-pharmacological interventions for cognitive impairment due to systemic cancer treatment. Cochrane Database of Systematic Reviews 2016, Issue 8. Art. No.: CD011325. DOI: 10.1002/14651858.CD011325.pub2. https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD011325.pub2/full ; 2) Lindner OC, Phillips B, McCabe MG, et al. A meta-analysis of cognitive impairment following adult cancer chemotherapy. Neuropsychology. 2014;28(5):726-40. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4143183/ ; 3) Hines S, Ramis MA, Pike S, Chang AM. The effectiveness of psychosocial interventions for cognitive dysfunction in cancer patients who have received chemotherapy: a systematic review. Worldviews on Evidence-Based Nursing. 2014;11(3):187-193. http://onlinelibrary.wiley.com/wol1/doi/10.1111/wvn.12042/abstract	1) The review concludes: Overall, the, albeit low-quality evidence may be interpreted to suggest that non-pharmacological interventions may have the potential to reduce the risk of, or ameliorate, cognitive impairment following systemic cancer treatment. More research is needed, particularly among cancer patient groups other than women with breast cancer. 2) This review does not answer how long it lasts, what the causes are or what treatments are effecive. Just shows 'chemobrain' exists. 3) The review concludes: Despite some evidence of an effect, there is insufficient evidence at this stage to strongly recommend any of the interventions to assist in decreasing the effects of chemotherapy-related cognitive dysfunction, except in terms of improving quality of life.
What are the best strategies for detecting and treating second primary cancers early?	'Second primary cancer' is a term used to describe a new cancer that develops in a person who has had cancer in the past. Follow up care has been well described, this, when in place, offers one place for surveillance for new cancers, based on diagnosis and treatment received. Follow up is not the only route, knowledge the young person has about their diagnosis can help them to be 'body aware', there could also be other strategies we do not yet know enough about. **Example submissions:** How can second primary malignancies be detected early and treated? ~ How should people who have have had cancer be screened for other cancers in the future?	**This was one of the 20 questions at the workshop that fell outside of the Top 10. These were not ranked in any order of priority**	Cochrane review protocol: Beverley Lim Høeg , Pernille Envold Bidstrup, Trine Allerslev Horsboel, Susanne Oksbjerg Dalton, Lena Saltbæk, Randi Valbjørn Karlsen, Klaus Kaae Andersen and Christoffer Johansen (2016) Follow-up strategies following completion of primary cancer treatment in adult cancer survivors https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD012425/full	Protocol for review - focus on adults with cancer, not young people.

For young people with incurable cancer, how should healthcare professionals communicate with them to improve quality of life and patient experience?	This question is complex, it is a very emotional time, requiring excellent communication and listening skills. How information is received is so individual. We do not know what works best for young people, our only evidence comes from those working with adult patients. **Example submissions:** What is best practice for discussing palliative care options with young adults and at what point in treatment should these conversations begin? ~ What are the most effective ways of discussing future treatment support options when cure is no longer possible?	**This was one of the 20 questions at the workshop that fell outside of the Top 10. These were not ranked in any order of priority**	1) Murray CD, McDonald C, Atkin H. The communication experiences of patients with palliative care needs: a systematic review and meta-synthesis of qualitative findings. Palliative and Supportive Care. 2015;13(2):369-83. https://www.cambridge.org/core/journals/palliative-and-supportive-care/article/communication-experiences-of-patients-with-palliative-care-needs-a-systematic-review-and-metasynthesis-of-qualitative-findings/AC097FB89F89AEA04BF4563D4C888E6D ; 2) Barnes S, Gardiner C, Gott M, Payne S, Chady B, Small N, Seamark D, Halpin D. Enhancing patient-professional communication about end-of-life issues in life-limiting conditions: a critical review of the literature. Journal of Pain and Symptom Management. 2012;44(6):866-879. http://www.sciencedirect.com/science/article/pii/S0885392412002060 ; 3) Fawole OA, Dy SM, Wilson RF, Lau BD, Martinez KA, Apostol CC, Vollenweider D, Bass EB, Aslakson RA. A systematic review of communication quality improvement interventions for patients with advanced and serious illness. Journal of General Internal Medicine. 2013;28(4):570-577. https://link.springer.com/article/10.1007%2Fs11606-012-2204-4	1) Focuses on communication with other people e.g. family, not just with health care professionals. Not focused on cancer although many of studies included participants with cancer. 2) Not young people-focused. Review concludes: there is a clear need for further research to lead to the evidence-based development and rigorous evaluation of communication interventions. 3) Most interventions addressed adult mixed-illness populations, predominantly in an intensive care unit setting, and focused either on improvements in family meetings or better utilisation of palliative care consultations.
What are the long-term physical effects of stem cell transplants, how long do they last and how could they be reduced?	More information is clearly being sought, and is needed, for young people to prepare for life after a transplant. **Example submissions:** What are the lengths of hormone imbalances after stem cell transplant? ~ What are the long term implications of STEM cell transplants? Will the side effects get better such as neuropathy or will the patient be left with the side effects for life? What can be done to reduce these if so? ~ What are the long term effects of having a donor stem cell transplant? ~ How long does the fatigue last after stem cell transplant.	**This was one of the 20 questions at the workshop that fell outside of the Top 10. These were not ranked in any order of priority**	No reviews identified.	
For young people with incurable cancer, how should parents/carers communicate with them to improve quality of life and experience?	Communication and sharing information at the right time is a hallmark of good care. Young people with incurable cancer need information to make the best decisions and to live their life to the full. How parents/carers can best communicate with young people will vary, and how they can be supported and educated to do so we still do not know. **Example submissions:** How is the best way to tell your child they are not going to get better ~ How to approach the subject if end of life care?	**This was one of the 20 questions at the workshop that fell outside of the Top 10. These were not ranked in any order of priority**	No reviews identified.	

What are the support needs of the family following the death of a young person with cancer?	Care for families following the death of a young person is recognised to be important, but who needs what, when and from whom, we know less about. **Example submissions:** Why is the family forgotten once a young person dies as this is the time they need the most support? ~ What are the bereavement needs of parents /carers following the death of their young person/child	**This was one of the 20 questions at the workshop that fell outside of the Top 10. These were not ranked in any order of priority**	No reviews identified.	

Teenage and Young Adult Cancer JLA PSP. Details of all questions received by the PSP

Uncertainty	Original uncertainty	Source of Uncertainty	Evidence at time of PSP	Evidence weblink	Does the evidence indicate the question answered/unanswered or is there an ongoing study?	Comments
B1: Are young people with germ cell tumours more likely to develop leukaemia?	Are germ cell cancers and leukaemia linked ~ Would leukaemia been the result of having a germ cell cancer	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	ongoing study	Correspondence with Chief Investigator – confirmed this question will be answered by this ongoing study.
B2: What factors contribute to poorer survival outcomes in young people with breast cancer compared to older women?	Why are younger women with breast cancer more likely to die than older women?	1 x patient			unanswered	
E1: 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)	Why do young people develop cancer? Environmental? ~ Why did a healthy young adult get cancer ~ What is the cause of Hodgkin's lymphoma? ~ What causes hodgkins lymphoma? ~ What causes us to get Leukaemia? ~ Are there any human factors that can affect the chances of developing a tumour on the appendix (and also the bowel itself) e.g. diet, life choices etc , or is it simply down to chance / luck? ~ What is it that causes hormones in the appendix to become cancerous? ~ What causes brain tumours?	6 x patient, 1 x relative, 1 x parent/carer			unanswered	
E2: What key factors (both cancer and individual) determine whether a treatment plan for children or adults will give better outcomes?	What are the clinically relevent differences in drug metabolism in TYA form children which can guide therapy choices? ~ My son was 14 and the question during treatment was whether to use child or adult doses as there was not much data on teensgers. Would like to see more research on this area ~ What is the best way of integrating the instances where the standard paediatric and adult management of the same cancer (e.g. Hodgkin lymphoma) differ? i.e. What is best for the TYA patient in this circumstance? ~ How do we ensure that treatment is suitable for the disease process/biology in a specific cancer in a TYA patient in order that they receive optimum treatment? ~ Why do age limits for clinical trials exist? ~ For drug development do we need phase 1 studies in TYA, why don't all kids over 12 just take the adult dose? ~ How do cancer treatments given in TYA compare to cancer treatments given in younger children and/or adults, and why?	6 x professional, 1 x parent/carer			unanswered	
E3: 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 likely are the chances of my children (if I ever did) and future generations of getting the disease? ~ Is my cancer genetic and am I at risk of passing it on to my future children? ~ What are the chances of my children developing cancer? ~ Is there a genetic link with my type of leukaemia? Could my children inherit it?	4 x patient			unanswered	
E4: 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)	How does the biological features of TYA cancer compare to children or older people? ~ Studying biology to understand whether TYA cancers are biologically more similar to their paediatric or adult counterparts ~ Are TYA brain tumour patients tumours different from those in adults or paediatrics ~ What are the pathological differences between teenage and then young adult Hodgkin lymphoma?	3 x professional, 1 x patient			unanswered	
E5: What is the genetic fingerprint of Ewing's Sarcoma?	What is the genetic fingerprint of Ewings Sarcoma	1 x parent/carer	Correspondence with Sarcoma expert - work on this question is ongoing in several labs. Publications exist from from Delattre/Ladhanyi.		ongoing study	
E6: How many liver cancers in young people are not related to lifestyle choices (diet, health, drinking)?	How rare is liver cancer without it being linked to diet, health or drinking?	1 x patient			unanswered	
E7: Is there an association between early psychosocial adversity (individual and family) and cancer aetiology?	Is there an association between early psychosocial adversity (individual and family) and cancer aetiology?	1 x professional			unanswered	
E8: Why is the incidence of brain cancer in young people high in comparison to older adults?	Why are so many young people getting brain tumours?	1 x patient			unanswered	
E9: Is there a link between HPV (Human papilloma virus) vaccines and blood cancers?	Is there a link between HPV vaccines and blood cancers	1 x parent/carer			unanswered	
E10: What is the interaction between pre-existing immune system disorders and lymphoma?	What is the interaction between pre-existing immune system disorders and lymphoma, and how does treatment for lymphoma affect outcomes for immune system diseases?	1 x parent/carer			unanswered	
E11:How does treatment for lymphoma affect outcomes for immune system diseases?	What is the interaction between pre-existing immune system disorders and lymphoma, and how does treatment for lymphoma affect outcomes for immune system diseases?	1 x parent/carer			unanswered	
E12: How does EBV (Epstein-Barr Virus) interact with T-cells and NK cells?	My grandson has a T-cell/NK cell lymphoma - how does EBV attack T-cells & NK cells. The role of B-cells seems to be well known in combating EBV but I can find very little on T-cells.	1 x relative			unanswered	
E13: Is there an association between young people's cancer and eating disorders?	Is there an association between TYA cancers (especially Hodgkins) and Eating Disorders	1 x professional			unanswered	
P1: How can cancer awareness campaigns be used/adapted to address the needs of young people without creating alarm?	How can family/friends/patients identify early signs/indicators of cancer? ~ How can we adapt health awareness campaigns linked with cancer to address the needs of the teenage and young adult age range without creating inappropriate alarm in the younger age groups? ~ How can we help teenagers and young adults understand potential symptoms of brain cancer without worrying them?	2 x professional, 1 x friend			unanswered	Notes: CanTeen - When Cancer Comes Along: CanTeen's high school cancer education program https://www.canteen.org.au/research/evaluating-school-cancer-awareness-program/ Gill Hubbard has also evaluated Teenage Cancer Trust's school cancer awareness programme. No review found. Steering group agreed need to consider other campaigns as well as school-based, therefore this question is unanswered.
P2: What lifestyle changes can young people make to prevent cancer in young people?	What are the best lifestyle changes to help stop cancer happening?	1 x patient			unanswered	
D1: What General Practitioner or young person strategies, such as awareness campaigns and education, improve early diagnosis for young people with suspected cancer?	What would improve the time to first diagnosis - symptom interval ~ What learning can be taken from the account of newly diagnosed patients about their experience before diagnosis- ie GP, hospital visits. ~ I have heard of a initiative that teenage cancer trust is endeavouring to bring in, A three strikes and your in , so a teenager/young person who is treated by their dr for the same thing is referred for tests, I.e. Cancer, ~ How can we diagnose cancer quicker in TYA ~ How can we get earlier stage diagnosis for young patients? ~ How do we improve delays in diagnosis ~ Could this (educating young people more on the signs and symptoms of cancer in young people) help increase early diagnosis and percentage survival? ~ How can we improve doctor diagnosis/early referral of cancer in young people? ~ How can we help young people presenting with symptoms or signs suggestive of cancer to be more easily recognised and offered diagnostic tests that will identify young people sooner to prevent unnecessary and damaging delays in diagnosis? ~ How to improve earlier diagnosis of cancer in TYA patients ~ How do we improve the diagnositic pathway for all young people to ensure they recieve 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. ? ~ What is being done to ensure that GPs are making an effort to spot signs of cancer in young people? ~ How can we improve the diagnosis and referral pathway for TYA ~ 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. ~ Will young people be educated more on the signs and symptoms of cancer in young people?	8 x professional, 3 x parent/carer, 3 x patient, 3 x friend			unanswered	
D2: 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?	Is there a place for screening of known genetic links for common childhood cancers?	1 x relative			unanswered	
D4: 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?	How important are the check ups every 3 months? ~ What is the balance between scans for reassurance and the damage they might do?	1 x patient, 1 x parent/carer			unanswered	Steering group discussed this review protocol: Høeg BL, Bidstrup PE, Allerslev Horsboel T, Dalton SO, Saltbæk L, Karlsen RV, Andersen KK, Johansen C. Follow-up strategies following completion of primary cancer treatment in adult cancer survivors (Protocol). Cochrane Database of Systematic Reviews 2016, Issue 11. Art. No.: CD012425. DOI: 10.1002/14651858.CD012425. http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD012425/full Focuses on adults aged 18+ - Steering Group agreed that this question will probably remain unanswered for young people.

D5: 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?	How do we ensure that all TYA get tumour molecular profiling	1 x professional			unanswered	
D6: What factors affect the time to diagnosis and what outcomes are affected?	Average delay in diagnosis due to age of patient? Ie clinical staff assuming you are too young for cancer ~ Why are GP''s lacking in awareness of the possible combo of symptoms that indicate something's happening. None one their own are enough,but together are worth upping the investigations. ~ Does diagnostic delay exist in local Aya population? ~ What signs and symptoms allow early recognition if sarcoma in young people? ~ What are the routes to diagnosis in TYA with cancer that are amenable to improvement? ~ Why do we have longer delays in diagnosis of cancer in this age group than any other country in Europe? ~ Why are GPs not picking up signs of cancer in young people? ~ How often are symptoms missed by GPs and how often are TYA with cancer treated for 'growing pains' before referral for appropriate testing? ~ Why do GP's not pick up cancer in teenagers and young adults? ~ Why can leukaemia have very little side effects and then take hold so quick ~How do socio-economic factors influence young adult's time to diagnosis and choice in their place of care? ~ Have we concrete evidence delays impact on survival (worse stage disease more metastatic disease etc) ~ What is the average wait between 1st symptoms and start of appropriate treatment ~ Route to diagnosis ~Could this (educating young people more on the signs and symptoms of cancer in young people) help increase early diagnosis and percentage survival?	7 x professional, 2 x parent/carer, 4 x patient, 1 x friend, 1 X relative			unanswered	
D7: In young peole on cancer treatment, what safety netting (information / support / education) can be given to improve the appropriate management and reduce toxic complications?	What do teenagers and young adults need for good safety needing for primary care I.e. Written information, websites etc.	1 x professional			unanswered	
T1: What impact does eating well during treatment have on patient outcomes?	What is the best diet to eat whilst I am on treatment? ~ Does a different diet help compliment chemotherapy? ~ What nutritional / supplements support work well to enhance chemotherapy ? to enhance radiotherapy? Why do most conventional medical approaches suggest removing all supplements during treatment? ~ What foods are good to gain weight in cancer ~ Are there specific foods that should be avoided during treatment that may hinder the treatment; equally are there certain foods that will assist the treatment or that can even be a part of the treatments? ~ What foods should we stay away from? ~ What kind of diet should a cancer patient or any person have to be healthy? A lot of people say a lot of things about diet. Ie "you should have gluten free foods", "you should become dairy free" etc Who is right and what should we follow? ~ How to put all the weight back on after treatment has finished	1 x professional, 2 x parent/carer, 4 x patient, 1 x friend			unanswered	
T2: What is the role and how effective is cannabis oil in treatment for young people with cancer?	Why is cannabis not being researched as a cure/aid to cancer treatment. ~ To what extent is marijuana oil/marijuana an effective option for getting rid of cancer cells? ~ What research is currently being undertaken regarding the use of cannabis in cancer treatment/symptom management? ~ Should medical professionals routinely explain to patients that certain treatments (particularly cannabis oil) have been shown to be effective in treating some cancers and though currently still illegal in the UK they are legally available for medical purposes in many European countries (e.g. Spain, Portugal, Netherlands) and several US states, and elsewhere?	2 x parent/carer, 1 x professional, 1 x patient			unanswered	
T3: What is the best treatment for brain cancers to increase survival and decrease toxicity?	Whether brain tumour patients should have intrathecal chemotherapy following/alongside their first initial treatment plan? As often their first initial treatment can put their cancer into all clear for number of years but then relapse. So the theory that intrathecal chemotherapy might mop up cells that are undetected on follow up scans. ~ What is the best treatment protocol for relapsed mixed germ cell brain tumour ~ What is the recommended protocol for re-irradiation of the brain ? ~ Why can we not find better and safer ways for treating brain tumours without causing damage to young people? ~ What treatment will eliminate an inoperable low grade tumour in the third ventricle? ~ What treatments will cure aninoperable brain tumour? ~ Is there a better way to deliver chemotherapy to brain tumours?	1 x partner, 6 x parent/carer			unanswered	
T4: Do the benefits outweigh the risks of continuing to use steroids in maintenance as part of the treatment protocol for young people with leukaemia?	Do the benefits outweigh the risks of continuing to use steroids in maintanece as part of the treatment protocol for leukimia?	1 x patient	Ongoing study: United Kingdom Trial for children and young adults with Acute lymphoblastic Leukaemia and Lymphoma 2011	http://www.cancerresearchuk.org/about-cancer/find-a-clinical-trial/a-trial-looking-treatment-children-young-people-acute-lymphoblastic-leukaemia-lymphoma-ukall-2011#undefined	ongoing study	Correspondence with expert haematologist - This question is being studied in the current ALL trial which includes TYA patients up to 25th birthday, UKALL2011
T5: Is proton radiotherapy more effective than photon radiotherapy for young people with brain tumours?	Is proton radiotherapy better than photon radiotherapy for children with brain tumours?	1 x parent/carer			unanswered	
T6: Is the use of Vincristine and Dexamethasone pulses required during maintenance treatment in young people with cancer?	Is the use of Vincristine and Dexamethasone pulses really required during Maintenance treatment?	1 x patient	Ongoing study: United Kingdom Trial for children and young adults with Acute lymphoblastic Leukaemia and Lymphoma 2011	http://www.cancerresearchuk.org/about-cancer/find-a-clinical-trial/a-trial-looking-treatment-children-young-people-acute-lymphoblastic-leukaemia-lymphoma-ukall-2011#undefined	ongoing study	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.
T7: What is the best treatment for young people with relapsed bone and soft tissue sarcomas?	What is the best treatment for relapsed bone cancers osteosarcoma and ewings?	1 x professional			unanswered	
T8: What targeted therapies are effective for young people with Ewing's Sarcoma?	Will targeted therapies work for Ewings Sarcoma	1 x parent/carer	Correspondence with Sarcoma expert - early phase studies are currently under way.		ongoing study	
T9: Why is Ewing's sarcoma drug resistant in some young people?	Why does Ewing's sarcoma not respond to chemo drugs	1 x parent/carer			unanswered	
T10: How can young people with osteosarcoma of the leg be successfully treated without amputation?	Will there ever be a successful alternative other than amputation for osteosracoma in the leg?	1 x patient	1) Salang K, Foocharoen T, Laopaiboon M, Jirarattanaphochai 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.; 2) 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.	1) http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD012146/full ; 2) https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3493816/	answered	Correspondence with Sarcoma expert - Most young people are treated successfully without amputation. Amputation rates ~ 10%
T11: Do PD1 pathway affecting drugs have a role in the treatment of young people with bone and soft tissue sarcomas?	Do PD1 pathway affecting drugs have a role in the treatment of bone & soft tissue sarcomas?	1 x professional	Correspondence with Sarcoma expert - work on this question is ongoing and some trials have reported in abstract.		ongoing study	
T12: How should we investigate novel targeted therapies in rare cancers?	How should we investigate novel targeted therapies in rare cancers?	1 x professional			unanswered	
T13: Is ABVD (adriamycin; bleomycin; vinblastine; dacarbazine) equally effective if bleomycin is omitted?	Is abvd equally effective if bleomycin is omitted?	1 x parent/carer			unanswered	
T14: What are the survival outcomes of second stem cell transplant for young people with cancer?	Do second STEM cell transplants work?	1 x friend			unanswered	
T15: Does a cancer diagnosis and treatment in young people during puberty affect survival?	What research is being done on correlating agressive cancer outcomes with point patient is with puberty at onset or during course of illness?	1 x relative			unanswered	
T17: What treatment is most effective for relapsed leukaemia in young people?	How can we cure young people with leukaemia who have had disease recurrence following standard treatments	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&rslt=&recrs=b&recrs=a&recrs=f&recrs=e&age_v=&gndr=&cond=Leukemia&intr=&titles=&outc=&spons=&lead=&id=&cntry1=&state1=&cntry2=&state2=&cntry3=&state3=&locn=&phase=2&sfpd_s=&sfpd_e=&lupd_s=&lupd_e=	ongoing study	138 studies recruiting or in set up
T18: What targeted treatments are effective and have fewer short and long term side-effects?	Are there more target treatment being developed that are better for the body's than chemo? ~ Is it possible to find agents which have fewer short and long term side effects?	1 x parent/carer, 1 x patient			unanswered	
T19: What are the most effective treatments for rare cancers in young people such as Sertoli cell tumours?	What are the most effective treatments for rare cancers such as Sertoli cell tumours	1 x parent/carer			unanswered	
PC1: 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 long term phycological effects on Cancer on a young person ~ What are the long term psychological effects of a cancer diagnosis/treatment on young adults/teenagers? ~ What is psychological impact poat treatment on young person and what input can be offered? ~ Will the traumas affect their mental health in later life? ~ What are the risks mental adverse health outcomes among survivors of TYA cancer ~ What is the long term psychological impact of having cancer as a child/young person and what can be done to alleviate negative impact? ~ What comes after cancer long term effects mentally and physically ~ Will the treatment affect the patient in adulthood? ~ What happens after treatment and having to live with the aftermath? Several years later? ~ Psychology impact of cancer On patient and family ~ What are the common emotional needs during and following treatment? ~ How do we prevent the high levels of mental illness seen in cancer survivors treated in the TYA age group? What are the levels of mental illness in this group post treatment? ~ What is the prevalence of PTSD within cancer survivors? ~ Why does the support disappear after treatment when it has been proven that a high % of patients suffer with PTSD and other mental illnesses once in remission? ~ is depression after cancer normal? ~ What are the most common mental health consequences of cancer treatment in teenagers and young adults?	6 x parent/carer, 7 x patient, 3 x professionals			unanswered	

PC2: What are the best ways to support young people getting back to 'everyday' life after treatment? (This question was asked about all cancers and specifically about brain tumours)	What is the most effective way of not having to think about the illness and just get on with life? ~ How can we best support AYAs in their integration back to "normality" after treatment ~ How can we help TYA patients with brain tumours get back to normal life ~ Should teenagers facing cancer have the same level of input into their mental health as they do in their physical health and should more cancer patients receive therapy to help them understand not only what is happening to them but the long term implications and help them to enter back into normal life following successful treatment? ~ What are the best ways/techniques to help young people integrate back into their normal lives after cancer treatment? ~ What is the best way to help young people come to terms with what has happened to them and rebuild a life beyond cancer ~ Suvivorship and reintegration into society. Patients experience of what influences the trasisition from being a patient to returning to normality - post treatment. ~ What are the best ways to help young people and their families come to terms with what has happened to them after treatment, and to deal with survivorship and normal life after treatment? ~ How do I fit back into society post treatment ? ~ How do we improve social re-integration after cancer in TYA? ~ how do we support young people to return to education and work? ~ What forms of assistance are most useful for young people returning to work after treatment? ~ Returning to education was so important to my son, but it felt like there was no one specific to answer our questions or give us help. Do young people feel it would benefit them to have a key worker assigned to them who would know their case and be able to help? ~ When a child goes into the working work and can't deal with it, who do they turn to? ~ How to return to work and normal life after going through cancer. ~ Do people need more support about going back to work ~ WHAT ABOUT LIAISON WIHT EDUCAION AND WORK, HOW TO ENSURE ALL YOUNG POLE HAVE ACCESS TO OPPORTUNITIES GOING FORWARD	7 x professional, 8 x patient, 1 x partner, 1 x relative			unanswered	
PC3: How effective is rehabilitation in assisting recovery from cancer?	Does rehabilitation help in the recovery from cancer? ~ What is the role of pre and rehabilitation in tya oncology?	1 x patient, 1 x professional			unanswered	
PC4: What is the ideal period of psychological support after treatment?	Why does the support disappear after treatment when it has been proven that a high % of patients suffer with PTSD and other mental illnesses once in remission?	1 x patient			unanswered	
PC5: How do young people describe the impact of a cancer diagnosis once treatment is completed at one year and two years?	What issues are survivors faced with 'in their words' 1 year, 2 years....off treatment?	1 x professional			unanswered	
PC6: What can young people do to help their recovery after chemotherapy or radiotherapy?	How Can a patient help their recovery after chemo/radiotherapy	1 x friend			unanswered	
PC7: 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?	Do young people that have had cancer, worry about passing cancer onto children, or not being around for them?	1 x patient			unanswered	
PC8: What is the psychological impact of hospital isolation (hospitalisation in single rooms) whether short term or long term when hospitalised?	psychological impact of isolation whether short term or long term when hospitalised?	1 x professional			unanswered	
PC9: How does having cancer as a young person shape identity across the life course?	How do does TYAC shape identity across the life course?	1 x professional			unanswered	
PC10: What is the best strategy for young people restarting fitness and exercise after treatment?	How to re-start fitness/exercise post treatment.	1 x professional			unanswered	
PC11: How can patient-reported outcome measures be used to improve care for young people?	Can patient-reported outcomes be used to improve clinical practice in AYA with cancer?	1 x professional			unanswered	
PC13: 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?	How frequently are young adults able to remain in their own home during cancer treatment vs. needing to move back in with parents, and how does this affect their mental health and quality of life?	1 x partner			unanswered	
PC14: How does having cancer as a teenager or young adult affect a person socially and emotionally in later life?	What is the nature of the life-stage disruptors for TYA, socially and emotionally?	1 x professional			unanswered	
PC15: Do young people receiving mental health therapies do better than those receiving physical treatment only?	Should teenagers facing cancer have the same level of input into their mental health as they do in their physical health and should more cancer patients receive therapy to help them understand not only what is happening to them but the long term implications and help them to enter back into normal life following successful treatment?	1 x partner			unanswered	
PC16: How effective is pre-habilitation in assisting recovery from cancer?	What is the role of pre and rehabilitation in tya oncology?	1 x professional			unanswered	
ES1: What interventions are most effective in supporting young people who are experiencing fatigue/tiredness when returning to work or education?	What can be done to support those going back to school/work when suffering from significant fatigue? ~ Cancer can make you change your life for the better. Is there any help for those who want to go back to uni? Working and studying isn't an option due to tiredness. ~ What is the best way to keep up with education after a major surgery or when constantly fatigued?	3 x patient			unanswered	
ES2: How are career choices and prospects affected by a cancer diagnosis and are some groups more at risk of encountering issues than others?	what are the long term impacts of a cancer diagnosis on employment/career prospects and how can these be mitigated ~ Are young people that have had cancer, more likely to have difficulty holding down work? ~ What impact did your diagnosis and treatment have on your work/career choices. ~ Why are educational and work-related outcomes so poor in many TYA survivors, and are there differences in which survivors are most affected?	3 x professional, 1 x patient			unanswered	
ES3: How do education outcomes for young people with cancer compare to young people without cancer?	Why are educational and work-related outcomes so poor in many TYA survivors, and are there differences in which survivors are most affected? ~ What impact did your diagnosis and treatment have on your education ~ How has your disgnosise affect your education and what can we do to help ~ How do the academic achievements of TYA who have been treated for cancer compare with other TYA?	3 x professional, 1 x patient	1) Review protocol: Andrew Thomas, Defne Saatchi, Alastair Sutcliffe. Educational progression of survivors of cancer diagnosed in childhood: a systematic review. PROSPERO 2017:CRD42017057501 2) ongoing study at UCL (see comments box)	http://www.crd.york.ac.uk/PROSPERO/display_record.asp?ID=CRD42017057501	ongoing study	Ongoing study: Study at UCL looking at this in children/teenagers: Educational Outcomes Following Childhood Cancer in England: A Population Based Linkage Study: Researchers at University College London are interested in finding out whether educational outcomes differ between children who have had a diagnosis of cancer and children in the general population. They will compare the educational outcomes at Key Stages 1-5 of children who have had cancer to their siblings and to other children who have not had cancer. The researchers also want to be able to influence educational policy to ensure children with childhood cancer receive appropriate educational support. They want to be able to answer the following questions: 1) Do children with different diagnoses of cancer (brain tumours, leukaemia, soft tissue tumours) perform differently during their Key Stages 1-5? 2) Do children who undergo specific treatments (radiotherapy vs. chemotherapy) perform differently during their Key Stages 1-5? 3) Do children who had cancer before starting school perform differently compared to those who have cancer during school years? 4) Do children who have had cancer during school years catch up with their peers during their Key Stages 1-5? 5) Do siblings of children who have had cancer perform differently to their peers during their Key Stages 1-5? 6) Do children with cancer have differing number of Special Educational Needs Status (SEN) and exclusion levels?
ES4: 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)	Why are universities so ill-equipped and uninformed for dealing with students with cancer? ~ Why aren't schools better educated to support teenagers who develop cancer? ~ Why is the understanding of schools so poor about cancer ~ Why is it hard to obtain support around brain tumours for under 16's. my son is now 17 and his current college is struggling and there is more talk of exclusion in a 'specialist' college when all through school it was about inclusion ~ What is the best way for school friends to provide support when a cancer patient is off school for long periods during treatment? ~ What support can a school provide a child or teenager with a brain tumour to reduce or eliminate the isolation of living with a brain tumour?	2 x patient, 4 x parent/carer			unanswered	
ES5: How are young people best supported to reintegrate with their peers when returning to school?	Is there help offered to patients when returning back to school when it comes to having to socialise again with their year group	1 x patient			unanswered	
ES6: What interventions are most effective in supporting young people to maintain their social lives whilst on treatment?	what is the most effective way of allowing children to stay up to speed with their school work and social life whilst spending so much time in hospital having treatment?	1 x patient			unanswered	
ES7: What interventions are most effective in supporting young people to maintain their education whilst on treatment?	what is the most effective way of allowing children to stay up to speed with their school work and social life whilst spending so much time in hospital having treatment? ~ is there work ongoing with other agencies - education, apprenticeships, work etc to support the intermittent nature of treatment and recovery with flexibility, benefits support and adaptations ~ A lot of teenagers and young adults suffer from rejection from universities due to not having the grades they need. This then means it costs them money to sit further exams if they are not of school age. They are also not recognised as mature students. Is there any way to help this situation? ~ How my teenage son is able to deal with the loss of education.	2 x patient, 1 x professional, 1 x parent/carer			unanswered	
ES8: 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 percentage of time is lost from school in TYA patients with cancer, leukaemia and brain tumours stratified by those diagnoses (possible subdiagnoses if sufficient numbers) in the 6 monthys before diagnosis, in the 6 months after diagnosies, in the next 6 months and then annually until the July after age 18 (may be better to analyse this by academic year)	1 x professional			unanswered	

ES9: How can schools and teachers better support young people with memory problems following cancer?	With memory problems with in school how will teachers be properly talked to about dealing with a pupil with more needs who have over come tumours and cancer?	1 x patient			unanswered	
ES10: What are the financial stresses on young people with cancer and their families?	Financial stress on cancer patients and family	1 x patient	Cancer Costs report by CLIC Sargent; No Small Change report by Macmillan Cancer Support	https://2efg7n2isxpg3ktk27mal9t1-wpengine.netdna-ssl.com/wp-	partially answered	Reports by CLIC Sargent and Macmillan partially answer this question but are not specifically focused on young people
ES11: What interventions can reduce the potential negative impact of a cancer diagnosis on a young person's employment and career prospects?	what are the long term impacts of a cancer diagnosis on employment/career prospects and how can these be mitigated	1 x professional			unanswered	
ES12: What interventions are most effective in supporting young people when returning to education or work?	How has your disgnosise affect your education and what can we do to help ~ is there work ongoing with other agencies - education, apprenticeships, work etc to support the intermittent nature of treatment and recovery with flexibility, benefits support and adaptations ~ A lot of teenagers and young adults suffer from rejection from universities due to not having the grades they need. This then means it costs them money to sit further exams if they are not of school age. They are also not recognised as mature students. Is there any way to help this situation? ~ how do we support young people to return to education and work? ~ What forms of assistance are most useful for young people returning to work after treatment? ~ Returning to education was so important to my son, but it felt like there was no one specific to answer our questions or give us help. Do young people feel it would benefit them to have a key worker assigned to them who would know their case and be able to help? ~ When a child goes into the working work and can't deal with it, who do they turn to? ~ How to return to work and normal life after going through cancer. ~ Do people need more support about going back to work ~ WHAT ABOUT LIAISON WIHT EDUCAION AND WORK, HOW TO ENSURE ALL YOUNG POLE HAVE ACCESS TO OPPORTUNITIES GOING FORWARD	6 x patient, 3 x professional, 1 x relative			unanswered	
R1: What fertility preservation techniques are effective for young women with cancer?	Can eggs from teenage girls be frozen for future plans ? ~ Can eggs from teenage girls be frozen for future plans ? ~ What new options are there for preserving female fertility? ~ What is the optimal strategy for fertility preservation among female TYA patients? ~ What female fertility preservation options and future fertility predictors are practically possible across the NHS? ~ Do we thoroughly explore fertility preservation in young women prior to starting chemotherapy?	2 x patient, 3 x professional, 1 x parent/carer	British Fertility Society Policy and Practice Guideline is under development		ongoing study	Correspondence with fertility expert - British Fertility Society Policy and Practice Guideline is under development.
R2: What information and support is required to improve patient experience and psychological wellbeing in young people with cancer exploring fertility preservation options?	What more support for fertility issues can be offered? ~ Support and guidance for him at 14yo regarding sperm banking. How does a 14yo make that choice or decision? ~ Why is fertility options for female not discussed in more detail before starting treatment?	2 x patient, 1 x parent/carer			unanswered	
R3: What is the psychological impact for young people whose fertility has been affected by treatment?	What is psychological impact on young person whose fertility has been affected by their treatment?	1 x parent/carer			unanswered	
R4: What are the long term effects on fertility for males who received high intensity chemotherapy?	What are the long term effects on fertility for a young male adult who received high intensity chemotherapy? (Chances of fertility returning)	1 x partner			unanswered	
R5: What is the long term impact of different cancer treatments on the fertility of women who are treated as young adults?	What is the long term impact of different cancer treatments on the fertility of women who are treated as children or young adults?	1 x patient			unanswered	
R6: What is the best intervention to support young women psychologically when their fertility has been affected by cancer?	Infertility as a consequence of treatment , what psychological help would benefit those young women still single and at what point .	1 x parent/carer			unanswered	
LT1: What causes problems with cognitive functioning (chemobrain), how long do they last and what are the most effective treatments and strategies?	What is chemo brain and how is it caused ~ Why does 'chemo brain' happen and who is more likely to be susceptible to it? ~ How long do the affects of chemo brain last? ~ How are you cognitively (memory, processing, planning etc) effected 10+ years after chemotherapy? ~ Chemo Brain - Is there any way of preventing it or treating it after main treatment? ~ Is there going to be research of combating the effects of chemo brain in young people to reduce side effects later in life? ~ Are there any treatments/things that can help with 'chemo-brain'? ~ What are the effective ways of supporting young people with cognitive late effects oftreatment?	6 x patient, 1 x friend, 1 x professional			unanswered	
LT2: 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)	How long after cancer do the side effects last? ~ Will my side effects go on forever? ~ When will my body get back to normal after treatment? ~ Can you still be affected by treatment 6 years later? ~ What issues are caused by chemotherapy/radiotherapy treatment after completing and how long do they last? ~ What are the long term side effects of cancer and its treatment, and how long can it take for these side effects to show? ~ What happens to young people after hodkins treatment ? How is their quality of life affected in later adulthood. Do they get more cancer ? ~ How long do the side effects of treatment last with relation to nerve pain? ~ What are the common after effects of chemotherapy treatment? ~ Will the treatment affect the patient in adulthood? ~ What are the most common late effects in tyas? ~ What are the late effects of treatment for young adult cancer patients? ~ Are there any life long side effects fro my treatment? ~ what is the liklihood of further complications to health in years to come? ~ What are the long term health problem associated with certain cancer treatments? (E.g. affects of radiotherapy on the heart and long term effects of healed lung tumours - will they present any lung health implications later in life?) ~ What are the long term consequences of receiving cytotoxic drug therapies in young adulthood (e.g. early twenties)? ~ What is the late effects burden of treatment of TYA cancer? ~ What are the (quantified) risks of long-term term effects (morbidity and mortality) of cancer and cancer treatments for TYA patients? (There is much research for paediatric patients, but much less for the TYA group) ~ What are the repercussions of the treatments given? ~ What issues are caused by chemotherapy/radiotherapy treatment after completing and how long do they last? ~ Which are the most significant long term risks ~ What are the long term side effects of cancer and its treatment, and how long can it take for these side effects to show? ~ What are the risks of physical adverse health outcomes among survivors of TYA cancer ~ What impact could be treatment have on me physically in the long term? If not known, what has so far been discovered by drug type/regimen in terms of expected effects? ~ What comes after cancer long term effects mentally and physically ~ What happens after treatment and having to live with the aftermath? Several years later? ~ Do young people have particular survivorship issues and how best managed. ~ what are the long term consequences of more modern treatment regimens for leukaemia that do not include radiation ~ What are the long term affects on day to day life for thyroid cancer survivors? ~ What are the possible late effects of spinal radiation? ~ Can surgery impact on an individual in later life? (if not had a detrimental affect during treatment) ~ Long term neurocognitive sequelae after brain tumours (+ 7 years) ~ Long term neurocognitive sequelae following ALL (+ 5 years) ~ What are the long term neurological effects on post transplant patients in particular DAN and peripheral neuropathy? ~ How long after a bone marrow transplant can you develop growth hormone deficiency? At what interval are patients tested? ~ What is the long term effects of being on Mercaptopurine and Methotrexate tablets during Maintenance treatment? ~ How and why does chemotherapy affect the body after finishing treatment for such a long time? (e.g. health problems as a result of chemo from years before) ~ Why do survivors suffer with pain conditions? ~ Is there research being conducted to help people with long term effects of treatment to know what to expect?	21 x patient, 6 x parent/carer, 8 x professional, 3 x partner, 1 x relative			unanswered	
LT3: Following cancer treatment, do young people have different cognitive functioning ('chemobrain') compared to young people without cancer?	Is there such thing as Chemo Brain? ~ What is the impact of cancer treatment on the teenagers brain development.	1 x patient, 1 x professional			unanswered	
LT4: What factors influence poorer health and psychological outcomes?	What are the factors that increase the risks of adverse health outcomes among TYA cancer survivors ~ Which patients have the hardest time adjusting to their survivorship experience in terms of physical and psychosocial side-effects?	2 x professional			unanswered	
LT5: In young people with cancer, what information should be delivered and by whom to improve knowledge and satisfaction and wellbeing?	What sort of physical and psychosocial issues should different healthcare professionals address/discuss primarily with TYA patients before and after their treatment out of all the ones literature suggests to be important?	1 x professional			unanswered	
LT6: In young people exposed to ototoxic agents, how long should hearing tests/assessments be undertaken in follow-up?	Should patients have regular follow up audiology assessments if received chemotherapy drugs that potentially could harm hearing in later life, even though their hearing might be of normal level after initial treatment.	1 x partner			unanswered	
LT7: 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 is the prevalence of avascular necrosis in young adult survivors and what are the best treatment options? ~ What causes avascular necrosis and what's being done to prevent this side effect? ~ What is the experience of TYA living with steroid induced avascular necrosis? ~ My son has avascular necrosis as a result of high dose steroids in his trial, could this be detected earlier other than when it becomes noticeable	2 x patient, 1 x professional, 1 x parent/carer			unanswered	
LT8: In young people who have anticancer treatments, are they at increased risk of autoimmune disease in later life?	The long term affect or chemo drugs and links to other conditions such as autoimmune diseases	1 x patient			unanswered	
LT9: Do young people with Hodgkin's disease have a higher incidence of second cancers than young people with other cancers?	What happens to young people after hodkins treatment ? How is their quality of life affected in later adulthood. Do they get more cancer ?	1 x patient	1) Second cancers among survivors of teenager and young adult cancer, National Cancer Intelligence Network Data Briefing 2) Ongoing study: Teenage and Young Adult Cancer Survivor Study	1) http://www.ncin.org.uk/view?rid=1606 2) http://www.birmingham.ac.uk/research/activity/mds/projects/HaPS/PHEB/CCCSS/TYACSS/index.aspx	ongoing study	Correspondence with Chief Investigator – confirmed this question will be answered by this ongoing study.
LT10: Do young people with posterior fossa tumours have higher rates of Autistic Spectrum Diagnoses than young people with other cancers/general population?	Frequency of traits of ASD following brain tumours (esp. posterior fossa tumours) - is there such a thing as 'aquired ASD'?	1 x professional			unanswered	
LT11: What are the long-term physical effects of stem cell transplants, how long do they last and how could they be reduced?	What are the lengths of hormone imbalances after stem cell transplant? ~ What are the long term implications of STEM cell transplants? Will the side effects get better such as neuropathy or will the patient be left with the side effects for life? What can be done to reduce these if so? ~ What are the long term effects of having a donor stem cell transplant? ~ How long does the fatigue last after stem cell transplant.	2 x patient, 1 x friend, 1 x parent/carer			unanswered	
LT12: Does taking blood thinners long-term cause health problems?	Will the life long blood thinners taken cause health problems in the future.	1 x parent/carer			unanswered	

SM1: 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?	Fatigue - Why do patient struggle with fatigue after chemotherapy? ~ How long do the side effects of treatment last with relation to fatigue? ~ Is there anything that can help with chronic fatigue following treatment? ~ How do you manage long term fatigue? ~ Tiredness and fatigue is a big problem within recovery. How can we overcome this? ~ Is there a role for psychostimulants to help TYA patients to cope with fatigue during and after treatment? ~ What fitness technique is best at reducing the fatigue experienced when on and off treatment? ~ What would be an effective treatment for cancer-related fatigue in TYAs? ~ What are the best ways to manage Chronic Fatigue, and are there any Chronic Fatigue specialists at hospitals? ~ Is there any supplements which would help overcome tiredness/exhaustion related to treatment or tiredness/exhaustion after treatment is finished?	8 x patient, 2 x professional	Boonstra A, van Dulmen-den Broeder E, Rovers MM, Blijlevens N, Knoop H, Loonen J. Severe fatigue in childhood cancer survivors (Protocol). Cochrane Database of Systematic Reviews 2017, Issue 6. Art. No.: CD012681. DOI: 10.1002/14651858.CD012681. Tomlinson D1, Diorio C, Beyene J, Sung L. Am J Phys Med Rehabil. 2014 Aug;93(8):675-86. doi: 10.1097/PHM.0000000000000083. Effect of exercise on cancer-related fatigue: a meta-analysis.	http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD012681/full https://www.ncbi.nlm.nih.gov/pubmed/24743466	unanswered	Steering Group added 'apart from exercise' to question as exercise part is answered - Know exercise is effective but unknown what other interventions help.
SM2: What are the differences in outcomes when febrile neutropenia/neutropenia is managed as outpatient compared to inpatient?	Can young people with febrile neutropenia safely be managed as out-patients? ~ Are there any real benefits of keeping neutropenic patients in hospital?	1 x patient, 1 x professional			unanswered	
SM3: What are the barriers and motivators to exercise during and after treatment?	What are the most effective ways of supporting young people (during or after cancer) to be more physically active? ~ What are the barriers to exercising during and after treatment ~ Adherence to physical activity - barriers and motivators	3 x professional			unanswered	
SM4: What interventions, including self-care, can reduce or reverse adverse short and long term effects of cancer treatment?	What's the best way to avoid long-term complications from treatment? ~ Can some of the damage caused by the illness and treatment be reversed ? ~ It's there any way out reducing long term side effects of treatment? ~ What are the best ways to help people with long term effects after treatment.	3 x parent/carer, 1 x patient			unanswered	
SM5: Are there effective less toxic treatments to corticosteriods for young people with cancer?	dexamethazone is often given to lessen the pressure of brain tumour. Whilst it's good for the brain it can be very bad for the mind. What options are there? Is there any other drug that would counter the scary psychotic effect? ~ Are there any other less harmful drugs that can be used instead of corticosteroids like Dexamethasone for cancer treatment?	1 x parent, 1 x professional			unanswered	
SM6: Does appropriate physical challenge improve confidence post treatment in young people with cancer?	Does appropriate physical challenge improve confidence post treatment?	1 x professional			unanswered	
SM7: What are the outcomes associated with physical activity during treatment for young people with cancer on managing fatigue?	To have an understanding of what are the effects, if any, of physical activity during treatment on the side effects of chemotherapy, including managing fatigue, social isolation and returning to school, leisure, work.	1 x professional	Am J Phys Med Rehabil. 2014 Aug;93(8):675-86. doi: 10.1097/PHM.0000000000000083. Effect of exercise on cancer-related fatigue: a meta-analysis. Tomlinson D1, Diorio C, Beyene J, Sung L.	https://www.ncbi.nlm.nih.gov/pubmed/24743466	answered	
SM8: How can the short and long term negative effects of radiotherapy be reduced?	How can the risks with radiotherapy be reduced?	1 x patient			unanswered	
SM9: Does the use of low-level laser therapy reduce the incidence of mucositis in highly mucositis provoking chemotherapy regimens for young people with cancer?	Does the use of low-level laser therapy reduce the incidence of mucositis in highly mucositis provoking chemotherapy regimens?	1 x professional	Oberoi S, Zamperlini-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	answered	
SM10: Is it safe to use NSAIDs (non-steroidal anti-inflammatory drugs) as an analgesic in young people undergoing chemotherapy treatment?	Is it safe to use NSAIDs as an analgesic in young people undergoing chemotherapy treatment?	1 x professional			unanswered	
SM11: What alternatives are there to loperamide for treating chemotherapy-induced diarrhoea?	What alternatives are there to loperamide for treating chemotherapy-induced diarrhoea, especially in patients without a colon?	1 x patient			unanswered	
SM12: How can sleep be improved in young people undergoing cancer treatment?	How can sleep be improved in teenagers undergoing cancer treatment?	1 x professional			unanswered	
SM13: Are the early warning indicators of sepsis the same in children, young people and adults?	Do TYA patients show the same early warning predictors when in sepsis as older and younger patients?	1 x professional			unanswered	
SM14: How does protocol adherence and toxicity impact prognosis for young people with cancer?	The prognosis at diagnosis is usually well reported. What is the prognosis at the end of treatment, given the new knowledge about adherence, compliance, toxicity, treatment actually received, etc?	1 x parent/carer	Systematic review protocol in this area is in development.		ongoing study	Correspondence with paediatric expert - A protocol for a systematic review in this area is in development.
SM15: Does early detection and treatment of GVHD (graft-versus-host disease) impact on recovery time for young people with cancer?	How long does gvhd last for if caught straight away	1 x patient			unanswered	
SM16: What is the most effective hormone support for post-transplant female survivors?	What is the best hormone support for post transplant female survivors?	1 x parent/carer			unanswered	
SM17: What is the relationship between daunorubicin and cytarabine doses and bowel problems?	Can big doses of Daunorubicin and Cytarabin cause bowl problems?	1 x patient			unanswered	
SM18: How can hair growth be stimulated following radiotherapy in young people with cancer?	After radio therapy with hair how can it become healthier and thicker? Back to normal for the patient?	1 x patient			unanswered	
SM19: How can we minimise the vascular effects of cisplatin in young people with cancer?	What can be done to minimise the vascular effects of cisplatin based chemotherapy ?	1 x professional			unanswered	
SM20: What are the factors that predict life threatening chemotherapy side effects?	Why do some people react with life threatening side effects to chemotherapy. I.e. Kidney failure, swelling of brain, heart and lung damage	1 x parent/carer			unanswered	
SM21: What is the incidence of heart disease and second cancers in young people following ABVD?	What is the likelihood of heart disease or another cancer after abvd?	1 x parent/carer	1) Henson KE, Reulen RC, Winter DL, et al. Cardiac Mortality Among 200 000 Five-Year Survivors of Cancer Diagnosed at 15 to 39 Years of Age: The Teenage and Young Adult Cancer Survivor Study. Circulation. 2016;134(20):1519-1531. doi:10.1161/CIRCULATIONAHA.116.022514. (see Table 4) 2) Ongoing study: Teenage and Young Adult Cancer Survivor Study	1) https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5106083/ 2) http://www.birmingham.ac.uk/research/activity/mds/projects/HaPS/PHEB/CCCSS/TYACSS/index.aspx	ongoing study	
SM22: How do disease and treatment impact patient experience of symptoms for young people with cancer?	What are the symptom burden experiences of TYA with cancer?	1 x professional			unanswered	
SM23: Would taking T3 alongside T4 after a thyroidectomy help with tiredness even when bloods are normal when taking T4 alone?	Would taking T3 alongside T4 after a thyroidectomy help with tiredness even when your bloods are normal when taking T4 alone?	1 x patient			unanswered	
SM24: How can GI (gastrointestinal) side effects be diagnosed and managed more effectively in young people with cancer?	Many GI side effects are not properly diagnosed. Have there been any longitudinal studies researching this?	1 x parent/carer			unanswered	
SM25: What are the side effects of chemotherapy in young people with cancer?	What are the side effect of chemo	1 x patient	1) 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; 2) Bukowinski AJ, Burns KC, Parsons K, Perentesis JP, O'Brien MM.Semin Oncol Nurs. 2015 Aug;31(3):216-26. doi: 10.1016/j.soncn.2015.05.003. Epub 2015 May 7. Toxicity of Cancer Therapy in Adolescents and Young Adults (AYAs).	1) http://www.bmj.com/content/354/bmj.i4567.long 2) https://www.ncbi.nlm.nih.gov/pubmed/26210200	answered	
SM26: 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?	To have an understanding of what are the effects, if any, of physical activity during treatment on the side effects of chemotherapy, including managing fatigue, social isolation and returning to school, leisure, work	1 x professional			unanswered	

I1: 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)	What is the most effective way to deliver psychological support to this patient group? ~ What are the most effective ways to support teens an young adults deal with the emotional effects of a cancer diagnosis ~ What are the most effective ways of supporting a young adult who has received a cancer diagnosis? ~ What is the best psychological support for teenagers and young adults? ~ What are the most effective ways of looking after young people with cancer from a mental health standpoint? ~ How can young people affected by lymphoma best be supported psychologically? ~ What are the Most effective methods of reducing negative psychological impact of cance in childhood? ~ What are the most effective stratigies to limit the emotional / mental health consequences associated with lengthy cancer treatments? ~ What practical and emotional support is of most value to young people and is there further and additional support that is required? ~ What things can we do to reduce mental health problems in Cancer Survivors? ~ What psychological care would benefit survivors of cancer living with long term effects ~ What is the long term psychological impact of having cancer as a child/young person and what can be done to alleviate negative impact? ~ Are counselling/psychological strategies (e.g. talking therapies) effective to promote the mental health of children who have been through cancer? ~ How do we prevent the high levels of mental illness seen in cancer survivors treated in the TYA age group? What are the levels of mental illness in this group post treatment? ~ Following a cancer diagosis and treatment did this make you re-consider/re-visit previous other life events/traumas? ~ What different approaches to trauma can be helpful for young people either during cancer treatment or post-treatment/at a late effects stafe? ~ What would help with young people in mentally keeping them active and in a positive mindset during/after treatment? ~ What was the best source of support and why - 1:1 sessions, peer support group evenings, activities or all of these. ~ (What was the best source of support and why - 1:1 sessions, peer support group evenings, activities or all of these.) What else could we offer? (TYA and peer support) ~ What are the best ways to help people come to terms with their cancer diagnosis? ~ brain tumour diagnosis. What support is available. What is helpful. ~ What is psychological impact poat treatment on young person and what input can be offered? ~ How important is psychological care during treatment for cancer, and how much is currently being done for those who need it? ~ I feel there should be more support for patients and parents regarding counselling during and after treatment ~ She witnessed so much death and illness at such a vulnerable age (12-16) yet was given no real councelling - why is that not considered. Her mother also suffered from a nervous breakdown after the treatment was over. Again, can't help thinking that more after support could be given. ~ Should teenagers facing cancer have the same level of input into their mental health as they do in their physical health? ~ Are the psychology support systems/strategies adequate for this group of patients? ~ Will counselling be offered as standard to patients and friends/family to deal with life not only during treatment but after treatment too? What are the most effective methods for caring for mental health? ~ How should clinical services help TYA with their psychological challenges when they have cancer? ~ What type of psychological support do young people and their families want? ~ Why is physiological support not seen as important after cancer treatment? ~ What counselling help is available after treatment. ~ What is the most effective way to support young people and their families to readjust after cancer treatment? ~ What are the best ways/techniques to help young people integrate back into their normal lives after cancer treatment? ~ What is the best way to help young people come to terms with what has happened to them and rebuild a life beyond cancer ~ Living and surviving cancer - what measures can be put into place to help people pshologically live a filled life ~ Should more cancer patients receive therapy to help them understand not only what is happening to them but the long term implications and help them to enter back into normal life following successful treatment? ~ Why is life so psychologically hard to deal with after cancer? ~ What help is there for young adults with survivors guilt? ~ 2. How to encourage patients to partake in activities organisied and take support offered. ~ Would the principles of 'detached youth work' transfer to the cancer heatlh care setting? ~ Should psychologic assessment be included up front at diagnosis? And what should the formal surveillance look like ~ What are the best ways to help people come to terms with their cancer diagnosis? ~ What types of support do young adults want during their treatment and how is this best offered to them ~ what support can we offer to young people who's treatment is ongoing? ~ Providing a nurse (pne to one) to navigate through the cancer experience would have been so good. Felt I was a number on a conveyor belt. Would having your own nurse make young people feel better ? ~ What is the best way to support TYA during their treatment particularly in relation to social relationships, employment and education. ~ What sort of education, health, and work-related information and services do TYA cancer patients and survivors need from the time of their diagnosis up to their short and medium-term survivorship period and how to deliver them efficiently? ~ Support specific to young adults that treats them like not like adults and not like children - specific to them ~ What is the best model of care to ensure that the holistic needs of TYA patients (social, educational, employment) are met appropriately? ~ At what point in the cancer journey is psychological support most helpful? ~ What strategies can be put in place prior to finishing treatment to prevent depression post treatment ~ What are the warning signs of depression and anxiety linked with treatment? ~ There is a terrible cycle of hope and failure for some cancer patients - so huge peaks and troughs emotionally for patients, friends and relatives alike probably worse of all of the patient. What can be done about this? How can the patient and relatives be supported better right from the start of the journey without taking away the hope that the patient will get better? ~ What is the best way to support young adults/teenagers with coming to terms with their diagnosis, during or after treatment? ~ When is the optimum time to begin supporting TYA with cancer ~ How can we help those who present as less resilient develop skills here, to improve coping and psychological outcomes? ~ What form of counselling if beneficial to people experiencing long-term mental affects of cancer and cancer treatment? ~ The best ways to deal with anxiety following finishing cancer treatment. ~ How to learn not to worry about the cancer coming back. ~ Scanxiety is a massive problem for me, so much so that I have rearranged appointments and cancelled scans because of the panic attacks I have. What support is out there for me?	25 x professional, 19 x patient, 9 x parent/carer, 3 x relative, 3 x friend, 2 x partner			unanswered	
I3: What complementary or relaxation therapies improve quality of life?	What is being done to propose alternative therapies (not just talking therapies) to teenage patients not as a cure but to help them relax or to improve quality of life during treatment. I mean things like reflexology, massage, aromatherapy, hand and foot massage and similar ~ Is hypnotherapy useful in any way. ~ What is 'integrated' cancer care - why can we not do better connecting the dots between conventional medicine and supplemental complementary medicine?	1 x relative, 2 x parent/carer			unanswered	
I5: Are the holistic care needs of young people with cancer being adequately assessed and met?	What evidence is there that the holistic care needs of TYA's are being adequately assessed, planned and subsequent services implemented?	1 x professional			unanswered	
I6: In young people with cancer which 'holistic care assessment', best delineates baseline psychological functioning, social functioning and mental health?	What is the most effective means of understanding the holistic needs of a young person diagnosed with cancer?	1 x professional			unanswered	
I7: 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? ('Adherence' refers to whether a person follows their treatment plan and the advice given to them by health professionals. 'Health outcomes' refers to the impact healthcare has on people and can include symptoms, ability to do what you want to do and survival)	How does 'Attachment Style' (quality of relationships / family psychosocial function) impact on acceptance, engagement compliance & clinical outcomes in TYA cancer? Can 'pre-emptied be' family and individual psycho-social interventions improve these outcomes?	1 x professional			unanswered	
I8: 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'?	Do interventions (for eating disorders) need to be modified to take account of factors that arise uniquely from the 'cancer journey'?	1 x professional			unanswered	
BF1: How are families and partners best included in communications and supported during and after treatment?	How can we better prepare and support carers post treatment ~ She witnessed so much death and illness at such a vulnerable age (12-16) yet was given no real councelling - why is that not considered. Her mother also suffered from a nervous breakdown after the treatment was over. Again, can't help thinking that more after support could be given. ~ I feel there should be more support for patients and parents regarding counselling during and after treatment ~ can support be Provided to extended family members i.e. Grandparents ~ Should teenage cancer patients be given more advice on relationships and should the family and partners also be able to receive advice and therapy? As a partner of a young patient who received treatment for cancer there was little discussion about the effects cancer had on a relationship and mostly we were told that relationships would not last. As a young person myself I struggled with my mental health during my partners treatment as it was very distressing for me and his family as well as him but there was no support for partners of teenagers and I was not really taken into account (things were more directed at his parents). There was also little advice around sex during cancer treatments and it was hard to decipher the exact implications the treatment would have. As teenagers have a higher sex drive than older patients maybe more research needs to be done into the effects of chemotherapy etc on sex in adolescents. There should also be more research into how we can support the young person themselves as well as their partners. ~ There is a terrible cycle of hope and failure for some cancer patients - so huge peaks and troughs emotionally for patients, friends and relatives alike probably worse of all of the patient. What can be done about this? How can the patient and relatives be supported better right from the start of the journey without taking away the hope that the patient will get better? ~ What is the best way to support siblings of young people with cancer ~ Can we offer more support to the siblings of the young people in hospital with cancer? ~ What support is available for siblings / how can we support them? ~ What are the most effective way of supporting siblings? ~ What are the support needs of partners (boyfriends/girlfriends/etc) of TYA patients with cancer? ~ Treating the family unit as a whole through the journey and being able and having ability to do this	1 x patient, 2 x relative, 2 x parent/carer, 1 x partner, 5 x professional, 1 x friend			unanswered	
BF2: What is the impact of a cancer diagnosis in a young person on the family?	Psychology impact of cancer On patient and family ~ The effects of a cancer diagnosis on the family unit especially understanding the role/feelings and views of the siblings. ~ How does it affect your relationship with your family	1 x patient, 2 x parent/carer			unanswered	
BF3: What are the best ways for families to re-establish normal life after treatment?	What are the best ways to help young people and their families come to terms with what has happened to them after treatment, and to deal with survivorship and normal life after treatment? ~ How does cancer effect families/carers/grand parents/siblings 10+ years after treatment of their child? ~ There's lots of support for patients and families from diagnosis through to the end of treatment. What's the best way to provide support after that time? ~ More needs to be understood about how we can help young people and their families live well after cancer. What works	2 x patient, 1 x parent/carer, 1 x professional			unanswered	
BF4: How can families best support young people through the emotional and social impact of a cancer diagnosis?	How can we support our teenage son with the effects this is having on him emotionally and socially, loss of friendships etc... ~ How can I help my child come to terms with their diagnosis	2 x parent/carer			unanswered	
BF5: What type of psychological support do families and partners want during and after treatment?	What type of psychological support do young people and their families want? ~ What are the support needs of partners (boyfriends/girlfriends/etc) of TYA patients with cancer? ~ What types of support fo families of young adults want during and after treatment completion	3 x professional			unanswered	
BF6: What are the most effective interventions to improve mental health in families and friends of young people with cancer?	Will counselling be offered as standard to patients and friends/family to deal with life not only during treatment but after treatment too? What are the most effective methods for caring for mental health?	1 x friend			unanswered	
BF7: What are the most effective ways of supporting a friend undergoing treatment?	What are the most effective ways of supporting a friend who has been diagnosed/going through treatment?	1 x friend			unanswered	
BF8: What support do young people with cancer and their families want from Grandparents?	How best can a Grandparent support both patient and Family?	1 x relative			unanswered	
BF9: How do young people manage their experience of their friend being diagnosed with cancer?	How do you come to terms yourself with a friend being diagnosed with cancer?	1 x friend			unanswered	
BF10: What are the support needs of the family following the death of a young person with cancer?	Why is the family forgotten once a young person dies as this is the time they need the most support? ~ What are the bereavement needs of parents /carers following the death of their young person/child	1 x parent/carer, 1 x professional			unanswered	
BF11: What is the impact of uncertainty and changes on a young person and their family following a brain tumour diagnosis?	Understand how it is for the Young person and families living with uncertainty or a new normal following brain tumour diagnosis.	1 x professional			unanswered	
BF12: How can grandparents who have a grandchild with cancer talk with them about their cancer?	How should a Grandparent discuss Cancer with the Oatient?	1 x relative			unanswered	
BF13: What are the best ways to provide peer support for families of young people with cancer?	What ways can we best promote and develop peer support for young people and their families affected by cancer?	1 x professional			unanswered	
BF14: What is the most effective way of supporting families at relapse?	If relaps occurred how can we explain and support the patient and the family? ~ How can TYA's and their families be best supported at the point of relapse	2 x professional			unanswered	
PCS1: What are the most effective ways to ensure that young people follow their treatment plan?	What strategies are most effective in promoting and ensuring adherence to treatment for young people with cancer? ~ What is the evidence around engagement/compliance with treatment - are there any models known to be effective that could be incorporated in treatment and follow up care to increase this ~ What are the best strategies to use in engaging non compliant patients	3 x professional			unanswered	

PCS2: How does cancer and its treatment impact a young person's friendships?	How does cancer and its treatment impact the young persons peer relationships? ~ What impact did your treatment have on your friendships.	2 x professional			unanswered	
PCS3: What are the most effective strategies for achieving long term health behaviour change with young people following cancer?	How can we achieve long term health behaviour change with young people following cancer?	1 x professional			unanswered	
PCS4: Does emergency admission to an adult ward impact on young people's compliance to treatment?	Does it matter to patients if they are treated on an adult ward, and what effect does this have on their compliance to treatment when they are admitted as emergency to an adult ward.	1 x professional			unanswered	
PS1: 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?	How do children respond to being encouraged to spend time with other cancer patients of similar ages while in hospital? ~ How important and effective is it for teenage and young adult cancer patients to develop friendship groups with others in the same position? ~ What are the effective group-based support/therapeutic groups (peer support and more guided groups) and what is the cost:benefit to aid commissioning? ~ What was the best source of support and why - 1:1 sessions, peer support group evenings, activities or all of these. ~ *(What was the best source of support and why - 1:1 sessions, peer support group evenings, activities or all of these.)* What else could we offer? (TYA and peer support) ~ What ways can we best promote and develop peer support for young people and their families affected by cancer? ~ Do young people want end of treatment/late effect support groups? What would they like included as part of these?	6 x professional, 1 x parent/carer			unanswered	
PS2: Does participation in support activities for young people with cancer differ by gender?	Why are women more likely than men to participate in support programs?	1 x patient			unanswered	
SC1: What is the best model of survivorship care based on risk stratification and individual needs?	What is the best model of survivorship care for tya survivors? ~ For how long should survivors be followed up and by whom? ~ What is the best form of follow-up for TYA patients after the end of treatment? ~ Should tya patients be followed up for longer or indefinitely? ~ Develop effective stratification of patients in follow-up based on risk of late-effects including running nurse-led clinics; telephone clinic etc ~ How do we assess and balance clinical needs and psychosocial needs when stratifying patients for follow up, e.g. to phone consultations, SOS only, GP or local follow up or treating team follow up? ~ What is tue most effective way of caring for someone after cancer? ~ Do young people have particular survivorship issues and how best managed. ~ How often should heart health be monitored by the gp post hospital follow/discharge? ~ How do we assess and balance clinical needs and psychosocial needs when stratifying patients for follow up, e.g. to phone consultations, SOS only, GP or local follow up or treating team follow up? ~ What is the best way to assess the needs of young people at the end of treatment?	7 x professional, 3 x patient, 1 x relative	Guidelines on models of care for childhood and adolescent cancer survivors are in development.		ongoing study	Correspondence with expert- guidelines on models of care for childhood and adolescent cancer survivors are in development. This involved looking for evidence concerning survivors treated for cancer up until 25 years age.
SC2: 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?	Do end of treatment clinics influence health behaviour in survivors of cancer in the TYA years in the first year of survival compared to those who do not receive/attend a clinic?	1 x professional			unanswered	
SC3: What are the most effective strategies to empower young people to engage with follow up?	Engagement with follow up - explore novel ways	1 x professional			unanswered	
SC4: What are the best strategies to empower young people to get their survivorship needs discussed and addressed by healthcare professionals?	What is the best strategy to help TYA cancer survivors get their problems discussed and actively addressed by healthcare professionals, and what are the best strategies to help healthcare professionals liaise to address these same issues?	1 x professional			unanswered	
SC5: What are the best strategies to help healthcare professionals to co-ordinate care to address survivorship needs raised by a young person?	What is the best strategy to help TYA cancer survivors get their problems discussed and actively addressed by healthcare professionals, and what are the best strategies to help healthcare professionals liaise to address these same issues?	1 x professional			unanswered	
SC6: What are the best strategies for detecting and treating second primary cancers early?	How can second primary malignancies be detected early and treated? ~ How should people who have have had cancer be screened for other cancers in the future?	1 x parent/carer, 1 x patient			unanswered	
SC7: What is the most effective strategy to embed end of treatment summaries into routine cancer care for young people with cancer?	How can we embed treatment summaries into routine cancer care?	1 x professional			unanswered	
SC8: What are the most effective ways of offering psychological support to young people with lymphedema?	What kind of psychological care is there and is able to help young people suffering from lymphadema?	1 x patient			unanswered	
SC9: 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?	*(Following a cancer diagosis and treatment did this make you re-consider/re-visit previous other life events/traumas?)* If so did speciailst TYA support help you to consider the impact of these events and how you now faced living with and beyond your cancer?	1 x professional			unanswered	
SC10: 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?	Do young people have particular survivorship issues and how best managed.	1 x professional			unanswered	
MS1: At the end of treatment and during long term follow up, what support services improve psychological well-being, social functioning and mental health?	What sort of support do TYA's really benefit from at the End of Treatment ~ What is the best way to "tail-off" regular meetings with doctors in order to minimise psychological impact of the end of care following a successful cancer treatment? ~ End of Treatment: what additional psycho social supports are needed to support young people following treatment? ~ What are the three most important ways young people can be supported to integrate back into their peer group? ~ How do u deal with life after treatment There's lots of support for patients and families from diagnosis through to the end of treatment. What's the best way to provide support after that time? ~ How do we support young people in recovery in the long term? What support would be useful for patients after cancer? ~ What are the three most important ways young people can be supported to integrate back into their peer group? ~ What are the best ways to support young people living with and beyond cancer once they are no longer eligable for TYA Services? ie once the two years post treatment point is reached ~ There's lots of support for patients and families from diagnosis through to the end of treatment. What's the best way to provide support after that time? ~ When should the formal cancer support structures end and when should they remain? ~ What sort of education, health, and work-related information and services do TYA cancer patients and survivors need from the time of their diagnosis up to their short and medium-term survivorship period and how to deliver them efficiently?	7 x professional, 4 x patient, 2 x parent/carer			unanswered	
MS2: How are young people best supported to talk about their cancer diagnosis with families, friends and schools?	What support should be given to young people as soon as they are diagnosed, when it comes to breaking the news to friends/family/school? ~ How should I tell my friends I have cancer? ~ How do I talk to my friends about my diagnosis?	1 x professional, 2 x patient			unanswered	
MS4: What is the most effective way of supporting young people with relapsed cancer?	How can TYA's and their families be best supported at the point of relapse ~ If relaps occurred how can we explain and support the patient and the family?	2 x professional			unanswered	
MS5: What prevents and helps young people access the support they need following a cancer diagnosis?	how easy is it for young people to access the support they need following a cancer diagnosis	1 x patient			unanswered	
MS6: 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)?	Do TYA with cancer who are parents themselves feel supported by exisiting TYA Services? If no what else do they need?	1 x professional			unanswered	
MS7: What written information do young people with cancer want at diagnosis in order to meet their needs without overloading them?	How much written information do TYA's really want when they are first diagnosed?	1 x professional			unanswered	
MS8: What factors influence young people with a recent cancer diagnosis to decline first line treatment and how are they best supported?	How can young people who refuse 1st line treatment be best supported ? ~ Why do some patients being treated with curative intent refuse conventional treatment?	2 x professional			unanswered	
SE1: What are the factors that should determine stopping treatment when the young person cannot be cured?	Appropriateness of treatment when patients not going to physically improve. ~ How to decide when enough treatment is enough?	1 x professional, 1 parent/carer			unanswered	
SE2: Are there regional differences in survival rates for acute myeloid leukaemia (AML) and acute lymphoblastic leukaemia (ALL)?	Are there regional differences in survival rates for AML and ALL?	1 parent/carer			unanswered	
SE3: What is the incidence of mixed leukaemia?	How rare is a mixed leukaemia diagnosis and how does treatment vary for it?	1 parent/carer			unanswered	
HS1: 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?	How do ensure young people who receive their treatment in hospitals other than principal treatment centres receive appropriate practical and emotional support? ~ What practical and emotional support do young people who are treated in hospitals other than principal treatment centres have access to? ~ Do young people who spend little or no time in hospital during treatment receive any appropriate practical or emotional support?	3 x professional			unanswered	
HS2: Do specialist cancer services for young people improve outcomes and patient experience?	Are there any differences in outcomes for young people treated at a) PTC b) TYADH c) neither of these ? ~ Is there a significant difference in outcomes for young people treated in paediatrics as opposed to young people treated in adults? ~ Does TYA Care actually make a difference to outcomes? ~ Does it matter to patients if they are treated on an adult ward, and what effect does this have on their compliance to treatment when they are admitted as emergency to an adult ward. ~ The impact of the introduction of Teenage and Young Adult wards on the treatment of cancer in young people	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/	ongoing study	

HS3: 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 is the composition of the ideal multiprofessional team caring for TYA patients during treatment? ~ Would be helpful to establish what services and professional groups are necessary / minimum for a TYA MDT. ~ What is the composition of the ideal multiprofessional team caring for TYA patients after treatment and into longterm survivorship? ~ What is the composition of the ideal multiprofessional team caring for TYA patients who are entering end of life?	4 x professional			unanswered	
HS4: Do clinical trial accrual rates vary across the UK for young people with cancer?	How do clinical trial accrual rates vary across the UK?	1 x professional			unanswered	
HS5: What proportion of young people with recurrence are offered clinical trials?	What proportion of TYA patients are offered clinical trials at recurrence?	1 x professional			unanswered	
HS6: What are the barriers to clinical trials for young people with cancer?	Why are clinical trial enrolment rates low in AyA?what are the local barriers?	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	answered	
HS7: What are the barriers for transition to adult services for young people and what are the most effective strategies to improve transition?	How does staff preference/barriers/opinions affect successful transition from paed to adult care? ~ How can transition to adult services be improved	2 x professional			unanswered	
HS8: What are the most effective strategies to support nurses caring for young people with cancer?	Can more be done to support nurses caring for young adults?	1 x patient			unanswered	
HS9: What are the most effective strategies for engaging primary care professionals (e.g. GPs) to listen to young people?	Is there any way as young people we can find a way for gp's to listen and not disregard our concerns?	1 x patient			unanswered	
HS10: What evidence is there of effective end of treatment transition on to community services?	What evidence is there of effective end of treatment transition on to community services?	1 x professional			unanswered	
HS11: What are the health outcomes of long term follow up and screening?	Does long term follow up/screening improve outcomes? Is it cost effective?	1 x professional			unanswered	
HS12: 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?	Do LGBT TYA with cancer have any different needs or seperate need set to the general TYA cancer poputation?	1 x professional			unanswered	
HS13: What is the most effective model of care for the delivery of regional teenage and young adult cancer services?	What is the most effective model of care for the delivery of Regional TYA services?	1 x professional			unanswered	
HS14: 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)?	How do socio-economic factors influence young adult's time to diagnosis and choice in their place of care?	1 x professional			unanswered	
HS15: Would young people prefer their Nurse Specialist to wear a uniform or not?	Would TYA patients prefer their Nurse Specialist to wear a uniform or not?	1 x professional			unanswered	
HS16: 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?	Why do some clinicians not engage fully with the TYA MDT and regional TYA service?	1 x professional			unanswered	
HS17: What are the best strategies to improve access to clinical trials?	How can we improve uptake of clinical trials in the TYAC population? ~ How do we improve access of TYA to investigative therapies ~ Why can't we have more TYA specific trials? ~ How can we ensure that new cancer drugs under trial do not exclude people's access by thoughtless use of age boundaries which are not related to the biology or social factors that determine the relevance of the research?	4 x professional			unanswered	
HS18: Is long term follow up and screening cost effective?	Does long term follow up/screening improve outcomes? Is it cost effective?	1 x professional			unanswered	
EC1: What is the role of social media and/or online support in supporting young people during and after treatment?	Where does social media fit in to support these patients - what do we know about what is helpful/unhelpful ~ What role can technology have to help address TYA's supportive care needs? ~ How can online support and social media provide a psychosocial extra level of support during and post treatment?	3 x professional			unanswered	
EC2: What is the best approach to prepare young people for treatment and long term side effects?	What evidence is there about the longer term side effects of treatment and whether patients should be prepared for them ~ How well do physicians explain before the start of treatment, how it effects people in the long term? ~ When is the best time to start talking to young people about the potential late effects of their cancer treatment. ~ How can we best prepare young people for the effects of chemotherapy? ~ Should teenagers facing cancer have the same level of input into their mental health as they do in their physical health and should more cancer patients receive therapy to help them understand not only what is happening to them but the long term implications and help them to enter back into normal life following successful treatment? ~ how do I cope with all my scaring after operation ~ How can we prepare patients for long term follow up conditions and co-morbidities, such as Avasculsr necrosis	2 x professional, 3 x patient, 1 x relative, 1 x partner			unanswered	
EC3: When do young people want family present in consultations with healthcare professionals and when would they prefer family not to be present?	The disclosure of bad news- should parents be the first to know? ~ Do teenagers want us to talk to them without their adult present	1 x professional, 1 x patient			unanswered	
EC4: What are the best ways to provide information about services and treatment and when do young people want this information?	At what stage of treatment should information about supportive services be provided. How to avoid overwhelming patients with information and resources while making sure they are aware of services. ~ How can be better provide information to teenagers and young people with cancer?	2 x professional			unanswered	
EC5: Do internet-based psychological support programmes delivered to young people and families during and off-treatment improve their mental health and wellbeing?	Does offering psychological support programmes for TYA/families during and off-treatment via the internet improve mental health & wellbeing?	1 x professional			unanswered	
EC6: How can communication methods between healthcare professionals and young people be enhanced in the current age of digital communication?	What technology could TYA Service be using to communicate with TYA with cancer? Is text / call /email still appropriate. Something about communication methods in the modern era?	1 x professional			unanswered	
EC7: 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?	How do parents feel when their child reaches 18 and all the discussions around treatment and management are now directed at the individual not the parent	1 x professional			unanswered	
EC8: How can electronic health records empower young people with cancer?	How can EHRs help empower TYA throughout their cancer experience?	1 x professional			unanswered	
EC9: What are the best ways of communicating information about treatment to young people with cancer who have learning difficulties or social communication disorders?	How best to explain lymphoma treatment to a 14 year old who has Autism (so suffers from information overload)	1 x relative			unanswered	
EC10: What are the most effective approaches to communicating prognosis?	Communication of prognosis with the young adult patient	1 x professional			unanswered	
EC11: 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?	Can a decision-making aid be developed that enables a young person/their parents to make an informed choice about their treatment, including being aware of possible future fertility issues and current options?	1 x relative			unanswered	
EC12: What are the most effective approaches to communicating end of treatment information to young people?	How can patient-consultant communication be improved when looking to end of treatment/all clear confirmation?	1 x friend			unanswered	
EC13: What interventions best support young people in developing and maintaining romantic and sexual relationships during and after treatment?	Should teenage cancer patients be given more advice on relationships and should the family and partners also be able to receive advice and therapy? As a partner of a young patient who received treatment for cancer there was little discussion about the effects cancer had on a relationship and mostly we were told that relationships would not last. As a young person myself I struggled with my mental health during my partners treatment as it was very distressing for me and his family as well as him but there was no support for partners of teenagers and I was not really taken into account (things were more directed at his parents). There was also little advice around sex during cancer treatments and it was hard to decipher the exact implications the treatment would have. As teenagers have a higher sex drive than older patients maybe more research needs to be done into the effects of chemotherapy etc on sex in adolescents. There should also be more research into how we can support the young person themselves as well as their partners. ~ What more support ca be offered for those on treatment and their partners who were sexually active prior to diagnosis?	1 x patient, 1 x partner			unanswered	

EOL1: What are the best ways of supporting a young person who has incurable cancer?	What are the best ways of supporting a young person who has incurable disease? ~ How can you support someone when they've just been told 'theres nothing more we can do' what's the best words? ~ Whats the best way to support a yound adult who has terminal cancer ~ what do palliatve services look like for this population - what are the gaps, what do we know about how best to support patients ~ How can the palliative care services available meet the needs of TYA's with poor prognosis earlier in their disease trajectory/treatment phase? ~ 1. Does early involvement with specialist palliative care services improve the quality of life of teenagers and young adults with cancer?	6 x professional			unanswered	
EOL2: How can parents/carers/siblings/partners be best supported following the death of a young person with cancer?	What bereavement support is most acceptable to parents who have lost a young adult to cancer? ~ How can young people best be supported after the loss of a sibling?	1 x professional, 1 x relative			unanswered	
EOL3: For young people with incurable cancer, how should healthcare professionals communicate with them to improve quality of life and patient experience?	What is best practice for discussing palliative care options with young adults and at what point in treatment should these conversations begin? ~ What are the most effective ways of discussing future treatment support options when cure is no longer possible? ~ If they are palliative again how much open communication do they want ~ What research is being done on introducing palliative care to teenage patients so its seen as a more positive option?	1 x partner, 1 x relative, 2 x professional			unanswered	
EOL4: For young people with incurable cancer, how should parents/carers communicate with them to improve quality of life and experience?	How is the best way to tell your child they are not going to get better ~ How to approach the subject if end if life care?	2 x parent/carer			unanswered	
EOL5: For young people with incurable cancer, what are the barriers and facilitators to accessing hospice/specialist palliative care?	How do existing TYA Services promote and work with exisiting hospice settings to ensure access to EoL services? Do TYA access local services? if not why not? What are barriers to access? ~ What is the best way to integrate palliative care into the TYA cancer pathway?	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	ongoing study	
EOL6: 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?	How do I talk to family /friends if I am palliative?	1 x professional			unanswered	
EOL7: How do young people with incurable disease choose their preferred place of death?	How do young people/families choose their place of death - are there real choices e.g. is there suitable hospice provision, is there an option of dying on a TYA ward, own home, one parents home if parents aren't together etc	1 x professional			unanswered	
EOL8: What are the most effective ways of supporting a friend with incurable disease?	In what way can you aid a friend who had been diagnosed teminally?	1 x friend			unanswered	
RI1: Is the life expectancy of teenagers and young adults with cancer shorter compared to the general population?	Am I likely to have a life expectancy like that of mine peers, or less? ~ What is the average life expectancy for ex-cancer patients who received successful treatment for cancer when younger? ~ Life span since diagnosis ~ Will I die younger because of all the treatment?	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	ongoing study	Correspondence with Chief Investigator – confirmed this question will be answered by this ongoing study.
RI2: What are the rates of relapse, predictive factors and survival outcomes?	What are the chances and survival rates of relapse? ~ What are the chances of relapse? ~ What are the risks of cancer returning after treatment has come to an end ? ~ What are the chances of relapsing? ~ Will the cancer come back? ~ How long will she be at risk of it coming back? ~ What is my chance of relapsing again? ~ Whats my chance of my cancer returning? ~ Is it possible to accurately predict relapse? ~ Does the regime of chemotherapy you have affect the likely hood to relapse? ~ Is there any links with relapse and lifestyle? ~ Does diet and lifestyle play a significant role in the prevention of relapse in children and young people, following successful cancer treatment? ~ Is there a correlation between age of diagnosis and relapse rate?	7 x patient, 3 x friend, 3 x parent/carer			unanswered	
RI3: What is the incidence of new primary and secondary cancers following cancer treatment as a young person?	What proportion of young people with cancer develop it again later in life? ~ Are yoy likely to get ither firms of cancer because you have had one? ~ What is the likely hood of getting a second cancer due to Radiotherapy?	2 x parent/carer, 1 x patient	1) Second cancers among survivors of teenager and young adult cancer; 2) NCIN Data Briefing; Specific to Hodgkin's disease - 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; 3) Ongoing study: Teenage and Young Adult Cancer Survivor Study	1) http://www.ncin.org.uk/view?rid=1606 2) http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD008814.pub2/epdf 3) http://www.birmingham.ac.uk/research/activity/mds/projects/HaPS/PHEB/CCCSS/TYACSS/index.aspx	answered	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.
RI4: What are the survival rates for young people with cancer?	Survival rate?	1 x patient	1) Trends in five-year survival for teenagers and adults with cancer in the UK; 2) 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	1) http://www.ncin.org.uk/view?rid=2751 ; 2) http://www.ncin.org.uk/view?rid=2134	answered	
RI5: What are the recurrence rates for melanoma?	How likely are the chances that melanoma will resurface?	1 x patient			unanswered	
RI6: What are the recurrence rates of thyroid cancer after five years?	What % of people have thyroid cancer reoccurrence in 5+ years time.	1 x patient			unanswered	
RI7: What proportion of young people who have had leukaemia relapse more than once?	What is the % of relapse after a relapse has already hapened with leukeamia	1 x patient			unanswered	
RI8: What are the survival rates for young people with leukaemia who have Down Syndrome?	My son had Down's Syndrome. He was successfully treated for Acute Lymphoblastic Leukemia when he was 7 and relapsed aged 21 after 12 years in remission. Palliative care was the first option suggested. It was really difficult to get info on Leukemia survival rates for young people with DS. Why?	1 x parent/carer			unanswered	
RI9: What are the key factors that impact on outcomes in osteosarcoma / soft tissue tumours?	What are the key factors that impact on outcomes in osteosarcoma / soft tissue tumours?	1 x professional			unanswered	
RI10: What are the barriers to accessing radiotherapy for young people with brain tumours?	What are the barriers to accessing radiotherapy for TYA patients with brain tumours?	1 x professional			unanswered	
RI11: Is cardiac screening post anthracyclines more effective if carried out by a cardiac specialist in late effects of cancer?	Is cardiac screening post anthacyclines better if carried out by a cardiac specialist in late effects of cancer?	1 x professional			unanswered	

answered
unanswered
ongoing study
unsure
partially answered