# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## Centre for Clinical Practice – Surveillance Programme

### Clinical guideline

Cancer service guidance: Improving outcomes for children and young people with cancer

### Publication date

Guideline issue date: August 2005

### Previous review dates

No previous reviews

### Surveillance report for GE (post consultation)

July 2014 (8 year surveillance review)

### Key findings

<table>
<tr><td colspan="3"></td><th colspan="2">Potential impact on guidance</th></tr>
<tr><td colspan="3"></td><th>Yes</th><th>No</th></tr>
<tr><td colspan="3">Evidence identified from literature search</td><td></td><td>✓</td></tr>
<tr><td colspan="3">Feedback from Guideline Development Group</td><td></td><td>✓</td></tr>
<tr><td colspan="3">Anti-discrimination and equalities considerations</td><td></td><td>✓</td></tr>
<tr><td>No update</td><td>Rapid update</td><td>Standard update</td><td>Transfer to static list</td><td>Change review cycle</td></tr>
<tr><td>✓</td><td></td><td></td><td></td><td></td></tr>
</table>

### Surveillance recommendation

GE is asked to consider the following proposals:

- The improving outcomes for children and young people with cancer service guidance should not be considered for an update at this time.
- The guideline should remain on the active list and be considered in light of results emerging from existing trials such as the BRIGHTLIGHT study.
- The section of the guideline relating to Febrile Neutropenia should be withdrawn as it has been updated by CG151 Neutropenic sepsis: prevention and management of neutropenic sepsis in cancer patients.

# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## Centre for Clinical Practice – Surveillance Programme

### Surveillance review of cancer service guidance: Improving outcomes for children and young people with cancer

## *Background information*

Guideline issue date: 2005
8 year review: 2014

## *Eight year surveillance review*

1. Two literature searches were undertaken for studies published between December 2004 (the end of the search period for the guidance) and November 2013: a high-level search for randomised controlled trials (RCTs) and systematic reviews; and a focused search for all study types relating to links between the number of cases of children and young people with cancer seen and outcomes. All relevant abstracts were assessed and clinical feedback on the Children and young people with cancer service guidance was obtained from three members of the GDG through a questionnaire.

2. No new evidence was identified which would invalidate the guidance recommendations.

## *On-going research*

3. Clinical feedback from one GDG member indicated that there is ongoing research relating to fertility options for patients with cancer, which would include implications for young people (See point 11 below). No further details were provided.

4. Through the consultation process, the Teenage Cancer Trust highlighted the BRIGHTLIGHT study (National Institute for Health Research funded programme) which is evaluating cancer services for young people aged 13 - 24 years in England. The overall aim of this study is to determine whether specialist cancer care, as outlined in the NICE guideline children and young people with cancer service guidance, is associated with improved outcomes during and after treatment compared to other forms of care. Central to the study is a cohort survey of 2,012 young people newly diagnosed with cancer. Data will be collected over 3 years at 5 time points. The study is still recruiting but

emerging results are anticipated by the end of 2015. The BRIGHTLIGHT programme also includes two other related projects focusing on the competencies of professionals caring for teenagers and young adults, which will be complete and in report format by Autumn 2014, and a case study using ethnographic methods which is an exploration of the environment of care, with emerging results from 2015.

## *Anti-discrimination and equalities considerations*

5. None identified.

## *Implications for other NICE programmes*

6. A Quality Standard for children and young people with cancer (QS55) was issued in February 2014.

## *Summary of stakeholder feedback*

7. Stakeholders were consulted about the following proposals over a two week consultation period:

- The children and young people with cancer improving outcomes guidance should not be considered for an update at this time.
- The section of the guideline relating to Febrile Neutropenia should be retired as it has been superseded by CG151 Neutropenic sepsis: prevention and management of neutropenic sepsis in cancer patients.
- The guidance should be transferred to the static guidance list because no evidence was identified that would impact on the current guidance and no major ongoing studies or research were identified as due to be published in the near future (that is, within the next 3-5 years).

8. In total, seven stakeholders commented on the surveillance review proposals. The table of stakeholder comments can be viewed in Appendix 1.

9. Two stakeholders agreed with the surveillance review proposal to not update the guidance at this time, four stakeholders disagreed, and one stakeholder strongly disagreed with the proposal.

10. Three stakeholders agreed with the proposal to transfer the children and young people with cancer service guidance to the static list, three stakeholders disagreed, and one strongly disagreed.

11. The stakeholders that disagreed with the decision not to update the guidance generally felt that the guidance needs to be updated to reflect changes to children and young people's cancer services since the guidance was published in 2005. A common theme was that guidance

on the care of teenagers and young adults, particularly place of care and multi-disciplinary models, no longer represents the current concepts of best practice. The Quality Standard for children and young people with cancer and the National Cancer Peer Review Programme Manual for Cancer Services: Teenage and Young Adults Measures were provided as evidence to support this view by some stakeholders, however, both documents used the guidance as a source in their development. Additionally NICE recognises that ongoing research into cancer services for teenagers and young adults (see section 13) has the potential to impact on current recommendations relating to these issues and that it would be prudent to consider the impact of the research findings once they are published.

12. One stakeholder also felt that the section on Long Term Sequelae requires updating in light of recent published recommendations regarding fertility preservation, breast cancer risk following radiotherapy, and cardiac monitoring following chemotherapy and/or mediastinal radiotherapy. With regards to fertility preservation, the guidance states that patients should have access to appropriate endocrine and fertility services in accordance with the NICE clinical guideline for Fertility. CG156 Fertility (published February 2013) makes a number of recommendations for people who are preparing for cancer treatment who may wish to preserve their fertility.

13. Through the consultation process, the Teenage Cancer Trust highlighted the BRIGHTLIGHT study (National Institute for Health Research funded programme) which is evaluating cancer services for young people aged 13 - 24 years in England. The overall aim of this study is to determine whether specialist cancer care, as outlined in the NICE Children and young people with cancer service guidance, is associated with improved outcomes during and after treatment compared to other forms of care. Central to the study is a cohort survey of 2,012 young people newly diagnosed with cancer with data collected over 3 years at 5 time points. The study is still recruiting but emerging results are anticipated by the end of 2015. The BRIGHTLIGHT programme also includes two other related projects focusing on the competencies of professionals caring for teenagers and young adults, which will be complete and in report format by Autumn 2014, and a case study using ethnographic methods which is an exploration of the environment of care, with emerging results from 2015. .

14. No comments were provided by any stakeholders suggesting any areas have been excluded from the original scope or equality issues.

15. Following consideration of the comments provided by stakeholders, it was determined that the guidance should not be recommended for the static guidance list at this time due to the ongoing studies highlighted in section 13 and changes to the way that services are now delivered which may have the potential to impact on the current guidance recommendations.

## *Conclusion*

16. Through the surveillance review of the children and young people with cancer service guidance and subsequent consultation with stakeholders, no new evidence which may potentially change the direction of guidance recommendations was identified. However ongoing studies, such as the BRIGHTLIGHT study may impact on the guidance in the future therefore the guideline should remain on the active surveillance list until the results of this study are published.

## ***Surveillance recommendation***

17. GE is asked to consider the proposal to not update the children and young people with cancer service guidance at this time.

Mark Baker – Centre Director
Sarah Willett – Associate Director
Diana O’Rourke – Technical Analyst

Centre for Clinical Practice
July 2014

# Appendix 1 Surveillance review consultation

| Stakeholder | Do you agree that the guidance should not be updated? | Do you agree that the guidance should be put on the static list? | Comments on equality issues or areas excluded from the original scope | Comments<br>If you disagree please explain why | Response |
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| The Royal College of Radiologists | Agree | Agree | | | Thank you for your comment. |
| NICE – Health and Social Care Quality Team | Agree - the quality standard for cancer in children and young people was published in February 2014. No placeholder statements were included in the quality standard that would require new recommendations to be produced. | Agree - we agree with the decision to place the guidance on the static list. | | | Thank you for your comments. |
| NHS England | Disagree | Disagree | | Paediatric Cancer services have changed since the publication of the initial guidance in 2005 and the guidance needs to be updated to reflect this. | Thank you for your comment. Through the surveillance review of the children and young people cancer service guidance, no significant new evidence which may potentially change the direction of guidance recommendations was identified, despite a focused search in this area that included studies of all designs. As such, NICE has proposed that this guidance should not be considered for an update at this time. However, NICE recognises the potential impact of the ongoing BRIGHTLIGHT study |

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| | | | | | which was highlighted by the Teenage Cancer Trust. It is therefore proposed that the guideline should remain on the active surveillance list until the results of this study are published.<br>NICE recognises that the delivery of paediatric cancer services has changed since the publication of this guidance but we feel that the existing recommendations do not preclude current service design. However, we will reconsider this at the next two year review of the guidance. The more recent publication of the quality standard for children and young people with cancer identifies key areas for quality improvement, based on the original guidance, across all aspects of cancer services for children and young people with cancer. The expert group that developed the quality standard identified no placeholder statements that would require new recommendations to be produced. |
| Together for Short Lives | Disagree | Agree | | Comments on proposal not to update the guidance<br>A more recent study than reference number 16 is available:<br>Place and provision of palliative care | Thank you for highlighting this study. The study highlights the effectiveness of coordinated palliative care services to support children with cancer to die in their place of choice. The study supports the current guideline recommendations relating to the core |

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| | | | | for children with progressive cancer: A study by the Paediatric Oncology Nurses Forum, United Kingdom Children's Cancer Study Group Palliative Care Working Group, J Clin Oncol, 2007 Oct 1, 25 (28) 4472-6 Vickers J, Thompson A, Collins GS, Childs M, Hain R<br>This can be accessed at: http://www.ncbi.nlm.nih.gov/pubmed/17906208?dopt=Citation<br>Comments on proposal to transfer guidance to static list | elements of palliative care, particularly death in the place of choice, coordination of services at home, where this is the chosen place of care, and access to 24-hour specialist advice and expertise. |
| Teenage Cancer Trust | Disagree | Disagree | | This guidance should now be updated as several pieces of research have been conducted since the publication the original guidance in 2005.<br>Teenage Cancer Trust represents teenagers and young adults with cancer aged 13-24; we now have 26 operational units across the UK following the model set out in the CYP IOG and fund over 30 specialist staff working in these age appropriate environments.<br>We were part of the guideline development group for this IOG and at the time the inclusion of young people | Thank you for your comments. NICE recognises that the delivery of teenage and young adult cancer services has changed since the publication of this guidance but we feel that the existing recommendations do not preclude current service design. However, we will consider this at the next review of the guidance in 2 years.<br>The quality standard for children and young people with cancer identifies key areas for quality improvement, based on the original guidance, across all aspects of cancer services for children and young people with |

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| | | | | with cancer up to the age of 24 had a huge impact on the development of the TYA cancer care. Over the last 9 years this specialty has grown significantly largely due to this recognition by NICE.<br>There are also a number of developments in the expert care and NHS processes since 2005 which have produced important information about young people with cancer which should be reviewed and used to update this guidance.<br>At the time of publication of the original guidance the focus and research used was mainly related to children and paediatric services. Since then a wealth of expertise, knowledge and structures have been built around TYA care which a review of this guidance would now benefit from.<br>Below is a list of relevant research, publications and guidance relevant to teenagers and young adults with cancer produced since 2005. | cancer. The expert group that developed the quality standard identified no placeholder statements that would require new recommendations to be produced. |
| | | | | **Brightlight Study**<br>One of the most significant studies (which is still ongoing), but not mentioned in the surveillance review document, is the current Brightlight | Thank you for highlighting this ongoing study. NICE recognises the potential impact the findings from this study may have on the guidance recommendations in the future. |

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| | | | | Study which is researching the impact of age appropriate care for teenagers and young adults with cancer: http://www.brightlightstudy.com/healthcare-professionals/about-the-study.aspx It is concerning that this study hasn't been picked up for the review process and there are so few clinical feedback comments in the surveillance document. | Therefore we propose not to update the guidance at this time but will retain the guideline on the active surveillance list and consider any published results at the next review of the guidance in 2 years. |
| | | | | **NICE and NHS guidance and groups**<br>• NICE Quality Standard for Children and Young People with Cancer, QS55: http://guidance.nice.org.uk/QS55 (February 2014)<br>• TYA Peer review measures: http://www.cquins.nhs.uk/?menu=resources<br>• NHS England TYA Clinical Reference Group service specifications. More information on this can be found here:<br>http://www.england.nhs.uk/ourwork/d-com/spec-serv/crg/<br>• North West Cancer Intelligence | Thank you for highlighting these resources. The decision not to update the guidance is based on no significant new evidence that contradicts the existing guidance being identified through our surveillance process or subsequent consultation with stakeholders.<br>The guideline was the primary source of guidance used for the development of the quality standard for children and young people with cancer (QS55). The quality standard aims to drive measurable quality improvements within key areas identified from the guidance. The expert group that developed the quality standard identified no placeholder statements that would require new recommendations to be produced.<br>The aim of the guidance is to provide |

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| | | | | Service – designated cancer registry for TYA cancers<br>- National Cancer Research Institute TYA Clinical Studies Group<br>- National Cancer Intelligence Network Children, Teenagers and Young Adult Site Specific Clinical Reference Group<br>- National Cancer Survivorship Initiative Children and Young People's Group | recommendations on service provision based on the best available evidence. The TYA Peer review measures are based on implementation of the guidance and are used for the assessment of cancer services. As with the peer review measures, the NHS England service specifications relate to the recommendations in the guidance and define what NHS England expects providers to offer in terms of evidence-based, safe and effective services. |
| | | | | **Professional groups and charity reports**<br>- Teenagers and Young Adults with Cancer (TYAC) – professional membership organisation<br>- Smith, S et al, February 2012, Blueprint of Care for Teenagers and Young Adults with Cancer: http://www.teenagecancertrust.org/workspace/documents/Blueprint-of-care.pdf<br>- Daly, S. February 2012, Young Voices: http://www.teenagecancertrust.org | Thank you for highlighting these resources. Having considered these, we do not feel they provide any further high quality evidence to contradict existing recommendations. The guidance recommends that all care for children and young people under 19 years old must be provided in age-appropriate facilities, and that young people of 19 years and older should also have unhindered access to age appropriate facilities and support when needed. Failure to follow the guidance recommendations is a local implementation issue. |

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| | | | | /workspace/documents/Young-Voices-report.pdf<br>• Cancer Research UK, 2013, TYA Cancer Stat's report: http://www.cancerresearchuk.org/cancer-info/cancerstats/keyfacts/teenage-and-young-adult-cancer/<br>• Teenage Cancer Trust is due to release reports later this year (2014) about piloting a new nursing model of care and about education on cancer to support prevention. | |
| | | | | **Diagnosis**<br>• Teenage Cancer Trust, 2014, Improving Diagnosis: http://www.teenagecancertrust.org/workspace/documents/Teenage-Cancer-Trust-s-Improving-Diagnosis-report-2013.pdf<br>• 'Cancer in Primary Care, An analysis of significant event audits (SEA) for diagnosis of lung cancer and cancers in teenagers and young adults' 2008-2009, Mitchell E, Macleod U, Rubin G, University of Dundee, University of Glasgow, | Thank you for highlighting these resources. Having considered these, we do not feel they provide any further evidence to contradict existing recommendations. The guidance states that commissioners should ensure appropriate training is provided for the implementation of the recommendations in the NICE clinical guideline on Referral for Suspected Cancer. Failure to follow the guidance recommendations is a local implementation issue. |

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| | | | | Durham University (2009)<br>- 'How frequently do young people with potential cancer symptoms present in primary care?' Fern L et al, British Journal of General Practice (2011)<br>- National audit of diagnosis in Primary Care, Royal College of General Practitioners (2011)<br>- Fern L, Birch R, Whelan J, Neal R, Gerrand C, Hubbard G, Smith S, Lethaby C, Dommett R and Gibson F (2013) Why can't we improve the timeliness of cancer diagnosis in children, teenagers and young adults? *British Medical Journal*, 347: October (2013)<br>- Lawton, K, October 2013, Diagnosing cancer in young people, GP Education 62 (2013)<br>- Dommett, R. et al, 2012, Features of childhood cancer in primary care: a population-based nested case-control study, British Journal of Cancer (2012) | |
| | | | | **Prevention**<br>- Kyle, R.G., Forbat, L., Hubbard, | Thank you for highlighting this study. Cancer awareness and perceived |

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| | | | | G. 2012, Cancer awareness among adolescents in Britain: a cross-sectional study, BMC Public Health, 12:580 (2012) | barriers are outside the scope of this guidance. The aim of the guidance is to provide recommendations on service provision based on the best available evidence. The decision not to update the guidance is based on no new evidence that contradicts the existing guidance being identified through our surveillance process or subsequent consultation with stakeholders. |
| | | | | **Treatment**<br>• Adolescent and young adult cancer: a revolution in evolution? Thomas DM, Seymour JF, O'Brien T, Sawyer SM, Ashley DM. Intern Med J. 2006 May;36(5):302-7. | Thank you for providing this reference, however, this type of information does not meet the criteria for the NICE surveillance process. The decision not to update the guidance is based on no new evidence that contradicts the existing guidance being identified through our surveillance process or subsequent consultation with stakeholders. |
| | | | | **Transition**<br>• A proposal on transition is currently in development as part of the paediatric cancer clinical reference group<br>• TYAC are soon to publish a practice statement on transition | Thank you for your comments. No specific new evidence was offered by the consultee. The decision not to update the guidance is based on no significant new evidence that contradicts the existing guidance being identified through our surveillance process or subsequent consultation with stakeholders. Further information when this is finalised may be useful at the next surveillance review. |

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| | | | | **Survival**<br>‘Survival from cancer in teenagers and young adults in England, 1979 – 2003’ Birch J et al, British Journal of Cancer (2008) 99, 830-835 | Thank you for highlighting this study. Having considered this, we do not feel it provides any further evidence to contradict existing recommendations. The decision not to update the guidance is based on no significant new evidence that contradicts the existing guidance being identified through our surveillance process or subsequent consultation with stakeholders. |
| | | | | **Fertility**<br>• Wright, C.I. et al, 20 October 2013, ‘Just in case’: the fertility information needs of teenagers and young adults with cancer, European Journal of Cancer, Vol 23, Issue 2.pp: 189-198 (2014) | Thank you for highlighting this study. The children and young people with cancer service guidance states that there should be fertility advice by appropriately trained personnel for all patients and/or their families at the time of diagnosis, and that as patients mature, they should have access to appropriate endocrine and fertility services in accordance with the NICE Clinical Guideline for Fertility. CG156 Fertility (published February 2013) makes a number of recommendations for people who are preparing for cancer treatment who may wish to preserve their fertility. Failure to follow the guidance recommendations is a local implementation issue. |
| | | | | **Clinical trials**<br>• Vassal, G. Geoerger, B., and Morland, B. 2013, Is the European | Thank you for highlighting these studies. The guidance makes a number of recommendations on the inclusion of children and young people |

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| | | | | Pediatric Medicine Regulation Working for Children and Adolescents with Cancer:. Clinical Cancer Research, March 15 2012, 19:1315 (2013)<br>• Pritchard-Jones K, Dixon-Woods M, Naafs-Wilstra M, Valsecchi MG. Improving recruitment to clinical trials for cancer in childhood. Lancet Oncol 2008;9:392-9<br>• Fern L, Davies S, Eden T, et al. Rates of inclusion of teenagers and young adults in England into National Cancer Research Network clinical trials: report from the National Cancer Research Institute (NCRI) Teenage and Young Adult Clinical Studies Development Group. Br J Cancer 2008 99:1967-74<br>• Whelan JS, Fern LA. Poor accrual of teenagers and young adults into clinical trials in the UK. Lancet Oncol 2008; 9:306-7. | in clinical trials, including that the development of clinical trials which include teenagers and young adults should be encouraged. NICE would welcome any new evidence from studies specifically in children and young people. The decision not to update the guidance is based on no significant new evidence that contradicts the existing guidance being identified through our surveillance process or subsequent consultation with stakeholders. |
| | | | | **Patient experience**<br>• National cancer patient experience survey results: http://www.quality- | Thank you for highlighting these studies. The studies support current guideline recommendations which state that all care for children and |

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| | | | | health.co.uk/surveys/national-cancer-patient-experience-survey (2011, 2012, 2014)<br>• Smith S, Davies S, Wright D, Chapman C, Whiteson M (2007) The experiences of teenagers and young adults with cancer- results of 2004 conference survey . *European Journal of Oncology Nursing.* 11, 362-368 (2007) | young people under 19 years old must be provided in age-appropriate facilities, and that young people of 19 years and older should also have unhindered access to age appropriate facilities and support when needed. Failure to follow the guidance recommendations is a local implementation issue. |
| | | | | **National Cancer Intelligence Network reports:**<br>• Frequency of non-specific morphology codes (ICD-O M) within the National Cancer Data Repository (2007-09) for cancer in Teenagers and Young Adults (TYA)<br>• Routes to diagnosis: investigating the different pathways for cancer referrals in England for Teenagers and Young Adults<br>• Pattern of deaths in the year following diagnosis in cancer patients aged 15-24 years in England<br>• Notifications of teenagers and young adults with cancer to a Principal Treatment Centre 2009-2010<br>• Short term survival for teenagers | Thank you for highlighting these reports. Having considered these, we do not feel they provide any further evidence to contradict existing recommendations. The decision not to update the guidance is based on no significant new evidence that contradicts the existing guidance being identified through our surveillance process or subsequent consultation with stakeholders. |

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| | | | | and young adults: 2005 to 2009<br>- Shared Care & Survival - CTYA SSCRG<br>- Second cancers among survivors of teenager and young adult cancer<br>- Survival in Teenagers and Young Adults with Cancer in the UK<br>- Gender differences in survival among Teenagers and Young Adults (TYA) with Cancer in England<br>- Place of Death for Children, Teenagers and Young Adults with Cancer in England<br>- Place of treatment for teenagers and young adults diagnosed with cancer 2003 - 2005<br>- Survival of Children, Teenagers and Young Adults with Cancer in England<br>- Teenagers and Young Adults with Cancer - 1st Annual Report of TYA Notifications (2009) | |
| Royal College of Physicians (RCP) | Strongly Disagree | Strongly Disagree | | The RCP is grateful for the opportunity to comment. Our experts believe that the recommendations in the CSGCYP 2005 have been superceded by other guidance and evolving practice in the development of Teenage and Young Adult Cancer Services. | Thank you for your comments. |

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| | | | | As such, the NICE CSGCYP 2005 no longer reflects current recommendations on standards of care for Young People (16 to 24 years) with cancer.<br>Evidence: See below | |
| | | | | Overview:<br>There have been substantial changes in the concept of how Teenage and Young Adult (TYA) cancer services should be delivered since 2005. When the CSGCYP was developed it was envisaged that TYA Cancer services would be along side or co-located with paediatric oncology units and largely run as an extension of paediatric oncology services.<br>The description of TYA Services proposed in the IOG does not fit current concepts of delivery of TYA care or the current shape of the emerging national TYA service.<br>Evidence:<br>Since 2005, 27 new TYA units have been opened, or in development. Some are extension of paediatric services, as envisaged, treating children aged 13/14 to 16 or 19 years. However 12 unit (45% of all) are now | Thank you for your comments. The decision not to update the guidance is based on no significant new evidence that contradicts the existing guidance being identified through our surveillance process, despite a focussed search for evidence on the association between treatment volume and outcome, or through subsequent consultation with stakeholders. The guidance recommends that all care for children and young people under 19 years old must be provided in age-appropriate facilities, and that young people of 19 years and older should also have unhindered access to age appropriate facilities and support when needed. NICE recognises that the delivery of teenage and young adult cancer services has evolved since the publication of this guidance but we feel that the existing recommendations do not preclude current service design. However, NICE recognises the potential impact |

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| | | | | sited in Adult Oncology Centres, run by adult oncologist/haematologists and treating patients aged 16/17 to 24 years.<br>[http://www.teenagecancertrust.org/what-we-do/specialist-services/units/](http://www.teenagecancertrust.org/what-we-do/specialist-services/units/) | of the ongoing BRIGHTLIGHT study which was highlighted by the Teenage Cancer Trust. It is therefore proposed that the guideline should remain on the active surveillance list until the results of this study are published.<br><br>The quality standard for children and young people with cancer identifies key areas for quality improvement, based on the original guidance, across all aspects of cancer services for children and young people with cancer. The expert group that developed the quality standard identified no placeholder statements that would require new recommendations to be produced. |
| | | | | Service organisation – Place of Care (CSGCYP pp103-112)<br>The description of Principle Treatment Centres (PTC) (p103-4) describes the organisation of paediatric UKCCSG oncology centres.<br>There is no clear description of specialist units for older teenagers and young adults up to 24 years sited within adult oncology centres and run by adult oncologists/haematologists. Nor is there any indication that these might exist as separate TYA PTCs in the future. | Thank you for your comments. The decision not to update the guidance is based on no significant new evidence being identified through our surveillance process or subsequent consultation with stakeholders.<br><br>The guidance makes a number of recommendations on Place of Care for children and young people with cancer (p106-112). Firstly, it recommends that all care for children and young people under 19 years old must be provided in age-appropriate facilities and that young people of 19 |

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| | | | | That almost half of specialist centres delivering TYA cancer care are within adult cancer centres demonstrates that the 2005 Guidance for TYA Cancer is no longer valid.<br>Evidence: http://www.teenagecancertrust.org/what-we-do/specialist-services/units/ | years and older should have unhindered access to age appropriate facilities and support when needed. Relating to principal treatment centres, it recommends that there should be designated principal treatment centres for teenagers and young adults and that they should be able to provide a sustainable range of services with defined minimum levels of staffing. The defined levels of staffing are described for both children (p107-108) and young people (p109-110). The guidance also states that partnerships between age-appropriate facilities, such as teenage wards/units and tumour-specific services, which may be primarily located within an adult setting, are required.<br>NICE recognises that there will have been changes to the organisation of services for teenagers and young adults with cancer since the publication of this guidance but we feel that the existing recommendations do not preclude current service design. However, NICE recognises the potential impact of the ongoing BRIGHTLIGHT study which was highlighted by the Teenage Cancer Trust. It is therefore proposed that the guideline should remain on |

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| | | | | | the active surveillance list until the results of this study are published.<br>The quality standard for children and young people with cancer identifies key areas for quality improvement, based on the original guidance, across all aspects of cancer services for children and young people with cancer. The expert group that developed the quality standard identified no placeholder statements that would require new recommendations to be produced. |
| | | | | Service organisation – Shared Care (CSGCYP p105)<br>The recommendation in the CSGCYP is shared care arrangements, similar to those in paediatric services, should be "established for the care of teenagers and young adult". This was later considered to be inappropriate and replaced by the concept of Designated Hospitals for the care of TYA cancer.<br>Evidence:<br>National Cancer Peer Review Programme, Manual for Cancer Services: Teenage and Young Adult Cancer. Version 2.0 (Gateway No. 16287) | Thank you for your comment. The guidance makes a number of recommendations on Place of Care for children and young people with cancer (p106-112). Shared-care arrangements are not specifically recommended for teenagers and young adults. The guidance recommends that all care for children and young people under 19 years old must be provided in age-appropriate facilities, and that young people of 19 years and older should have unhindered access to age appropriate facilities and support when needed. It also states that all shared care arrangements should involve the provision of an agreed level of coordinated care with the principal |

| Stakeholder | Do you agree that the guidance should not be updated? | Do you agree that the guidance should be put on the static list? | Comments on equality issues or areas excluded from the original scope | Comments<br>If you disagree please explain why | Response |
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| | | | | | treatment centre and there should be a responsible MDT within that treatment setting.<br>The TYA Peer review measures are based on implementation of the guidance and are used for the assessment of cancer services. The measures require the teenage and young adults' cancer network to designate certain hospitals outside the principal treatment centre (PTC) which are the hospitals to be recommended to TYAs should they choose not to be treated in the PTC. The designated hospital will effectively operate as a shared care hospital with the PTC and the recommendations from the guidance on shared care will therefore apply to them.<br>NICE recognises that the organisation of services for teenagers and young adults with cancer services has changed since the publication of this guidance but we feel that the existing recommendations do not preclude current service design. However, NICE recognises the potential impact of the ongoing BRIGHTLIGHT study which was highlighted by the Teenage Cancer Trust. It is therefore proposed that the guideline should remain on |

| Stakeholder | Do you agree that the guidance should not be updated? | Do you agree that the guidance should be put on the static list? | Comments on equality issues or areas excluded from the original scope | Comments<br>If you disagree please explain why | Response |
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| | | | | | the active surveillance list until the results of this study are published.<br>The quality standard for children and young people with cancer identifies key areas for quality improvement, based on the original guidance, across all aspects of cancer services for children and young people with cancer. The expert group that developed the quality standard identified no placeholder statements that would require new recommendations to be produced. |
| | | | | Designated Hospitals<br>The specification of service delivery for TYA (14-24 years) within Designated Hospitals, as described in the Cancer Measures* (topic 11-1D-1z) is inadequate.<br>The minimum service within the Designated Hospital as described does not adequately fulfil the requirements laid out in the CSGCYP (Key Recommendations) that "Young People of 19 years and older should have unhindered access to age appropriate facilities and support when needed", nor do they meet the new Quality Standards.<br>* National Cancer Peer Review Programme, Manual for Cancer | Thank you for highlighting this issue. The aim of the guidance is to provide recommendations on service provision based on the best available evidence. The guideline was the primary source of guidance used for the development of the quality standard for children and young people with cancer which aims to drive measurable quality improvements within key areas identified from the guidance. The expert group that developed the quality standard identified no placeholder statements that would require new recommendations to be produced.<br>The decision not to update the guidance is based on no significant |

| Stakeholder | Do you agree that the guidance should not be updated? | Do you agree that the guidance should be put on the static list? | Comments on equality issues or areas excluded from the original scope | Comments<br>If you disagree please explain why | Response |
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| | | | | Services: Teenage and Young Adult Cancer. Version 2.0 (Gateway No. 16287)<br>NICE Quality Standard 55: Children and Young People with Cancer. February 2014 | new evidence that contradicts the existing guidance being identified through our surveillance process or subsequent consultation with stakeholders. The guidance does not intend to define how recommendations should be delivered. Failure to follow the guidance recommendations is a local implementation issue. |
| | | | | Service organisation – Multi-disciplinary teams (MDT) (CSGCYP pp91, 92, table 4)<br>The CSGCYP 2005 describes a single MDT model for delivering care in both paediatric oncology and TYA cancer services. This has been superceded by the TYA Cancer Measures and NICE Quality Standards which recommend that for TYA patients their care should be delivered jointly by a Tumour Site Specific MDT and a 'TYA MDT'.<br>The composition of the TYA MDT, as currently conceived for best practice, is best described in the NICE QS55 (2014) Statement 1.<br>This model of care delivery for patients 16-24 years needs to be incorporated into the revised CSG for Young People with Cancer.<br><br>Evidence: | Thank you for your comments. The guidance make a number of recommendations on MDTs (p93-94), In particular, it recommends that care should be delivered throughout the care pathway by MDTs, including all relevant staff and that decisions should be recorded and disseminated to all relevant health professionals. Where care involves more than one treatment setting or specialist team, the remit and membership of the MDTs should reflect the arrangements for shared care.<br><br>Recommendations on MDTs and principal treatment centres from the guidance were the source for Quality Statement 1 in the quality standard. Based on the guidance, the quality standard identifies key areas for quality improvement across all aspects of cancer services for children |

| Stakeholder | Do you agree that the guidance should not be updated? | Do you agree that the guidance should be put on the static list? | Comments on equality issues or areas excluded from the original scope | Comments<br>If you disagree please explain why | Response |
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| | | | | NICE Quality Standard 55: Children and Young People with Cancer. February 2014 | and young people with cancer. The expert group that developed the quality standard identified no placeholder statements that would require new recommendations to be produced.<br>The TYA Peer review measures are also based on implementation of the guidance and are used for the assessment of cancer services. The measures require the teenage and young adults' cancer network to agree a single TYA MDT for the network and for there to be shared responsibility for patient management between the TYA MDT and site specific MDTs.<br>NICE recognises that the organisation of services for teenagers and young adults with cancer services has changed since the publication of this guidance but we feel that the existing recommendations do not preclude current service design. However, NICE recognises the potential impact of the ongoing BRIGHTLIGHT study which was highlighted by the Teenage Cancer Trust. It is therefore proposed that the guideline should remain on the active surveillance list until the results of this study are published. |
| | | | | Long Term Sequelae (CSGCYP pp77- | Thank you for highlighting these |

| Stakeholder | Do you agree that the guidance should not be updated? | Do you agree that the guidance should be put on the static list? | Comments on equality issues or areas excluded from the original scope | Comments<br>If you disagree please explain why | Response |
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|  |  |  |  | 78)<br>This should be updated in the light of recent published recommendations, regarding 1) fertility preservation, 2) breast cancer risk following radiotherapy, 3) cardiac monitoring following cardiotoxic chemotherapy and/or mediastinal radiotherapy.<br>Evidence:<br>1. Loren AW et al. Fertility preservation for patients with Cancer: American Society of Clinical Oncology Clinical Practice Guidelines Update. J Clin Oncol. 2013, 31:2500-2510<br>2. NHS Cancer Screening Programmes. Protocol for the surveillance of women at high risk of developing breast cancer, V4. NHSBSP Pub no.74 – June 2013<br>3. Lancellotti P et al. Expert consensus for multi-modal imaging evaluation of cardiovascular complications of radiotherapy in adults: a report from the European Association of Cardiovascular Imaging and the American Society of echocardiography. EU Heart J 2013, 14:721-740 | studies. The decision not to update the guidance is based on no new evidence that contradicts the existing guidance being identified through our surveillance process or subsequent consultation with stakeholders. The guidance recommends that there should be robust and appropriate surveillance of survivors. It also states that patients should have access to appropriate endocrine and fertility services in accordance with the NICE Clinical Guideline for Fertility. CG156 Fertility recommends cryopreservation to men and adolescent boys and women of reproductive age (including adolescent girls) who are preparing for medical treatment for cancer that is likely to make them infertile. The guideline also states that a lower age limit for cryopreservation for fertility preservation in people diagnosed with cancer should not be used.<br>The Quality Standard includes two quality statements relating to Follow-up and monitoring of late effects (quality statement 6) and Fertility support (quality statement 7). The expert group that developed the quality standard identified no placeholder statements that would |

| Stakeholder | Do you agree that the guidance should not be updated? | Do you agree that the guidance should be put on the static list? | Comments on equality issues or areas excluded from the original scope | Comments<br>If you disagree please explain why | Response |
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| | | | | | require new recommendations to be produced. |
| | | | | Bereavement (CSGCYP p87-88)<br>There is inadequate signposting to the needs of and support for younger siblings of TYA who die from cancer.<br>Evidence:<br>Childhood Bereavement Network.<br>http://www.childhoodbereavementnetwork.org.uk/aboutUs.htm | Thank you for highlighting this issue. The guidance recommends that cancer networks should ensure that all families who have experienced the death of a child or young person have access to specialist bereavement support, and that the specific needs of siblings should be recognised. Failure to follow the guidance recommendations is a local implementation issue. |
| TYA CRG, NHS England | Disagree | Disagree | | The initial CYP cancer guidance was published in 2005, at which stage TYA cancer services were in their infancy. Since then, the guidance has been rolled out nationally, with much learning. Services have been shaped within local frameworks and the existing NICE guidance does not accurately reflect current best practice. It is essential that the TYA guidance is updated to reflect this learning and to ensure that TYA cancer patients have access to the best medical and holistic care. | Thank you for your comment. Through the surveillance review of the children and young people cancer service guidance, no significant new evidence which may potentially change the direction of guidance recommendations was identified.<br>We are pleased that this guidance has been implemented and rolled out nationally as it is the intention of guidelines developed by NICE to address national variation in practice and not necessarily to reflect current practice as it is. NICE recognises that the organisation of services for children and young people with cancer services has evolved since the publication of this guidance but we feel that the existing |

| Stakeholder | Do you agree that the guidance should not be updated? | Do you agree that the guidance should be put on the static list? | Comments on equality issues or areas excluded from the original scope | Comments<br>If you disagree please explain why | Response |
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|  |  |  |  |  | recommendations do not preclude current service design.<br>A quality standard for children and young people with cancer, based on this guidance, was published in February 2014. This identifies key areas for quality improvement across all aspects of cancer services for children and young people with cancer. The expert group that developed the quality standard identified no placeholder statements that would require new recommendations to be produced.<br>As such, NICE has proposed that this guidance should not be considered for an update at this time but the guideline will remain on the active surveillance list and will consider any new results emerging from the BRIGHTLIGHT study. |

# Appendix 2 Decision matrix

The table below provides summaries of the evidence for key questions for which studies were identified.

| Conclusions from guideline | Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion? | Clinical feedback from the GDG | Conclusion of this 8-year surveillance review (2014) |
|---|---|---|---|
| **A. Presentation, Referral & Diagnosis** | | | |
| **CSGCYP-01: What is the evidence for delays in presentation, referral and diagnosis in children and young people with cancer?** | | | |
| Data was extracted from 15 studies for this review question:<br>• 10 historical case series<br>• 1 retrospective comparative study<br>• 1 qualitative study<br>• 2 surveys<br>• 1 audit<br>There was a scarcity of papers that evaluated the reasons behind diagnostic delays. Furthermore the studies did not always distinguish between primary and secondary care related delays. Diagnostic delays do however appear to be correlated with age and the older the child, the longer the delay between presentation and diagnosis. For some cancers there is a lack of awareness by parents of the warning signs and symptoms. Delays are also contributed towards by difficulties that general practitioners have in recognising symptoms that may be vague and occur in other less serious illnesses. | A systematic review[1] found that there is variation in the time to diagnosis between tumour types and that long delays are associated with a number of determinants, including older age, qualification of the first doctor contacted and non-specific symptoms. Delays in diagnosis are linked with poor outcomes in retinoblastoma and possibly leukaemia, nephroblastoma, and rhabdomyosarcoma (although data was inconclusive).<br>Another systematic review[2] was identified that assessed time to diagnosis in children and young adults with cancer. The results were not published in the abstract, however, it was reported that in the majority of studies considered, time to diagnosis varied between type of cancer and with age at diagnosis. | No clinical feedback provided. | New evidence is consistent with guideline recommendations:<br>Two systematic reviews were identified which indicated that time to diagnosis of children and young people with cancer varied between cancer type and that delays were linked with age. One of the studies found that delays in diagnosis are linked with poor outcomes in certain types of cancer but not in others. The findings of these studies are generally in line with the evidence presented in the guideline which indicates that delays in diagnosis appear to be correlated with age and that delays vary between cancer types. |

| Conclusions from guideline | Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion? | Clinical feedback from the GDG | Conclusion of this 8-year surveillance review (2014) |
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| There was consensus from the GDG members that implementation of the NICE GP referral guidelines for cancer should improve delays in referrals but that training and resources would be required. | | | |
| **B. Treatment - Chemotherapy** | | | |
| Evidence included:<br>• CSGCYP-02: 2 RCTs and 4 systematic reviews.<br>• CSGCYP-03: 2 systematic reviews and 2 historical case series.<br>• CSGCYP-04/05: 3 case series and 1 review.<br>• CSGCYP-06: 1 systematic review of RCTs; 1 non-randomised controlled trial; 2 qualitative studies; 1 historical case series; 1 guideline; 1 literature review; 1 review; 1 expert opinion; 1 expert position paper.<br><br>There was insufficient evidence on place of delivery of chemotherapy and its effect on outcomes and on the feasibility of home delivery of chemotherapy, although there was some evidence to indicate that home delivery produces improved quality of life for patients and carers. The importance of suitable facilities and | **CSGCYP-02: Does the place of administration and management of chemotherapy (CT) affect outcome?** | | |
| | A randomised cross-over trial[3] of 23 children with acute lymphoblastic leukaemia was identified which examined the impact of a hospital-based and a home-based chemotherapy programme. The results indicated that children receiving home-based treatment were better able to maintain a usual routine but experienced greater emotional distress. There was no difference between home and hospital-based care on the burden of care to parents, adverse events or societal costs. | No clinical feedback provided. | New evidence is consistent with guideline recommendations:<br><br>In summary, one study was identified which found that the place of administration of chemotherapy had no effect on the burden of care to parents, adverse events or costs. The results of these studies are generally in line with the recommendations in the guideline relating to chemotherapy, particularly that chemotherapy should only be delivered in an environment capable of providing the predicted level of support required and should be appropriately resourced. |
| | **CSGCYP-03: What evidence is there that community delivered chemotherapy is delivered more safely and effectively by nursing staff than by parents?** | | |
| | No studies identified. | No clinical feedback provided. | No relevant evidence identified. |
| | **CSGCYP-04: Are there reliable methods to monitor chemotherapy treatment compliance?** | | |
| | No studies identified. | No clinical feedback provided. | No relevant evidence identified. |
| | **CSGCYP-05: Are protocol compliance and effectiveness greater when treatment is performed by a shared care centre compared with a tertiary care centre?** | | |

<table>
<tr><th>Conclusions from guideline</th><th>Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?</th><th>Clinical feedback from the GDG</th><th>Conclusion of this 8-year surveillance review (2014)</th></tr>
<tr><td rowspan="3">the presence of appropriately trained staff were confirmed by some Level 3 evidence. There was evidence indicating that compliance is a particular problem in teenagers and young people. Electronic transfer of prescriptions (ETP) does appear to reduce prescribing errors, but there was no evidence specific for children and young people. Data is lacking for the effect of ETP on compliance in children and young people with cancer.</td><td>No studies identified.</td><td>No clinical feedback provided.</td><td>No relevant evidence identified.</td></tr>
<tr><td colspan="3"><b>CSGCYP-06: What evidence is there for non-compliance with cancer therapy in children and young people?</b></td></tr>
<tr><td>No studies identified.</td><td>No clinical feedback provided.</td><td>No relevant evidence identified.</td></tr>
<tr><td colspan="4"><b>C. Treatment - Surgery</b></td></tr>
<tr><td colspan="4"><b>CSGCYP-07: Does specialist (surgical) care improve outcomes for children and young people with cancer?</b></td></tr>
<tr><td>11 studies were included for this review question (2 systematic reviews, 3 guidelines, 2 reviews and 4 expert opinions).<br><br>There is general consensus that specialisation is associated with improved patient outcomes, but there is a lack of good evidence to support this. The requirements to provide optimum surgical treatment are specified in a number of UK guidelines and strategic documents. There is some observational evidence that specialisation is required in anaesthetic and pathology service provision.</td><td>No studies identified.</td><td>No clinical feedback provided.</td><td>No relevant evidence identified.</td></tr>
<tr><td colspan="4"><b>D. Treatment - Neurosurgery</b></td></tr>
</table>

| Conclusions from guideline | Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion? | Clinical feedback from the GDG | Conclusion of this 8-year surveillance review (2014) |
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| **CSGCYP-08: Do specialist paediatric neuro-oncology surgeons produce improved outcomes for children and young people with cancer?** | | | |
| The following studies were included: 1 historical case series, 4 guidance/guidelines/policy documents, 2 commentaries/expert opinions and 1 overview.<br>There is evidence from expert opinion and formal consensus that care of children and young people with brain tumours should be delivered in the context of multidisciplinary teams (MDTs). | No studies identified. | No clinical feedback provided. | No relevant evidence identified. |
| **E. Treatment - Radiotherapy** | | | |
| 11 studies were included for this review question (3 RCTs, 2 retrospective cohort studies, 1 systematic review, 4 historical case series and 1 literature review).<br>There was a lack of consistent evidence for the effect of delays of radiotherapy on outcomes. The recommendations for the provision of specialist RT facilities are in agreement with a move to sub specialisation in clinical oncology as outlined in the Calman Hine report and the publications from the royal colleges. The resource requirements are also specified in guidance from the UKCCSG and there is emphasis on the need to provide age | **CSGCYP-09: Do delays in radiotherapy (RT) and quality of radiotherapy affect patient outcomes in children and young people with cancer?** | | |
| | No studies identified. | No clinical feedback provided. | No relevant evidence identified. |
| | **CSGCYP-10: What evidence is there for the provision of specialist radiotherapy facilities producing improved outcomes?** | | |
| | No studies identified. | No clinical feedback provided. | No relevant evidence identified. |

| Conclusions from guideline | Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion? | Clinical feedback from the GDG | Conclusion of this 8-year surveillance review (2014) |
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| appropriate facilities in line with the general recommendation in the children’s National Service Framework. | | | |
| **F. Supportive Care - Febrile Neutropenia** | | | |
| **CSGCYP-11: Does the place of treatment of febrile neutropenia (FNP) episodes for children and young people with cancer affect outcome?**<br>**CSGCYP-12: Are there safe and reliable methods for selecting and treating children and young people with FNP in an outpatient setting?** | | | |
| Evidence included:<br>i) 4 studies including 3 RCTs, 1 guideline and 1 literature review).<br>ii) 7 studies including 1 systematic review, 1 prospective case series, 1 prospective cohort, 2 guidelines and 2 historical case series.<br>The guidelines that exist are from the United States and there is consensus that there is an urgent need for UK guidelines on the management of FNP. As yet there is insufficient high quality evidence to determine whether it is safe to treat FNP in an outpatient setting. | No studies identified.<br>In September 2012, the clinical guideline CG151 Neuropenic sepsis was published. This guideline makes recommendations on the prevention and management of neutropenic sepsis in cancer patients, including children and young people. In particular, the guideline makes recommendations relating to providing patients and carers with information and support, identification and assessment, and place of treatment.<br>This section of the CSGCYP should be retired as it has been superseded by CG151. | No clinical feedback provided. | No relevant evidence was identified. However, this section of the guideline should be retired as it has been superseded by CG151. |
| **G. Supportive Care - Central Venous Access** | | | |
| **CSGCYP-13: What is the evidence for the optimum method of central venous catheter (CVC) insertion in children and young people with cancer?** | | | |
| 10 studies were included for this review question (1 RCT, 1 non-randomised controlled study, 2 systematic reviews, 1 prospective cohort study, 1 retrospective | No studies identified. | No clinical feedback provided. | No relevant evidence identified. |

| Conclusions from guideline | Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion? | Clinical feedback from the GDG | Conclusion of this 8-year surveillance review (2014) |
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| comparative study, 2 guidelines, 1 audit and 1 non-systematic literature review).<br>No randomised evidence specific for child or adolescent cancer patients was identified. No clear evidence was found to indicate the best model of care for CVC insertion in children and young people with cancer. | | | |
| **H. Supportive Care - Blood Product Support** | | | |
| **CSGCYP-14: Blood Product Support** | | | |
| 3 national guidelines, 1 national surveillance report and 1 expert position paper were included for this review question.<br>The expert position paper was accepted by the GDG as providing advice on this topic and a detailed literature search was not performed. The three guidelines and the expert position paper recommended the use of agreed protocols although there was no supporting evidence specific for children and young people with cancer. The results of the national surveillance of adverse incidents indicated that medical and nursing and laboratory staff should be aware of the specific transfusion requirements of children. | No studies identified. | No clinical feedback provided. | No relevant evidence identified. |
| **I. Supportive Care - Pain Management** | | | |

| Conclusions from guideline | Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion? | Clinical feedback from the GDG | Conclusion of this 8-year surveillance review (2014) |
|---|---|---|---|
| **CSGCYP-15: What are effective methods for pain management in children and young people with cancer?** | | | |
| Five studies were included for this review question (1 systematic review, 2 guidelines, 1 government policy and 1 expert opinion).<br>It was clear from the evidence that multidisciplinary protocols should be in place for pain assessment and treatment and all children should have access to play specialists. There is evidence from a systematic review that relaxation and cognitive behavioural therapy (CBT) are effective in reducing effects of headache. | One observational study[4] was identified which examined the use of the WHO Analgesic Ladder for managing pain in children with cancer. 84 children with cancer pain were studied for a 3 week period. By the third week 82.1% were on step 3 of the ladder and there was a significant reduction in pain as time progressed. The findings suggest that the ladder is an effective tool for managing pain in children with cancer.<br>A small RCT[5] was identified including 40 children with leukaemia, followed by interviews with half the group. The study aimed to evaluate music therapy to reduce pain and anxiety in children with cancer undergoing lumbar punctures. Those receiving music therapy had lower pain scores and in interviews described feeling less pain and fear. | No clinical feedback provided. | New evidence is consistent with guideline recommendations:<br>Two studies were identified which examined methods of pain management in children and young people with cancer. The findings of one of the studies indicated that the WHO Analgesic Ladder is an effective tool for managing pain in children with cancer. The second study found limited evidence that music therapy is an effective method of pain relief in children undergoing lumbar punctures. Both studies are generally in line with the current guideline which references the WHO Analgesic Ladder for the systematic control of pain, and use of distraction techniques for painful procedures. |
| **J. Supportive Care - Management of Nausea and Vomiting** | | | |
| **CSGCYP-16: What is the evidence for the optimum management of nausea and vomiting?** | | | |
| Five studies were included for this review question (1 quasi randomised controlled trial, 3 guidelines and 1 expert opinion).<br>There is evidence that the use of | No studies identified. | No clinical feedback provided. | No relevant evidence identified. |

| Conclusions from guideline | Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion? | Clinical feedback from the GDG | Conclusion of this 8-year surveillance review (2014) |
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| evidence based guidelines on the symptoms of nausea and vomiting showed that such guidelines do improve control of nausea and vomiting. | | | |
| **K. Supportive Care - Nutrition** | | | |
| **CSGCYP-17: What is the evidence for the optimum method of provision of nutritional support for children and young people with cancer?** | | | |
| 1 historical case series, 1 guideline, 2 expert opinions and 1 expert position paper were included for this review question.<br>The expert position paper was accepted by the GDG as providing advice on this topic and a detailed literature search was not performed. This paper stated that nutritional support to prevent loss of lean body mass is an integral part of treatment of paediatric oncology patients. It will improve tolerance of therapy, immune competence, quality of life and promote growth and development. It is necessary to choose the most appropriate method of nutritional support taking into account the child's age, condition and treatment. It is imperative that the effect on nutritional status is monitored to ensure the optimum support is being given and a multidisciplinary team approach is the best way of ensuring this. | A systematic review[6] was identified which aimed to assess the effects of parenteral or enteral nutritional support in children and young people with cancer undergoing chemotherapy. 8 trials were included in the review although the results of just two trials were presented in the abstract. The results from the two trials provided limited evidence that parenteral nutrition is more effective than enteral nutrition in terms of weight gain and calorie intake. However, the study did not consider the nutritional content of parenteral or enteral nutritional support, or other methods of nutritional support thus making it difficult to assess what the optimum method of nutritional support is. | No clinical feedback provided. | New evidence is unlikely to impact on guideline recommendations:<br>One systematic review was identified which indicated that parenteral nutrition is more effective than enteral nutrition. However, the study did not assess what the optimum method of nutritional. As such, the findings are unlikely to impact on the current recommendation which states that nutritional support, enteral or parenteral, should be designed to provide adequate protein, energy, vitamins and minerals for all children and young people. |

| Conclusions from guideline | Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion? | Clinical feedback from the GDG | Conclusion of this 8-year surveillance review (2014) |
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| **L. Supportive Care - Oral & Dental Care** | | | |
| **CSGCYP-18: What is the evidence for the optimum method of provision of oral and dental care for children and young people with cancer?** | | | |
| 7 studies were included for this review question (1 systematic review, 2 historical case series, 1 survey, 2 guidelines and 1 expert opinion).<br>There is a lack of high quality evidence for effective treatment for oral infections and mucositis. A survey of paediatric oncology centres in the UK revealed variation in service provision for oral and dental care. Two guidelines provided some recommendations for oral care and the management of oral and dental problems occurring during cancer treatment. The author of one expert opinion concluded that the development and implementation of evidence based guidelines could improve the oral and dental care of children and young people with cancer. | A retrospective study[7] was identified that aimed to assess the safety of dental treatment in children with acute lymphoblastic leukaemia, and Hodgkin lymphoma and non-Hodgkin lymphoma. 124 children received dental treatment and the majority had no complications following treatment. However, the study did not specifically explore the best methods of provision of oral and dental care for children with cancer. | No clinical feedback provided. | New evidence is unlikely to impact on guideline recommendations:<br>One study was identified which indicated that children with cancer had no complications following dental treatment. However, the study did not specifically explore the best methods of provision of oral and dental care for children with cancer. As such, the results of this study are unlikely to impact on the current recommendations. |
| **M. Rehabilitation** | | | |
| **CSGCYP-19: What is the most effective strategy to provide effective rehabilitation services for children and young people with cancer?** | | | |
| 3 studies were included for this question (2 systematic reviews and 1 literature review).<br>There is a lack of good quality evidence for children and young people with cancer. Consensus | An observational study[8] including 32 children and young people was identified which evaluated the outcomes of a social skills intervention programme for child brain tumour survivors. The results indicated that the treatment led to | No clinical feedback provided. | New evidence is unlikely to impact on guideline recommendations:<br>Six studies were identified relating to rehabilitation services for children and young people with cancer. The new evidence identified was |

| Conclusions from guideline | Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion? | Clinical feedback from the GDG | Conclusion of this 8-year surveillance review (2014) |
|---|---|---|---|
| opinion exists that adequate allied health professional input is vital and that timing of commencement of rehabilitation is important.<br>The NICE guidance on Improving Supportive and Palliative Care for Adults with Cancer provides comprehensive evidence for effective rehabilitation services for adults with cancer and some of the recommendations can be extended to address children and young people with cancer. | significant improvements in social skills and quality of life, and that the intervention is feasible in terms of acceptability, retention and recruitment.<br>Another observational study[9] was identified which aimed to investigate the impact of a family-oriented inpatient rehabilitation programme on psychological symptoms and quality of life of chronically ill children, including children with cancer. The study found that there was a negative correlation between psychological symptoms and quality of life for both patients and parents. Following rehabilitation, psychological symptoms improved significantly, and in those followed up, those improvements were maintained at 6 month follow-up.<br>A small pilot study[10] was identified which aimed to assess the effectiveness of a home-based aerobic exercise intervention to reduce fatigue in children with acute lymphoblastic leukaemia. At 1-month follow-up, those receiving the intervention reported significantly lower levels of "general fatigue" than those in the control group. | | heterogeneous and assessed different types of interventions and their impact on outcomes including quality of life, anxiety, psychological and physical symptoms. None of the studies considered strategies to provide effective rehabilitation services thus the new evidence is unlikely to impact on the current recommendations. |

| Conclusions from guideline | Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion? | Clinical feedback from the GDG | Conclusion of this 8-year surveillance review (2014) |
|---|---|---|---|
|  | A small pilot study[11] was identified which evaluated the effects of creative arts therapy on the quality of life of children receiving chemotherapy. Results were not presented in the abstract, however, the randomised controlled phase of the study indicated that the intervention led to an improvement in child's hurt and nausea (as reported by parents), and the nonrandomized phase suggested improvements to patients' mood following therapy.<br>A study[12] was identified which aimed to evaluate the impact of music on children with leukaemia receiving maintenance or consolidation outpatient treatment. The study compared music therapy to rest and found that child's relaxation and heart rate variability improved more with music than rest.<br>A small pilot study[13] was identified which aimed to assess the impact of massage on symptoms and anxiety in children with cancer receiving chemotherapy. The results indicated that massage was more effective than quiet time at reducing heart rate and anxiety in children under 14 years, as well as parental anxiety. |  |  |
| **N. Psychosocial Care** |  |  |  |

| Conclusions from guideline | Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion? | Clinical feedback from the GDG | Conclusion of this 8-year surveillance review (2014) |
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| **CSGCYP-20: What is the evidence for the best model of psychosocial care for children and young people with cancer?** | | | |
| 6 studies were included for this question (2 systematic reviews, 1 overview survey, 1 questionnaire study, 1 expert opinion and 1 expert position paper).<br>Whilst high quality evidence was lacking on the optimum psychosocial service provision, the NICE guidance on Improving Outcomes in Palliative and Supportive Care for Adults with Cancer recommended that cancer networks have an important role in coordinating service improvement to meet the demonstrated unmet need for psychosocial input. | No studies identified. | No clinical feedback provided. | No relevant evidence identified. |
| **O. Long Term Follow Up/Sequelae** | | | |
| The evidence included:<br>• CSGCYP-21: 1 historical case series, 1 guideline, 1 questionnaire survey, 1 expert opinion, 1 review, 1 qualitative study and 1 expert position paper.<br>• CSGCYP-22: 1 retrospective cohort study, 1 cross sectional study, 1 expert opinion and 1 expert position paper.<br>• CSGCYP-23: 1 audit, 1 questionnaire survey, 1 survey and 1 expert position paper. | **CSGCYP-21: What is the evidence for the most effective strategy to provide long term follow up (FU) for children and young people with cancer?** | | |
| | A study[14] was identified which aimed to assess the feasibility of shared-care by paediatric oncologists and family doctors in the long-term follow-up of survivors of childhood cancers. Over a 3 year period, patients received yearly assessments at a long term follow up clinic and by a family doctor. The results of study indicated that 88% of patients and 82% of family doctors were satisfied with the shared-care model. | No clinical feedback provided. | New evidence is unlikely to impact on guideline recommendations:<br>One study was identified which indicated that a shared-care model of follow-up was a satisfactory approach for patients and family doctors. However, no details were provided on outcomes relating to the adoption of this model. The findings are therefore unlikely to impact on guideline recommendations at this time. |

| **Conclusions from guideline** | **Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?** | **Clinical feedback from the GDG** | **Conclusion of this 8-year surveillance review (2014)** |
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| The variability of follow-up provided by different centres in the United Kingdom has also been highlighted in the evidence. 1 guideline describes three levels of follow up care and makes recommendations for GP and patient/carer information. An audit of current provision of fertility services and the development of service guidance makes a series of recommendations for the development of comprehensive fertility services. | | | |
| | **CSGCYP-22: What is the evidence for the optimum type of late effects services for children and young people with cancer?** | | |
| | No studies identified. | No clinical feedback provided. | No relevant evidence identified. |
| | **CSGCYP-23: Should fertility (cryo) preservation strategies be routinely offered to all young people deemed at significant risk of infertility and competent to consent?** | | |
| | A small study[15] was identified which found that treatment for acute lymphoblastic leukaemia has a negative effect on testicular function in prepubertal and pubertal boys. | One GDG member indicated that they were aware of ongoing research relating to fertility options for patients with cancer, which will include implications for children and young people. However, no detailed references were provided. | New evidence is consistent with guideline recommendations:<br>One study was identified which supported the current guideline recommendation that there should be access to semen storage for peripubertal and postpubertal boys. |
| **P. Palliative Care** | | | |
| **CSGCYP-24: For children and young people with cancer what is the evidence for the requirements for a comprehensive palliative care service?** | | | |
| The following studies were included for this question:<br>• 1 systematic review<br>• 1 guideline<br>• 4 questionnaire surveys<br>• 7 expert opinions<br>• 1 expert position paper<br>• 1 strategic document<br>There is a considerable amount of observational evidence on the requirements for effective palliative care service provision to children and young people with cancer. Outcome measurement is difficult and there is a need for well designed high quality studies to evaluate different models | One study[16] was identified which evaluated caregivers' experiences of caring for a terminally ill relative at home. The study found that overall, caregivers had greater satisfaction with the experience of caring for those who died at home and had access to a home palliative care programme. | No clinical feedback provided. | New evidence is consistent with guideline recommendations:<br>One study was identified which indicated access to a home palliative care service improved the experience of caring for someone at home at the end of life. This is broadly consistent with current recommendations concerning the core elements of a palliative care service, particularly coordination of services at home where this is the chosen place of care; and emotional, spiritual and practical support for all family members. |

| Conclusions from guideline | Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion? | Clinical feedback from the GDG | Conclusion of this 8-year surveillance review (2014) |
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| of service provision.<br>The NICE guidance on Improving Supportive and Palliative Care for Adults with Cancer provides good-quality evidence for the requirements of a palliative care service for adults, many of which can be extrapolated to children's services. | | | |
| **Q. Bereavement** | | | |
| **CSGCYP-25: What is the evidence for best practice in the provision of bereavement services for children and young people with cancer, their families and carers?** | | | |
| Four studies were included for this question (1 systematic review, 1 draft guideline and 2 questionnaire surveys).<br>There is a lack of evidence on what constitutes an effective bereavement service but there is consensus on the need for key worker support and that each treatment centre should provide bereavement support for a suitable period depending on the needs of individual families. Good communication skills and the provision of adequate information are vital in providing bereavement support. | No studies identified. | No clinical feedback provided. | No relevant evidence identified. |
| **R. Multidisciplinary Teams/Care** | | | |
| **CSGCYP-26: What is the evidence for the role of the multidisciplinary team (MDT) on the outcomes of care of children and young people with cancer?** | | | |
| The following studies were included: | No studies identified. | One GDG member reported that | No new evidence identified. Issues |

| Conclusions from guideline | Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion? | Clinical feedback from the GDG | Conclusion of this 8-year surveillance review (2014) |
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| • 1 RCT<br>• 2 case series<br>• 2 expert opinions<br>• 1 survey<br>• 1 guide/guidance<br>• 1 consensus<br>In children and young people with cancer there is a lack of high quality evidence that directly supports the positive effect of multidisciplinary care on survival. Observational evidence suggests that such care leads to improved quality of life for patients. | | there was concern about the inevitable variation in clinical practice for delivery of care for children and young people with cancer (e.g. configuration of multidisciplinary teams, implementation of late effects guidance etc.). However, they felt that these concerns would be addressed through a process of ongoing peer review. | raised through clinical feedback are unlikely to impact on current guideline recommendations. |
| **S. Continuity of Care** | | | |
| The evidence included:<br>i) 1 review, 2 formal consensus papers and 2 expert opinion papers.<br>ii) 1 RCT, 1 policy document, 1 questionnaire survey, 1 literature review and 1 guidance/resource pack.<br>No evidence from high level research was identified to indicate the optimum model of service provision to ensure continuity of care for children and young people with cancer; this also applied to disabled children. The Children Act states the importance of the key worker in | **CSGCYP-27: How can the transition from paediatric to adult services best be managed to ensure quality services for teenagers and young people?** | | |
| | No studies identified. | No clinical feedback provided. | No relevant evidence identified. |
| | **CSGCYP-28: What is the evidence for the role of the key worker in the care of children and young people with cancer?** | | |
| | No studies identified. | No clinical feedback provided. | No relevant evidence identified. |

| Conclusions from guideline | Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion? | Clinical feedback from the GDG | Conclusion of this 8-year surveillance review (2014) |
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| coordinating the care of children. Observational evidence supports the role of the key worker in successful coordination in the transition of care. | | | |
| **T. Protocol Based Care** | | | |
| **CSGCYP-29: What is the evidence that protocol driven treatment improves outcomes for children and young people with cancer?** | | | |
| 5 studies were included for this question (1 systematic review, 1 prospective cohort study, 2 historical case series and 1 literature review).<br>There is some evidence to support the positive effect of protocol-based care on outcomes. | The results of a systematic review[17] suggest that adolescents with acute lymphoblastic leukaemia have improved survival outcomes when treated using paediatric protocols. However, detailed results were not published in the abstract. | No clinical feedback provided. | New evidence is consistent with guideline recommendations:<br>One study was identified which suggested that young people with acute lymphoblastic leukaemia have improved survival outcomes when treated using paediatric protocols. This new evidence is consistent with current guideline recommendations which state that choice of paediatric or adult protocol for treatment should be based on clear evidence of the best outcomes. |
| **U. Place of Care** | | | |
| The evidence included:<br>• CSGCYP-30: 1 non randomised controlled trial, 1 systematic review, 1 retrospective cohort study, 3 reviews, 6 historical case series, 1 guidance, 1 dissertation/evidence review and 1 expert opinion.<br>• CSGCYP-31: 2 systematic reviews, 1 thesis/expert opinion, 1 literature review and 1 survey. | **CSGCYP-30: What evidence is there for the optimum place of treatment for children and young people with cancer?** | | |
| | A retrospective review[18] of adolescents diagnosed with acute lymphoblastic leukaemia was identified which aimed to determine the impact on survival of treatment at paediatric versus adult hospitals. The findings indicated that there was no significant difference in survival between patients treated at a paediatric centre or adult centre. | One GDG member indicated that they were aware of concerns regarding the current structural relationships between Principal Treatment Centres (PTCs) and Paediatric Oncology Shared Care Units (POSCUs) in the South East of England and that work was ongoing regarding re-defining relationships and oncology pathways. | New evidence is consistent with guideline recommendations:<br>One study was identified relating to the optimum place of treatment for children and young people with cancer. The findings support the existing guideline recommendation which states that care for children and young people must be provided |

| Conclusions from guideline | Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion? | Clinical feedback from the GDG | Conclusion of this 8-year surveillance review (2014) |
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| • CSGCYP-32: 2 systematic reviews, 1 literature review and 4 historical case series.<br>• CSGCYP-33: 1 RCT, 1 systematic review, 2 qualitative studies, 1 review, 3 reports/guidance and 1 expert opinion.<br><br>There is limited good quality evidence to suggest the optimum place of treatment for children and young people with cancer. The choice of outcome measures is difficult and survival has most frequently been used, with no conclusive supporting evidence being found. Other measures such as quality of life and patient satisfaction are also important and several studies have addressed these outcomes. The evidence for shared care improving outcomes appears to depend on whether the care is well coordinated with good communication methods. | However, most patients treated at an adult centre received paediatric protocols. | One GDG member felt that the guideline requires an update to take account of workforce issues, in particular, at Paediatric Oncology Shared Care Units/District General Hospital level, availability of middle grade cover and therefore the clinical input of consultants has changed reflecting changes in how clinical care is now delivered e.g. more resident consultants; more clinical nurse specialists; and the role of clinical care practitioners etc. | in age-appropriate facilities.<br><br>One GDG member felt the guideline should be updated to take account of workforce issues, particularly relating to shared care units. However, this is unlikely to impact on any of the current guideline recommendations. |
| | **CSGCYP-31: What evidence is there for the effects of accessibility and centralisation of cancer services for children and young people?** | | |
| | No studies identified. | No clinical feedback provided. | No relevant evidence identified. |
| | **CSGCYP-32: Is there evidence for an association between the number of cases of children and young people with cancer seen and outcome?** | | |
| | A study[19] was identified which aimed to assess the prognostic significance of hospital surgical volume on outcomes for neuroblastoma and Wilms tumor in children and young people. The findings indicated that 5 and 10 year survival rates for both diagnoses were the same for those treated at a high volume centre as for a low volume centre.<br><br>A systematic review[20] of 14 studies found that outcomes were improved | No clinical feedback provided. | New evidence is unlikely to impact on guideline recommendations:<br><br>Two studies were identified which considered the outcomes of treatment at high volume providers. One of the studies found no difference in survival rates between low and high volume centre. However, the second study (a systematic review) suggested that outcomes were improved as a result of treatment at a high volume |

| Conclusions from guideline | Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion? | Clinical feedback from the GDG | Conclusion of this 8-year surveillance review (2014) |
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| | for children with various cancer diagnoses treated in higher volume hospitals, specialised hospitals, or by high case volume providers. | | provider for certain diagnoses of cancer. There were no details in the abstracts for the optimum number of cases seen at a high volume centre therefore the evidence is unlikely to impact on current guideline recommendations. |
| | **CSGCYP-33: Is there evidence that shared care improves patient outcomes?** | | |
| | No studies identified. | No clinical feedback provided. | No relevant evidence identified. |
| **V. Communication/Information** | | | |
| **CSGCYP-34: What is the evidence for effective means of communication and information giving?** | | | |
| The following studies were included for this question:<br>• 1 RCT<br>• 4 systematic reviews<br>• 2 qualitative studies<br>• 1 guideline<br>• 1 policy/expert opinion<br>• 2 surveys<br>There is very little high quality evidence to indicate the optimum service provision for children and young people with cancer who have very specific information requirements.<br>There is expert opinion, consensus and evidence, reviewed in the NICE guidance on Improving Supportive and Palliative Care for Adults with Cancer, to suggest the information requirements of patients with cancer. | An update to a Cochrane systematic review[21] used in the development of the original guideline was identified. The review aimed to assess the effects of interventions for improving communication with children and young people about their cancer. One new study was identified which found that a multifaceted interactive intervention reported a reduction in distress related to radiation therapy. Overall, the studies considered were heterogeneous both in terms of the interventions evaluated and the study designs used. It is therefore difficult to draw any conclusions as to the effectiveness of any specific means of communication. | No clinical feedback provided. | New evidence is unlikely to impact on guideline recommendations:<br>One systematic review was identified although this was an update to a review used in the development of the existing guideline. The heterogeneous nature of the interventions considered makes it difficult to draw any conclusions as to the effectiveness of any specific means of communication. The new evidence is therefore unlikely to impact on guideline recommendations. |

| Conclusions from guideline | Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion? | Clinical feedback from the GDG | Conclusion of this 8-year surveillance review (2014) |
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| **W. Research** | | | |
| The evidence included:<br>• CSGCYP-35: 2 retrospective analyses and 2 expert opinions.<br>• CSGCYP-36: 1 prospective cohort study, 1 literature review, 1 literature review of selected cancer trials, 2 historical case series and 1 expert opinion.<br>It is accepted that, while there is currently insufficient high quality evidence to definitely conclude that entry into a clinical trial improves outcomes in children and young people with cancer, patients should be encouraged to enrol in trials.<br>There is observational evidence to indicate that adolescents and young people do not have as good access to clinical trials as children. | **CSGCYP-35: Do children and young people with cancer have equal access to entry into clinical trials?** | | |
| | No studies identified. | No clinical feedback provided. | No relevant evidence identified. |
| | **CSGCYP-36: Does inclusion in a clinical trial improve outcomes for children and young people with cancer?** | | |
| | No studies identified. | No clinical feedback provided. | No relevant evidence identified. |

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