NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Centre for Clinical Practice – Surveillance Programme

Surveillance review consultation document

8 year surveillance review of cancer service guidance: Improving outcomes for children and young people with cancer

Background information

Guideline issue date: August 2005
8-year review: 2014 (no previous reviews)

Surveillance review recommendation

Surveillance review proposal put to consultees:

The children and young people with cancer 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The section of the guideline relating to Febrile Neutropenia should be retired as it has been superseded by CG151 Neutropenic sepsis: prevention and management of neutropenic sepsis in cancer patients.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 it fulfils the following criteria:

- No evidence was identified that would impact on the current guidance and no major ongoing studies or research has been identified as due to be published in the near future (that is, within the next 3-5 years).

Main findings of current (8-year) surveillance review

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.

New evidence was identified for the current 8 year surveillance review relating to the following areas of clinical management within the children and young people with cancer service guidance.

Clinical area 1: Presentation, Referral & Diagnosis		
Q. What is the evidence for delays in presentation, referral and diagnosis in children and young people with cancer?		
Evidence summary	**GDG/clinical perspective**	**Impact**
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). 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: 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.
Clinical area 2: Treatment		
Q. Does the place of administration and management of chemotherapy (CT) affect outcome?		
Evidence summary	**GDG/clinical perspective**	**Impact**
A randomised cross-over trial[3] of 23 children with acute lymphoblastic leukaemia was identified which examined the impact of a	No clinical feedback provided.	New evidence is consistent with guideline recommendations:

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.		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.
Clinical area 3: Supportive Care		
Q. Does the place of treatment of febrile neutropenia (FNP) episodes for children and young people with cancer affect outcome? Q. Are there safe and reliable methods for selecting and treating children and young people with FNP in an outpatient setting?		
Evidence summary	**GDG/clinical perspective**	**Impact**
No studies identified. 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. 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.
Clinical area 4: Supportive Care		
Q. What are effective methods for pain management in children and young people with cancer?		
Evidence summary	**GDG/clinical perspective**	**Impact**

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. 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: 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.
Clinical area 5: Supportive Care		
Q. What is the evidence for the optimum method of provision of nutritional support for children and young people with cancer?		
Evidence summary	**GDG/clinical perspective**	**Impact**
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	No clinical feedback provided.	New evidence is unlikely to impact on guideline recommendations: 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

nutritional support, or other methods of nutritional support thus making it difficult to assess what the optimum method of nutritional support is.		for all children and young people.
Clinical area 6: Supportive Care		
Q. What is the evidence for the optimum method of provision of oral and dental care for children and young people with cancer?		
Evidence summary	**GDG/clinical perspective**	**Impact**
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: 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.
Clinical area 7: Rehabilitation		
Q. What is the most effective strategy to provide effective rehabilitation services for children and young people with cancer?		
Evidence summary	**GDG/clinical perspective**	**Impact**
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 significant improvements in social skills and quality of life, and that the intervention is feasible in terms of acceptability, retention and recruitment. Another observational study[9] was identified which aimed to investigate the impact of a	No clinical feedback provided.	New evidence is unlikely to impact on guideline recommendations: Six studies were identified relating to rehabilitation services for children and young people with cancer. The new evidence identified was 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

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. 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. 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. A study[12] was identified which aimed to evaluate the impact of music on children with		evidence is unlikely to impact on the current recommendations.

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. 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.		
Clinical area 8: Long Term Follow Up/Sequelae		
Q. What is the evidence for the most effective strategy to provide long term follow up (FU) for children and young people with cancer?		
Evidence summary	**GDG/clinical perspective**	**Impact**
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: 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.
Clinical area 9: Long Term Follow Up/Sequelae		
Q. Should fertility (cryo) preservation strategies be routinely offered to all young people deemed at significant risk of infertility and competent to consent?		
Evidence summary	**GDG/clinical perspective**	**Impact**
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	New evidence is consistent with guideline recommendations: One study was identified which supported the

	and young people. However, no detailed references were provided and we are not aware of any new studies due to be published in the near future that will impact on the guideline.	current guideline recommendation that there should be access to semen storage for peripubertal and postpubertal boys.
Clinical area 10: Palliative Care		
Q. For children and young people with cancer what is the evidence for the requirements for a comprehensive palliative care service?		
Evidence summary	**GDG/clinical perspective**	**Impact**
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: 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.
Clinical area 11: Delivery of Care		
Q. What is the evidence that protocol driven treatment improves outcomes for children and young people with cancer?		
Evidence summary	**GDG/clinical perspective**	**Impact**
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: 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.
Clinical area 12: Place of Care		
Q. What evidence is there for the optimum place of treatment for children and young people with cancer?		
Evidence summary	**GDG/clinical perspective**	**Impact**
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. However, most patients treated at an adult centre received paediatric protocols.	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. 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.	New evidence is consistent with guideline recommendations: 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 in age-appropriate facilities. 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.
Clinical area 13: Place of Care		
Q. Is there evidence for an association between the number of cases of children and young people with cancer seen and outcome?		
Evidence summary	**GDG/clinical perspective**	**Impact**
A study[19] was identified which aimed to assess the prognostic significance of hospital surgical	No clinical feedback provided.	New evidence is unlikely to impact on guideline recommendations:

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. A systematic review[20] of 14 studies found that outcomes were improved for children with various cancer diagnoses treated in higher volume hospitals, specialised hospitals, or by high case volume providers.		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 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.
Clinical area 14: Communication/Information		
Q. What is the evidence for effective means of communication and information giving?		
Evidence summary	**GDG/clinical perspective**	**Impact**
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: 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.

For the following areas of the guideline no evidence was identified:

- Evidence that community delivered chemotherapy is delivered more safely and effectively by nursing staff than parents
- Reliable methods to monitor chemotherapy treatment compliance
- Impact on protocol compliance and effectiveness of chemotherapy at a shared care centre compared with a tertiary care centre
- Evidence for non-compliance with cancer therapy
- Impact of specialist surgical care on outcomes
- Impact of specialist paediatric neuro-oncology surgery on outcomes
- Impact of delays and quality of radiotherapy on outcomes
- Impact on outcomes of the provision of specialist radiotherapy facilities
- Evidence for the optimum method of central venous catheter (CVC) insertion
- Blood Product Support
- Evidence for the optimum management of Nausea and Vomiting
- Evidence for the best model of psychosocial care
- Evidence for the optimum type of late effects services
- Evidence for best practice in the provision of bereavement services
- Evidence for the role of the multidisciplinary team (MDT) on the outcomes of care
- Management of the transition from paediatric to adult services
- Evidence for the role of the key worker
- Evidence for the effects of accessibility and centralisation of cancer services
- Evidence that shared care improves patient outcomes
- Equality of access to entry into clinical trials and impact on outcomes

Ongoing research

Clinical feedback from one GDG member indicated that there is 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 and we are not aware of any new studies due to be published in the near future that will impact on the guideline.

Anti-discrimination and equalities considerations

None identified.

Conclusion

Through the 8 year surveillance review of the cancer service guidance: Improving outcomes for children and young people with cancer no new evidence which may potentially change the direction of guideline recommendations was identified. The proposal is not to update the children and young people cancer service guidance at this time and to move this guidance onto the static list because it fulfils the following criteria:

- No evidence was identified that would impact on the current guidance and no major ongoing studies or research has been identified as due to be published in the near future (that is, within the next 3-5 years).

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