

Improving the effectiveness of written communication between paediatric oncologists, primary care and childhood cancer survivors. A pilot study.

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Introduction 1 in 715 young adults is a childhood cancer survivor (CCS)¹. Approximately 60% of these survivors endure at least one lasting medical problem, whilst about 30% have a severe, life threatening or disabling chronic condition². To manage these late-effects of cancer treatment, paediatric oncology centres often arrange for the survivor's transition to age-appropriate care, typically to non-specialist primary care physicians who receive no formal training in dealing with survivorship associated morbidity in CCS. Thus, synoptic documents like treatment summaries and transfer letters are imperative in bridging knowledge gaps. **To date and to our knowledge, the effectiveness of these documents in terms of content and format has not been appraised within the UK, although there has been some indication that the quality of this written communication could be improved.**

Aim To evaluate existing written communication (transfer letters [TL] and treatment summary/care plans [TSCP] for childhood cancer survivors [CCS]) by seeking the opinions of various stakeholders involved in transitioning, collating this questionnaire feedback and if indicated, improving these templates.

Method

Stage 1: Evaluating existing templates

A questionnaire was created as a tool to assess examples of existing written communication, in terms of clarity of content, and format (refer to **Box 1**). This, along with real examples of existing transfer documents (from the Department of Paediatric and Adolescent Haematology / Oncology in the Great North Children's Hospital) were distributed to 14 stakeholders including paediatric oncologists, hospital specialists, GPs and survivors for assessment.

Stage 2: Feedback analysis and template improvements

Questionnaire responses were collated and analysed. According to the feedback, improvements made to the documents included: synoptic cover pages, number-based morbidity risk scales relating to previous cancer treatment received and systems at risk, and a bullet-point list of action items for the receiving care provider and the survivor explicitly outlining their roles and responsibilities with respect to management of follow-up care. The documents were also aesthetically enhanced.

The Newcastle upon Tyne Hospitals NHS Foundation Trust

Contact details of Long-term follow up service:
Long-term follow up
Telephone 0191 200 0000
Fax 0191 200 0000
xxx (Specialist Nurse) 0191 200 0000

Treatment Summary and Long Term Follow Up Plan

Name: _____ Hosp/NHS No: _____
Date of birth: _____ Sex: _____
Address: _____ Consultant: _____

Diagnosis: _____ Diagnosis date: _____
Stage/Group: _____ Treatment end date: _____
Treat/Process: _____

Recurrence of Disease YES
Date: _____ Site(s): _____ Management Summary: _____

Chemotherapy YES
Drug Effects to Monitor: _____ Dose IM: _____ Total Dose: _____

Surgery YES
Date: _____ Details: _____

Radiotherapy YES
Date: _____ Site(s): _____ Total Dose: _____ Fractions: _____ Normal Issues within field: _____ Notes: _____

Figure 1: Existing treatment summary template

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Long Term Follow Up Care Plan and Treatment Summary

Patient Name: _____
NHS No: _____ Hospital No: _____
Date of Birth: _____ Sex: _____
Address: _____
Initially Treating Consultant: _____ Hospital/Department: _____

Diagnosis/Stage: _____ Diagnosis date: _____
Treatment (including relapse): _____ Final treatment end date (including relapse): _____

Long term follow up provider (for any initial concerns regarding health & wellness)
Name: _____ Designation: _____
Phone Number: _____ Email: _____
Hospital/Clinic address: _____
Key worker
Name: _____ Designation: _____
Phone Number: _____ Email: _____
Hospital/GP address: _____

Potential long-term effects of treatment (require monitoring - see treatment summary for details)

Risk of...	Importance of risk	Reason	Surveillance instructions
e.g. Heart problems	Some	Anti-hypertensive treatment	Echocardiogram every 3 years

Figure 2: Improved treatment summary template

Box 1: Template domains assessed using the questionnaire

- Q1-3) Details of previous cancer diagnosis, cancer treatment and past test results
 - Q4) Surveillance instructions for long-term side effects
 - Q5) Protocol if side-effects become apparent
 - Q6) Patient-specific concerns
 - Q7) General comments regarding level of medical jargon, highlighting of important information etc.
- Note: the question numbers above correspond to the x-axes on results Graphs 1, 2 and 3.**

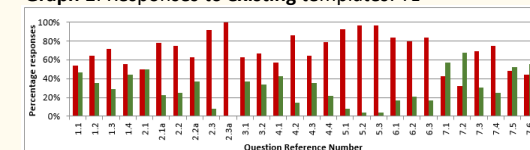
Stage 3: Evaluating improved templates: The 'improved' templates were re-distributed to the initially contacted stakeholders for re-assessment.

Conclusion Transfer documents play an important role in facilitating smooth transitioning of CCS care from paediatric oncologists to other care providers, including primary care clinicians. Many units within the UK currently follow a national template, which needs to be enhanced both content and format-wise. Our study has yielded an improved template which presents important transfer information (likely problems, monitoring required, what to do with results of surveillance tests etc.) in a more accessible manner for future carers and survivors. As a carry-forward from this pilot study, forthcoming research should endeavor to seek the opinions of teams nation-wide regarding these or similar transfer documents. The improved template should also be piloted in real clinical scenarios.

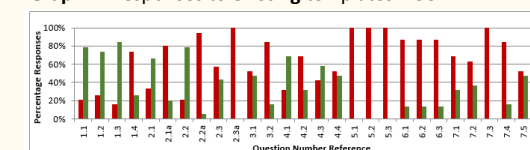
Results The graphs below present the questionnaire responses for both the existing and improved templates. The feedback indicated a significant improvement in the modified templates (refer to green bars on **Graph 3**) and a potential direction for future changes to these documents.

- Not mentioned, Unclear or Satisfactory / Strongly disagree, Disagree or Neutral
- Clear or Very clear / Agree or Strongly agree

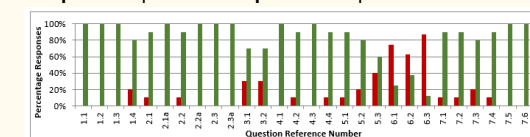
Graph 1: Responses to existing templates: TL



Graph 2: Responses to existing templates: TSCP



Graph 3: Responses to improved template: TL & TSCP



¹ Campbell J, Wallace WHB, Bhatti LA, et al. Childhood cancer in Scotland: trends in incidence, mortality and survival 1975-1999. Edinburgh: NHS Scotland Information and Statistics Division 2004.
² Oeffinger KC, Mertens AC, Sklar CA, Kawashima T, Hudson MM, Meadows A, et al. Chronic health conditions in adult survivors of childhood cancer. New England Journal of Medicine. 2006;355:1572-82