APPENDIX 3

Consultation Report

Topic details

Title of Service Specification:	Children’s Cancer Services
Programme of Care:	Cancer
Clinical Reference Group:	Children and Young People
URN:	1746

1. Summary

This report summarises the outcome of a public consultation that was undertaken to test the service specification proposals.

2. Background

Children’s cancer services encompass the diagnosis, management, and follow up of children and teenagers with cancer from 0 years of age up to their 16th birthday. Services are overseen by Principal Treatment Centres (PTCs), working in conjunction with Paediatric Oncology Shared Care Units (POSCUs) which provide some elements of cancer care closer to home.

Under the proposals, the existing Paediatric Oncology Service Specification will be replaced with separate service specifications for both PTCs, including the Children’s Cancer Operational Delivery Network (ODN) function, and POSCUs. Chemotherapy services for children have also been integrated into each of these service specifications, replacing the current standalone Chemotherapy Service Specification for Children, Teenagers and Young Adults.

The revised specifications do not alter the overall model of care for children’s cancer services, however they do enable:

- The establishment of ODNs to replace Children’s Cancer Network Co-ordinating Groups (CCNCG), where these still exist and function. They will have responsibility for driving improvements within the Network and across partner organisations, including relating to shared care arrangements, fertility preservation and recruitment to clinical trials and tissue banking.
- Greater standardisation of POSCUs provision, with POSCUs designated as either ‘Standard’ or ‘Enhanced’, depending on whether they provide chemotherapy and the type of chemotherapy offered. Information is provided within the specification to support the ODN to develop and improve local access

arrangements for the benefit of patients, for example, appropriate staffing and facilities together with guide activity volumes.

3. Consultation Activities

The service specification was published and sign-posted on NHS England's website and was open to consultation feedback for a period of 60 days from Wednesday 5th June 2019 to Sunday 4th August 2019.

Three webinars were held as part of the consultation which were attended by parents, clinicians, professional organisations, charities, cancer alliances and service providers. The webinars were well attended, and feedback indicated support for the proposals and that the impact of the proposals had been understood.

The primary way to participate in the public consultation was to submit a response to the set consultation questions, via an online portal, which asked:

- Do you support our proposals to enable hospitals to take greater responsibility for local care pathways through the establishment of Children's Cancer Operational Delivery Networks?
- Do you support out proposals to help improve participation in clinical trials and research?
- Is there anything more that we could do to encourage and increase participation?
- Do you support our proposals to simplify and standardise shared care through the introduction of Standard and Enhanced shared care units?
- Do you support the Children's Cancer Operational Delivery Networks taking a greater role in shaping how chemotherapy is delivered across the Network to improve outcomes and patient experience?
- Do you think the proposed quality indicators included in the service specifications are appropriate to measure and monitor this service in the future?
- Are there any changes or additions you think need to be made to the proposed service specifications?

Five of the questions involved a rating scale, with respondents being asked to assign a value between very supportive (1) and not supportive (5). These questions also had an option for respondents to include any additional comments and feedback.

4. How have consultation responses been considered?

Responses have been carefully considered and noted in line with the following categories:

- Level 1: Incorporated into draft document immediately to improve accuracy or clarity.
- Level 2: Issue has already been considered by the CRG in its development and therefore draft document requires no further change.
- Level 3: Could result in a more substantial change, requiring further consideration by the CRG in its work programme and as part of the next iteration of the document.

- Level 4: Falls outside of the scope of the specification and NHS England's direct commissioning responsibility.

Consultation responses were shared with both Professor Sir Mike Richards to inform his independent review, and the Chair of the CYP CRG.

The membership of the CYP CRG received and considered an analysis of the themes emerging from consultation, supported by the CRG Chair. The CYP CRG then met with Professor Sir Mike Richards to discuss what it considered to be the key issues arising from consultation.

5. Results of consultation

A total of 139 responses were received, comprising online responses (n=126) and individual letters (n=13).

Of the online survey responses, it was possible to analyse the types of responder:

- Clinicians - 40%
- Parents/guardians - 25%
- Service providers - 16%
- Professional organisations - 8%
- Charitable organisations - 7%
- Patients - 2%
- A further 2% of respondents did not state which stakeholder group they fell into.

In addition, 1,096 letters were received in relation to the CLIC Sargent Young Cancer Patient Travel Fund campaign. These responses requested that a paragraph be added to the specifications stating that Networks will assess the costs families spend on travelling to treatment and will administer a travel fund.

The responses received were largely positive and supportive of the proposed changes, with only minor changes being required, either related to inadvertent omissions, i.e., to reflect peer review requirements, or to provide clarification, i.e., community chemotherapy. In addition, some aspects of the proposals have been improved and strengthened, such as the addition of new quality metrics to enable monitoring of proposed changes, i.e., time to opening a clinical trial etc.

The most significant area of feedback related to colocation of PTCs with Level 3 paediatric critical care (PICU), with the majority of respondents in favour of tightening the requirements put forward at consultation, so that PTCs were co-located with PICUs. This issue formed the main issue considered by Professor Sir Mike Richards and is dealt with in a separate report.

6.Has anything been changed in the service specification as a result of the consultation?

A. <u>Operational Delivery Networks</u>

86% of online responses were either very supportive or supportive of the proposals to enable hospitals to take greater responsibility for local care pathways through the establishment of ODNs.

Furthermore, 86% of online responses were either very supportive or supportive of the ODNs taking a greater role in shaping how chemotherapy is delivered across the Network to improve outcomes and patient experience.

Due to the high level of support, there have not been any significant changes to this element of the service specification. However, references to CCNCG have been removed and replaced with ‘ODN’ to ensure consistency throughout the document suite.

This has been categorised as Level 1 feedback.
A handful of respondents also raised the issue of colocation of PTCs and neurosurgical services – however, the CRG considered that there was still a lack of clinical consensus about this issue and that the proposals put forward to consultation were still appropriate.

In respect of the colocation of PTCs and paediatric neurosurgical services, the responses were categorised as Level 2 feedback.

B. Clinical Trials and Research
91% of online responses were either very supportive or supportive of the proposals to help improve participation in clinical trials and research.

Due to the high level of support, no changes have been made to the specifications. However, a developmental quality metric relating to the time taken to open clinical trials has been added with a view that this will constitute a Data Quality Improvement Plan item for all providers in 2020-21.

This has been categorised as Level 1 feedback.

C. Shared Care
76% of online responses were either very supportive or supportive of the proposals to simplify and standardise shared care through the introduction of Standard and Enhanced POSCU designations.

Further clarification was requested regarding the Enhanced POSCU lead and lead nurse roles, which has been included. The Service Specification has also been updated to include a named nurse trainer, in accordance with existing Cancer Peer Review measures.

In response to the feedback received, the MDT membership section has been clarified in relation to: (i) in-patient and outpatient nursing teams being extended members of the MDT; and (ii) pharmacy membership being permissible in a number of different ways, i.e., direct attendance or through access to the MDT outcomes and direct attendance at other MDT meetings where SACT treatment planning is undertaken.

This section has also been reworded to make the expected cross cover arrangements clearer.

Finally, more information relating to community chemotherapy was requested to be included, in line with current clinical and service practices. These changes have been made.
This has been categorised as Level 1 feedback.

D. Quality Indicators
63% of online responses were either very supportive or supportive of the proposed quality indicators included in the service specifications being appropriate to measure and monitor the service in the future.
Respondents suggested that a quality measure be added in response to the National Confidential Enquiry into Patient Outcome and Death report (NCEPOD) to enable measurement of the time from onset of fever to administration of antibiotics in neutropenic fever. This has been added.
This has been categorised as Level 1 feedback.

E. Travel
The recommendation to amend the Service Specification to add in a requirement that hospitals oversee and administer a Travel Fund is considered to be outside the scope of the specification.

This assessment has been made because any decision to extend the current arrangements (Healthcare Travel Costs Scheme, HTCS) to routinely include children that are undergoing treatment for cancer, would require agreement by other parties, including the Department of Health and Social Care.

7.Are there any remaining concerns outstanding following the consultation that have not been resolved in the final service specification proposal?

The CYP CRG considered that the issues raised by respondents in relation to the CLIC Sargent Travel Fund campaign were important and warranted further exploration by the Department of Health and Social Care.