

Engagement Report for Service Specifications

Unique Reference Number	URN: 1746
Specification Title	Children's Cancer Networks
Lead Commissioner	Rupi Dev
Clinical Reference Group	Children and Young People's Cancer Clinical Reference Group
Which stakeholders were contacted to be involved in service specification development?	<p>Development of the service specification has been primarily led by the Children and Young People's Cancer Clinical Reference Group (CRG). Members of the CRG include:</p> <ul style="list-style-type: none"> • Parent representative • CLIC Sargent (Charity) • Teenage Cancer Trust (Charity); • Children's Cancer and Leukaemia Group (CCLG) (Professional Membership Group and Charity) • Teenage and Young Adult with Cancer (TYAC) (Professional Membership Group and Charity) • Royal College of Nursing (RCN) (Professional Group) • Royal College of General Practitioners (Professional Group) <p>In addition, in developing the recommendations and key principles for the service specification, the CRG established 7 work-streams through the service review framework. These work-streams ensured involvement of a wider group of</p>

	<p>stakeholders including non-CRG clinicians and Public Health England.</p> <p>Prior to drafting the service specification, a series of engagement events were held in September 2017 across England with clinicians, providers and patients/families to test the initial recommendations from the work-streams. <i>N.B The recommendations from the work-streams were supported by the majority of attendees at these events.</i></p>
Identify the relevant Royal College or Professional Society to the specification and indicate how they have been involved	<p>The relevant major professional membership groups for paediatric cancer services – i.e., CCLG, TYAC and the RCN - have been involved in the service specification development and were also asked to formally comment on the draft service specification during stakeholder testing; a response was received during stakeholder testing from CCLG on behalf of their members.</p> <p>The Royal College of Paediatrics and Child Health are registered stakeholders for the CYP Cancer CRG and were asked to comment on the service specification during stakeholder testing; no response was received from the organisation.</p>
Which stakeholders have actually been involved?	<p>The draft service specification was circulated to the following stakeholders for comment:</p> <ul style="list-style-type: none"> • CYP Cancer CRG Members • Registered stakeholders for the CYP Cancer CRG • Women and Children’s Programme of Care Board (NHS England) • Chair of the Chemotherapy CRG • Chair of the Specialised Cancer Surgery CRG • Chair of the Radiotherapy CRG • Chair of the Specialised Cancer Diagnostics CRG • Cancer Policy and Strategy Programme (NHS England)
Explain reason if there is any difference from previous question	<p>Not applicable.</p> <p>Formal responses to the draft service specification have been received from the following stakeholders:</p> <ul style="list-style-type: none"> • CCLG • CLIC Sargent • Teenage Cancer Trust • Women and Children’s Programme of Care Board • Cancer Policy and Strategy Programme
Identify any particular	None identified.

<p>stakeholder organisations that may be key to the specification development that you have approached that have yet to be engaged. Indicate why?</p>	<p>The CYP Cancer CRG will undertake a further impact analysis with the current providers of children's cancer services to fully understand the impact of these proposals ahead of public consultation.</p>
<p>How have stakeholders been involved? What engagement methods have been used?</p>	<p>The draft service specification was distributed to stakeholders via email between 10th-25th May 2018 for a period of stakeholder testing. Stakeholders were asked to submit their responses via email, using a standard response and in line with NHS England's standard processes for developing service specifications.</p> <p>Stakeholder testing asked the following questions:</p> <ul style="list-style-type: none"> • It is proposed that highly specialised products will go for period of public consultation. Please select the consultation level that you consider to be most appropriate. (6 weeks or up to 12 weeks) • Do you have any further comments on the proposed changes to the document? • If Yes, please describe below, in no more than 500 words, any further comments on the proposed changes to the document as part of this initial 'sense check'. • Please declare any conflict of interests relating to this document or service area.
<p>What has happened or changed as a result of their input?</p>	<p>There were 38 responses to stakeholder testing. One response was a duplicate response, leaving 37 responses to be analysed.</p> <p>13 respondents actively welcomed the proposals and listed their support for the service specification. The remainder of the responses did not explicitly state approval; however, no disapproval was stated in relation to proposals overall.</p> <p>No changes have been made to the proposed service model, because of stakeholder feedback. However, following Stakeholder Engagement it was decided that there should be two service specifications. The first setting out the responsibilities of the Principal Treatment Centre and the Children's Cancer Network and the second describing the responsibilities of Paediatric Oncology Shared Care Units. This more accurately reflects contracting arrangements.</p>

Feedback from stakeholders primarily sought clarity on some of the standards included in the draft service specification. As a result, additional information has been included and clarifications / amendments have been made.

The key themes raised during stakeholder testing focused on:

1. **POSCU standards:** 16 respondents (approximately 40%) asked for further clarity on the described POSCU standards. As a result of the feedback, the POSCU standards have been revised to ensure clarity on the proposed standards for each level of service. For example:

- Clarity has been provided on the standard relating to 24 hour access to clinical advice and whether that advice is PTC/POSCU led.
- Clarity has been provided for all Enhanced Level 1 POSCUs to provide all the standards stipulated in the service specification.
- The roles/responsibilities of a POSCU Lead Nurse have been added into an appendix.
- The requirement for POSCUs to ring fence beds and transfer out less than 5% of patients has been removed and replaced with a requirement for POSCUs to ensure they have a dedicated inpatient ward for children with cancer and are able to provide sufficient beds for the service they provide.
- The training requirement for POSCU Lead Clinicians have been revised to accommodate training in paediatric cancer at both a PTC and POSCU setting as opposed to training in a tertiary provider only.

In addition, the categories for Enhanced POSCU have been renamed (from Levels 1 and 2 to Levels A and B) to make it clear to stakeholders these standards are different to the current POSCU measures and prevent any further confusion between current and proposed POSCU levels.

2. **PTC Clinical Co-dependencies:**

- One respondent actively disagreed with the inclusion of clinical co-dependencies and two additional respondents queried if the co-dependencies were required for all PTCs regardless of the types of services provided. These respondents felt that clinical co-dependencies should reflect (i) the different requirements for disease specific pathways and (ii) access arrangements for these co-dependencies across split-site PTCs and 'networks of care'. The CRG acknowledges that for some pathways (such

as neuroblastoma), there may be different clinical co-dependency requirements. However, the CRG are also aware that access to certain co-dependencies varies depending on the stage of the care pathway; for example, the need for paediatric intensive care can be greatest at diagnosis and at the induction phase of treatment. This makes describing disease specific pathway difficult and overly complicated to include within a single national service specification.

In the view of the CRG, the co-dependencies listed in category 1 are the default position and, where possible, all PTCs should look to provide these services on every PTC site, where possible. However, the CRG acknowledges that some PTC services are provided across different hospital sites and access to clinical co-dependencies are provided across 'networks of care'. As a result, the service specification has now been amended to reflect this practice. To support PTCs and Commissioners in ensuring that the absence of all co-dependencies on every PTC site does not disadvantage any patients and their families, the CRG have also drafted a series of additional standards and quality standards for inclusion in the service specification.

It should be noted that the specific inclusion of clinical co-dependencies was referenced as a positive development in the service specification by 6 other respondents.

- One respondent noted that radiotherapy was incorrectly categorised in the service specification; this has now been corrected in the service specification and radiotherapy has moved from a category 3 clinical co-dependency to a category 2 clinical co-dependency.
- One respondent noted that both ophthalmology and gastro-enterology were missed from the list of clinical co-dependencies. These have now been included as category 2 clinical co-dependencies.

3. Quality Indicators:

- 4 respondents recommended that Network measures be included in the service specification as quality indicators. These have now been developed and included in the revised service specification.
- One respondent queried the absence of survival measures in the quality outcomes; 1 year and 5 year survival measures have now been added into the service specification.
- For note, additional measures have been included in the service specification to support alterations to the

	<p>clinical co-dependency requirements for PTCs including: (i) ICU admissions post 30 days chemotherapy; (ii) deaths within 30 days of chemotherapy; (iii) number of emergency transfers from the PTC to another provider within the Network or another PTC; and (iv) average time taken to transfer from the PTC to a paediatric intensive care within the Network or another PTC.</p> <p>4. Fertility and pregnancy: one respondent noted that the service specification included no detail on fertility preservation or pregnancy. Additional requirements have been added to the service specification for fertility preservation and pregnancy testing.</p> <p>The remainder of the comments received from stakeholders were minor and have resulted in the following changes:</p> <ul style="list-style-type: none"> • PTC MDT membership and Lead Effects MDT membership has been amended in the appendices to reflect stakeholder feedback and current pathways; • Amendments have been made to appropriately reference Sarcoma Advisory Groups and their interaction with Children’s Cancer Networks; and • Survival data has been updated for accuracy purposes as identified by one stakeholder. <p>All other comments were noted by the CYP CRG but no additional changes were made to the draft service specification.</p> <p>Implementation of the proposals will be driven and resourced through the establishment of Children’s Cancer Operational Delivery Networks. This is reflected within the Service Specifications.</p>
<p>How are stakeholders being kept informed of progress with specification development as a result of their input?</p>	<p>The key professional stakeholder organisations are members of the CYP Cancer CRG and will therefore be kept informed of the progress with the specification development through the CRG. In addition, both CLIC Sargent and TCT are members of the CRG and have offered to support a joint launch of the public consultation when the proposals are ready.</p> <p>All other stakeholders will be kept informed of progress with the service specification development as registered stakeholders of the CYP Cancer CRG and through the National Programme of Care generic email system. All stakeholders involved in stakeholder testing will be notified when the draft revised service specification is sent out for public consultation.</p>

<p>What level of wider public consultation is recommended by the CRG for the NPOC Board to agree as a result of stakeholder involvement?</p>	<p>Out of the 36 responses received, half of the respondents recommended a 12 week public consultation (18 respondents). Less than a quarter of respondents recommended a 6 week public consultation (8 respondents), and the remainder did not suggest a consultation time frame.</p> <p>The CRG is recommending a 6 – 8 week public consultation with a series of face to face workshops and webinars to discuss the revised proposals and gather feedback from service providers, patients and families and the public.</p>
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