

**Are there any changes or additions you think need to be made to the proposed service specifications?**

There is much to welcome in these proposed service specifications. And yet we are concerned that without some key improvements, there is a real risk that these proposals will mean NHS England will fall short of its aim to improve cancer treatment and survival and its guiding principle that care must be 'age appropriate, safe, effective and delivered as locally as possible'.

These services are focused on treating and caring for acutely unwell children and young people. The specifications should ensure that these needs are met safely, effectively and as locally as possible, in line with all relevant clinical standards and guidance.

Oncology treatment can be intensive and can be associated with known risks of serious and severe adverse effects. In addition, for those children and young people recruited into clinical trials, the risks of a severe reaction may be expected but less well understood. Given these circumstances, and the expectation that rates of cancer will increase, the aim of these service specifications should be to manage these known and unknown risks in an appropriate and timely manner.

Models of care that are built around networks are good, but it is important that the needs of its members are understood. The need to seek and respond to feedback from children and young people, and their families is core to this, and we would expect to see the specifications placing a greater emphasis on this aspect of service design. Good parent / child representation on Operational Delivery Network boards is vital and embedding the voices of children and their families so that they have an influence over service delivery and design should be well evidenced.

Our comments on changes and additions to the specifications fall under three themes:

- variation across service specifications
- co-location of essential clinical services
- managing transition to new arrangements.

**Variation across service specifications**

Cancer services for children, teenagers and young people should provide high quality care and treatment. Any variation in the specifications should be driven by the aim of improving the safety and effectiveness of care.

Having reviewed the four specifications under consultation, it appears that NHS England's approach is embedding variation into its commissioning which could impact on the delivery of care. For example, the specification for Teenage and Young Adult designated hospitals (TYA-DH) has more stringent requirements for co-location of clinical services than the associated TYA Principal Treatment Centres (PTC). A similar difference exists between the two Children's Cancer Network (CCN) specifications. A further example is seen in the requirements for supporting staff:

- a CCN-PTC only needs to 'ensure ready access' to supporting staff (allied health professionals, social workers etc) while for CCN-Paediatric Oncology Shared Care Units (POSCUs) at Enhanced Level B, must 'guarantee access to AHPs'
- a TYA-PTC 'must' provide access to range of supporting professionals, and requires that staffing levels are sufficient, whereas the TYA-DH specification sets out the detailed whole-time equivalents for social workers and youth workers.

No evidence is provided in support of these differing approaches, and so it is not clear to us what the benefits are to patients when the specifications all share the aim of improving cancer treatment outcomes and survival. It is a potentially confusing basis for commissioning services.

### **Co-location of essential clinical services**

Alongside variation in the specification of services, the requirements placed on PTCs as drafted are less prescriptive than would be expected for seriously ill children and young people. Most notably, these draft specifications represent a step back from previous requirements for intensive care provision under the [2013 service specification for Paediatric Oncology](#). This listed intensive care as a facility that should be available, requiring all services to comply with [Commissioning Safe and Sustainable Specialised Paediatric Services \(2008\)](#). This report required co-location of intensive care units with paediatric oncology services because of the risk of acute septic shock and multi-organ failure. The 2013 specification notes 'the high intensity of treatment which means that children often become acutely ill during treatment and require a high level of medical support.'

We note these specifications place a much greater emphasis on services recruiting children and young people into clinical trials. When this development is coupled with the risks already inherent in intensive oncology treatment, the current proposals do not explain why the requirements around critical care provision and other core interdependent services have been relaxed and appears to undermine the services' aims and principles.

It is a specification requirement that POSCUs which undertake higher-risk interventions (as defined by the Network) must also have Level 2 Paediatric Critical Care. We would suggest that such level 2 units must themselves conform to NHS England specifications.

Similarly, we would suggest that the PTCs where treatment risks must be at their highest, inherent both in the intensive oncology treatment and potentially new more exploratory treatment regimens must be co-located with NHS England level 3 units.

If the service plans to give high intensity treatment to a child on a site, then that site should have a paediatric intensive care unit service in the same site that can be accessed without the need of a transport team or ambulance transfer.

### **Managing transition to new specifications**

Bringing the cancer networks in line with other network arrangements (such as neonatal) is a sensible approach in terms of governance arrangements and clarity of responsibility. The consultation does not discuss NHS England's plans and support for transition between the current and future arrangements. For children and their families, any risks arising from the transition to the new approach will need careful management. Networks should actively seek and respond to feedback from children and their families throughout the transition phase. Transition could generate anxiety among provider units and it is essential that networks are actively engaged throughout this process and focus is maintained on delivering high quality care for children and young people. It is

important that there is a clear line of communication from the representatives on the Operational Delivery Network through their organisations' contracts teams to the commissioner.

We would expect that the adoption of new network arrangements will be accompanied by specific training and support for network members that covers responsibilities for oversight of the network, decision making and ensuring clear lines of communication across the participating organisations (including commissioners). This is crucial to the success of the new arrangements for children and young people and their families and will help to ensure that network decisions are not overruled by strong provider interests.

### **Conclusion**

In conclusion, while we welcome the direction of travel and the move towards networked care, we have identified a number of areas for improvement to these service specifications that will give NHS England greater confidence that it is commissioning services that will allow it to meet its guiding principle that care must be 'safe, effective and delivered as locally as possible'.