

# Improving cancer services for children, teenagers and young adults in Wessex

Louise Hooker

Report to the Wessex Cancer Alliance Board				
Title:	Improving cancer services for children, teenagers and young adults in Wessex			
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Purpose	Assurance or reassurance	Approval	Ratification	Information Y
Summary of paper:	<p>This briefing sets out an overview of the Wessex Cancer Alliance workstream for Children, Teenage and Young Adult (CTYA) cancer services, led by a WCA CTYA clinical advisor role, in response to the NHS Long Term Plan for childhood cancer. The release of revised NHS Specialised service specifications for children's services has been much delayed; they were published on 11/11/21. These specification will drive improvements in the delivery of networked care, and local quality initiatives. NHS England commission all elements of specialist cancer services for CTYA at designated hospitals.</p> <p>This Update provides details of progress made in advance of specification release as follows:</p> <ol style="list-style-type: none"> <li>1. Operational Delivery Networks for Thames Valley and Wessex.</li> <li>2. Service Specification Gap Analysis for paediatric oncology shared care services</li> <li>3. Key appointment: Wessex Lead Nurse for children's Cancer Lead Nurse</li> <li>4. Whole Genome Sequencing:.</li> <li>5. Whole-system co-production: Our Cancer, Our Way</li> </ol>			
Implications:(Clinical, Organisational, Governance, Legal?)	The Service Specification work has clinical, organisational and governance implications. Changes may be proposed via option appraisal that trigger NHS legal requirement for formal public and patient consultation.			
Key risks and mitigations:	Some Wessex paediatric oncology shared care provider Trusts do not meet the new service specification criteria for minimum patient number criteria to deliver paediatric SACT. The newly-established TV&W CTYA cancer ODN is undertaking detailed mapping and pathway analysis to develop options for future services.			
Summary: Conclusion and/or recommendation	The workstream has made progress in developing insight and knowledge to embed CTYA issues within WCA activity where appropriate, and started to deliver discrete aspects of the LTP for CTYA cancer e.g. Whole Genome Sequencing. The CTYA advisor role has ensured WCA partnership in the establishment of new organisational structures (ODNs) as required to operationalise revised NHS service specifications. There is potential for service changes to be considered in order to meet the new specification. A process for provider Trust, Cancer Alliance and commissioner engagement and decision-making is in development at ODN level. The WCA co-production project seeks to embed service user engagement and influence in service developments and build these approaches into WCA patient and public involvement strategic plans.			



# Background: Childhood cancer

- It is rare (<1% of cancer in UK age under 15) = 1,600 pa in UK.
- Children get different cancers from adults
- Treatment often complex and intensive
- 2/3 patients on clinical trials
- Cure rates around 80%; 10year survival
- Tumour banking for future research a priority – 40% at present.
- Networked services
  - Specialist Paediatric Principal Treatment Centres (PTC)
  - Paediatric cancer MDTs – haematology, solid tumours, Brain and CNS.
  - Paediatric Oncology Shared Care Unit (POSCUs) in DGH children's units.
- Networks to provide 'Safe care as locally as possible – not local care as safely as possible'



## Background – TYA cancer:



- It is rare (<1% of cancer in age 15-24yrs) = 2,200 pa in UK.
- Cancer is leading cause of death from disease in TYA in UK
- Unique pattern of childhood-type cancers and adult-type cancers.
- 10-25% of patients on clinical trials.
- Survival similar to children, but significantly lower in some cancer types.
- TYA needs are different from those of children and those of older adults.
- Networked services
  - Specialist TYA Principal Treatment Centres
  - Regional TYA multidisciplinary in partnership with site-specific MDTs
  - Designated TYA hospitals who can offer local care to 19+
- Networks to provide unhindered access to TYA PTC, informed choice about place of care for 19+yrs



# NHS Long Term Plan commitments - children and young people with cancer



- Networked care
- Whole genome sequencing
- CAR-T\* therapies
- Proton Beam Therapy\*
- Clinical trials access
- Data and tissue samples for research
- National Cancer Patient Experience Survey (NCPES) for under 16's
- Human papillomavirus vaccination for boys aged 12 and 13
- Match CCG additional funding for local children's palliative and end of life care services including children's hospices.

\*CAR-T is a new type of cancer treatment that uses the immune system to kill cancer cells

\*Proton beam therapy is a type of radiotherapy treatment that uses proton beams to treat cancer



# 2019 Service spec review – 6 key changes



1. Both Children's and TYA Cancer Networks Coordinating groups will become Operational Delivery Networks.
2. All Children and TYA will be offered the opportunity to have data and tumour collected for future research studies.
3. POSCUs will be defined as Standard or Enhanced depending on whether they provide chemotherapy services.
4. POSCUs delivering chemotherapy should expect to treat a minimum number of patients/year.
5. Clear standards for TYA designated hospitals will be introduced.
6. 'Joint Care' between TYA PTC and designated hospitals will be introduced.
  - Implementation led by the new ODNs, with Cancer Alliances and commissioners.
  - If changes to local services impact access and travel times = public consultation.



# Whole Genome Sequencing (WGS)



- LTP states all children with cancer to be offered WGS – soon to be extended up to 25 years.
- Phased approach started Summer 2021 at UHS children's PTC (all under 16 patients are referred to PTC).
- Childhood solid tumours MDT introducing WGS into standard of care, via coordination between clinical team, WGS CNS, UHS pathology, WGS centre Birmingham and Central and South Genomic Medicine Service Alliance programme manager.
- Paediatric leukaemia and brain & CNS tumour MDTs to adapt and adopt once pathway defined.
- TYA WGS pathways under early discussion – starting with those patients having biopsy under adult site specific cancer teams at UHS.



# CTYA System-Wide Co-Production “Our Cancer Our Way”



<https://vimeo.com/567570501/3b36fefec5>

- Project funded by NHS Experience of Care,
- Partnership between WCA, Wessex Voices and Healthwatch Dorset.
- **Phase 1.** Initial engagement of children, TYA and their parent/carers using a range of age-appropriate methods – drawing, filming, talking, writing.
- “What’s good, what’s not so good, what could be better?” Currently analysing feedback - lots from parents, some from children, less from TYA.
- **Phase 2.** Using ‘Always Event’ approach and wider circle of engagement to decide ‘what matters most’ and to co-produce solutions for pilot projects.
- 2021 Wessex TYA patient survey and NCPES Under 16 survey have been completed and results will inform and complement this work.



# Appendices



*Appendices provide granular detail for Board members about the Operational Delivery Networks which may be useful for future reference but is not required reading for this meeting.*

# Thames Valley and Wessex ODN implementation: Children's cancer



Item	Comments				
<b>Key posts recruited to</b>	<b>Clinical director</b>	<b>Manager</b>	<b>Clinical leads</b>	<b>Lead nurse</b>	
	Aabir Chakraborty	Tara Parker starting 1st Nov	Juliet Gray/ Shaun Wilson	Jacqueline Kidd	
<b>Governance structures in place/agreed?</b>	<i>Currently being reviewed with implementation of ICS changes but ODN boards continue to meet 3 monthly and feeds up into the children's and young people's programme board</i>				
<b>Memorandum of Understanding</b>	<i>Plan to have across the 10 different ODN MoUs in TV &amp; W as one sign off-by April 2022</i>				
<b>Work programme in place/agreed</b>	<b>Workstreams</b> <ol style="list-style-type: none"> <li>1. Governance</li> <li>2. Model of Care (Clinical pathways)</li> <li>3. Service Specifications</li> <li>4. Radiotherapy</li> <li>5. Sustainability/safety</li> <li>6. Commissioning</li> </ol>	<b>Strategic priorities:</b> <ul style="list-style-type: none"> <li>• Undertake gap analysis against new draft Service Specification</li> <li>• Improve access to local services/experience of care</li> <li>• Support workforce sustainability/ skills and development</li> <li>• Improve the transition between children's and TYA services</li> <li>• Eliminating age gap between services (16-18 years)</li> <li>• Improved long term follow and integration of care between services</li> <li>• Formalising pathways to support and increase access to clinical trials, Increase bio-banking and genomic medicine</li> </ul>			
<b>Support needed to succeed:</b> <ul style="list-style-type: none"> <li>- local</li> <li>- national</li> <li>- from this group</li> </ul>	<b>Clinical Networks</b>	<b>Alliances</b>	<b>Transformation</b>	<b>Commissioning</b>	<b>National</b>
	<i>ODN representation at clinical forums has been received well</i>	<i>Cancer alliance representation at ODN meetings</i>	<i>TV &amp; W ODNs links developing with the 7 ICS partnerships and Transform boards</i>	<i>Spec/ comm SE lead link Nat Hughes</i>	<i>Guidance/ Shared learning will be beneficial</i>

# Thames Valley and Wessex ODN implementation: TYA Cancer ODN

Item	Comments				
<b>Key posts recruited to</b>	<b>Clinical director</b>	<b>Manager</b>	<b>Clinical leads</b>	<b>Lead nurses</b>	<b>QI Project manager</b>
	Aabir Chakraborty	Tara Parker 1st Nov	Andy Davies/ Georgina Hall	Louise Hooker/ Karen Sherbourne	Linda Penney
<b>Governance structures in place/agreed</b>	<i>Currently being reviewed with implementation of ICS changes but ODN boards continue to meet 3 monthly and feeds up into the children's and young people's programme board</i>				
<b>Memorandum of Understanding</b>	<i>Plan to have across the 10 different ODN MoUs in TV &amp; W as one sign off-by April 2022</i>				
<b>Work programme in place/agreed</b>	<b>Workstreams</b> 1. Governance 2. Model of Care (Clinical pathways) 3. Service Specifications 4. Radiotherapy 5. Sustainability/safety 6. Commissioning		<b>Strategic priorities:</b> • Fertility preservation pathways • Undertake gap analysis against new draft Service Specification • Dedicated space for TYA in Primary Units • Improved transition (with children's cancer ODN) • Improvement to diagnostic pathways • Formalising pathways to support and increase access to clinical trials, Increase bio-banking and genomic medicine • Improvements in long term follow up		
<b>Support needed to succeed:</b> - local - national - from this group	<b>Clinical Networks</b> <i>ODN representation planned at clinical forums</i>	<b>Alliances</b> <i>Cancer alliance representation at ODN meetings</i>	<b>Transformation</b> <i>TV &amp; W ODNs links developing with the 7 ICS partnerships and Transform boards</i>	<b>Commissioning</b> <i>Spec/ comm SE lead link Nat Hughes</i>	<b>National</b> <i>Guidance/ Shared learning will be beneficial</i>