

# College response to NHS England's consultations on Children's/Teenager and Young Adult's Cancer Services

## Introduction

The Royal College of Pathologists is a professional membership organisation with more than 11,000 fellows, affiliates and trainees worldwide. We are committed to setting and maintaining professional standards and promoting excellence in the teaching and practice of pathology, for the benefit of patients.

Our members include medically and veterinary qualified pathologists and clinical scientists in 17 specialties, including cellular pathology, haematology, clinical biochemistry, medical microbiology and veterinary pathology.

The College works with pathologists at every stage of their career. We set curricula, organise training and run exams, publish clinical guidelines and best practice recommendations and provide continuing professional development. We engage a wide range of stakeholders to improve awareness and understanding of pathology and the vital role it plays in everybody's healthcare. Working with members, we run programmes to inspire the next generation to study science and join the profession.

Pathologists, from a range of specialties, are involved in children and young people's cancer care, from initial diagnosis through treatment to post-treatment monitoring.

The College shares the concerns expressed by the Royal College of Paediatrics and Child Health about the proposed service specifications. Overall, however, we are supportive of the proposals and think there is real potential to ensure that cancer services work together to provide safe, effective care that is given as close to home as possible, for children, teenagers and young adults.

The following sections set out the College's response to <u>NHS England's consultation on cancer</u> services for children, teenagers and young adults, with a focus on how the service specifications may effect the diagnosis, treatment and management of cancer.

## **Laboratory services**

The laboratory handling of a tumour sample and access to methods of diagnosis, clinical trial, research and whole genome sequencing requiring frozen tissue should be the same in a child, teenager or young adult with the same diagnosis. To support accurate diagnosis, it is essential that a tumour biopsy is handled correctly and reported by a histopathologist with appropriate expertise.

Laboratories will need to be adequately resourced to:

- receive tumour samples fresh for snap freezing for all required diagnostic purposes including tumour banking, clinical trials, possible research and whole genome sequencing
- receive samples and snap freeze tissue at any time of day (including out of hours).

Where tissue samples, such as core biopsies, are small, care must be taken to ensure they are not rendered non-diagnostic by division of samples to allow banking and ancillary testing. Because of this, we would suggest that this is recognised in the specifications such that:

Each patient is offered an opportunity at diagnosis to consent – in accordance with the General Data Protection Regulation and the Human Tissue Act 2004 – for their data, a tissue sample and/or a liquid sample, to be collected for use in future research studies and development of services; the College suggests adding that this should be the case where *where to do so would not compromise an initial diagnosis*.

Where consent is given, these samples must be banked. All teenagers and young adult patients must be offered the opportunity to consent to banking of their samples by March 2021. <sup>1</sup>

General histopathologists need to have timely access to paediatric histopathological expertise, should it be required for tumours more usually occurring in childhood.

The genomic laboratory hubs may need to revise their cut-off age for whole genome sequencing of paediatric-type tumours in teenagers and young adults to ensure parity of investigation for the same tumour type in children and adults aged 18–25 (the current proposed cut-off age is 19).

# Joint care core service requirements

We welcome the specification's support for joint care core services including blood transfusion. Where regional pathways for this have not previously been defined, the specifications will require them to be developed to ensure that there is robust communication of special transfusion requirements between transfusion laboratories in principal treatment centres and joint care centres. We suggest that this is specified in the joint care core service requirements.

<sup>&</sup>lt;sup>1</sup> NHS England Service Specification B17: Teenage and Young Adult Cancer Networks – Designated Hospitals



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## Survivorship, long-term follow-up and late effects service

We support the specification of a risk-stratified, long-term follow-up programme for patients who, by definition, have the potential for many decades of survivorship. Appropriate screening for late effects of treatment including endocrinological dysfunction and secondary malignancy will require the involvement of local pathology services. We would emphasise the need for early dialogue with those leading regional pathology teams where workload will be affected by the appropriate expansion of late effects services.

## Cellular immunotherapies

Recent developments in the use of cellular immunotherapies such as CAR T-cell and other immune effector cell therapies may be transformative in the treatment of some cancers among children, teenagers and young adults, despite the complex laboratory and other infrastructure required for delivery. We suggest that clear referral pathways are put in place for cellular immunotherapy.<sup>2</sup>

### Resources

While we support the transition to networked cancer services for children, teenagers and young adults, it is vital that the change to new arrangements is managed carefully for patients, their families and the staff affected. We welcome the mandating of staffing and other resources to drive improvements in care for children, teenagers and young adults in designated hospitals.

A recent survey<sup>3</sup> by the College of members affected by the pathology network implementation (to consolidate pathology services into 29 networks) showed that key concerns centred around how the change was communicated, the extent of consultation/involvement in discussions and the need for interoperability of IT systems.

There are shortages across the range of pathology specialties and our workforce census, *Meeting* pathology demand, found that only 3% of NHS histopathology departments have enough staff to meet clinical demand. There is a national shortage of paediatric histopathologists, which may lead to difficulty in diagnostic service provision in short-staffed regions.

For many children, teenagers and young adults, treatment and care closer to home will bring real benefits. However, it will be necessary to plan for any effect on local pathology services, such as an increase in routine workload for transfusion, clinical chemistry and haematology laboratories.

The new service specifications will help ensure patients receive a more precise diagnosis and the best available treatment options through the development of pathways for whole genome sequencing for all eligible patients. They will also boost research to find new and better treatments.

<sup>&</sup>lt;sup>3</sup> Pathology Consolidation Survey – England. The Royal College of Pathologists. August 2019



<sup>&</sup>lt;sup>2</sup> NHS England Service Specification B17 – Teenage and Young Adult Cancer Networks – Principal **Treatment Centres** 

There are challenges, however, with the need to invest in staff with the right training, skills and expertise and to ensure robust laboratory infrastructure.

The College, along with the Royal College of Physicians and the British Society for Genetic Medicine, published <u>Consent and confidentiality in genomic medicine</u> – new guidance to assist healthcare professionals to support and guide patients through some of the complexities and challenges that genomic testing can bring.

We welcome the commitment that children, teenagers and young adult cancer principal treatment centres will have access to digital pathology and networked services, including remote working.

#### Digital pathology:

- benefits patients by enabling the rapid referral of cases between organisations or across pathology networks, enhancing access to expert advice and opinion on diagnoses
- improves laboratory workflow and connectivity and increases flexibility and efficiency of the workforce, helping create digital training resources that support the development of specialists in training
- increases opportunities to share slides and other information, making it easier for practitioners to benefit from the expertise of others
- sets the scene for the use of artificial intelligence, which will help bring advances to pathology services.

The College published its <u>Best practice recommendations for implementing digital pathology</u> in 2018, which provides an overview of the technology involved in digital pathology and of the currently available evidence on its diagnostic use, together with practical advice for pathologists on implementing digital pathology.

## **Conclusion**

The College is supportive of the establishment of cancer operational delivery networks (ODNs) for children, and for teenagers and young adults. The proposals are ambitious but realistic. The cancer ODNs have the potential to ensure delivery of safe and high-quality care that meets the needs of patients and their families. They may also help to improve participation in clinical trials, leading to better understanding and new treatments.

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## **Contact details**

This consultation response was compiled by Samantha Jayaram, Press and Communications Manager.

E: samantha.jayaram@rcpath.org T: 020 7451 6752

