



## **SOUTH WEST CHILDREN, TEENAGERS AND YOUNG ADULTS (CTYA) CANCER REGIONAL NETWORK MEETING**

**Date:** Thursday 17<sup>th</sup> September 2020

**Time:** 10:00-12:00; 12:00-13:00

**Venue:** MS Teams Meeting

### **NOTES**

### **ACTIONS**

#### **TYA Care South West Update February 2020**

##### **1. Apologies and Introductions**

Prior to the meeting apologies were received from Alison Cameron, Brendan McIntyre, Caren Attree, Emma Wheatfill, Fiona Minear, Hannah Hunter, Jim Murray, Lucy Henderson, Sam Brenton, Sue Dolby and Tamsin Mauri.

##### **2. PTC Update**

###### **2.1 Workforce**

###### **Presented by Dr R Dommett**

Changes to personnel include Nicola Clapson, who has re-joined the team taking up the TYA CNS post in Royal Cornwall Trust Truro. Hannah Heayn (TYA CNS) has moved to Plymouth since the meeting in February. Two consultant posts have been filled: Dr Kath Hodby is TYA Lead at UHBW for Leukaemia and Dr Claire Burney (currently on maternity leave) is TYA Lead for Lymphoma. Dr Nik Chavda is covering Dr Burney maternity leave

It was highlighted following the impact of the COVID-19 pandemic that the MDaT has been resilient due to the long-term use of WebEx. All attendees are using WebEx given the issues previously raised by some members of the difficulties of dialling in to meetings and being heard by colleagues in the face to face meeting at UHBW. The MDaT has continued throughout the Pandemic weekly and has been beneficial in keeping in touch with the wider team.

The proposed ODN remain stalled as NHSe are yet to formally publish the new service specifications. ODN set up is awaiting finalisation of the SLA and financial arrangements before core posts staff can be recruited.

###### **2.2 TYA Service in 2020 – COVID-19 Impact and Recovery**

###### **Presented by J Cargill**

###### **Please see the presentation uploaded on to the SWCN website**

The slides outline the key dates of the PTC's response to COVID-19. The first COVID patient was identified on 12<sup>th</sup> March 2020. UHBW commandeered the TYA inpatient and day unit in response to the pandemic. Subsequently all young people were accommodated

## **SOUTH WEST CHILDREN, TEENAGERS AND YOUNG ADULTS (CTYA) CANCER REGIONAL NETWORK MEETING**

across paediatric and adult cancer services. Elective day SACT activity was transferred to the UHBW Dental Hospital on 6<sup>th</sup> April and returned to BHOC on 24<sup>th</sup> August.

One benefit of the pandemic was the speeding up of changes the team had hoped to make. A combined acute haematology and oncology services was one such benefit and reconfiguration continued in August.

As part of the recovery phase, TYA inpatients returned from 7<sup>th</sup> September and are using both day and inpatient spaces, although due to availability of side-rooms, elective admission to age appropriate accommodation can't be guaranteed. Teenage Cancer Trust were aware and activity supporting. All TYA patients managed by the paediatric team will remain in BRCH until after the winter.

Services are expected to be compromised should there be a second wave during the autumn/winter 2020/21. The Senior Leadership Team and wider Trust management are aware and are strongly advocating that the unit is not the default option, however alternative options are limited

Most CNSs remained in post during the pandemic lockdown throughout the region. Tamsin Mauri (TYA ACP) and Jamie (Nurse Consultant) were both redeployed for five months to support the COVID response at UHBW but the south west service has shown resilience.

### **2.3 Fertility Preservation Update**

**Presented by Dr Kath Hodby**

A new service has been developed to provide fertility preservation surgery at UHBW. This is a spoke service from the Oxford Tissue Cryopreservation Service hub based at the John Radcliffe Hospital, which is run by Dr Sheila Lane. This will give patients from across the SW a local option and pathway to reduce their travel burden when in accessing surgical fertility preservation options. Referral age limit for both males and females has increased from 25- to 35-years-old.

From existing data, Bristol has made 54 referrals; with other centres making 14 referrals with 75% of patients had a haematological malignancy. 50% of referrals were in the TYA age group, a small percentage was up to 25s and just under 50% were paediatric patients under 16-years-old.

The service model includes pathway changes and coordination of care. Temporary funding is being explored to appoint a Coordinator post, but funding is expected from NHS England in 2021. **The SOP has been ratified and Kath is happy to circulate this. Fertility guidelines will be shared as part of the minutes.**

**KH, HD**

## **SOUTH WEST CHILDREN, TEENAGERS AND YOUNG ADULTS (CTYA) CANCER REGIONAL NETWORK MEETING**

### **3. DH – Individual Centre Feedback**

Cheltenham/Gloucester report the Trust dealt with COVID-19 well. Gloucester was used as the COVID centre, while Cheltenham remained the green site. This worked well. There was very little change to TYA services. The testicular patients on treatment and small number of patients on surveillance were not affected. Although Meg remained in her TYA CNS post throughout she supported the adult Day Unit when required. She continued to support patients with socially distanced visits outdoors. The Lead Nurse was redeployed to Medicine but has now returned. The paediatrics team is currently busy.

Taunton report Beacon Centre remained a green area. CNSs were reskilled as back-up. There were no TYA inpatients during the first wave. One patient was seen on the Day Unit and one had radiotherapy. Generally patients remained very resilient. Nic provided telephone support and the lockdown allowed for reflection regarding CNS activities and approaches. Patient numbers are steady now. Some patients are facing a difficult time as a couple of them are between jobs. Nic has done some peer support research on Survey Monkey: 50% wanted a virtual platform. The Trust has used Skype but is transferring to MS Teams. There is fertility documentation and a pathway in place.

RD&E were able to maintain the TYA service although it was moved from the Yeo ward TYA space. There were minimal modifications to treatment. Lorraine continued working throughout the first wave but was unable to go to North Devon or Torbay; she is now able to do this but has not so far. Lorraine reports that during March and April the service had a spike of 10 new patients. Referrals have since calmed down. Patients faced anxiety about receiving treatment during lockdown. There are a high number of patients with complex social histories and poor mental health (not COVID related). The team provided face to face support for all patients who wanted this and facilitated walk-ins. Patients were also supported with telephone calls. Lorraine felt valued throughout the pandemic lockdown. CLIC Sargent stepped back but Lorraine managed to support social work aspects of patient care. The FORCE counselling service has been invaluable. They offer a blended option of virtual or face to face support; most patients choose telephone contact. There are plans being developed to have a 17-25 year-old general TYA ward, potentially of up to 8 beds in a mixed unit. The Teenage Cancer Trust currently will not be able to support this financially but will offer design advice.

Plymouth report lots of changes. UHP has not seen huge numbers of COVID patients. The oncology and chemotherapy wards were moved to the Nuffield private hospital during the pandemic. Haematology services remained within the main campus. CNSs were upskilled for redeployment to staff clinical haematology and oncology services. Hannah started in March and saw new and palliative patients in the hospital. Lucy worked remotely managing patients on existing treatments. The haematology unit had a rough time with patients relapsing or entering palliative care. One staff nurse died. The patient caseload

## **SOUTH WEST CHILDREN, TEENAGERS AND YOUNG ADULTS (CTYA) CANCER REGIONAL NETWORK MEETING**

has picked up again. There are no plans to introduced new service improvements until the New Year to watch and wait through any second wave situation. Improvements include developing TYA psychology services and updating the UHP website.

Truro report that Nicola has been in post since September. Previously she worked in adult palliative care. The oncology and haematology services move to the Duchy private hospital. Patients referrals have been steady.

### **4. R&D Update**

#### **4.1 Research Update**

##### **Presented by Gerard Kenny**

Since joining the service, Gerard's focus has been on improving trial uptake and bio banking.

Access to the NIHR database and the F Cluster has proved that this is not 'the source of truth'. EDGE is used locally in hospitals but Gerard cannot access each site or see information at a regional level. Typically at MDaT patients have already started treatment, so this does not highlight patients eligible for trials. Gerard is trying to find work arounds but the national NIHR focus remains on COVID.

Gerard is providing significant focus to ways of working to improve clinical trial initiation for TYAs across paediatric and adult CTUs at UHBW. Recent success has been the opening on a trial for Hodgkin Lymphoma

Internal research is being developed, including looking at young people's health risk behaviours, with a recently completed literature review. Team are considering next steps.

### **5. Performance**

#### **MDaT – New IMMS Update**

##### **Presented by J Cargill**

A new IAM Portal platform and MDT management new system was implemented in July. Improvements continue to be made to the system with Jamie and Sue Dolby representing the SW at the national clinical operational group hosted by Teenage Cancer Trust.

Teenage Cancer Trust CEO Kate Collins joined the MDaT in July to appraise herself of the new system but also learn about the complexity of service delivery within the South West – feedback was very positive.

Medical attendance at MDaT continues to improve from nearly all SiSp funded teams – representation from CNS consultant remains a concern. The service hopes to introduce a

## **SOUTH WEST CHILDREN, TEENAGERS AND YOUNG ADULTS (CTYA) CANCER REGIONAL NETWORK MEETING**

consultant in palliative and supportive care to the MDaT soon.

### **6. QI**

#### **6.1 Update**

**Presented by Dr Laura Baker/J Cargill**

There have been a number of different projects worked on by the team. Many have involved a Psychological Research Assistant, whose post was funded for the last year through Above & Beyond. Funding will continue into financial year 2021/22.

There was good feedback from the TYA EOT clinics evaluation. Regional webinars have taken place to address the psychological impact of COVID-19. Live webinars did not have great uptake but a huge number of patients have accessed them since, watching in their own time. These remain available through the Psychological Health Services website and Laura is happy to provide the access code to anyone who requests it.

A list of completed projects ready for publication in various journals was presented. A final draft of the Cardiff University project will be circulated for feedback before that is ready for publication.

### **7. Charitable Stakeholders Update**

#### **7.1 Teenage Cancer Trust**

Brendan McIntyre was unable to attend this meeting.

#### **7.2 CLIC Sargent**

This update will be given during the combined CTYA meeting which follows the end of the TYA network meeting.

### **8. Any Other Business**

Truro raised the issue of reinstating outreach. Jamie will visit Truro next week to discuss this.

All attendees report they are happy to continue using MS Teams as a virtual platform for future meetings where necessary.

**Date of next meeting: February 2021, date TBA (virtual meeting)**

**-END-**