



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

Date: Thursday 17th September 2020

Time: 12:00-13:00

Venue: Cisco WebEx virtual meeting

NOTES

ACTIONS

Joint CTYA Cancer Regional Network Meeting September 2020

1. Apologies and Introductions

Prior to the meeting apologies were received from Alison Cameron, Augusta Isaac, Brendan McIntyre, Caren Attree, Claire Harrison, Deborah Turner, Emma Wheatfill, Fiona Minear, Hannah Hunter, Jax Hulbert, Jim Murray, Louise Taylor, Lucy Henderson, Sam Brenton, Sue Dolby and Tamsin Mauri.

2. Shared Learning Post COVID

TYA update:

The Bristol TYA unit was commandeered as a COVID space at the beginning of the pandemic until the beginning of September. This resulted in TYA patients being treated across the paediatric and adult wards. The service remained well supported with many Clinical Nurse Specialists (CNSs) continuing in their specialist posts.

There was a variety of virtual and face to face clinics between centres.

The focus is now on recovering to business as usual and reinstating research.

Paediatric update:

Positive feedback was received on the use of online platforms.

The paediatric oncology service has continued to deliver care as normal throughout the pandemic. The Trust strategy was always to prioritise care of cancer patients over benign disorders, should services become overwhelmed, but this has not been required to date.

Network communications have been enhanced, despite initially having to manage conflicting pandemic advice, by having a nominated COVID Lead. The aim is to continue weekly or monthly updates. Initially, the challenge had been getting people to attend and keeping up with routine line removal; the service is very busy now, and availability of COVID testing prior to treatment and hub space are now the main issues.

Many patients received shielding letters unnecessarily, which caused great anxiety.

The huge impact on young people having to stay home from school and away from friends

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was recognised.

The European Society of Blood and Marrow Transplantation (EBMT) have developed useful COVID [resources](#) for patients and clinicians.

Patients with long-term health conditions resulting from cancer treatment are a cause for concern. Patients who have had splenic radiotherapy should be on penicillin prophylaxis for example.

3. Service Specification and the South West Operational Delivery Network (ODN)

Service specifications were expected to be available in August 2020, but have yet to be published, so nothing has changed following the most recent network meeting held in February 2020.

South West Specialist Commissioning Medical Director Peter Wilson and Specialist Commissioner Nigel Andrews confirmed that the South West ODN is in the process of being set up. The Service Level Agreement (SLA) is currently with the Finance Department awaiting renegotiation of costs. There is a national review of all ODNs and how they are funded across the board. UHBW will host the service; the posts will be advertised as soon as the SLA is completed.

Action: An update on funding for the ODNs will be requested from Chief Operating Officer Luke Culverwell P Wilson

4. CLIC Sargent Position and Implications for CYP Network Provision

Presented by Rachel Banks

CLIC Sargent has taken a huge financial hit to income during COVID, dropping from 28 million to 9 million. Significant changes to the way the service operates have been required in order to protect frontline services. Workforce has already reduced staff by 15%, and needs to reduce by a further 7%. The charity is currently going through a 30 day internal staff consultation so there is limited information to share at present, but the group will be informed of the changes as soon as possible.

Funding agreements held with local authorities have been reviewed, and it is confirmed that CLIC Sargent have served notice to Devon County Council affecting the post holder there.

Reductions have had to be made to financial grants.

Young People Community Workers and Cancer Support roles will be discontinued, as will the music service and the nurse educators.

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CLIC Sargent is committed to continue the Home from Home service; however the number of families that can stay has had to reduce to comply with social distancing.

The priority is also to retain a Chief Nurse and the Social Worker service, but how this will look across the South West is still under review. As the travel budget no longer exists there is a need to address how patients can be seen, although the team are keen to not to lose the face to face contact.

All of the CLIC Sargent Social Workers were thanked for their remarkable adaptation to the crisis.

SW CAG needs to have a wider conversation on how to address the service provision as a network, as the impact will be particularly significant for the group in comparison with other network groups, due to the disparate geographical spread of centres.

The CLIC Sargent Young Person's Social Worker in Truro is leaving in three weeks resulting in a gap in the service. It is uncertain when roles can be re-advertised.

Social Workers may need to be more flexible to provide cover across the region and take on a case load with a wider age range.

5. Fertility Preservation Update

Presented by Dr Kath Hodby

A new fertility cryopreservation service is now available at Bristol Children's Hospital and the TYA unit. Consultant Gynaecologist Amanda Jefferys is the Clinical Lead.

The service is available for patients who are about to have chemotherapy that can cause infertility where no other fertility preserving options are available. The referral age criteria has increased from birth to age 25 to 35 years-old.

The service is a replica of the existing spoke and hub model, coordinated by the Oxford Tissue Cryopreservation Service hub. This will improve the patient experience by reducing the need to travel.

Eligible patients who are interested are referred to the Oxford team who contact the patient via WebEx, consent the patient remotely then surgery is arranged by Oxford as a day or overnight session.

The majority of referrals from the South West come from UHBW, totalling 75%, and 25% come from the District General Hospitals, probably due to Paediatric Oncology being based in UHBW. 75% of patients had a haematological malignancy and there was a small number of referrals with rare metabolic diseases. Numbers of TYA and Paediatric referrals

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are about 50/50.

A small percentage of referrals were in the 25 age range but adult referrals are expected to increase now that the upper age limit has been expanded.

On average, 12 patients are referred to Oxford; 6 from adult, 6 from paediatrics. The clinical team are to continue to refer to Oxford, who will continue to consent, but now include the Bristol team in the referral so that surgery can be arranged locally, either in the Bristol Royal Children's Hospitals or St. Michael's. Samples are taken back to Oxford by a representative and stored in the normal way.

The team are in the process of applying for funding for a coordinator to help with the service.

The newly ratified Standard Operational Procedure (SOP) includes how the service is organised in Bristol.

Action 028/2020: The fertility preservation SOP will be circulated with the CTYA Report

**K Hodbry / H
Dunderdale**

Additional information will be sought on a pathway for fertility preservation for those patients at the end of treatment, who did not have the opportunity to have this discussion at the beginning.

6. ALLTogether Trial

Presented by John Moppett

The trial is very nearly ready to open. Implementation packs were sent to sites 2 days ago, with a deadline of 70 days to open. For the South West, this will open in the Primary Treatment Centre (PTC), in Bristol Haematology Oncology Centre for adults aged 18 to 29, and in Plymouth for adults aged 18 to 29. Young people aged 16-17 will continue to access their care at the PTC and have access to the trial. Although numbers are small, individual centres need to look for solutions on how to support these patients throughout the treatment pathway, with the length of treatment and travel being recognised as a burden associated with the trial.

For the 18+ patients that can have treatment at either Bristol or Plymouth, referrals between Truro, Exeter and the north of the region will have to be managed to ensure that the maximum number of people can access the trial.

Having 2 sites open for the adult population is uncommon in comparison with the rest of the UK, where most ALLTogether trials are run solely through the PTC, and should help with recruitment in the region.

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It is thought that a significant majority of patients will be randomised to receive the trial drug Inotuzumab which it is hoped will increase survival from 70% to 80%.

The Principal Investigator for Plymouth is Hannah Hunter.

The protocol will not be circulated to the other centres, as it is a trial rather than clinical protocol.

The adult haematologist network will need to decide on the treatment offered off trial to make sure that this is consistent. There will definitely be a group of patients that are unwilling to travel who will need a substitute plan, but it is thought that most people will want the opportunity to join the trial.

If a patient starts the trial aged 17 ¼ in paediatric, it could be that they transition for treatment to adult services. This has been achieved in the past from Bristol to Plymouth with patients on UKALL. Shared care will be defined in the trial file delegation logs.

The trial also has the backing of the new Service Specification as it will provide the opportunity for more joint care with adult services.

7. Any other business

The current orthopaedic cancer pathway / interim pathway since the recent change to the Birmingham Orthopaedic service is for referrals to continue to be sent to Royal Orthopaedic Hospital (ROH) Birmingham for screening, and then referred on for biopsy at Stanmore Hospital. This has led to significant delays and impacted on the patient experience. It is anticipated that the service will resume before Christmas.

Action: All delays / related problems with the ROH interim pathway are to be flagged with the PTC and will be fed back to the ROH team.

POSCUs

Date of next meeting: February 2021, date to be confirmed (virtual meeting)

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