SOUTH WEST PAEDIATRIC ONCOLOGY REGIONAL NETWORK MEETING

Date: Thursday 17th September 2020
Time: 10:00-12:00
Venue: WebEx

NOTES	ACTIONS

1. Apologies, minutes, introductions and matters arising

Please see the separate list of attendees and apologies uploaded on to the South West Clinical Network website here.

Notes from the previous meeting on Thursday 13th February 2020 had been circulated for ratification; no amendments have been suggested.

Representatives from each centre have joined the call.

Clinical Psychologist Amanda Laffen is now in post in RUH Bath, and was welcomed to the group.

2. Confirmation of new departmental structure

Following a review of the departmental structure, undertaken by Professor Michael Stevens last year, a number of recommendations have been made, including the need for clinical leadership. The department has had no clinical leadership over the past 5 years, which has had an impact on the implementation of service developments. Funding has now been allocated for this purpose and Consultant Paediatric Oncologist Rachel Cox has been appointed as Clinical Director for the service.

There are three Clinical Directors in the Bristol Royal Hospital for Children (BRHC), covering Surgery, Medicine, and now Haematology, Oncology and Bone Marrow Transplant (BMT). Each Director reports to Clinical Chair Martin Gargan who escalates any medical issues to the Trust Board.

Helen Morris will continue as Lead Nurse.

The cross cutting issues of benign haematology, aftercare, solid tumours, neuro-oncology, malignant haematology, plus the management of the Consultant Team come under the remit of the Clinical Director.

The tier below comprises 3 Clinical Leads: Helen Rees is the Clinical Lead for cancer, Ollie Tunstall for benign haematology, including sickle cell and haemophilia as BRHC is now the regional centre for these diseases, and John Moppett in a locum capacity for BMT, with the intention that he returns to manage leukaemia as soon as the BMT team workforce is at full capacity.

Three substantive BMT Consultants are due to join John Moppett, with Julianne Silver continuing in the locum post.

An additional Consultant Haematologist is due to be appointed, and a 5th Oncologist will join Helen Rees.

This considerable expansion of the medical workforce will make the service fit for purpose to implement the changes necessary to comply with the National Service Specifications.

The network structure and leadership, which will comprise a non-clinical Network Manager and a clinical Network Lead, have yet to be put in place.

The way that the tertiary service in UHBW (UH Bristol has now merged with Weston), will work with the independent network service will be determined in the near future.

Now that the specialty has expanded, regular specialty business meetings will be held, with the first meeting scheduled for next week. This will include representatives from the Clinical Nurse Specialist Team, Psychology, Allied Health Professionals (AHPs) and Pharmacy to ensure that the holistic needs of the department are met.

It is the opinion of the Yeovil Representative that the UHBW team should run the network, rather than someone independent.

The Network Clinical Lead post will not be appointed by UHBW but will be advertised and appointed by the Commissioners, and therefore anyone across the region with the right skillset will be able to apply for the post. The job description has yet to be finalised.

The non-clinical network manager will be based in UHBW with the other Operational Delivery Network (ODN) Managers so that they can cross-fertilise ideas, as their regions are similar.

Advertising the posts is still on hold as funding has not been agreed due to the Service Level Agreement being rejected by the Trust. It is expected to be renegotiated in the near future.

3. News items in brief from each Shared Care Centre (SCC)

Royal Cornwall Trust:

There has been an exponential increase in the number of cases over the last 2 years by approximately 60%, which has been sustained over two consecutive years. This has had a significant impact on the workload, compounded by changes to the team.

Although a second Consultant has been appointed, the total time dedicated to oncology has been split so that the original 52 week cover has been reduced to 40 week cover. Service Managers have been tasked with producing a business case to ensure that additional funding is provided to return to 52 week cover.

The increased demand and reduced cover has affected everything operational including the outreach and inpatient service, especially during COVID, and support has been required from the Bristol team. This has been highlighted on the Trust risk register. The current Associate Specialist is getting an upgraded contract which should help to retain the post although this will not change workforce numbers.

Additional nursing hours have been requested to help with the outreach service.

The Psychology Service had recently disintegrated, but a Clinical Psychologist has now been

appointed, and support is expected in the near future. It would be helpful to link with the Psychology Service in Bristol for advice on setting up the service. The Clinical Psychologist in Bristol is happy to support development of the service and look at working more creatively together, as some services are finding it difficult to recruit.

It was noted that a 5-10% increase in referrals to General Paediatrics each year has not altered, so the rise from 14 cases per year to 41 new patients in 18 months is confusing and does not seem to be related to an increase in population.

Action 020/20: All relevant issues on local risk registers will be put on to an informal network risk register before this becomes a formal ODN register. **H Dunderdale**

University Hospital Plymouth:

The previous experienced Clinical Nurse Specialist has retired, leading to a dearth of knowledge, and attempts to recruit to the post have been unsuccessful. However, a ward nurse has been temporarily seconded to the role, bringing a lot of new energy to the post, and it is hoped that she will gain enough experience to make a strong candidate when the role is re-advertised in November 2020.

There is concern about the maintenance of Social Worker posts. The current post holder is doing a fantastic job, and had been due to finish at the end of the month. This has now been extended until November, after which time the team will not have a replacement funded by CLIC Sargent. The TYA Social Worker is also leaving in November.

The dedicated Psychology Service, provided by Katy Farrell-Wright is currently well funded by a local charity, but this may not be sustainable long term. Ideally the hospital would fund this, but they have confirmed that they would only be able to provide a basic service, not dedicated to the Paed-Onc team.

An issue recently arose with one Consultant on Annual Leave, and the other becoming febrile and requiring a COVID test, as these are the only 2 Consultants that can deliver intrathecal chemotherapy in the centre. Luckily, the COVID test was processed quickly and was negative, but raised the need for a contingency plan to provide cover across the network, should there be patients that need time dependent therapy, such as providing this at a neighbouring centre or in Bristol.

Action 021/2020: Development of a Network Contingency Plan for provision of intrathecal therapy in the event of workforce shortages. **ODN**

The Pharmacy Service is working well and cover is available when the main pharmacist is on leave.

A Registrar is interested in specialising in Paediatric Oncology, and the question of whether training is available was raised.

The first draft of a new Specialist Interest In (SPIN) Paediatric Oncologist curriculum was drafted in August. Sign off is expected by Christmas, after which time it will be made available on the

Royal College of Paediatrics and Child Health (RCPCH) website. Consultant Paediatric Oncologist Simon Parke is continuing as SPIN Lead, and invites the interested Registrar to get in touch.

The main changes are that Consultants in the Paediatric Oncology Shared Care Units (POSCUs) can be Supervisors, the curriculum is now more competency-based, and competencies must be completed within 12 months to be approved by the RCPCH.

Royal Devon and Exeter:

The team echo the concerns about the discontinuation of CLIC Sargent posts. Clinical Nurse Specialist provision remains stable. Medical cover has been a bit strained as Consultant Paediatric Oncologist Corrine Hayes has been running a sub COVID response service.

There are many Registrars at present; 2 are due to be assigned in the coming months who will be able to help with the workload.

The dedicated Pharmacist is due to go on Maternity Leave in the New Year.

The paperless hospital system EPIC is due to launch in RD&E in the next couple of weeks, which is expected to cause some challenges at first as people become accustomed to using it.

Somerset Foundation Trust:

One Consultant is returning from Maternity Leave in October, which will free up the second Consultant, who has recently been unable to take leave and frequently had to work extra hours.

Full time CNS support is provided between the two appointed CNSs.

Psychology support is available for 2 hours per week, so the team try to prioritise the patients with the highest needs. Patient numbers are low at present, but there are a number that are complicated to manage. In particular, there is a family who are finding management of a Portacath very traumatic and in retrospect would have rather had a Hickman line.

The decision for a family to choose the line that they prefer is usually a nurse led conversation where the devices are shown both lines, and talked through the pros and cons. Hickman Lines are considered the least preferable in terms of the potential for infection.

The surgeons also talk through the options prior to consenting for the procedure. It is considered a difficult decision to make at a time when there is so much information to process.

The issue will be discussed further outside the meeting today, and all CTYA members are asked to inform the Bristol team if other centres have had similar experiences.

Action 022/2020: POSCUs to flag any experiences where families have struggled with the decision to choose a Portacath versus Hickman, for further discussion with the Somerset and Bristol Team **POSCUs**

Yeovil District Trust:

There are no issues to report with workforce aside from the complete lack of psychological support for patients, which ideally should be provided from diagnosis onwards. The team request help from the Network Group to resolve this.

Action 023/2020: SW CTYA to escalate the need for provision of a Psychology Service in YDH **S Unsworth-Davies**

Royal United Bath:

Medical and Nursing workforce and patient numbers are stable.

The team are hugely excited to welcome the new Clinical Psychologist who, in additions to providing support to patients, is also providing clinical supervision for staff.

The team echo concerns about the discontinuation of CLIC Sargent posts. The current Social Worker is excellent but will be unable to provide sufficient cover if working hours are reduced.

The centre has increased ability to remove and site Portacath lines as one of the breast cancer surgeons has agreed to insert the lines in teenagers. Radiology has also agreed to take out Hickman lines in teenagers who are willing to undergo the procedure under local anaesthetic.

Gloucestershire Foundation Trust:

The current MDT Coordinator is stepping down on the 28th September 2020; a replacement has already been appointed to help with the minutes and meeting planning.

There are ongoing issues with medical cover which is on the Trust risk register. Matron also retired 2 months ago, and the team are feeling extremely busy with numbers on the rise.

The dedicated Pharmacist is training another Pharmacist, who will be able to provide cover for Annual Leave.

4. CLIC Sargent update / 3rd Sector

Update provided 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.

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.

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.

Action 24/20: SW CAG to address changes to CLIC Sargent service provision as a network — **Future agenda item**

5. Nursing update

Within the CNS team, there was a shortage of one person over the summer; the team now has Christine Morris and Vicky O'Sullivan in post. The BMT team has one CNS returning from maternity leave and one due to go, but cover has already been arranged, so the services will be back at strength going forward. Online communication meetings are being held regularly.

A 17th bed is being opened on the Starlight unit on the back of opening the ALL Together trial. It has also been possible to secure funding for the Band 6 to be supernumerary to improve patient flow, and attend MDT meetings to improve communications.

After some negotiation with CLIC Sargent, an additional 8 beds have been opened in Sam's House, but it is not going to be possible to open more.

A National review of the telephone triage paperwork has been completed. There have been a few amendments based on feedback and to ensure it is up to date with current guidance. The finalised version will be circulated to all in the near future.

SW Paed-Onc is to encourage completion of the Children's Priority Setting Partnership Survey by professionals and families.

Work is currently underway to develop a Paediatric Survey for children to complete.

As detailed in the previous meeting, the Trust Transition Group was attended in the Spring, where it was understood that the group was counting every single patient that transitions to adult services across the region. It is probable that some patients are being double counted and others being missed. Work needs to be undertaken by the ODN to address this.

Action 025/2020: ODN to implement process for clear reporting of patient numbers transitioning to adult services. — **ODN**

6. BHOC Pharmacy update

The two dedicated Pharmacists both have permanent contracts plus assistance from two rotational pharmacists that stay for 6 months in varied capacities each week.

The ALL Together protocol has been built on Chemo Care and is ready to go live.

The EPSALL protocol is due to be built on Chemo Care in the near future, which will only be relevant for BRHC patients.

The Anti-fungal prophylaxis policy has also been rewritten for BMT inpatients.

GCSF policy has had a COVID update to allow extended use over and above pre-COVID guidelines, as has the PEG GCSF policy; these should be accessible on the external website for regional use.

As discussed in the previous meeting, pre and post use of fluids is being evaluated to align practice across the region, and feedback will be provided at a future meeting.

The BRHC Pharmacy team were thanked for their help across POSCUs.

7. COVID-19 lessons learnt

Throughout this interesting time, the main lesson learned was the capacity for the network to work together by enhancing communication and ensuring that all were working to the same guidelines. This was achieved by having dedicated COVID Leads (Helen Rees and Rachel Cox) to provide daily updates on current guidance and information on who is currently in service and available. The idea is then to reduce frequency to weekly and then monthly, but continue to evolve and develop the communication process.

The change of many regional clinics to virtual platforms is still in place, and the team are awaiting feedback from the Trust of their expectations for the future. There is a variety of views on the value of virtual clinics including whether value is reduced due to the absence of face to face meetings.

The same number of regional clinics should still be held to ensure that the tertiary centre is delivering the activity funded by POSCUs. These should be slotted into the diary as scheduled pre-COVID.

Line removals became the biggest challenge to overcome, with many POSCUs unable to remove lines giving rise to a backlog; this has been resolved, and liaison with the Theatre teams has, as a result, much improved.

Current data suggests that the second wave is expected in Bristol in November 2020, this is expected to have an impact on workforce waiting to get COVID swab results. There is also a huge number of patients who have had treatment delayed; this is expected to have a knock on effect on all services.

Fortunately, the Children's Cancer and Leukaemia Group (CCLG) have not seen any significant

problems with paediatric cancer patients and COVID-19. The group of BMT patients are of the greatest concern.

Consistent communication with aligned terminology needs to be used by all when having conversations about risks and COVID. The COVID bulletin will be reinstated for the purpose of general communications.

The number of regional clinics was negotiated 20 years ago, and the number that should be delivered now needs to be clarified, This could be renegotiated with each centre when things have settled down.

It is understood that the contract for solid tumours is to provide 6 clinics a year. It is unclear if this is the same for Haematology clinics.

The other range of services delivered by the Tertiary hospital need to be taken into consideration when reviewing the network service. When in post, this should be a priority for the ODN Lead and Manager to investigate to ensure equity across the region, and also ensure that services receive appropriate recompense.

Action 026/2020: Review of network service provision of clinics by ODN **ODN**

It was noted that the virtual clinics allow for more ad hoc consultations as and when required, which has been very beneficial.

There are problems in RD&E this morning with obtaining COVID swabs; patients that are due to be treated tomorrow are still awaiting the tests. An email sent by Bristol Ambulance, who have been providing an excellent service to date, has confirmed that there are problems with capacity due to the increasing volumes of tests required in Bristol.

Local teams are to track the patients where swabs are outstanding prior to treatment.

8. Two week wait pathways across the region by age

Teams are to remind the group of the age of transition to adult services within each centre. A request has been sent to the Cancer Managers for this purpose.

9. Service Specification review

Implementation of the Service Specification remains at the stage of the previous September meeting, when the Primary Treatment Centre (PTC) put forward recommendations for how this could be interpreted at a local level. This has yet to be finalised as awaiting further feedback. The recommendations were written to reflect that the Service Specification has been written with safety measures in mind. This was not to be interpreted as the patients were not safe receiving certain treatments in POSCUs, but that there are a minimum number of patients that need to be seen for a centre to comply with the treatment guidance in the Service Specification.

The rising numbers in RCH have been noted, but further data is required before this can be confirmed as an upward trend.

Anyone who feels challenged not to follow the new guidance can contact the PTC for support.

To manage patient and family expectations, new patients should be told upfront that it is likely that the majority of their treatment will be delivered in Bristol.

At present, patients on the new Hodgkin's trial will all need to be treated in Bristol, as it is not possible to change the stance of this with the Chief Investigator. However, the trial will probably close relatively quickly.

10. Communication pathways

A generic email for the Paediatric Oncology registrars and grid trainees has been set up to improve communication across the network. This will be checked on a regular basis.

All patient consent forms should be uploaded on to Chemo Care. If this is not available, all team members delivering SACT treatment should endeavour to get a copy of the document.

SACT will not be delivered in the treatment centre unless the following documents are available:

- Consent form
- Protocol
- Flow sheet detailing the chemotherapy given or not given to date.

Any changes to treatment require the patient to be re-consented.

Action 027/2020: POSCUs to confirm if the nursing teams have the same checking processes in place. **POSCUs**

11. Regional Study Day

The 2020 Study Day had to be cancelled due to COVID. A half day virtual meeting may be arranged in Spring or move to next Winter.

12. Any other business

There are some problems when opening encrypted files sent between UHBW and nhs.net emails. There is no plan for UHBW to move to nhs.net, but teams are to report when this happens.

Date of next meeting: To be confirmed

-END-