



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

Date: Thursday 13th February 2020

Time: 09.30-15:30

Venue: Taunton Hyde Park Conference Centre, Towergate Stadium, Hyde Ln, Taunton TA2 8BU

NOTES

ACTIONS

Paediatric Oncology breakout session:

The format of future network meetings is expected to change once the Operational Delivery Network (ODN) is established.

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](#).

The notes from the previous meeting held on Tuesday 17th September 2019 were amended to clarify that CLIC Sargent's eligibility criteria has been refreshed and low grade/benign tumour diagnoses which have been medically assessed as a high burden of treatment are now included. As there were no further amendments, the notes were accepted.

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

Team members from the SCCs are welcome to arrange visits with the Paediatric Oncology Team in the BRHC.

Royal Cornwall Hospital:

Consultant Paediatrician Shama Goyal is now splitting her workload with a second consultant – Dr Andy Mullett.

A new associate specialist (initially to join in a trust doctor position pending approval for AS post), has joined RCHT to replace Katrina McDonald. Dr Mairi Vella is very welcome and comes with much experience following 4 years of oncology training at the Marsden, Sutton.

There have been many challenges over recent months with absences in the team and reduced Clinical Nurse Specialist (CNS) cover. A CNS is due to start a phased return from maternity leave in the near future.

Patient numbers have doubled over the past year; it is unclear if this is just a temporary increase, and the situation will be monitored.

The psychology service is in the process of being redesigned. A private service is available in the interim.

Action 02/2020: The division of responsibilities between benign and oncology workloads will be

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documented and shared with the group.

Shama Goyal

University Hospitals Plymouth:

CNS Petra Russell is due to return in 3 months. The CLIC Sargent social worker role comes up for renewal in June 2020. It is hoped that this will be extended for another year; a decision is awaited from the new CLIC Sargent Associate Director. Workload is split between the two Consultants.

Royal United Hospitals Bath:

Consultant cover remains the same. A social worker from Bristol has been providing dedicated help. It is hoped that additional support from psychological services can be sourced in March.

A full time Band 8A nursing post has been appointed to cover the Neonatal Intensive Care Unit (NICU), General Paediatrics and Oncology.

Musgrove Park Hospital:

There have been problems with appointing to the CNS post in Musgrove Park Hospital, which has now been rebanded from a Band 7 to a Band 8A. This is thought to be partly due to the geography, and might be made more attractive to potential applicants if advertised as a job share.

The medical service is also understaffed, with one Consultant currently in post, and help required from the Bristol team when on leave; Locum cover is required to cover maternity leave but thus far it's not been possible to find anyone.

Provision of psychological services is a problem, with one hour per week allocated currently, and patients with unmet needs.

Action 03/2020: A business case for additional psychologist time needs to be drafted; to discuss with Bristol Psychology Service for advice and support if possible

**Taunton &
support from
Bristol
Psychology
Service**

Gloucestershire Hospitals:

The Consultant in attendance provides paediatric oncology cover generally 3 days per week, but 5 days per week when covering the oncology on call rota. The second Consultant is appointed to cover 4 days per week. There have been some issues with workload due to increased patient numbers (higher than ever experienced previously), and staff sickness that has since resolved. Psychological support is provided with the service shared. An advert specifically for an additional oncology nurse went out last week. The oncology matron is due to retire in 3 months.

Yeovil District Hospital:

The service is compliant with everything, including provision of psychology services, apart from patient numbers which are currently low.

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Royal Devon and Exeter Hospitals:

Staffing levels remain as they were with no impending problems on the horizon. However, the Barnstaple service has some issues with sustaining psychological support, which is currently provided by the generic paediatric service. There are two impending retirements. The excellent communication with the North Devon paediatric team enables cross-cover when required. A trainee medic is currently undertaking the paediatric oncologist course.

3. Network Quality Standards

Psychology:

There could be an opportunity to provide psychological support as a networked service.

Action 04/2020: Contact details of all psychology support staff will be added to the CTYA distribution list, and the group will be provided with the opportunity to liaise about current service provision.

H Dunderdale

The same arrangement could be relevant to organise for the palliative medicine team, who have a practitioners' network but not with traditional network functions, and have a complicated set up to manage as it currently sits between local and specialist commissioners.

Aspirations on the delivery of 24/7 care could come under the umbrella of the ODN.

To support cross-working, a weekly online forum is now being held at BCH (Currently internally and externally by webex) on Thursdays at 10:00 to discuss cases with complex needs and share learning. Shared care centres are invited to bring a question for the group to address, for example, symptom management at end of life care.

Action 05/2020: An email will be sent to all to formalise the process.

H Dunderdale

Action 06/2020: A referral form will be developed by the Lead of the Palliative Care Forum

S-T-Unsworth

Feedback on the meeting content would be welcomed.

Aftercare:

A new aftercare nurse has been appointed 3 days per week. This is a separate role from the endocrine team. Holding outpatient appointments using web-based technology is currently being explored. A system used in Australia and in the Scottish Isles works well and is a potential option. A link to the system is simply included in the patient letter. This could enable increased engagement of patients with the service, which is available to young persons across the region aged 11-16 who are more than 5 years post diagnosis.

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Palliative medicine:

Professor Mike Stevens has produced a report on palliative care that can be shared with the group.

A new Palliative Care Multi-Disciplinary Team meeting has been arranged and it is hoped that all will find this useful.

Transition

The age at which each Trust's transition patients from children's to adult services needs to be clarified and ideally organised with equipoise across the region.

Action 07/2020: Matron Helen Morris is attending a regional Transition Board to explain the needs of oncology, and will provide feedback to the group

H Morris

There is some merging of work between aftercare and transition, where education from a holistic view (memory, cardiovascular, continence for example) needs to be provided on the late effects that may occur as an adult, which is not thought to be provided when transitioned to adult services.

Action 08/2020: A comparison of adult surveillance protocols with paediatric surveillance protocols, plus where and who should be responsible to scan, and follow up transitioned patients, will be clarified.

ODN

The Brain Tumour Charity has undertaken a project looking at sequelae and survivorship in neuro-oncology; outcomes would be useful to review at a future meeting.

Future agenda
item

BRHC has set up a Teenage and Young Adult clinic for patients in active follow up prior to transition into aftercare.

BRHC is currently the only principal treatment centre not undertaking fertility preservation surgery, although consent and storage occurs at North Bristol Trust.

Action 09:2020: A process could be agreed to arrange for ovarian tissue to be removed at the time of oncological surgery.

Helen Rees

A Consultant Menopause Specialist, appointed in UH Bristol, is gathering evidence on numbers of women suffering from menopausal symptoms post cancer treatment so that a business case can be made for provision of a local clinic.

Action 10/2020: Details of the number of patients on ovarian hormone replacement therapy in the paediatric and TYA settings will be shared for this purpose.

Aftercare
Teams

4. Nursing update

Nursing posts in the BRHC are relatively stable at present. It may be possible to recruit many

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newly qualified nurses.

A 7th bed will be available for the ALL trial, resulting in many extra bed days from May 2020.

An update on genomics has been provided for the nursing team by Genetic Counsellor Amanda Pichini.

Due to the extensive building work underway at the University of the West of England near to the BMT patients, there has been a temporary swap of building / beds to a quieter environment.

Completion of Holistic Needs Assessments has been working well, and results will be discussed further at the Paediatric Oncology Network Group conference.

A national audit has been undertaken to review use of the triaging phone tool, which has resulted in a recommendation that this should be used to mitigate issues by adult services.

Nursing Standards are also being reviewed, which is timely with the recent publication of the new Paediatric Oncology Service Specifications.

All those involved in the network audit of planned admissions, coordinated by Christina Parfitt for the months December 2019, January and February 2020, are to send in their returns as soon as they are complete.

The CNS team are offering end of treatment clinical appointments (available via telephone for Truro patients), which have received positive patient feedback.

An audit on the management of Craniopharyngioma is currently underway.

The nurse led follow up clinic held once every three months is becoming very busy, with more patients added to the returning list for a service that is currently not funded, whereas nurse led clinics are funded for adult services. A process for tracking telephone consultations needs to be put in place to ensure that this activity is properly recompensed.

It is hoped that continued funding of the Cancer Support Worker post, responsible for managing the phones for BMT and SACT patients, and organising TYA clinics, and other administrative support, can be secured.

The number of chemotherapy nurses required overnight is the same in the latest Service Specification as the previous Manual for Cancer Services, requiring two to be available in order for intravenous (IV) chemotherapy to be administered in SCCs, even though IV chemotherapy was routinely administered in the day, and complications arising from this were the main issues to manage overnight. Any SCC that has workforce issues with this provision is to contact the BRHC team to see if support can be provided. Any decision to provide services outside the realms of the service specification will be raised for wider discussion.

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5. Pharmacy update

Access to the ChemoCare online system has now gone live. Feedback on the system is welcomed. Any issues with logging on to the system are to be raised with the Information Technology Help Desk. It is possible to share individualised protocols across the region, add treatment notes and blood results and discharge letters, streamlining the workload.

The problem with needing to have nhs.net accounts is something that is being worked through. Many of the nurses on the ward do not have access.

Action 11/2020: Generic nhs.net email accounts for nursing teams are to be requested

H Morris

The aspiration is to have a central repository available across the network.

Communication of drug doses will be included in the Medway Discharge Letters when the system has been updated.

The centres that have started to use ChemoCare are GHT, RCH, RD&E and BRHC.

The need for fluid standardisation guidelines due to variation in practice across the group will be discussed by the pharmacy network group.

Action 12/2020: A Fluid Standardisation Standard Operating Procedure will be produced and shared across the region.

V McLelland

Vincristine mini bags (50 mls over 10 minutes) were noted to be a cheap, safe option that can be administered by nurses. In comparison, treatment by bolus could be delivered quickly with no need for a bed, although have an increased risk of causing extravasation.

Action 13/2020: All protocols will be amended to be in line with National Guidance on the standard fluid type to use for dilution.

V McLelland

The addition of bicarbonate will be discussed with the pharmacy group after looking at the research available and templates used in other centres.

Guidance on antifungal prophylaxis has been updated.

All confirmed that the latest guidance on antiemetics is being followed.

The G-CSF policy is due to be reviewed in the near future; it is thought to be unlikely to change.

6. Risk register and Incidences

- Provision of psychological support
- Continued provision of support from CLIC Sargent
- Provision of 24/7 service
- Access to nhs.net accounts.

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Information on the care delivered by the primary treatment centre should be available to SCCs on the discharge letter given to patients, which is routinely printed when arranging a patient's take home medication (TTAs). The information was however not always available, although it is hoped that changes to the Medway system will automate this process.

Action 14/2020: A Short term working group will convene to look at 2 way information flow with nursing and consultant input to define what information is needed and at what points this should be provided.

H Rees

7. Quality audits

A project to look at the clinic configuration in chemotherapy day beds would be helpful, as would a project to define when weight can be used for prescribing purposes, for example, a weight taken within the last 2 weeks could be used if there has been no acute event in the interim.

Action 15/2020: To create a guideline for weights that can be used for prescribing

H Rees

Any incidences related to weight calculation anomalies are to be sent to H Rees.

Action 16/2020: Formalised guidance on medical cover for patients receiving chemotherapy in SCC will be added to the Work Programme along with creation of a template handover sheet of standard information for SCCs.

ODN

The BRHC front of note paperwork has recently been improved so that the diagnosis including staging information is available, plus sufficient information to manage ongoing patient care. RUH, RD&E also have a similar e-handover, and GHT provides an oncology handover diary.

Registrars routinely call centres about patients that they are particularly worried about.

A system where all required patient information is securely available across the region (a system called WATCH was mentioned) would be ideal. A survey of national practice would be beneficial.

For those patients on treatment, a weekly update to SCCs would help to facilitate maintaining the relationship with the local team once the family are repatriated. SCCs are to prompt the BRHC team when this isn't provided, although any significant events would usually be automatically provided.

Action 17/2020: ODN to create a network website/workspace for sharing information.

ODN

8. User / patient experience

CLIC Sargent Home from Home accommodation is available near the BRHC. Social Worker posts in place are noted to be stable at present. A new Director and Chief Executive Officer are currently being appointed, and while the strategy for the coming year is on hold until the post holders are in place, the essence of what CLIC Sargent provides is not expected to change.

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9. Clinical pathways/guidance

The usual clinical pathway was for orthopaedic patients to go to Birmingham. However, this is not available at present due to a lack of out of hours cover, meaning that patients will need to be referred elsewhere for the time being.

Age of transition to adult services in each Trust:

- RDE: 18
- RUH: 18
- Truro: 16, although some room for paediatric taking over
- Glos: 16, although some room for paediatric taking over
- TST: 18
- YDH: 16
- Bristol: 16.

Action 18/2020: To find out the age of transition to adult services from each Trust

H Dunderdale

10. Any other business

The next Annual regional study Day will be held on Thursday 26th March 2020. The programme will contain MDT meeting updates, Clinical Trials, Genetics in a real time setting, complicated case studies and a similar process to Schwartz Rounds. Volunteers from attendees at the meeting today will be required to get the discussions underway, from Nursing, Allied Health Professionals and Medics; a theme needs to be identified.

The Bone Marrow Transplant service is fully functional and secure, now that an additional 2 local Consultants have been appointed in addition to John Moppet who has undertaken the role of Clinical Lead in the short term.

Both the neuro-oncology and solid tumour MDTs have generic MDT referral forms. The deadline for Solid MDT referrals is by end of the day, Thursday, and for neuro-onc, by 5pm Monday. Stephen Lewis is now Clinical Lead for neurofibromatosis (NF), and will talk about the NF clinics at the regional meeting. Currently, patients diagnosed with NF do not have access to a keyworker.

All guidelines, protocols and flowsheets are version controlled and available on the NIHR hub.

Action 19/2020: A team member should be responsible for document control in each SCC.

SCCs

Date of next meeting: Thursday 17th September 2020 via WebEx

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