



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

TYA breakout session:

TYA Care South West Update February 2020

Presented by R Dommett and J Cargill

Please see the presentation uploaded on to the SWCN website

Service specification

There is a delay to the finalisation of the Service specification linked to co-location of paediatrics. Professor Sir Mike Richards has undertaken an external review, which was reported back to NHS England on 30 January 2020. This stated the need for on-site intensive care facilities for all PTCs. The team expects the service spec to be released in the near future and recruitment into ODN roles can then begin. This will include a dedicated Manager, lead clinician, lead nurse and admin support. The Network will be hosted in BRHC to support streamlining of back office functionality with other ODNs. The network will evolve and will need to meet set up and reporting (metrics and KPIs) deadlines.

The SW TYA Cancer service is already delivering networked care and the ODN will provide resource and improved governance to give it more rigour. Location of care was discussed and it was highlighted that the current model of care does not dictate care for all 16-18year olds in the PTC as stated in the service specifications. This reflects conscious decisions made when the network was set up 10 years ago recognising the geographical and cultural challenges.

Across the TYA age range approximately 50% of patients receive care in the PTC and 50% in Designated hospitals (DH). The REACH audit data confirms our ability to support the young people in the network irrespective of location of care. Moving forwards we will have to articulate and mitigate for any risks associated with areas of the model of care out with the service specification. We will be reliant on Clinical leads in the DHs to support the model of care. The service will have to be able to demonstrate that a transparent conversation about service delivery/treatment location has taken place. This is easier to define when the patient has been referred through paediatrics or adult medical teams but

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more of a challenge when patients present via surgical pathways. Defining age boundaries will also be important and regionally teams need to be signed up to the SAME set of rules. These will override departmental and individual interpretations and require clinical engagement.

PTC Update

TYA workforce.

Nursing-Ward Sister, Amy Dipple, appointed in October 2019. Her background was in adult oncology with an interest in TYA. Her remit includes rebuilding a core TYA nursing team.

Medical-Consultant Haematology locum, Kath Hodby , appointed in October 2019 to replace Caroline Besley who has now moved into a CAR T cell therapy/SCT post.

Substantive Consultant posts in Acute Leukaemia and Lymphoma will be advertised in February 2020 with the expectation that appointees will contribute to the TYA MDaT.

ACP role- The TYA Advanced Clinical Practitioner (ACP) role is evolving and developing. Measuring effectiveness and building the business case to secure long term funding is the challenge.

Social work- Suzie Holmes has returned from Maternity leave and Anna Regan has moved to Paediatrics.

Research- Gerard Kenny has been appointed as the new dedicated TYA research nurse with a PTC and network remit.

Regional coordinator -This role has been unfilled following staff absence but a fixed term appointment has been made and Tom Eveleigh has joined the team. His remit will include MDT coordination and project work.

Activity

Patient numbers have fluctuated and TYA beds and outpatient spaces have been used by adult services.

REACH 2019 is paused but we will plan to pursue this data as soon as possible. This is an important quality indicator for our service.

The new version of ChemoCare, 6.0, is now fully rolled out across Paediatrics and TYA. Adult services in the PTC use a different system. It was acknowledged that Paediatrics use a hub and spoke model in Chemocare supporting the network/shared care model. In adult services across the network different electronic chemotherapy prescribing systems are

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used which would need to be considered in developing potential future joint care arrangements.

Refurbishment – more storage and office space needed. More staff puts pressure on this. Teenage Cancer Trust has allowed funding for office space being built into the unit. The refurbishment will be finished soon.

Complementary therapies are an initiative from the On Target programme. This was not part of core NHS funding. Four different charities support this and the service has been pretty rigorous in capturing evidence. The challenge is sustaining that investment. Funding is secured until September 2020. Beyond that, funding will have to be found from somewhere else, possibly Third Sector or industry support. How to standardise regional support is really important. Therapists provide quality care. CLIC Sargent and Teenage Cancer Trust are trying to standardise support regionally and nationally.

A Maggie's Centre has been approved for the UHB site, location to be confirmed.

Designated Hospital Updates

Truro

TYA lead Toby Talbot has stepped down and been replaced by Fiona Minear, Clinical Oncologist specialising in colorectal and CNS. Louise Morris has been in the TYA CNS post for six months; she is funded by LARF (a local Cornish cancer charity) for 15 hours per week. Hannah Heayn will be leaving Truro to work in Plymouth and recruitment into her post is planned

Standard offer to TYA in Truro includes psychology and physiotherapy support. Current discussions regarding age appropriate care for 16-19 year-olds across paediatric, TYA and adult teams. There is no arbitrary line but the focus is meeting patient needs and earlier engagement. There was a recent mention in the CQC report around outpatients (Outstanding Care Young Adults Care) which is not yet in the public domain but will be soon. Service demand was strong in 2019 but has dropped recently.

The service has five age appropriate areas: 2 outpatients, 2 inpatients, 1 quiet area plus the Cove peer support space. There is peer support funding issues. LARF pay for every other peer support night.

Cheltenham and Gloucester

Meg Wilsher has been in post for nine years. COBALT fund the role and review ongoing funding every few years; next review in April but the Chief Executive has given first year funding agreement already.

The Oncology Haematology build on one site in Cheltenham has not moved forward. Sally



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Hayes has flagged this. Money still needs to be raised.

Plymouth

The team were unable to attend this meeting; J Cargill provided a summary. Kerry Mckay was seconded to a senior role for which funding has been secured. Lucy Figg has been funded. Hannah Heayn will start at the end of March.

Exeter

The haematology outpatients refurbishment is underway and progressing positively, as the Oncology refurbishment was very well received. There will be a parent support group in March. 25 parents attended the previous event. The breast care group is held on an ad-hoc basis. This event could run anywhere in South West if other teams were interested.

Peer support is going well. There is a lot of activity in Torbay and North Devon. There are good links with the Ellen McArthur Cancer Trust.

Risk: Switching to Epic in June – electronic patient record.

Taunton

TYA lead Belinda Austin has been replaced by Deepak Mannari, Consultant Haematologist. Peer support events have had between 5 and 8 patients attend, some bring partners. Thrive Not Survive grant has funded one patient's cake business. Ongoing concerns regarding communication for patients receiving care in PTC who live locally to Taunton, particularly patients undergoing SCT.

Discussion regarding care in non-designated hospitals and whether the ODN will be able to influence this. Concerns raised regarding patients treated in Torbay and whether they are being given the choice of location of care. There have been six patients treated there in the last 12 months. These are complex patients, including one high grade lymphoma. The Exeter TYA team are supporting patients but communication is often challenging.

Research

Gerard Kenny newly appointed TYA Research nurse introduced to the team. Gerard is an Adult and Children's dual qualified nurse. Previous roles include working for CAMHS and safeguarding

In 2015 the independent Cancer Taskforce set a goal of 50% recruitment to trials for TYA patients by 2025. In 2019 a meeting was held involving the TYA Clinical and Research

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communities highlighting a number of the challenges to achieving this goal. These include trial availability, visibility and funding. PTCs and DHs face governance issues; emulating the paediatric model is appropriate. Trial budgets are getting smaller so teams need intelligent ways of working. Review of age inclusion criteria, having a lower or upper age limit, may improve access.

Gerard will work between Adult, TYA and Paediatric services to bring people together. The Government and regional agenda is for a blended portfolio of research. This includes: peer support; parent support; and emotional, physical, practical and educational support. Gerard is keen to discuss research questions to see if teams can run pilots. R Dommett reinforced there are things that TYA are doing which are not captured. This is another opportunity to get qualitative studies opened regionally. The service has established academic relationships – with Cardiff, Southampton, UCLH. There is a need for network-wide studies, a broadened portfolio which is not skewed by pharmaceutical trials.

Two CRNs serve the TYA network: the Peninsula Research Delivery Manager (RDM), Chris Levett, is based in Taunton. There will be a Peninsula meeting. The SWAG RDM is Dave Rea.

The TYA spec includes tissue banking responsibility; young people can access CCLG tissue bank up to the age of 25. This will be developed at UHB and then rolled out regionally but is not an onerous consent process. If teams can demonstrate an improvement, that is an outcome which supports the whole model of care. Current costs are approximately £40 for tissue and £20 for a blood sample.

Upcoming studies include the new Hodgkin's trial open in Paediatrics and TYA, EuroNet-PHL-C2. There will be a new ALL trial later in year called ALL Together, with an age limit of up to 30 in the UK (up to 40 the Scandinavia). Bristol should be the first site to open. Plymouth has been agreed as a second centre.

MDT/MDaT

Clinical leads- Peter Stephens has joined the MDaT as the Sarcoma lead. Representation from Neuro Oncology remains a challenge. We are keen to support Palliative care representation but this would need additional funding.

MDaT is an opportunity to review patient experience and treatment plans. R Dommett reported first-hand experience of the different experience of dial-in presence at the meetings. What a TYA MDT looks like varies across the country. The major purpose should be to support all professionals delivering patient care. In terms of quoracy, the level of medical engagement has improved significantly in the last 12 months. There is

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greater intelligence about different treatment regimes, e.g. a breast patient needing gynaecological input. This adds value to outcomes.

Tone, value, and technology are areas for improvement. MDaT is not a forum to put people on the spot or criticise them if information is unavailable. Technology is difficult. The Webex platform and SWIMMS database both have vulnerabilities. Dial in sound quality may be due to the microphone position in the room and the technology used for the meeting needs improvement. There have been problems with the current IAM system. HMA will be the new system provider for SWIMMS from 1 April 2020. The functionality, look, feel and data fields should be much improved. Current administrator input will be done automatically. CNSs spend time populating fields but data isn't saved. Therefore, they have all the paperwork handwritten out on Wednesday.

Timing- Time pressures mean the team has 15 minutes to discuss each patient. Focus should be on ensuring a clear medical update of where each patient is on their pathway, with accurate diagnosis details and dates. MDT coordinator role should support Quality Assurance of data going in and out. Regional teams are far better with data than Bristol. From a haematology perspective, unless you have medical detail you can't think about treatment pathways and some of those key decisions will have already been made.

Conduct-Professional respect for contributors was discussed and it was acknowledged that it can feel intimidating to those dialling in. This is compounded by background noise in the meeting room in the PTC

Admin support and preparation- Good administrator support is needed regionally. There should be more time for complex patients. A ranking system for complexity might flag importance. Patients should be registered or discussed within 7 days of diagnosis. Newly diagnosed or registered patients should be listed first. Important questions are "Is there a trial?" and "What about fertility?" Inviting more people to present their patients rather than presenting on their behalf.

There is a lack of debrief for regional colleagues after meetings. MDaTs need a different ending to make sure everyone's OK and give an opportunity to feedback. Inequalities include Bristol have got access to psychological support; for the other teams CNSs have to support patients

Third sector updates

The Prince's Trust has relaunched in the north of the region. This includes a mentoring programme with guidance for young people.



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Macmillan has moved away from supporting Children and Young People. Signpost to CLIC etc. Macmillan does still support long-term follow up patients.

Teenage Cancer Trust update

Brendon McIntyre said Teenage Cancer Trust had raised £17.6m; therefore they have really strong reserves. The biggest investment is staff; there are 80 funded staff. They are about 16 nurses short. Wessex should have 100% cover by end March, with a nurse in Poole coming on line. After treatment/post treatment support will be good

Any Other Business

Gerard will link with the Teenage Cancer Trust policy team.

There is a generic NHS England TYA cancer services leaflet on their website. This discusses location of care and was developed by Choices a few years ago. The group generally considered it to be out-of-date but some members had not seen until recently.

A charity annual report and service annual reports are due for publication. 45 patient responses have been received and input closes in February. There is a bid to supplement Youth Support. This was discussed at a regional meeting at the end of last year. Social and peer support. 1 YAC so far. Minimal. Looking to put together.

The Strictly event is oversubscribed. Last year this was held in Exeter but it would be good to host elsewhere. This is education based, with lots of professionals attending including representatives from hospices and primary care. Plymouth could be a potential location – it needs to be somewhere with a suitable education centre.

The Way Forward event will probably take place over a Friday/Saturday in September 2020 – 7 venues have been identified. The two most likely venue options are: Double Tree Hilton at Congresbury or The Imperial Hotel in Torquay. The venue will be confirmed ASAP.

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