NHS
Northern
Cancer Alliance

Meeting:	Brain and CNS NSSG	
Date:	2 November 2018	
Time:	9.00 – 12.00	
Venue:	Evolve Business Centre	
P resent:	Sarah Azndarinia, Nurse Specialist Neuro- oncology, Nuth	SA
	Jean Gardner, Patient Representative	JG
	Serena Hartley, Neuro-Oncology Physiotherapist, South Tees	SH
	Gill Hendry, Macmillan neuro-oncology CNS South Tees	GH
	Jenny Hunt, Occupational Therapist Neuro- oncology Nuth	JH
	Phil Kane, Consultant Neurosurgeon, South Tees	PJ
	Beth Millard, Speech and Language Therapist, Nuth	BM
	Raigan Rees, Occupational Therapist Neuro- oncology Nuth	RR
	Emily Rees, Neuro-oncology Support Sister, S Tees	ER
	Chris Tasker, GP Cancer Lead, NESCN	CT
	Sophie Williams, Clinical Neuropsychologist Newcastle	SW
	Anil Varma, Consultant Neurosurgeon, South Tees	AV
	Linda Wintersgill, Information and Data Manager, NCA	LW
In Attendance	Claire McNeill, Senior Administrator, NCA	CM
Apologies:	Caroline Barbermiller, Neuro-Oncology Occ Health, South Tees	CB
	John Crossman Neuro Surgeon Newcastle Hospitals	JCr
	Andy James, Consultant, Newcastle	AJ
	Anil Kumar, North Cumbria	AK
	Joanne Lewis Clinical Oncologist Newcastle Hospitals	JL
	Jonathan Slade, Deputy Medical Director and Responsible Officer, Cumbria and the North East	JSL
	Pauline Sturdy, Macmillan Neuro-Oncology Specialist Nurse, South Tees	PS
	Katie Elliott, GP clinical Lead, Cancer Alliance	KE
	Alison Featherstone, Cancer Alliance Manager	AF
	Jonathan Slade, Deputy Medical Director and Responsible Officer, Cumbria and the North East	JSL

MINUTES

1.	INTRODUCTION		Lead	Enc
	1.1	**Welcome and Apologies**		
		AV welcomed all to the meeting, apologises as listed above.		
	1.2	**Declaration of conflict of Interest**		
		No declarations of interest were made.		
	1.3	**Minutes of the previous meeting 04.05.18**		
		PV is to be amended to and shown in attendance .		Enc1

		Minutes agreed as a true and accurate record.		
	1.4	**Matters arising**		
		• **Neuro Pathologist South Tees Vacancy Update**		
		AF updated via email and had contacted Tony Branson. TB confirmed via email he wrote to Paul Barrett about this and suggested specialised commissioning might have a view but I don't know if he has taken it any further. PK asked if the digital system would be in place soon as South Tees are concern the lack of cover will impact their trust significantly and cause delays in treatment. LW to discuss with AF and will obtain update for the minutes.		
		• **Digital Solution Update**		
		AF emailed to confirm details of South Tees representatives in relation to this piece of work; • Dr Mehrdad Lavaei and Jacqui Richards attend the Digital Board meetings on behalf of S Tees. • Dr Adrienne Mutton attends the subgroup looking more specifically at the new ways of working and a Memorandum of Understanding agreement to underpin it AV will liaise with the people mentioned above.		
		• **2WW Referral Update**		
		Presentation attached for information. PK advised the use of the form has improved since this was discussed at the last meeting. Group discussed the issue of Radiologist escalating patients to contrast scans and the issues around this. This had previously been taken to the Radiology group however there were a number of objections and no progress was made. CT to draft wording to be approved by both Trusts. Once agreed this would be taken back to Radiology Group as well as Clinical leadership group. Only 9% of patients on 2ww referral were found appropriate for this. Most patients enter by stroke pathway. Group discuss the efficiency of this pathway.	**CT**	**Enc**

		Significant event- PK advised a CT plus and minus contrast could be done in place of MRI before referral. Group discussed a specific case within the presentations and agreed that any delay in getting MRI, CT plus and minus contrast could be used. 2WW Form discussed in detail. Discussions highlighted the fact not every Trust has a Cancer Unknown Primary MDT. Joanne….. can you please comment or correct this ?Newcastle Hospitals have the only Metastasis Of Unknown origin. South Tees has a CUP (Care of unknown primary) Oncology team. CT advised he was aware of this issue and need to ensure wording on the form reflects this. CT discussed the additional advice and guidance provided by Newcastle Trust- where he can obtain specific referral advise for a patient within 3 days. The CCG has agreed to fund this but charge is only applied if patient does not get referred in. For those patients who are referred in this cost is deducted from the cost of the first referral appointment. South Tees don't provide a similar service but PK thought this would help greatly with referrals. LW to discuss with AF to see if the Alliance could take this to commissioning group as an inequity of service. Group discussed the need for primary care to take ownership of the 2ww referral forms and if they are completed by admin these need to be checked before sending. CT suggested all practice reviewed their submissions. EMIS adds some information after the form has been submitted which is sometimes duplicated. Primary card needs education and CT will keep pushing this but asked Trusts to feedback badly completed forms to GPs. Vague symptoms are being introduced to Newcastle, South Tees and North Tees. (check this) Claire, I am not sure what this was meant to be??? Joanne… any Ideas?? If we are not clear, can confirm in the meeting with members what this was about….. is it a clinic for vague symptoms??? Group endorsed the 2ww form agreed and also agreed to review in 6 months' time at the next meeting. CM to add to agenda		

		• **Flow of tumour patients from stroke pathway**		
		AF updated via email and confirmed this was queried with the regional stroke group. The regional stroke group's reply is detailed below. This has been discussed with CDD stroke physicians. They could only recall 1 patient that had "gone the wrong way", but will address the issue. It may not be an issue in the future as it is highly likely that Darlington patients will go to the single HASU on Teesside (initial reconfiguration work commenced) when it is established.		
		• **Definitions of skull based tumours**		
		PK agreed to share further definitions when received from expert colleague PK will forward list on for circulation include the guidelines.	**PK**	
2.	**AGENDA ITEMS**			
	2.1	**Cancer Alliance Update**		
		The Northern cancer alliance was one of only two cancer alliances to received 100% of transformation funding. This is linked to 62 day performance, which we had failed but there were exceptionally high volumes of Urology referrals and this was taken into account and once recalculated managed to meet the target. Transformation programme regarding digital solution is stalled at the moment. And held up There is some additional funding which is currently going through bidding process. Focus is on Urology as this is a priority pathway. There is also some service improvement money and awaiting national funding decisions.		
	2.2	**Clinical Guidelines**		
		Clinical guidelines discuss and a number of updated needed so group could not endorse these. Number of updates are detailed below; • WHO classification is to be added with pathology. • Pathology – AV to liaise with David Scoones		

		• Sarcoma- extract from Sarcoma guidelines to be inserted. • Rehabilitation lead role- to be discussed outside of the meeting. • Update from services needs to be reviewed. Will bring that back to the next meeting. Group agreed the following were updated; • Oncology part updated • Neuro rehabilitation policy was updated AV to send details to CM when completed. Future Pathology delay in pathways were also discussed. Once the Leeds hub is opened South Tees would have to refer to Newcastle first and then on to Leeds. This is to be referred to David Scoones		
	2.3	**Research Network Presentation**		
		Presentation Attached for information . Group asked for a briefing to go with the minutes. CM to email Penny Williams.	**CM**	**Enc**
	2.4	**Terms of Reference – for Agreement and Sign off**		
		A number of suggested were made. CM to amend and send updated copy to group. With a view to review via email. All comments to be sent by 1.12.18, if not comments received this will be considered endorsed.	**CM** **All**	**Enc**
	2.5	**2WW referral Form – Neuro**		
		Discussed previously.		
	2.6	**Inter Provider Transfers (Clinical Datasets)**		
		LW discussed the inter provider transfers and breach reallocation is now a national directive. After lengthy discussions group agreed this was not necessary due to no breaches in 2017/2018		

		CT discussed the fact that imaging co-ordinators were being funded for lung cancer patients which was improving patients pathways. PK asked if alliance has a minimum numbers of staffing. PK advised an MDT coordinator taking on additional MDTs. PK asked if the cancer alliance could raise this as a concern. LW to discuss with AF with a view to take this to leadership group – what is the level of support at MDT / tracking and for cancer services. LW also agreed to take cancer managers meeting.	**LW** **LW**	
3.	**STANDING ITEMS**			
	3.1	**Performance Reporting**		
		Presentation attached for information LW to go back to registry to look at mortality rates. PK suggested looking at age breakdown of these patients PK discussed elderly patients living in rural areas not wanting to travel due to the effects on quality of life and suggested patients may chose palliative care • Risk factors 2% of obesity – group discussed this fact and couldn't remember treating an obese patients. Only 1 patient could be remembered as being obese. LW to investigate further. LW advised if this section wasn't relevant she could remove it from future presentations Database showed 229 cases and Newcastle was 20 cases adrift. LW to look into. Wait days were discussed as this looked excessive. LW would send out a list of codes for people to investigate further. Low grade patients could possible choose best supportive care – if patients decline treatment that might account for the high mortality rate. LW to investigate further. Data completeness was discussed as only 96% patients were discussed at MDT. Which meant approximately 8 patients were		**Enc**

		either not discussed of data had not been entered into the system. PK asked for further investigates into this. Conformance discussed and the fact a number of patients would refuse treatment and numbers of patients on best supportive care and asked if there was scope to do additional analysis. CADIAS – currently looking at the dashboard and looking to make if more interactively. National Patient Survey This group number are so low all information is suppressed but our trusts normally are Please look at presentation and any suggestions send to L.wintersgill@nhs.net		
	3.2	**Clinical Governance Issues**		
		• Pathology – still on-going • Radiology – South Tees concern re one locum contract coming to an end but in negotiations. • Workforce- as discussed earlier		
		Walkergate Hospital		
		Group expressed concerns re waiting times for acute neurosurgical beds for level 1 patients and reasons for delays as patients not clinically stable. Request has been made for a referral criteria.. LW to look into any data to measure delays and to discuss with AF. AF to discuss with specialised commissioning.		
	3.3	**Any other business**		
		Shared Care Decision		
		Group discussed Shared decision making. Some trusts were allocating up to 45 mins however South Tees only offer 30 min slot. Group agreed to look at what practise is across the alliance.		

		To be considered for the next clinical guidelines to ensure equity of service. PK to pull together information on shared care to be discussed at the next meeting.		
		NICE guidance ref …..		
		NICE guidance – early resection for high grade tumours should be normal practice for Neuro oncology this needs to be agreed between two sites. AV to speak to JC for agreement		
		Patient Self-management presentation By Linda Sharp		
		SH to Invite her again to next meeting.	**SH**	
		Patient and Carer		
		JG advised Northumbria patient group going well but looking to link up with other patient groups across the alliance. A number of Patient representatives currently working on the Cancer Alliance Involvement strategy policy.		
		Rehabilitation		
		Post meeting note; Request received to ensure Rehabilitation is added as a standard agenda item. CM to add.	**CM**	
	3.4	**Meeting dates**		
		Friday 3 May 2019, 9.00 -12.00 Evolve Business Centre **Friday 8 November 2019, 9.00 – 12.00 Evolve Business Centre**		
4.	**MEETING CLOSE**			

Contact Claire.mcneill@nhs.net tel 01138252976