

Yorkshire and the Humber Kidney Transplant Forum

Friday 15th May 2015, 0930-1300

Hatfeild Hall, Wakefield

NOTES

	AGENDA ITEMS	Action Owner
1.	<p>Welcome, Introductions, Overview & Discussion Dr John Stoves, Y&H Renal SCN Clinical Lead & Consultant Nephrologist, BTHFT</p> <p>Dr John Stoves welcomed all attendees to the forum and conducted introductions throughout the room. Dr Stoves advised the forum of the role of the SCN and its links into Specialised Commissioning. Dr Stoves also advised the forum that the SCN covers a number of disciplines and keenly encourages patient participation. Dr Stoves stated that the Renal Network is part of the wider CVD Network and is also participating actively in the CVD Prevention agenda.</p> <p>Dr Stoves then advised the forum of the priorities of the Renal Network and indicated that Transplant is one of the top three priorities for the Network.</p> <p>Discussion and Actions:</p> <p>Transplant Rates in Black and Ethnic Minorities (BAME) Dr Stoves updated the forum on work conducted across the region on increasing Transplant rates in Black and Ethnic Minorities (BAME). There was discussion at the previous forum about setting up a community-led project in West Yorkshire. Dr Stoves has visited Birmingham to learn from the Sadaqa Project and maintained communication with Mr Mukhtar Ali, Mr Nadeem Butt, the NBTA and NHSBT. Dr Stoves then invited Mr Mukhtar Ali to provide an update on the work he has undertaken in this area.</p> <p>Mr Ali advised the forum that he had arranged for an event to encourage organ donation in the BAME community, which will take place on 27th July 13:00-16:00 at the Trident Community Centre in Bradford. Mr Ali advised the forum that the purpose of the event was to raise awareness of the need for organ donation, to increase the number of organ donors (and subsequently transplants) in the BAME community. The event will include patient speakers and clinicians. Mr Ali advised that the event would be attended by faith communities who would be able to advise people that organ donation is not against faith. Mr Ali also advised that representatives from Latvian, Slovakian,</p>	

<p>Polish and Syrian communities would be attending. Dr Stoves has invited NBTA and NHSBT representatives to support the meeting.</p> <p><i>ACTION: For further information and to register an interest in attending please email Mr Ali directly on kingmaker786786@yahoo.co.uk.</i></p> <p>ATTOM Dr Stoves next provided the forum with a brief update on ATTOM (attitudes of patients to transplant listing). Dr Stoves summarised a qualitative study published in NDT, which revealed patient attitudes to the transplant listing process. A further study is due to be released in the next 12 months. Dr Baker commented that the ATTOM findings are now a little dated and there is a general view that communication with patients has improved considerably in the intervening period.</p> <p>Listing and Low Clearance Clinics The forum then briefly discussed the Leeds Low Clearance Clinic and the importance of the role of specialist nurses in listing patients and discussing transplants. Dr Richard Baker and Dr Matthew Wellberry-Smith reinforced the importance of the role of specialist nurses in this area for patients in Leeds. Dr Keith McCulloch advised that in York Hospital the nurses also hold a key role in the transplant process. Dr McCulloch stated that IT systems should be able to automatically list patients and Dr Stoves concurred stating that IT systems could have the capacity to do more. Dr Baker stated that learning could be taken from areas such as Conservative Care with regards to the Gold Standard Framework. The forum discussed the merits of conducting a regional audit on patients who had an eGFR less than 20 and did not have a recorded decision regarding transplant suitability and agreed that this would be a useful study. This information is already recorded for patients who start renal replacement therapy (as part of renal unit NHS England dashboard returns).</p> <p><i>ACTION: JS to identify who in the region may have the capacity to undertake an audit of patients with eGFR less than 20 who are not listed.</i></p> <p>Workforce The forum then briefly discussed regional staffing issues in terms of nursing staff and specialist nurses in Transplant. Julie Hill advised the forum that it was difficult to undertake listing and work up patients and it is better to have a clearly defined specialist role. Julie Hill also advised that there is an expectation that nursing staff are to provide support on other ward areas if needed. Dr Wellberry-Smith stated that he supported ring fenced posts for transplant nurses and the group discussed if there would be value in collating workforce information across the</p>	<p>All</p> <p>John Stoves to liaise with Lizzi Lindley</p>
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	<p>Guidelines for the Management of the Acutely Unwell Transplant Patient Dr Stoves explained that he was producing such guidelines in collaboration with Dr Mansoor Ali in Calderdale. It was noted that Dr Wellberry-Smith and Dr Baker had had previously written guidelines for acute physicians treating transplant patients and, though this required updating, it was agreed that this should be shared with the forum. It was also agreed that Dr Mansoor Ali could lead on producing a regional guideline.</p> <p><i>ACTION: MWS to share PDF version of guide for acute physicians treating transplant patients.</i></p> <p><i>ACTION: MA to incorporate the contents of the articles to produce a final guideline</i></p> <p>BK Screening This has been undertaken in Bradford following Dr Matt Edey's presentation at the last transplant forum. Dr Stoves explained that 3 cases had been identified, although in 2 cases this was in response to a change in serum creatinine rather than being part of routine screening. Dr Baker suggested that BK was put on the agenda for the next forum and that updates are sought from around the region on where people are up to with this work. Dr Kanaa advised the group that he would seek an update from Dr Will McKane on screening in Sheffield.</p> <p><i>ACTION: SB to put BK Screening Update on the agenda for the next forum.</i></p> <p><i>ACTION: MK to obtain update from Dr McKane on BK screening in Sheffield.</i></p> <p>Gain/Share The forum briefly discussed gain/share around transplantation drugs and in particular discussed Valganciclovir prophylaxis. Jackie Parr suggested that Dr Baker contact Paul McManus in specialised Commissioning to discuss ideas around gain/share and Valganciclovir.</p> <p><i>ACTION: SB to provide RB with contact details for Paul McManus.</i></p>	<p>Matthew Wellberry-Smith</p> <p>John Stoves Mansoor Ali</p> <p>Sarah Boul</p> <p>Muhammad Kanaa</p> <p>Sarah Boul</p>
<p>3.</p>	<p>Sharing Outcome Data Across the Region Dr John Stoves, Y&H Renal SCN Clinical Lead & Consultant Nephrologist, BTHFT</p> <p>Dr Stoves provided the group with a brief overview of the outcomes from patient satisfaction surveys undertaken in Bradford Teaching Hospitals. Dr Stoves was keen for the forum</p>	

	<p>to review the surveys, feedback on their usefulness and agree on a regional questionnaire. Please see the presentation slides for more information.</p> <p>Discussion and Actions:</p> <p><i>ACTION: SB to circulate the patient satisfaction surveys to the forum and collect feedback prior to the next meeting.</i></p> <p>Patient Transport The satisfaction surveys highlighted that there were issues with patient transport for transplant patients. It was noted that patients on dialysis received transport but once transplanted patients no longer received transport. However, Linda Pickering advised the forum that there is a charity that provides money for transplant patients to assist with transport costs and if anyone has patients in need of this service they can contact Linda directly for assistance.</p>	<p>Sarah Boul</p>
<p>4.</p>	<p>The Consent Model and Patient Pathway in Yorkshire and the Humber Dr Matthew Wellberry-Smith, Consultant Renal Physician, LTHFT</p> <p>Dr Wellberry-Smith provided the forum with an update on the work undertaken in Leeds around renal transplant listing and annual patient consent clinics. Please see the presentation for more information.</p> <p>Discussion and Actions: Following the presentation Dr Wellberry-Smith asked the forum to discuss what they had heard and provide feedback/ask questions.</p> <p>Patient Opt Out Clare Corps enquired why patients were offered the opportunity to opt out of attending the consent clinic, as Clare felt it was very important that patients should meet their surgeon and understand the procedure they are going to undergo. Jackie Parr concurred with Clare and stated that there is an individual responsibility on each patient to attend and understand what is going to occur, the surgery is a complex and life changing occurrence and patients need to understand what is going to happen.</p> <p>Dr Baker stated that he felt patients should have the option to be able to opt-out. Dr Wellberry-Smith commented that a variety of options should be available to patients. Dr Matthew Edey stated that he was supportive of the opt out but went on to suggest that it may be interesting to follow up those patients who opted out to see if their outcomes are similar or worse to those patients who</p>	

	<p>attended clinic. Dr Kanaa advised that in Sheffield all patients had to see a surgeon no opt out option was available.</p> <p>Julie Hill commented that the circumstances of dialysis patients should be considered in terms of an opt out option. Julie stated that patients who are dialysing several times a week may not wish to use a day when they are not dialysing to attend another clinic.</p> <p>Central vs Local Clinics Dr Tarun Bansal enquired if patients had to return to the consent clinic annually and Dr Wellberry-Smith advised yes. Dr Kanaa stated that for Sheffield patients had initial consent taken at Sheffield but for annual reviews these could be undertaken at the local hospitals such as Doncaster. The forum agreed that surgical consent clinics were needed but also discussed the benefits of surgeons providing outreach clinics as well as patients travelling to the centre for clinics. Julie Hill stated that these clinics should be about the patient and surgeons should be encouraged to consider patient perspectives on attending the clinic.</p> <p>Metrics Dr Wellberry-Smith advised that from his clinics suspension rates, requested tests and outcomes could be measured. He also stated that it would be useful to collect information as to whether living donor rates went up or down following attendance at these clinics.</p> <p>Dr Bansal enquired if a patient is suspended would he be informed. Dr Wellberry-Smith advised that a letter would be sent confirming the suspension.</p> <p>Donation Types Dr McCulloch enquired if patients were consented specifically on the types of kidneys they may receive. Dr Wellberry-Smith advised yes. The forum then discussed the different types of kidneys that could be used in transplantation such as heart beating, non heart beating etc. Julie Hill stated that it was extremely important for all healthcare professionals to carefully document the discussions held with patients around kidney types.</p> <p>Visiting the Consent Clinic Dr Baker stated that it would be beneficial to colleagues around the region if they had the opportunity to visit the consent clinic in Leeds to see how it operated. The forum agreed that this would be very welcome.</p>	
5.	<p>BTS, ATC and KPAG update Dr Richard Baker, Consultant Nephrologist, LTHFT</p>	

	<p>This item was deferred to the next Transplant Forum.</p> <p><i>ACTION: SB to ensure this item is on the next Transplant Forum agenda.</i></p>	Sarah Boul
6.	<p>Next Steps and Closing Remarks Dr Richard Baker, Consultant Nephrologist, LTHFT</p> <p>Dr Richard Baker closed the meeting remarking on the useful discussions and debate that had taken place throughout the meeting. Dr Baker thanked all speakers and attendees.</p>	
7.	<p>Any Other Business</p> <p>There were no matters of any other business arising.</p>	
8.	<p>Date of the Next Meeting</p> <p>The group agreed that another forum should be held in approximately 6 months times. Time, date and location are to be confirmed.</p> <p><i>ACTION: SB to liaise with JS for potential dates for the next Transplant Forum.</i></p>	Sarah Boul