

Yorkshire and the Humber Kidney Transplant Forum

Friday 7th November 2014

NOTES

Action
Owner

1. Welcome, Introductions, Overview & Discussion

Dr John Stoves, Y&H Renal SCN Clinical Lead & Consultant Nephrologist, BTHFT

John welcomed everyone to the forum and thanked all the patient representatives who were in attendance.

John provided the forum with an overview of the structure of the network and how renal priorities linked in to cardiac, stroke and diabetes. It was reiterated that transplant, and in particular access to renal transplantation, is one of the key priorities of the renal network.

It was noted that in each area in Yorkshire and the Humber a key person should be established to link with over renal priorities in primary care. John advised that for Bradford CCG the link person was Dr Beaini. Keith Kocinski advised the group that Yorkshire and Humber Commissioning Support Unit (CSU) were also making progress with establishing leads but that it was important to note that they may not always be clinical and that there is unlikely to be a GP lead for Renal. Dr Dave Border, York Hospitals, advised the forum that the York link person was standing for parliament which may cause a potential conflict of interest.

John also provided the forum with an overview of the national picture and advised the group that he can feedback any issues or concerns to Dr Richard Fluck, National Clinical Director.

An update followed on the key actions from the last Forum:

a) *Metrics*

There was an update on the development of a set of metrics for renal that are intended to provide a picture of the renal work programmes. The collection of a pre-emptive listing metric will soon be underway. John welcomed comments and ideas from members of the forum around how to develop metrics. Matt Welberry Smith also alluded to future collection of metrics relating to the proposed regional consent clinic in Leeds

b) *BAME Transplantation*

The patient representatives and campaigners from Bradford were invited to provide an update on their progress around encouraging an increase in live donors in the BAME community. Mohammed, Mukhtar and Nadeem advised that they had procured some free television time to promote

donations and the television networks have offered to provide this time again. There have also been campaigns in newspapers and on radio. The Urdu Times and Yorkshire Post have carried featured articles, others too. It was stated that there is still work to be done and it would be beneficial to have a Consultant, such as John, to appear on one of the television programmes to answer questions from patients. John praised the good work being undertaken and that he will provide continued support.

Mohammed advised that he has been in contact with a professional filmmaker regarding making a documentary about kidney care. John recommended seeking endorsement from the NBTA and NHS Blood and Transplant.

John congratulated Mohammed, Mukhtar and Nadeem on their hard work. John stated that patient stories are key to promoting these messages to the BAME community. He relayed discussions that took place in Solihull at a Sadaqa Project launch event supported by NBTA and the Department of Health. At this meeting, the importance of linking in with Imams to encourage donations was emphasised, also the role of the British Muslim Council.

John discussed the need to support the promotion of organ donation within BAME communities, involving all key stakeholders. He asked the forum for ideas for a regional gathering to promote donations, and mentioned initiatives in the North West . Richard Baker suggested that the forum link in as a “Northern region” to do an event utilising enthusiastic individuals and patients who would like to share their stories.

Action: We will continue to explore ways of establishing a sustainable programme to promote organ donation in the BAME community.

Action: Invite a lead from the North West to present at the next meeting.

c) *Harmonisation of Pathways*

It was also suggested that the Altruistic pathway requires promotion and the group discussed altruistic donors. Leeds have supported altruistic donation and that they link in with primary care to do some of the initial testing. Sheffield advised that they do not actively promote altruistic donations but do get altruistic donors coming forward.

Dr Richard Baker, Leeds Teaching Hospitals, informed the group of a DVD containing information on transplantation which has been developed for patients. Copies were made available to the group.

There was a discussion regarding evening clinics, particularly for live donors. Sheffield has evening sessions for live donors led by the live donor coordinators. Leeds has not yet established an evening clinic, but is interested in setting up some informal groups.

d) *Timely Listing*

The forum discussed the impact of BMI on transplantation. Leeds advised that they are considering BMI in light of individual body habitus.

All

**John
Stoves/
Rebecca
Campbell**

Sheffield advised that they have issues with obese donors and that obesity can be a barrier to the live donor scheme. Bradford advised that they are trying to do a weight management scheme to reduce the rejection rate of obese donors. The weight management service is being driven by enthusiasm in the dietetic team. However, it was acknowledged that weight management needs to be driven by primary care, as it is the responsibility of CCGs to commission tier 3 weight management programmes. It was mentioned that Bradford City Council is supporting community projects to help people lose weight by encouraging lunchtime walks and exercise groups.

York has a well-established patient driven exercise programme but it is generally not used by patients trying to lose weight for transplantation.

2. A Comparison of Cardiovascular Risk Assessment Tools for Patients Undergoing Work-Up for Kidney Transplantation

Dr Dave Border, Consultant Nephrologist, York Teaching Hospitals NHSFT

Dave presented provisional data and an early audit of work done in York Hospital. The audit was based on the use of the Newcastle cardiovascular score and included a comparison with the Leeds score, developed by Richard Baker and colleagues. There are questions regarding how well validated the Newcastle Score is and how appropriate it is for use.

Please see the presentation for more information.

Questions, Answers and Comments:

Question: What are the views on the findings?

Answer: This issue needs to be tackled nationally not regionally. It needs a large data set and research behind it to change behaviour, particularly of surgical colleagues.

Comment: Currently patients have to go through a lot of tests some of which are unnecessary and cause delays in the patient pathway. A simple screening test should be used rather than a very complicated route.

Comment: Myoview stress tests are used to varying degrees across the region. It is not used in Leeds & Hull due to waiting times. Exercise tolerance testing and stress echo are used instead. Doncaster currently has a waiting time of 6 months for Myoview.

Comment: There was a discussion regarding the use of stress echo versus Myoview. A stress echo is more likely to produce a definitive negative result.

Comment: If our tools don't detect the people we need to change our tools.

Question: If we were to change a scoring tool do we make it more physician based rather than surgeon based?

Comment: Surgeons are primarily responsible for perioperative mortality and are therefore likely to be more risk averse, although it was noted that mortality after transplant is incredibly low. It would be difficult to change the scoring tools based on this.

Comment: There is a piece of work to consider here. We could look at the group that get medium Newcastle scores and low Leeds scores and then see how they did post-transplant. This could be taken forward as a research paper by a registrar.

Comment: The general feeling around the region is that we over investigate patients.

Question: Do you screen to exclude?

Answer: No, we risk assess. For example, we could do an angiogram and it may show moderate heart disease. This patient could then be listed but we would then discuss with the patient that their mortality rate is higher.

Comment: It is difficult to assess immunological risk (relevant to both transplant rejection and early sepsis) alongside cardiovascular risk, although the latter is considered by the group to be significantly higher.

Question (to patient representatives): Do you think you get too many tests?

Answer: I was happy with having all the tests and think it should be offered to everyone.

Comment: Although there is limited money, it should be the patient's choice if they would like to have the tests done and go on the transplant list.

Comment: I would rather go with the hospital opinion.

Comment: Patients need to know the risk. The tests did cause an extended wait for me but if the tests are explained properly to patients then they understand why they are having tests or are having to wait. Communication is key and explaining why tests are being conducted is very important.

Comment: The group discussed CPEX (Cardio Pulmonary Exercise) testing and it was reported that Newcastle are using this test for medium risks, as are Manchester. York does not routinely run CPEX tests. It was noted that there is evidence of benefit in liver transplant but not evidence based for kidney transplantation.

Comment: It is good to share how we do things differently across the region.

Comment: The region needs to put in place a risk stratification score, but the detail behind this is very difficult.

Comment: We could use BHLY and agree a risk stratification tool.

Action: CPEX - no strong views were expressed about the additional value of CPEX. John Stoves to have a conversation with the KP transplant team in Manchester (one of the anaesthetists) and share any feedback. ATTOM opinion survey pending.

**John
Stoves**

Patient Perspectives: Questions & Discussion

Linda Pickering from the National Kidney Federation raised a few issues that she had received from patients.

a) *Leeds Transplant Ward*

Linda read an email from Paul Taylor, Secretary of West Riding Kidney Patients Association, regarding the fact that there is no specific transplant ward at Leeds. Patients, and nursing staff, feel strongly that there should be a specific transplant ward. Linda asked the forum if there was anything that could be done to influence this.

Comment: The forum agreed with the sentiment in the email but it was stressed that transplant patients currently take priority for beds over other patients with renal conditions. A transplant, deceased or live, has never yet been turned down. There are many other departments in the Trust with the same problem.

Comment: Sheffield does not have a dedicated renal transplant beds, there were two bays, but not anymore.

The forum advised that they would prefer to have more beds and side rooms for transplant patients.

Comment: The forum discussed the impact of infections on transplant patients and considered whether a study of c-diff rates may impact the necessity to have a separate ward. Mike May fed back to the forum that as a Leeds transplant patient it caused him concern to be on a general renal ward following transplant with patients who were vomiting etc. and then having to share a bathroom with them. It was felt by the patient representatives that following transplant surgery and with increased infection risk it would be preferable to have a private room with private bathroom or a transplant specific area for their recovery period.

Question: Do you cohort the patients at Leeds?

Answer: No. All patients are mixed up.

Comment: We as a forum would support a transplant ward. This is an aspiration.

Comment: We do get very good feedback from patients on experience at Leeds though.

Comment: There has been no negative feedback on the experience of York patients in Leeds.

Action: The forum gave an expression of support for a dedicated transplant facility at St James's. John Stoves will speak to Emma Dunn about this when they meet later in the month.

**John
Stoves**

b) *Policy for managing post-transplant patients presenting at Hospital*

Linda asked the forum for views on the implementation of a national policy for post-transplant patients to be admitted straight to a renal ward rather

than waiting in MAU, A&E etc.

Comment: There are three scenarios: i) Patient presents back at the centre where the transplant was carried out, in which case the transplant team will see the patient; ii) Patient presents at a hospital with a renal centre, in which case the renal team are likely to be consulted and admit the patient; iii) Patient presents at a district General Hospital with no renal centre, this would make admission more complicated.

Comment: If you are a transplant patient with a transplant problem you will get fast tracked and admitted to the renal bed base, if the patient presents at the transplanting centre. If you are a transplant patient with another problem you would be admitted to the relevant area.

Claire Corps, kidney & liver transplant patient, advised the forum that she had recently had a negative patient experience. Claire had experienced an issue with a small bowel obstruction causing vomiting and was sent to a hospital away from base. Claire had to ask for extra fluids and manage her own condition and despite asking for contact to be made with Leeds hospital this was not done. Claire felt that this breakdown in agreement/communication should be investigated.

Comment: The agreement between renal staff and other teams in all of the regions hospitals will be reviewed.

Question: Is there anything in place for non renal wards about fluid management? For example, as a transplant patient on a non renal ward I was not given a drink pre-operation and was left without fluids for 15 hours.
Answer: This is just basic good care not happening, and patients should feel able to alert staff directly in such circumstances.

Comment: Sheffield have agreements in place with the big specialities to advise when they have a transplant patient on the ward. However, it cannot be said that it happens in all specialities. The onus is on the patient to call the renal unit to say they have been admitted.

Comment: Patients know their condition and often get in touch with their own renal unit.

Comment: Rotations of junior doctors makes it difficult to get the messages across.

Comment: We need to educate the patients and the ward.

Comment: Patients are not confident to challenge doctors and nurses and this needs to change.

Action: With regards to information for acute medical/surgical teams looking after renal transplant patients in hospital and in the community, John will circulate a draft document that has been developed with Mansoor Ali for comment.

**John
Stoves**

c) *The Times*

Linda advised the forum each read page 31 of today's Times newspaper for a relevant article about commissioning of renal services.

3. Surveillance Strategies to Detect and Treat Post Transplant CMV and Polyoma Virus Infection

Dr Matthew Edey, Consultant Nephrologist, Hull & East Yorkshire NHS Trust

Please see the presentation notes for more information.

Questions, Answers and Comments:

Question: Very interesting presentation and a different process from Sheffield. Which CMV prophylaxis are you using?

Answer: 100 days

Comment: We have received a letter from NHS England which states that treatment is not supported over 100 days.

Answer: Leeds are considering switching to CMV screening but this cannot be run on the current staff and would require two more nurses. It would save money.

Comment: 10-12% generally relapses. Screening would be better but it currently isn't possible. It could save £100K.

Question: We try to audit the CMV rate each year. Can you predict when CMV may occur after stopping prophylaxis?

Answer: No, the audits show it could happen whenever.

Question: Can BHLY prompt you to test for BK virus at present?

Answer: No, this has been done with test schedules for HD patients and a similar arrangement for BK screening will be explored.

Comment: Cases are still missed because there is not an absolutely robust recall system.

Comment: Everyone in the area should screen at 1, 2 and 6 months but then with a reset if their levels are low. Regional consensus on testing could be met. Audit shows impressive results so we should take it forward as a forum.

Action: The forum endorsed a regional 1, 2 and 6 months post-transplant polyomavirus screening strategy (and after escalating treatment for episodes of acute rejection) - blood PCR, 1000 copies/mL as a threshold for considering intervention. John Stoves will explore the potential for a surveillance prompting system within BHLY.

**John
Stoves/
All**

4. Progress with the Consent Model for Potential Transplant Recipients in Leeds

Dr Matthew Wellberry-Smith, Leeds Teaching Hospitals NHS Trust

Guidance states that the consent of the potential transplant recipient should be obtained at three points:

- At listing

- At transplantation
- Annually whilst on waiting list

The presentation focused on the process for obtaining consent annually. Matthew advised the forum that the purpose of his presentation was to provoke discussion; it was not to present a “final model” for patient consent.

Matthew clarified that waiting list patients at York, Hull and Bradford are usually seen and reviewed but not always. Sheffield does see waiting list patients for review of consent. Surgical consent has been deferred to 3 yearly but patients will be reviewed face to face by a nephrologist annually.

Matthew stated that for patient consent a regional pathway would provide consistency of experience for patients.

Please see the presentation notes for more information.

Questions, Answers and Comments:

Question: Would it be possible for surgeons to come out to local units as an out-reach service to gain patient consent?

Answer: Surgical colleagues have said that will take too much time in which they might otherwise be treating patients. Also it is good for the patients to come to the unit to see where they might have the transplant, as a dummy run. When people do come for transplant it is a better experience if they have previously seen where they are going to be treated.

Comment: Sheffield has considered sending surgeons to Doncaster. It might be worth running both models and see what works best for patients. Sheffield are driving out-reach services and Doncaster are keen on doing more.

Question: What if the patient does not want to come to follow up consent conversations? If nothing has changed why do they have to come, and if they do not attend will they be removed from the list?

Answer: That is difficult to answer. There is a valid argument that the nephrologist knows the patient best, but this is not always the case if the service does not operate a named consultant model. Also at the opposite end of the spectrum is the, not uncommon, case of a patient presenting in the middle of the night with changes that were not known. This has considerable implications.

Comment: The forum debated that patients who have been 3-4 years on the transplant list might not want to come to Leeds. However, patient representatives stated that the annual meetings made them feel like they were still involved in the process.

Question: Could a Nephrologist decide who can come along or not?

Comment: It is the surgical consent which is causing the issue.

Comment: Discussing the expectations around transplant with patients is

very important. With live donation, the recipient often knows very little about the risk.

Question: Could you do group sessions?

Answer: No. You need to do 1-1 sessions.

Comment: We should involve staff from other units in running the consent clinic and give feedback.

Comment: Centralisation could de-skill DGH staff. Annual reviews should be done locally.

Comment: We are in agreement that reviews should be done locally and then the results go to the central unit. The annual consent could perhaps be done locally but the first consent meeting should be in the centre.

Comment: At the first appointments patients should be given all the information about transplant so they can make an informed decision rather than waiting until the second or third appointment to be given this information.

Comment: In Leeds we have specialist nurses that have this conversation, they link in with one patient and then the nurses give information at the listing point. They give all the information. Annual review is helpful as it makes patients feel like they are still involved and not forgotten about.

Comment: First consent needs to be in central unit and then further consideration regarding what to do about annual review.

Action: The group endorsed a regional consent clinic for potential transplant recipients in Leeds, York, Hull and Bradford, with IT support from new functionality in BHLY. John will raise this with Sara Eastwood. Matt and Richard will oversee this and lead on setting guidance for work-up investigations (ATTOM study recommendations pending).

**Matt
Wellberry
Smith/
Richard
Baker**

5. Next Steps, the Next Meeting and Closing Remarks

Dr John Stoves

Renal Clinical Lead, Yorkshire and the Humber Strategic Clinical Network

John thanked everyone for attending.

The group were reminded to share topics to discuss at any upcoming forums to ensure the content is relevant and fresh.

John raised patient experience surveys with the forum. John stated that he would like to pool resources on patient satisfaction surveys to design a new survey that could be sent out by each unit.

Action: With regards to Patient satisfaction surveys, John agreed to forward 4 transplant-related surveys from Bradford and requested that the rest of the group please share any other resources that are used to obtain

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patient feedback and this will then be collated and discussed at the next meeting.

John advised the forum that Rebecca Campbell, Sarah Boul and John would summarise the points made at the forum and would circulate along with potential dates for the next forum. It was agreed that the forum would meet every 6 months.

Action: Rebecca Campbell, Sarah Boul and John Stoves to summarise notes and circulate to the group along with dates for the next meeting.

Date of the next meeting: Friday 15th May, 0930-1300, Hatfeild Hall, Wakefield.

**John
Stoves/
Rebecca
Campbell/
Sarah
Boul**

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