Yorkshire and the Humber Strategic Clinical Networks

Yorkshire and the Humber Renal Clinical Expert Group
Monday 15th December 2014, Hatfeild Hall, Normanton Golf Club, Wakefield, WF3 4JP

Present:	
Sarah Boul (SB)	Quality Improvement Lead, Y&H SCN
Rebecca Campbell (RC)	Quality Improvement Manager, Y&H SCN
Emma Dunn (ED)	Clinical Lead, Leeds Teaching Hospitals NHS Trust (LTHT)
Sarah Jenkins (SJ)	Nephrologist, Sheffield Teaching Hospitals NHS Trust (STHT)
Paul Laboi (PL)	Consultant Nephrologist, York Hospitals NHS FT
Andrew Lee (AL)	Public Health Consultant, Public Health England
Elizabeth Lindley (EL)	Clinical Scientist, LTHT
Jackie Parr (JP)	Specialised Commissioning - Service Specialist, NHS England
John Stoves (Chair) (JS)	Consultant Nephrologist, Bradford Teaching Hospitals NHS Trust, & Renal Clinical Lead for Yorkshire & the Humber Strategic Clinical Network (Y&H SCN)
Paul Taylor (PT)	Patient (WRKPA)
Apologies:	
Oli Anderson	Patient (Bradford)
Dave Border	Clinical Lead, York Hospitals NHS Foundation Trust
Helen Collinson	Consultant Nephrologist, Hull & East Yorks Hospital NHS Trust
Bev Craggs	Renal Matron, Leeds Teaching Hospitals NHS Trust
Andy Henwood	Patient (York)
Melinda Howard	Nurse Manager, York Hospitals NHS Foundation Trust
Chis Lacey	Renal Dialysis Matron, Bradford Teaching Hospitals NHS Trust
Will McKane	Consultant Nephrologist, STHT, YH Representative Dialysis Clinical Reference Group (CRG)
Sarah Naudeer	Clinical Lead, Hull & East Yorks Hospital NHS Trust
Chas Newstead	Consultant Nephrologist, LTHT, Chair Dialysis CRG, YH Representative Transplant CRG
Linda Pickering	Patient Advocacy Officer, National Kidney Federation
Russell Roberts	Clinical Lead, Bradford Teaching Hospitals NHS Trust
Ian Stott	Clinical Lead, Doncaster & Bassetlaw NHS Trust

	AGENDA ITEMS	Action
1.	**Minutes from last meeting 22nd September 2014** JS enquired if there were any corrections required to the minutes from the last meeting. The group responded no and the minutes were agreed as an accurate record. The group reviewed the actions from the last meeting: *Transplant Tariff* – Spreadsheet: JS advised the group that he had asked for an update on the pricing data information and templates that had been received from Paul Fenlon. JS has shared the latest version with the group and received feedback. JS has now been advised that another set of templates would be circulated. JS has been chasing these and will share when they are received. ACTION: JS to share transplant pricing templates etc. when received. JS also advised the group about patient feedback from the Transplant Forum regarding a cohort of beds for transplanted patients at Leeds. ED advised that she has been pursuing this with the Trust. JS reiterated that there was regional support had been confirmed at the Forum. *PD Procurement*: JS advised the group that Richard Fluck is involved in the national PD procurement strategy but Nesta Hawker is the lead. SJ reported that some information on this has recently been circulated. *Consumable / Procurement QI Work*: This issue was raised by Sarah Naudeer at the last meeting and the main concern highlighted was an insufficient number of cases of vasculitis in some centres and so patients are now to be referred to one of three main centres in the Yorkshire and Humber region. Renal teams have not been actively involved in the vasculitis discussions and the new service specifications are still being negotiated. JS has seen a draft document and SJ/ED asked for this to be shared. ACTION: JS/ RC to circulate a link to the information on vasculitis. JP advised the group that she will be meeting with Tim Tait who works in Rheumatology at STH and also sits on the Rheumatology CRG. The purpose of the meeting will be to define appropriate networks for this speciality. There will be a focus on providing local services for local people but where cases cannot be managed by a capable local team they will need to be referred to one of the three centres. SJ asked that JP remind people that specialities such as Renal, ENT etc. deal directly with vasculitis and they should be involved in discussions where appropriate. JS commented that rheumatology teams have been asked to assess their links with other specialties as part of the service specification and this should include Nephrology. *IV Iron*: Sarah Naudeer raised this issue at the last meeting and agreed to share the	**John Stoves** **Rebecca Campbell**

	Hull documentation when it had been agreed by the Trust. ED stated that for Leeds patients current IV iron patients can sign a disclaimer to continue receiving IV iron at home but new patients are not allowed IV iron at home. PT expressed issues with equity of access with this approach and enquired what the rationale behind this decision was. ED stated that the decision was taken based on national guidance around patient safety. PT stated that this was still inequitable to patients. JS stated that Helen Collinson had taken a similar approach in preparing the Hull guidance. SJ advised that STH have developed an in house disclaimer. JS enquired if there was appetite for a regional approach to this. The group advised yes. JS to work with Helen Collinson to develop a regional document for sharing. ACTION: JS asked all Clinical Leads to share their policies and disclaimers so a regional document could be developed. *Sustainability Report*: JS advised that in Bradford there was linkage with a consultancy firm to look at sustainability and procurement in Bradford Teaching Hospitals. Renal services are a relatively large consumer is a big consumer of resource within the NHS and therefore an appropriate starting point for establishing sustainable working practices. JS and MDT colleagues at Bradford Hospital have worked with the consultancy firm for one day on the renal unit and other dates are scheduled. JS will share the sustainability report when it is completed. ACTION: JS to share Bradford report when it is available.	**All Clinical Leads** **John Stoves**
2.	**Patient Updates** JS advised the group that Linda Pickering had forwarded four issues/updates for the group to consider. JS read these out to the group and they are replicated below along with subsequent comments from the group: **Transport:** Pleased to report back on the York transport problems. A meeting was held and YAS did turn up this time, lots of progress was made. Regular meeting dates have been set up with the patient rep, a dialysis patient, attending. I am pleased to say I have had no irate patient phone calls from York since we set the meetings up. Mike May HKPA Chair and I also attended a meeting with YAS at Willerby to discuss patient transport problems for patients attending the Hull unit. Mike will be keeping an eye on this with NKF help if needed. **Comments:** PT stated that Huddersfield CCG has a questionnaire online regarding transport for West Yorkshire and will subsequently have a meeting about this. PT will attend and feedback to the group. JS enquired of PT how development of the GPS app was going. PT stated that a funding bid has been completed and a “Devices for Dignity” funding group	

	was held and a poster display was made. Sarah Fatchett, who is taking this forward, is working with patients and trusts. The only issue currently is WIFI access for patients but it is hoped that renal units will put WIFI in. JS asked if the app had been piloted anywhere else. PT stated no and that the Leeds twilight shift will be the pilot. **CCG Dialysis Commissioning:** As NKF Advocacy for this area LP has contacted all CCG's in Yorkshire and the Humber for information about the changes to commissioning of this service, so far 11 have got back to with varied replies, one of which has been sent to RC. Both the NKF and BKPA has serious concerns about the decision to change the status of dialysis commissioning and about the process adopted for introducing this change, we believe it to be hurried and without proper consultation, nor have we seen any sound reasons to support this change. We are now requesting a delay to any decisions and an urgent meeting with NHS England. The consultation has 4 weeks left to run. **Dialysis Away From Base (DAFB):** LP requested information once again from Nesta Hawker about the consultation on this policy and once again is told it is imminent. **Reimbursement for Home Patients:** LP has been working on this for 2 years and the NKF have sent a letter to the Dialysis Clinical Reference Group asking that the 1974 guidelines are updated and that Trusts are reminded to look at their calculations for payments to patients as it is felt this is a barrier for some to home treatments. **Comments:** JS stated that there needs to be clear consistent guidelines and all guidance needs updating so patients are correctly reimbursed. There should be no financial disincentives for patients who wish to have treatment at home. PT stated that Linda Pickering had covered the necessary points in her letter and advised that nothing had been heard back in terms of a response as yet. PT advised the group of his experience of home dialysis and issues with reimbursement. SJ advised the group that she is currently reviewing the North Staffs model on home reimbursement to see if it is a model that would work for Sheffield. ED/JS asked for this to be forwarded so she could also review it for patients in other centres. ACTION: SJ to share North Staffs model with Clinical Leads and RC. **Other Issues Raised:** SJ advised that she currently has two patients who have had transplants but are now back on home haemodialysis and want to continue receiving care under STH. Unfortunately STH are struggling to support this as the area in which these patients live is no longer covered by STH and patients are upset about this. SJ stated that it was very difficult to send STH staff to the other side of Yorkshire; it is hard to balance patient choice over resources and equity. SJ also stated that STH are concerned about the quality of care they are providing to patients who live so far away if they are only going to visit them once every	**Sarah Jenkins**

	six weeks. JP stated that there is no simple answer to this situation as there are issues for both patients and services. JP enquired if STH could be the main provider but contract out to another local provider who could give the necessary service to the patient. SJ enquired how this would affect tariff. JP stated that a small fee would have to be paid to the contractor but other costs would stay as tariff. ED stated that the key issue was that the patient wanted to see the STH clinical team not another team. PT agreed and stated that the patient would want to maintain current relationships and rapport. Andrew Lee enquired if telemedicine could be used in this situation. SJ stated that a physical presence was required. The group agreed that any solutions required compromise and this situation required reflection.	
3.	**Metrics** JS provided an overview to the group of the high level metrics that have been decided upon for collection as a region. JS also stated that there is work being undertaken on a regional CVD dashboard which will include renal metrics. The key areas for regional renal metrics are: • AKI stage 3 reporting (for the 14 Trusts across the region) • Shared haemodialysis care (for all main and satellite dialysis facilities in the region) • Pre-emptive transplant listing (for the 6 renal centres in the region) **AKI Stage 3 Reporting:** JS stated that there are issues around how to collect these data across the region especially with regards to AKI community acquired versus AKI hospital acquired. JS stated that work is being undertaken to produce an agreed simple data reporting toolkit for the region. One issue is the categorisation of 'community-acquired' and 'hospital-acquired' AKI. This could be done by location or time since admission, the choice being mainly dependent on which is most feasible. JS advised the group that Leeds, Bradford and Calderdale were working on a project around data collection and that progress with this will be presented at the AKI forum on 13th Feb 2015. **Shared Haemodialysis Care:** The Shared Care metrics are based on the information that should be inputted to the regional shared care website. JS stated that the website is not currently being updated and asked the group to ensure that updates were made on a 6 monthly basis. ACTION: All in the group to encourage shared care website to be updated. **Andrew Lee Presentation:** AL advised that there is a wealth of data for renal services and that the approach to data collection and analysis was very positive. AL reiterated that renal metrics would be used to provide a strategic overview rather than be used to monitor performance.	**All Clinical Leads**

	Please see the presentation for further details. **Discussion/Questions:** SJ enquired if the data discussed were the same data as currently collected for the CVD dashboard. RC advised yes and stated that it is intended that areas only have to provide the information once. JS enquired how the data would be analysed and fed back. AL stated that this information is not a public document and is only intended for use by the strategy group and CEGs. AL stated that it is for RC to identify trends or anomalies and highlight to JS. AL stated that he is interested in the AKI work being undertaken by the hospital trusts with regards to community care.	
4.	**Dialysis Capacity Survey** RC thanked everyone for returning the survey. RC stated that regionally there has not been much variation over last 4 years. There has been an increase in the number of patients on dialysis across the region but the number of stations has remained the same. In addition, RC stated that the trend lines indicate an increase in the number of patients on home dialysis, but that there has been a decrease in PD patients. EL concurred with this and stated PD numbers are dropping. ED stated that the drop in PD is due to increase in pre-emptive listing for transplant. SJ agreed. SJ reported STH have seen a big increase in patients for dialysis and have seen more patients coming off transplant. ED stated Leeds is also seeing more patients but they have capacity to manage the demand currently. EL stated that due to pre-emptive listing that for a period there will be an increase in patients on HHD as there are less patient leaving HHD. JS noted a similar pattern of increase in HD and drop in PD numbers in Bradford, with some work being done to promote acute PD and shorten the pathway for PD preparation. SJ reported that having a change in staffing on the ward has led to an increase in patient choice, as the presence of a consultant leads to better choice. JS enquired if information was collected on self-care. RC stated no but that this could be included next year. SJ discussed the potential effect on service provision with a transition to CCG-based commissioning.	
5.	**National Clinical Director & Specialised Commissioning Update** JS advised the group that he had received a general update from Richard Fluck. JS read the update to the group and highlighted that it referred to - the Five Year Forward View (a focus on prevention) - changes to QOF, which will have a significant impact on collection of primary care CKD data - NICE guidelines have been updated including an update on anaemia and it was agreed that these updates would be circulated to the group	

	ACTION: RC to circulate NICE updates. JS advised that AKI quality standards are currently on hold. JS also stated that an AKI CQUIN based on the Derby AKI CQUIN is being developed and has the potential to become a national CQUIN. JP advised that this is a CQUIN for GPs not specialised commissioning. JP advised that Nesta Hawker has recently sent an email to each CCG requesting interest in the CQUIN. JS had previously forwarded a slide from Nick Selby regarding the same to members of the regional AKI forum. JS also advised that the AKI tariff was discussed on 1st October 2014 and agreement on the tariff was deferred and new guidelines are now out for consultation. It was requested by the group that these were circulated. ACTION: RC to circulate a link to the new AKI guidelines. JS also advised that the "Think Kidneys" website, part of the AKI workstream, had been launched. https://www.thinkkidneys.nhs.uk/ JS lastly advised that the update referred to the pricing methodology for transplant as discussed earlier in the meeting and provided some information on secondary care prescribing of post-transplant drugs.	**Rebecca Campbell** **Rebecca Campbell**
6.	**Dialysis Commissioning Consultation** The consultations can be accessed at the following link: https://www.gov.uk/government/consultations/transferring-services-from-nhs-england-to-ccgs JS reviewed the issues raised by Linda Pickering in the patient updates section of the meeting. JS stated that all parties felt that this change in commissioning is being carried out too quickly and sufficient consideration of any potential negative consequences. JS advised that CCG commissioning was considered by the NHS England alongside a piece of work on the commissioning of morbid obesity and it was concluded that both services could proceed to consultation. JS advised that Richard Fluck and the NKF have responded to the consultation and encouraged all clinical leads and managers to also write a response. JP stated that a positive outcome of the work being commissioned by CCGs rather than Specialised Commissioning would be to engage CCGs with the prevention process. JP stated that there are a range of arguments for and against moving the commissioning of dialysis and stated that if the commissioning is moved to CCGs it would have to be co-commissioned or CCGs would have to work via consortia as the potential risk to individual CCGs would be too great. SJ stated that they had been advised that dialysis would be commissioned by individual CCGs. JP stated that this would not work. All in the group agreed that there were major issues with the process and that this change in commissioning could pose a threat to patent safety and patient choice. PL asked how this should be highlighted. JP stated that all clinical	

	leaders needed to feedback on the patient risk. PT stated that patients are responding to the consultation but back up from senior clinicians is also very important. AL suggested passing this issue to the Clinical Senate for review and opinion. SJ raised that due process may not have been followed as the dialysis CRG has not been consulted. SJ has drafted a response to the consultation and offered to share this with the group. ACTION: SJ to share the draft response. AL enquired of the group what the plan was for March 2015 if issues raised via the consultation are not addressed. PL stated that people should write to MPs or potentially raise a legal challenge to the way in which the review has been conducted. JP recommended that PL speaks to his corporate team and ask them to check that the right consultation criteria have been applied to the process. If due process has not been correctly followed then a legal challenge could be justifiably raised.	**Sarah Jenkins**
7.	**Vascular – Presentation** **Paul Laboi, Consultant Nephrologist, York Teaching Hospitals NHS FT** PL advised the group that the corporate team at York took on the vascular problem and worked together with vascular surgeons to improve vascular access for renal patients. The purpose of the work was to ensure that patients had access to the vascular surgeons' lists. An access co-ordinator has been appointed and improvements to the process subsequently made. The access co-ordinator speaks on behalf of the nephrologists. She has direct access to lists etc. Teaching sessions to help prevent early fistula failure are also improving patient care. Please see the presentations notes for further details. **Discussion/Questions:** JS enquired if the responsibilities of the access coordinator had developed over time or whether they had been agreed in advance of her appointment. PL stated that a conscious decision was made to let the access coordinator lead the meeting. The access coordinator advises prior to the meeting who is waiting and then at the meeting arrangements for treatment are agreed. JS enquired if this way of working was limited to York-based patients. PL stated yes and advised that this may change with the acquisition of Scarborough but this is work in progress. JS enquired if turnover provides an access problem. PL stated not really and that the main issues were caused by "crash landers". JS enquired if York has an effective vascular access salvage pathway? PL stated yes and advised that this would improve further as space at York increases. Increased space may also lead to general nephrology clinics also being held. JS enquired if York would be affected by the centralisation of vascular	

	services. PL stated yes and that the impact would be very significant.	
8.	Any Other Business - Health Foundation Scaling Up This item was not discussed and will be deferred to the next meeting.	
	ITEMS FOR INFORMATION:	
	Future Meetings: Monday 23rd March 2015 Monday 22nd June 2015 Monday 21st September 2015 Monday 14 December 2015 All meetings 0915-1115 at Hatfeild Hall, Wakefield.	