Yorkshire and the Humber Strategic Clinical Networks

Yorkshire and the Humber Renal Clinical Expert Group
Monday 23rd March 2015, Hatfeild Hall, Normanton Golf Club, Wakefield, WF3 4JP

Present:	
Youseff Beaini (YB)	CVD Lead and Regional GP Advisor
Dave Border (DB)	Clinical Lead, York Hospitals NHS Foundation Trust
Sarah Boul (SB)	Quality Improvement Lead, Y&H SCN
Rebecca Campbell (RC)	Quality Improvement Manager, Y&H SCN
Melinda Howard (MH)	Nurse Manager, York Hospitals NHS Foundation Trust
Sarah Jenkins (SJ)	Nephrologist, Sheffield Teaching Hospitals NHS Trust (STHT)
Elizabeth Lindley (EL)	Clinical Scientist, LTHT
Jackie Parr (JP)	Specialised Commissioning - Service Specialist, NHS England
Linda Pickering (LP)	Patient Advocacy Officer, National Kidney Federation
John Stoves (Chair) (JS)	Consultant Nephrologist, Bradford Teaching Hospitals NHS Trust, & Renal Clinical Lead for Yorkshire & the Humber Strategic Clinical Network (Y&H SCN)
Apologies:	
Helen Collinson	Consultant Nephrologist, Hull & East Yorks Hospital NHS Trust
Martin Chanayireh	Consultant Nephrologist, Hull & East Yorks Hospital NHS Trust
Emma Dunn (ED)	Clinical Lead, Leeds Teaching Hospitals NHS Trust (LTHT)
Russell Roberts	Clinical Lead, Bradford Teaching Hospitals NHS Trust
Ian Stott	Clinical Lead, Doncaster & Bassetlaw NHS Trust
Paul Taylor	Patient (WRKPA)

AGENDA ITEMS		Action
2.	**Minutes from last meeting 15th December 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 then reviewed the actions from the last meeting: *a. Transplant Tariff* To be covered in Item 7. *b. IV Iron Policies* EL enquired of the group if patients were allowed to start IV iron at home. SJ and JS advised the group that the decision to allow patients to start IV iron at home was a trust by trust decision. SJ advised that Sheffield Teaching Hospitals are allowing patients to have IV iron at home provided that they sign a waiver to do so. It was agreed that all Clinical Leads would share their IV Iron documentation. ***ACTION: All Clinical Leads to share their IV Iron documentation.***	**All**
	c. Reimbursement for home dialysis JS advised that LP had raised this issue with the group and this was now being investigated by the BRS. SJ had access to a document from North Staffs regarding reimbursement that she intends to share with the group once permission from North Staffs to share has been obtained. ***ACTION: SJ to follow up permission to share the North Staffs documentation and, once permission is obtained, share with the group.***	**Sarah Jenkins**
	d. Metrics for regional dashboard JS reminded the group of the metrics which had been agreed for collection across the region. JS stated that three metrics would be collected and these have been agreed by Graham Venables, Clinical Director of the SCN and Julia Jessop, CVD Network Manager. JS also advised the group that SB would be taking a role in collecting the data on a regional level. The intention of the data collection is to provide an overview of activity in the region, share information and assist in identifying trends and best practice. JS advised that the first agreed metric is pre-emptive listing for renal transplantation. From a Renal Registry perspective, EL enquired if the data collected would include re-transplants and JS confirmed that all re-listed patients would be included. SJ stated that currently data indicates a growing trend but it does not reflect that there is approximately a seven to one work up rate. SJ advised that it is difficult to capture the level of work that goes into pre-emptive transplant. EL concurred with SJ. JS suggested that activity data from the proposed transplant currency codes could be used as a balance measure. EL advised that BHLY figures would also need to be included here. JS advised that the second metric is based on Shared Care and the data would be extracted from the regional Shared Care website. SJ enquired what the Shared Care metrics were. JS advised that they were as follows: percentage of patients who currently undertake at least 5 aspects of their Shared Care (this will include HHD / self care units); percentage of patients who have been asked whether they would like to participate in their Shared Care; percentage of patients who would recommend Shared Care to another	

	patient. This data is available on the regional website but are not up to date. EL advised that the Renal Registry were considering collecting data on Shared Care but as yet have not made a decision on this. JS advised that the third metric is based on Stage 3 incidence of AKI, which will be collected as a snapshot. JS stated that he had attended a recent meeting in Calderdale to discuss how different LIMS will process this data. The main focus of the data extraction will be on AKI incidence in a hospital location, which can then be broken down to differentiate between community or hospital-acquired by looking at 'front door' locations (A&E, MAU etc). Hotspots in the hospital can also be identified so that education can be targeted appropriately. JS advised that the work undertaken by Calderdale and Bradford will be presented at the next AKI forum. ***ACTION: John Stoves to present the work undertaken by Calderdale and Bradford at the next AKI Forum.*** SJ advised that Sheffield are presenting live data and are undertaking a programme of education. JS enquired if this was already highlighting hotspots. SJ advised yes and stated that there is an expectation that, following education, coding of AKI should increase as staff should be recognising it more easily. SJ advised that the coding data is very complex and is requiring a significant amount of extra work. SJ also advised that their data currently is checked via a clinical scientist. JS enquired if a member of the laboratory team at Sheffield could attend the next AKI Forum and help to produce a flow chart of the current data collection process at Sheffield. SJ stated yes to both questions. ***ACTION: SJ to enquire if a member of the laboratory team can attend the next AKI Forum and help to produce a flow chart of how AKI incidence data can be collected.*** JS enquired if DB was collecting AKI incidence data also. DB advised yes in York but currently work was still to be done on this on the Scarborough site, as Scarborough are currently on a different system to York. DB advised that Dr Donald Richardson and Sally Slack are working on the data collection of AKI incidence as a project. JS stated that the metrics will be collected every six months and intention of the regional dashboard is to collect headline data and share best practice based on the metrics. JS stated that he would like to present a copy of the regional dashboard at the meeting in June. ***ACTION: SB to ensure an update of the regional dashboard is prepared for the June meeting.***	**John Stoves** **Sarah Jenkins** **Sarah Boul**
3.	**Patient and NKF Updates** LP advised the group that she had received an update on reimbursement. LP stated that she had been contacted by Karen Jenkins, a Nurse Consultant from Canterbury and Vice-President at the BRS. Karen will be investigating the reimbursement situation and will feedback her findings around Easter. LP stated that she was very pleased that the reimbursement issue is being investigated but is concerned that the investigation is not including APD patients. Recently LP has been contacted by two patients on APD who have been struggling to pay their electricity bills and has therefore asked Karen Jenkins to consider APD patients also. JS enquired if the different machines	

	had different power consumption. LP advised yes. LP enquired of DB regarding staffing levels in York. DB advised a letter had been sent to patients to apologise for the delays they are currently experiencing and outlined that changes to the service may have to take place. DB stated that he and the team have identified 14 areas that could be improved and that they are looking at ways to implement these improvements. DB advised LP that currently there are simply not enough staff members. MH advised that there are staffing issues in York in all wards and that for renal they are currently trying to recruit via a dialysis agency and are considering internal staffing levels. LP also enquired about transport issues in York. MH advised that James Larkin is leading on this issue for patients and progress is beginning to be made on this. MH also stated that John Hague from York CCG is also taking part in trying to improve patient transport and a series of transport trials are being tested out in a bid to improve the situation. LP advised that currently Hull are looking at zoning patients and stated that she could not feedback on patient transport issues in Leeds as Paul Taylor leads on this. LP also advised the group that it was the KPA AGM this weekend and that it would be held in Birmingham. The group discussed staffing issues. JS stated that the regional renal nurses course used to create more staffing interest and training. MH advised that the closure of the course was raised as a risk, as people now do not get the exposure or training that they used to. MH advised the group that she is reviewing how the course can be reinstated and how nursing staff training can be developed. MH stated that in ideal circumstances staff should rotate from ward, to dialysis unit etc. but currently there are simply not enough staff to allow this. JS advised that fragmentation of renal services within centres can mean less opportunity for staff to experience work in different subspecialty areas. JS enquired if the group felt regional advocacy for the reinstatement of the regional renal course was needed. MH offered to investigate if there was any appetite for this across the region. ***ACTION: MH to investigate interest across the region in reinstating a version of the regional renal course.***	**Melinda Howard**
4.	**CRG and NCD Updates** JS provided the group with an update from Dr Chas Newstead and advised that from April 2015 Dr Newstead would be stepping down as Chair of the CRG. JS advised the group that the key messages received were: • Currently, due to the election, not much progress is being made on any policy decisions. • CCG dialysis commissioning is likely to be revisited in a year or so. • Tariffs are being considered (to be enacted in 2016) and the national group are discussing whether current tariffs are a disincentive for home based treatments • Service specifications will continue to be updated annually • Dashboards will be reconfigured and data collected via the Registry. • Rituximab for membranous GN will become part of commissioning by	

	evaluation. JS then advised the group that he had requested information on LIMS reporting of AKI and the national CQUIN for AKI. JS had enquired how information would be collected to achieve the CQUIN. NHS England has advised that trusts need to operationalise the information collection and determine locally how it should be collected. However, JS advised that Calderdale have received a very specific description of the rules for in year payment and partial payment, and advised the group of the numerator and denominator wording. DB enquired if the CQUIN applied to all stages of AKI. JS advised yes. JP updated the group about the national tariff guidance. JP advised that the tariff went through a consultation and it became clear that the majority of trusts did not want to sign up to the initial proposal. Therefore, Monitor and Simon Stevens became involved in the discussions and presented two options back to trusts. Option one was a slight improvement of the initially proposed tariff and option two was for trusts to take a roll-over of the previous years' tariff. If trusts took option one they could also have CQUINS. However, if they opted for option two they could not take part in CQUINS. JP advised that Leeds and Sheffield did not make a choice on the tariff and so have been put on the default tariff and cannot claim CQUINs. SJ advised that Leeds and Sheffield are still in negotiations with Monitor. JP agreed that it is a difficult situation. SJ advised that all CQUINs, CCG and Specialised, are suspended until a decision has been made. DB and JS advised that York and Bradford have opted for the enhanced tariff. JP advised that the only specialised CQUIN recommended in renal is for home therapies and Specialised Commissioning are not recommending that it be taken up, as home therapies have already undergone an extensive programme of quality improvement and other areas need to be considered. YB stated that the secondary care systems appeared to be much more complex than those in primary care. DB stated that in terms of implementing the AKI CQUIN the COPD/CCF reporting CQUIN worked on the York IT system, as it automatically sent information to Primary Care. DB stated that he would be interested to investigate if something similar could be developed for the AKI CQUIN. ***ACTION: DB to investigate if the York IT system can retrieve information on AKI incidence from the secondary care systems and transmit it to primary care systems as per the COPD/CCF information. DB to feedback results to the next meeting.***	**Dave Border**
	JP enquired if the AKI CQUIN was mandatory. RC advised yes. JS shared feedback from Richard Fluck with the group as follows: He favours 'a national 'assurance' mechanism via an evolved CRG, and operational renal networks that have responsibility for the entire CKD pathway plus AKI. The national jobs would be about exemplar service specification, data collation and report writing and linkage with other national bodies – NICE, Monitor, CQC etc.The networks would hold a budget and bring primary and	

	secondary care together with commissioners.'	
5.	**Prevention & Primary Care** **(Dr Youseff Beaini, CVD Lead and Regional Advisor)** JS introduced Dr Youseff Beaini to the group and thanked Dr Beaini for attending the meeting. Dr Beaini provided the group with a presentation on his role and the current work ongoing in primary care around the wider CVD prevention agenda, including the Healthy Hearts campaign in Bradford. Please see the presentation notes for further information. JS stated that the primary care focus on CVD prevention provides a holistic focus and it has been beneficial for primary and secondary care to work together. YB stated that in Bradford there had been a big focus on joint working and prevention since September 2014. DB enquired if their have there been any voices in secondary care against the prevention work in primary care. YB stated that most energy has been directed towards engaging a majority and not trying to please everyone. JS stated that healthy lifestyle is also important in prevention. YB stated that their current focus is on medicating patients and pushing the healthy living agenda. JP enquired if the work in Bradford was a time limited programme. YB advised yes. JP stated that if the programme could demonstrate good results then this can be shared across the region. JP stated that we needed to commit to gathering evidence for this work and sharing it regionally. SJ advised that she was extremely impressed by the collaborative work ongoing in Bradford and both SJ and DB stated that they would be keen to assist in replicating this work in their areas. ***ACTION: YB agreed to circulate his presentation for DB and SJ to share amongst their teams.*** SJ stated that she was interested in the cardiology work conducted in primary care and advised that Sheffield were exploring how nephrology could also be delivered in the community. SJ enquired if YB had a perspective on this might work. YB stated that collaborative clinics between GPs and Consultants could be a help, as they provide a version of a "step down" facility. YB also stated that low risk patients could be identified and then put forward for blood pressure monitoring, which could be done by GPs in conjunction with Consultants. JS advised that Bradford provides a remote e-consultation service for GPs and is looking at telephone clinics supported by access to the primary care record. EL advised that ED from Leeds does outreach clinics in Wakefield. YB also stated that IT prompts are useful, as they assist GPs in managing patents. JS advised that these may be available as part of a quality improvement tool that will be linked to the National CKD Audit. ***ACTION: YB to develop a list of primary care contacts who would be interested in driving forward collaborative working (including regional work around dialysis commissioning) and share with the group.***	**Youseff Beaini** **Youseff Beaini**

6.	**Dialysis Commissioning** JS thanked the group for their contributions to the consultation and extended to especial thanks to SJ for her help with responses. JS stated that we now need to prepare for CCG-based dialysis commissioning. SJ agreed that we need to be working proactively to engage CCGs in making a future transition work well. LP concurred and stated that the NKF does not object to CCGs commissioning dialysis but feels that the transfer of commissioning needs to be completed over a length of time and be supported. JS stated that this issue requires monitoring. There is support from clinical leads and CVD leads for the suggestion of a regional stakeholder event in late summer, supported by Jackie Parr. Further details will follow. **Dialysis Away From Base** JS advised the group that this policy is still out for consultation. SJ enquired if the group could assist in providing some clarity. SJ advised that currently if a patient is away for more than four weeks they have to be referred to another unit and then the receiving unit has to refer the patient back to the main unit. This causes many issues in Sheffield as many patients will take a long break on the east coast during the summer and constantly have to be re-referred. JS suggested that there may be scope for reciprocal agreements between centres. DB advised York have experienced issues with patients transferring between Harrogate and London but have not experienced issues on the same scale as Sheffield, as their numbers are small by comparison. SJ advised that this issue is made more complex, as so many different parts of the pathway are run by different organisations. DB advised writing to the affected patients to inform them of the situation. JP stated that a conversation about expectations with patients' needs to be held. SJ enquired if Sheffield could converse directly with Hull to put in place an agreement without involving Commissioners. JP advised that this was acceptable. JP stated that as long as the right clinical arrangements are in place that is all that matters and the situation does not need to be further complicated by commissioner involvement. LP advised the group that a patient had been in contact to inform LP that they had been refused treatment in Spain and were advised that the reason for this was because NHS England was not up to date with their payments. JP stated that patients should never be affected in such a way. JP reminded the group to access the consultation and provide comments. The group enquired when the consultation closed and SB is to investigate this. ***ACTION: SB to advise the group of the closing date of the DAFB consultation.***	**Sarah Boul**
7.	**Repatriation of Transplant Medication** JS advised that information on the repatriation of transplant medication had been included in the e-bulletin and the key message was about making choices that were clinically cost effective. It was important to establish the best treatment for patients at the most effective cost. JS advised that EL had provided a list of patients receiving branded formulations of tacrolimus for review to Bradford. EL offered the same service to York and DB accepted. ***ACTION: EL to provide York with a list of patients and their medications for review.***	**Elizabeth Lindley**

	Renal Transplant National Tariff Update JS advised the group that Keith Rigg and Richard Fluck had issued a letter providing an update on the tariff discussions. The letter was circulated to the group with the papers for this meeting. JS advised the group that he had asked Paul Fenlon about the role of telephone clinics, e-reviews etc and Paul Fenlon has agreed to let JS have the relevant information in due course. JS stated that the costing issues have caused concern in the units and this is being discussed at the Transplant Forum. Consideration is being given to what needs to be done by financial and IT teams within individual Trusts to make this work. **Renal Transplantation – Immunosuppressants Guidance** This item was not discussed. The Guidance was included in the March E-Bulletin.	
8.	**Any Other Business** *a. E-Bulletins* JS enquired of the group if they found the e-bulletins useful or if the group had any suggestions for improvement. The group replied with positive feedback regarding the e-bulletin and EL stated that the website link nature of the e-bulletin was useful and kept it succinct. *b. AKI CQUIN* This was discussed in Item 4. *c. CKD Audit Year 1 Report* JS stated that the CKD Audit had recently circulated their Year 1 report and that the audit will help to reestablish a primary care focus on CKD, as QOF CKD data collection and reporting has been significantly diluted. JS advised that the audit also came with a Quality Improvement tool to increase interest in the take up of collecting this data. *d. NHS Sustainability Day* JS advised that NHS Sustainability Day was on 26th March and Bradford hospital will be planting 160 trees to mark the day. In addition, JS has been involved in helping to produce a NKF/ Green Nephrology Group patient leaflet on sustainability. SJ enquired if the leaflet could be shared and JS stated yes. ***ACTION: JS to share the patient leaflet on sustainability with the group.***	**John Stoves**
	e. AAPD Funding SJ stated that the prices for APPD have increased and Sheffield are now considering developing their own model for this. SJ enquired if the group felt there was scope for developing a regional model. EL advised that Liz Garthwaite was considering home haemodialysis carers. SJ stated that Sheffield also use carers and would be happy to share the documentation on this. ***ACTION: SJ to share the Sheffield documentation on haemodialysis carers.*** The group agreed that there could be scope for a regional piece of work on this	**Sarah Jenkins**

	and it was agreed to explore the idea further. ***ACTION: SJ to explore AAPD funding across the region and feedback at the next meeting.***	**Sarah Jenkins**
	f. Harrogate Self-Care Open Day DB advised that the April 10th Harrogate Self Care open day – all invited.	
	g. Issues With Baxter DB advised that York and Scarborough are continuing to experience problems with Baxter and enquired if any others areas were also experiencing issues. The group concurred that issues were also being experienced. MH advised the group that she had taken the lead in trying to resolve issues with Baxter and has now been given a named contact, for a set period of time, who does appear to be making a difference. JS enquired if there was a problem with staff shortages. MH advised that Baxter have had a new computer system installed and this, combined with poorly trained staff, is contributing to the issues. RC informed the group that this was an agenda item for the forthcoming Home Therapies Forum and that a Baxter representative was being sought to attend the meeting.	
	h. PD Tender SJ advised the group that a new PD tender is in development and this should be widely circulated so everyone can feed into its development. JP enquired who the contract was held by. SJ advised NHS England. SJ advised that comments on the tender can be sent via Richard Platt. **ACTION: SJ to share email on the PD Tender to allow others to feed into this.**	**Sarah Jenkins**
	i. E16 Contract DB raised issues with the current E16 contract. JP advised that she and DB were to meet on Friday 27th March to discuss this further. JP advised that an exit strategy is being devised and that DB/JP will be meeting to discuss an exit strategy for Scarborough, which will include a communications plan to ensure that accurate messages reach patients and staff. JP also advised that she had asked Hull, as a trust in its own right, to state their position on the E16 contract. SJ enquired about Doncaster and JP advised that their contract does not expire until 2017.	
	j. Vascular Services JS advised the group that Ian Stott had again raised a concern about vascular services. JS stated that Bradford is also involved in negotiations to retain a local vascular access service. DB advised that the vascular service at York is now more stable and may be allowed to continue as they have expanded services out across the area. JP advised NHS England will shortly be publishing the outcome of their vascular review. ***ACTION: JP to share the outcome of the vascular review once available.***	**Jackie Parr**
	ITEMS FOR INFORMATION:	
	Future Meetings: Monday 22nd June 2015 Monday 21st September 2015 Monday 14 December 2015	

	All meetings 0915-1115 at Hatfeild Hall, Wakefield.	