Yorkshire and the Humber Renal Clinical Expert Group Meeting

Monday 30th June 2014 - Hatfeild Hall, Wakefield, WF3 4JP

Present:

John Stoves (Chair)	Consultant Nephrologist, Bradford Teaching Hospitals NHS Trust, & Renal Clinical Lead for Yorkshire & the Humber Strategic Clinical Network (Y&H SCN)
Dave Border	Clinical Lead, York Hospitals NHS Foundation Trust
Rebecca Campbell	Quality Improvement Manager, Y&H SCN
Kath Cope	Quality Improvement Lead, Y&H SCN
Sarah Hope	Administration and Support Officer, Y&H SCN
Sarah Jenkins	Nephrologist, Sheffield Teaching Hospitals NHS Trust (STHT)
Melinda Howard	Nurse Manager, York Hospitals NHS Foundation Trust
Helen Collinson	Consultant Nephrologist, Hull & East Yorks Hospital NHS Trust
Ian Stott	Clinical Lead, Doncaster & Bassetlaw NHS Trust
Emma Dunn	Clinical Lead, Leeds Teaching Hospitals NHS Trust (LTHT)
Elizabeth Lindley	Clinical Scientist, LTHT
Oli Anderson	Patient (Bradford)
Paul Taylor	Patient (WRKPA)
Andy Henwood	Patient (York)

Apologies:

Jackie Parr	Specialised Commissioning - Service Specialist, NHS England
Russell Roberts	Clinical Lead, Bradford Teaching Hospitals NHS Trust
Bev Craggs	Renal Matron, Leeds Teaching Hospitals NHS Trust
Will McKane	Consultant Nephrologist, STHT, YH Representative Dialysis Clinical Reference Group (CRG)
Chis Lacey	Renal Dialysis Matron, Bradford Teaching Hospitals NHS Trust
Chas Newstead	Consultant Nephrologist, LTHT, Chair Dialysis CRG, YH Representative Transplant CRG
Sarah Naudeer	Clinical Lead, Hull & East Yorks Hospital NHS Trust
Linda Pickering	Patient Advocacy Officer, National Kidney Federation

	AGENDA ITEMS	Action
1.	**Welcome, Apologies and Introductions** John Stoves welcomed all to the meeting and everyone made introductions round the table.	
2.	**Transitional Care in Hull**  Hull - Getting it Right Together Leaflet.pdf Dr Helen Collinson shared a PowerPoint presentation with the group regarding Transitional Care in the Hull area. The problem with transition from Child to Adult services is that young people find it a stressful time so services need to provide viable care for the patient during that time. The work commenced when a consultant from Leeds spoke to the Hull service to help improve their services. The team in Hull spoke to the patients to find out why there were issues and a long list came out of it which included the need for planning in	

	advance. Changes to the clinic to make it an orientation clinic made it more understandable for the patient which helped ease the patient into the transition period. Hull services invited different nurses to the clinics so the patients could build a relationship with the right people. The patient also became more involved so each individual had a more tailored service for their medical condition. The team tried using paper questionnaires to find out how their service was working but there was a poor response from the patients, so Survey Monkey was used which provided much better feedback. It was mentioned after the presentation that there is scope to create a regional model to help with transition across the region. Lizzi Lindley noted that the BHLY labs do not report eGFR fpr patients under 18 years but a calculated value can be added to the U&E screen. The Schwarz formula eGFR is required for the Registry but there is almost always a step change when moving from Schwartz to an adult formula (MDRD or CKD-EPI). If this step change occurs at 18, it could be misleading for patients who have gone straight into the adult service at 16 or 17. Andrew Mooney would also prefer this step change to occur at 16 if there are no objections from others. Andy Henwood queried how the funding provided for the service from NHS Kidney Care had been lost. Helen circulated a resource pack which has been created for patients. The information is contained on a CD which can be adapted by other Trusts. Both Doncaster and York reported that there are very small number of patients in Transition, the service is therefore ad hoc and bespoke. Dave Border reported that a 'Have your Say' event for young people was held in York but there were no attenders. Andy suggested that the small numbers reinforced the argument for a more generic service. Paul Taylor reported that there is not a patient group to support young people, but that this is difficult to achieve. It seems the case that peer support is led by staff rather than patients. Emma Dunn reported that major changes are required in Leeds and that work is ongoing in this area. Anna Hemens is no longer undertaking the role of Young Person Support Worker as the funding ran out and could not be sustained. Sarah Jenkins informed the group of national work led by Rachel Gair and will share some documentation with John.	**Sarah Jenkins**
3.	**Minutes from last meeting 31st March 2014** The minutes were agreed to be an accurate record with no comments made. **Transitional Care** This was covered in the previous item. It was not known whether the national Specification for Transition has been released. **Discussion Maps** Rebecca Campbell has been unable to locate any of the NHS Kidney Care discussion maps. John reported that there are four in Bradford which have not yet been used. It was agreed that these could be shared across the region. John will also determine whether there are any digital versions of the discussion maps. Oli Anderson said that these would be useful for patient forum discussions. John also has some other NHS Kidney Care Materials. Further to discussions at the last meeting, John and Sarah confirmed that E-Kiosks are now in place in Bradford & Sheffield. **Transport**	**John Stoves**

	Dave reported that the interface issue between Leeds and Harrogate has been resolved. Although it is not known whether this was discussed at the CCG Collaborative Meeting. There was a brief discussion regarding the role of the group in relation to transport and whether the group should have an overview of performance metrics. It was proposed that this data is sourced for review at the next meeting. The responsibility for patient transport services sits with CCGs and there are multiple contracts with multiple providers. Paul informed the group that a web-based app has been developed to allow patients to book and manage their own transport in real-time. The system will be tested at St James's Hospital with patients on the twilight shift. If this proof of concept is successful then the company, 365response.org aims to go-live nationally in September / October 2014. Lizzi noted that it is possible to access data on arrival times, etc from BHLY. Lizzi agreed to source this. **Specialised Services** There was a further discussion regarding the achievement of 85% for vascular access. Feedback from the Clinical Director's Forum was that 1/3 of units nationally had derogated on this item, but that derogation has not been applied consistently. Ian Stott reported that he had discussed this matter with Jackie Parr and that the derogation would be removed, nothing formal had been received to date. Dave volunteered to attend a future meeting with the York Vascular Access Coordinator who could provide details as to how the York service is managing to achieve the target. **York / Whitby / Scarborough Developments** Dave updated the group on progress with the transfer of services to York. York has now taken on out-patient work from Scarborough, this is not dialysis patients. In relation to dialysis, the majority of patients have confirmed that they want the service locally and so will transfer. There are also plans to open a self-care, holiday service in Whitby. However, this has been put on hold due to there being no mains water at Whitby hospital. York now owns the Whitby hospital site and the team will be pushing for a resolution. The Harrogate Self-Care unit is due to open at the end of August.	**Rebecca Campbell** **Lizzi Lindley**
4.	**Agree Terms of reference** There were no comments from the group. The terms of reference were agreed.	
5.	**National Clinical Director & Clinical Reference Group Updates** John Stoves provided an update from the National Clinical Director. Rebecca will circulate the update which John has provided to the SYB CVD Strategy Group. Richard Fluck has a particular focus on AKI and is leading the national Programme Board. Richard presented at the recent YH AKI Forum and highlighted the AKI Safety Alert. It was also noted that the NICE AKI guideline has been released. In addition, John reported that the Cardiovascular Intelligence Network and Public Health England are developing a CVD report which will be broken down by CCG and will include renal chapters. The reported is expected in July or August. John is involved in a monthly teleconference with Richard. If there are any questions or comments that any member of the group would like to put to Richard, John would be happy to do so. With regards to the CRG updates, the minutes from both the dialysis and transplant	**Rebecca Campbell** **John Stoves**

	group will be circulated when they are available.	
6.	**Renal Metrics for CVD Dashboard** John informed the group of plans to develop a regional CVD dashboard which will include 4-5 measures for renal. The circulated renal report card includes draft renal measures of which 5 have been selected (highlighted in yellow on the circulated document). There was a discussion regarding these proposed measures. In relation to AKI it was agreed that there were issues with the education measure for AKI. It was felt that this would be hard to measure and that more guidance would be required. The group agreed to remove this measure. The measure 'incidence of stage 3 AKI' should be for all Trusts and collected longitudinally. There was further discussion regarding the Shared Haemodialysis Care metric. Three options were presented: i. % patients undertaking 5 aspects of care ii. % of patients asked whether they want to participate in shared care iii. % of patients established on SHC who would recommend SHC There were mixed views as to which would be the most appropriate and a consensus was not reached. It was also noted that data collection methods vary across the Trusts so further guidance may be required. It was agreed that John will speak to Paul Laboi to finalise this measure.	**John Stoves**
7.	**Work Programme** There was insufficient time to discuss the work programme, so John provided a brief update. Rebecca reported that the CVD Work Programme includes AKI as a priority for Renal. The CVD work programme will be circulated.	**Rebecca Campbell**
8.	**Any Other Business** **Dialysis Away From Base (DAFB)** It was noted that there are some discrepancies between the draft national policy and existing Trust policies. The national policy has yet to be released for formal consultation. Reference was made to PBR and the rate for quarantine. John will raise this with Richard Fluck. There was some discussion regarding the revised Carbapenemase-Producing Enterobacteriaceae (CPE) Policy which John will circulate. **BHLY** There will be an opportunity for questions and discussion following the meeting. **Patient Representation and Input** It was agreed that there should be a specific agenda item, preferably not at the end of the meeting. **Shared Haemodialysis & Self - Care** Andy thanked Dave and Melinda for their ongoing work on developing shared and self-care, and increasing patient choice. **Kath Cope's Retirement** John thanked Kath for her excellent contribution to the renal network over the past 18 months and wished her all the best for the future.	**John Stoves** **John Stoves**