NHS England

West Midlands Renal Peer Review 2017

West Midlands Renal Peer Review 2017

Version number: 2

First published: 15/11/2017

Updated: 22/01/2018

Prepared by: Clara Day & Elizabeth Choney

Contents

1 Executive summary

The renal community has a history of working together with patients and a broad multi-professional team to ensure best outcomes for patients. As a speciality, we have produced a wide range of collectively approved, evidence based guidelines for care. Mandated data collection is impressive and very significant compared to many other specialities. Kidney Quality Improvement Partnership (KQuIP) leads nationally on encouraging quality improvement within areas of kidney care. Within the West Midlands the Renal Network has a good reputation for leading quality improvement across the region, undergoing a previous peer review with WMQRS.

To establish a baseline for future unit and regional QI projects, and to facilitate learning the West Midlands Renal Network has again performed a peer review process, the details of which are summarised within this document. This was outcome-driven, with standards developed by consensus by a multi-professional and patient group, based on national standards.

Individual units have been sent specific feedback where it was felt that changes in process may be beneficial. A summary of main findings is included below and in Summary/ Next Steps

I would like to thank all the units for working hard to establish this new model of peer review for the region, collecting and compiling all their data and contributing with such enthusiasm, mutual respect and commitment on the peer review day.

I would also like to thank NHS England and KQuIP for all their support in helping with the smooth running of this event.

Chronic kidney disease

Across the region models for advanced CKD care differ depending on size of cohort of patients and geographic location. There is, however, widespread availability of patient education programmes. Variation exists in uptake of home therapies and pre-emptive transplantation which will be addressed in other work streams. Units need to ensure methods are in place to ensure timely referral but that care is organised so that it is delivered efficiently to those most likely to have progressive renal disease.

Home therapies

There is variation in rates of home therapy use across the region. This also reflects national variation. All units valued the discussion possible on the peer review day and will be able to continue to learn from each other. This will be an ongoing focus of QI within the region. A regional home therapies day has been organised for February 15th 2018.

Transplantation

This review continues to highlight lower transplant rates in the region when compared to national rates. It also indicates differences in referral for pre-emptive transplantation, pancreas kidney transplantation and immunologically complex transplantation.

Repatriation of patients with kidney transplants for care close to home is variable. This needs addressing in the region to ensure effective transplant care close to home if this is what the

patient desires. A West Midlands wide service specification for effective repatriation of renal transplant patients will be produced.

There is ongoing QI work locally in the Transplant First programme which has now been nationally adopted

A regional transplant interest group (TIG) will also be formally established for QI purposes with meetings three times a year to include education and focused audit as well as ensuring appropriate specifications of care for all units. The first meeting is scheduled for April 26th 2018 and will focus on live donation.

Haemodialysis

Hepatitis B vaccination is very variable and a vital part of provision of control against blood borne virus. A regional working group will be set up to help co-ordinate and ensure all units are working as efficiently as possible in this area.

Dialysis patient transport remains a considerable issue for many patients. The region will continue to support patient groups and units to work with the relevant CCGs and providers to ensure a sensible service locally. In addition the region will support any national work in this area.

Vascular access rates within the region are generally very good with all units at national average or above. The two lower performing units may wish to engage with higher performing units and assess whether performance can be improved.

Infection is the major cause of death in dialysis patients. All units should record all bacteraemias in this group, not just MSSA/MRSA and work hard to limit.

Nursing roles and competencies differ across the region and discussion may enable differing methods of working within units.

Acute kidney injury

This was removed from the original areas to be reviewed in this process and is being addressed in a separate regional working group.

Patient feedback

This is now collected by all units via the national PREM for dialysis patients but not necessarily for patients elsewhere within the renal pathway. Such patient feedback should be routinely collected and analysed promptly with adjustment of service models if necessary.

Data

All units struggled to obtain aspects of data for this review, with more of a problem at some units and in some areas than others. All of the datasets were agreed by the units as being reflective of national guidance before collection. All units agreed that data is not as routinely reviewed as it could be, and that this process has been very useful in highlighting this in specific areas

Future events

Feedback from the process was positive with an agreement that such a process will be held every two years, with the next event in 2019. Before this event there will be review of the suggested data sets with adjustment as needed, based on experience of this event. It was also noted that a larger organising group would be helpful reflecting the considerable workload.

Dr Clara Day

Clinical Director West Midlands Renal Network

2 Background

The renal community has a history of working together with patients and a broad multi-professional team to ensure best outcome for patients. As a speciality, we have produced many collectively approved, evidence based guidelines for care. These include NICE guidance and professional society guidance (Renal Association, British Renal Society, British Transplant Society) as well as aspirations for care outlined by the multi-agency 'Kidney Health: Delivering Excellence' report. As such we are able to broadly define what good care should look like. Mandated data collection is impressive and very significant compared to many other specialities via for example UK Renal Registry, NHS Blood and Transplant, NHS England Dashboards and Rightcare. However, these data sets continue to indicate considerable variation in care across the UK.

Quality improvement requires recognition of areas where improvement may be needed, as well as leadership and team ownership to change. Within the daily life of NHS care, despite regular unit audits, focus on such improvements can be difficult. Units can also be working in isolation, not sharing with others areas of innovation and excellence, or learning from others where improvement may be required.

In 2009-2011 the West Midlands region worked with WMQRS in a wide-ranging peer review exercise. This involved individual unit visits by trained peers with self-assessment and subsequent evidence review against an extensive procedural-based data set. These initial visits were followed in 2012 by a 'table-top' review process based on outcomes of the original review. These processes were very valuable in defining pathways and protocols for the units, with areas of concern highlighted within the Trusts, facilitating Board level discussion for areas of improvement where required.

On this occasion, the West Midlands region, via the West Midlands Renal Network, proposed a different method of peer review. As discussed, guidelines for care are produced nationally with data already collected for national datasets to indicate performance. Variation in practice and outcomes exist across the region, as across the whole of the UK. The 2017 peer review process focussed on several key elements of specialised commissioned renal care, with examination of submitted data from each unit accompanied by 'deep dives' in certain areas to assess reasons for variation. It is accepted that within many areas, exact metrics for ideal care are difficult to define and thus data interpretation nuanced. However, it is essential that basic guidelines for care are adhered to and that opportunity for excellent patient care is provided wherever the patient resides, and is provided irrespective of the make-up of the community that the unit serves.

Areas for investigation were agreed upon by a group convened by open invitation from the Renal Expert Advisory Group of the West Midlands Renal Network with widespread opportunity for review. They also reflect national priorities for quality improvement as laid down by the KQuIP partnership. The process was intended to be supportive and constructive for all involved, with opportunities to learn about successful innovation across the region and for units to provide peer support to others where helpful. This included, for example, sharing of local protocols and patient information leaflets, as well as successful QI methodology. (Appendix 1)

The trusts that contributed to the West Midlands Renal Peer Review 2017 were:

- The Royal Wolverhampton NHS Trust (RWT)
- Heart of England NHS Foundation Trust (HEFT)
- Shrewsbury and Telford Hospital NHS Trust (SATH)
- University Hospitals Coventry and Warwickshire NHS Trust (UHCW)
- University Hospitals of North Midlands NHS Trust (UHNM)
- Dudley Group NHS Foundation Trust (DGH)
- University Hospitals Birmingham NHS Foundation Trust (UHB)

The full Terms of Reference can be found in Appendix 2.

2.1 Process

2.1.1 KQuIP/ UKRR Regional day, West Midlands Region. March 23rd 2017.

Agenda as per appendix 3

This regional QI day was held in partnership with KQuIP and the UK renal registry. Part of the day was devoted to review of a West Midlands specific data set produced by UKRR ahead of publication of the 19th Annual Report with data from 2015. This highlighted areas of variation in and is included as appendix 4.

- Transplantation in the region compared with UK as a whole
- Difference in pre-emptive listing and transplantation exist within the region and in comparison to UK as a whole
- Rate of home therapy usage within the region
- Vascular access rates within the region
- Peritonitis in peritoneal dialysis within the region
- MSSA bacteraemias within the region.

This day allowed identification of QI leads for each unit; one lead a doctor, and one an MDT member.

The UKRR is a highly defined and cleansed data set which takes some time to produce. Standard arguments made by units pertaining to the UKRR data is that it is not current and that practice has changed since the time period represented. In general, such change is not substantial, but to remove this argument from the current peer review process, data sets submitted to the peer review day itself were based on more current practice. Exact data sets and dates are defined in appendix 5.

2.1.2 Peer review day; Oct 11th 2017

Agenda as per Appendix 6

Units were informed via clinical leads and QI leads of required data sets in July 2017. Attendance was encouraged from whole MDT via the West Midlands Clinical Network EAG and via cascade within the units. Patient attendance was also encouraged by the same processes.

Areas represented were as below:

- CKD/ ESKD Interface
- Haemodialysis

- Home Haemodialysis
- Peritoneal Dialysis
- Transplant
- Miscellaneous; to include staffing, transport, patient feedback, CKD advice services, other specialised services

Data submission deadline was a week before peer review day allowing the organising team to assimilate into summaries for all units. This was presented by chairs of individual sessions.
It was apparent on analysis by the organising team, that there had been differing interpretations of data set requirements. Where data were obviously not matching requirements, the submitting team were contacted to amend if possible. Despite mandation of data submission for this process within Trust NHS England contracts, not all data was submitted by all units. Gaps within the data sets have been left and comments have been made where data was not submitted in summaries to individual units. **Since the data set had been agreed with ample time for review prior to agreement, and an opportunity to contact the organising team prior to the deadline had been provided, it is felt to be important that units collate data that they had not done so before peer review and ensure assessed within their units.**

Because of some differences in data set compilation, it is important to note that direct comparison between unit outcomes in this exercise is not possible.

However this should not be used as an 'excuse' to disregard variation. Each unit should be aware of how their data set was compiled, and whether it met the pre-set data set specification and review data critically to ensure effective quality improvement. Where the organising team feels that unit data shows sufficient variation from the rest of the region to raise questions, this is highlighted in individual reports.

All units were also asked to provide a short summary in relation to the above key areas on three topics:

- Examples practice of which they are particularly proud
- Examples of areas where they feel they struggle with details of plans to improve
- Examples of areas where they would really welcome advice

Themes were drawn from presentations and then discussed by attendees. This highlighted areas where units were struggling to facilitate peer discussion and solutions where possible.

During the sessions all delegates were encouraged to complete hand written peer review forms to be passed directly to each unit with comments and helpful hints on areas of practice presented. Example attached within Appendix 6.

This report includes all presentations of data summaries and unit presentations along with a summary of ensuing discussions. Where a unit was identified as struggling to provide a service within a specialised commissioning specification, this is highlighted in the unit's own summary. A follow up session will occur in Oct 2018 where all units will be expected to present how they have progressed against specific items identified for their unit, as well as more general observations made in this report for the whole region.

3 CKD/ ESKD interface

Click here for presentations

Issues arising from data submitted and discussion

- Total population. This appeared to have been calculated using different metrics in each unit and spectrum did not reflect the total renal replacement population in a given unit. Data with regards to numbers should therefore be interpreted with caution.
- There are differing rates of PD and transplant as start modality for RRT. This variation needs further exploration. In addition there appears to be little alteration in modality at 3 months.
- There is variability across region of patients starting with definitive access (AVF/AVG/PD/Tx) although most units at about 70%. Units could explore further to improve performance.
- The line start data suggests units have different ways of reviewing their line starts and determining a cause. This is an area we would encourage units to review internally.
- Wide variation in percentage of CKD 5 patients for conservative care and this needs further exploration regionally as suggests different practice
- Unplanned start data; variation across the patch. Data does vary in that some units state no AKI to ESKD which is unlikely. There is however also variation in other categories. Different monitoring methods exist at different unit. May need further explanation.
- Anaemia management.
    - As stated above, differing populations were analysed in each unit so direct comparison difficult. Percentage in target 100-120 g/l did not specifically include just those on ESA. Units have apparently interpreted this category in differing ways making interpretation difficult.
    - There do however appear to be differing practices around intravenous iron or ESA usage. This may need further exploration especially as wide regional variation of Hb level at commencement of RRT in UKRR data.
    - https://www.renalreg.org/wp-content/uploads/2017/09/07-Chap-07.pdf
- Hepatitis B vaccination variation was significant due to different method of delivering vaccination programs. This requires more work regionally due to difficulty in acquiring vaccine and service provisions needed for this to be delivered in-house

Areas discussed

Following on from each units' presentations the group pulled out key themes to discuss in more detail:

- What should be in a low clearance clinic?
- Hepatitis B vaccination provision
- Conservative care
- Nurse –led clinics

3.1.1 What should be in a low clearance clinic?

- Organisation of care for patient with advanced chronic kidney diseases varies between units. All units have a dedicated education programme for patients approaching the need for a decision about renal replacement therapy. Some units have MDT clinics where all low clearance seen in one cohort with access to wider MDT eg dietetics and VA as one stop, whereas others remain under named consultant care with access to a pre-dialysis MDT separately. In some units the exact organisation of care depends on geographic location of patient. This is necessary to provide a sensible balance between the need for significant patient travel versus the need for cohort care. The limitation of specific MDT clinics may be the number of patients within a low clearance cohort at a given geographic location and balance of MDT workload to make population care efficient.

- Patient feedback should be used to assess satisfaction with all levels of care

- Identifying patients to be included within the low clearance clinic was discussed. Although standard definitions include progressive eGFR less than 20ml/min/1.73m2, the 'in practice' nature of difficulties around this were discussed. All recognised the importance of early identification of those likely to progress to ESKD vs over prediction of progression. Using Tangri risk equation is being investigated in one unit.

- Patient choosing peritoneal dialysis may benefit from a separate low clearance stream to allow continuity of message.

3.1.2 Hepatitis B vaccination provision

This was also discussed in Haemodialysis session where summary is included

3.1.3 Conservative care

- The definition of conservative care was discussed. It was accepted that in a significant proportion of cases, a patient may be categorised as receiving conservative renal care, but may not have progressive renal disease that is technically end stage, and therefore may die from other causes. In house discussion of best use of nursing resources may be appropriate in this situation.

- Most units offer a community delivered service. There is then variable interaction with palliative and community services depending on local and renal unit infrastructure. It was suggested that close liaison with palliative care may be worth exploring if not already in place.
- The use of ESA in conservatively managed patients was discussed. The benefit to those patients who have very limited mobility may be small especially of then inconvenienced by more frequent blood testing that may be difficult to facilitate.

3.1.4 Nurse- led Clinics

- Nursing roles in advanced CKD clinics vary across the region with corresponding levels of training and competency.
- Some units have solely nurse led clinics for RRT preparation with consultant back up if required.
- Some units have nurse prescribers
- Individual unit infrastructure needs to be considered to structure care that is both resource efficient and provides appropriate expertise. This may well vary between units.

4 Haemodialysis

See presentations in attachments

Issues arising from data submitted and discussion

- Vascular access; the West Midlands is generally a very high performing region with five of the seven units above 80%. Two units UHB and UHCW are at just over 70%. This is around the national average but regional comparison suggests improvement possible.
- Bacteraemia rates; all units are collecting MRSA/MSSA. There are however some concerns as to whether all dashboard data is truly 'rolling year' data as depicted.
- Collection and thus depiction of general bacteraemia data is variable. Most units were not able to access data on bacteraemias other than MSSA/MRSA. Since infection is a leading cause of dialysis patient death, it is suggested that this is collected prospectively for audit purposes. UHB and UHCW submitted full data sets whereas this was not complete for other units
- There appeared to be considerable variation in percentage of patients prescribed less than 12 hrs dialysis a week. There are no specific targets around this measure but shortening must not be used because of capacity constraints. If used in context of tailoring dialysis around residual renal function or patient frailty then appropriate but units where higher percentage may wish to check. Equally where units have very few patients prescribed less than 12 hrs, tailored approach may be explored for those initiating dialysis with significant residual renal function.
- Hepatitis B immunity; this should be regularly audited and thus easily accessible. Units providing in-house vaccination for CKD and HD patients had higher levels of immunity. UHNM had a higher proportion of patients with no immunity than other units and may need internal appraisal. DGH did not submit data and this should be reviewed in the context of this report.

Areas discussed

- Hepatitis B immunisation
- Funding for wider MDT
- Dialysis capacity management
- Nursing challenges

4.1.1 Hepatitis B immunisation

- All units recognise importance of immunisation against Hepatitis B as a vital part of haemodialysis blood borne virus policy. Recognised that patients are more likely to

respond to vaccination by producing protective antibodies if immunised within in the pre-dialysis period.

- All vaccination has been recently more difficult because of a national shortage of vaccine.
- Hepatitis B vaccination is commissioned variably by either CCG or NHS England.
- Units differ in facilitation of Hepatitis B vaccination.
    - Most use primary care to vaccinate within the pre-dialysis period. Units report that GPs are happy to provide. However, several units do not have fully structured programmes to ensure actually happening but all now working to ensure in place.
    - Most units felt that having the ability to offer patients Hepatitis B vaccination as a routine part of both pre-dialysis and haemodialysis care would be highly beneficial. One unit already does this for both groups of patients, with other units offering for those established on renal replacement therapy.
- Funding for such a programme was discussed. It was felt that ideally units should be able to deliver as part of an MDT tariff or renal replacement tariff but that reimbursement should be provided by current commissioners for vaccine itself. Should be a cost saving for commissioners as no dispensing fee and pass through costs could be at true cost rather than list price.
- Timing of vaccination pre-dialysis discussed. It was recognised that early immunisation is best to ensure immunity at commencement of RRT but that this may also result in unnecessary vaccination. Risk based scores may be useful to predict progression rather than eGFR alone.

- <u>Actions:</u>
    - Policies for BBV vaccination should be pooled across the region to aid consistency. New Renal Association guidelines are also due publication shortly.
    - All units to ensure robust arrangements in place around current vaccination processes
    - Units to approach CCGs and establish who commissions vaccine locally and then discuss with commissioners feasibility of bringing ‘in house’
    - Network approach via NHS England to aid such an approach.

4.1.2 Funding for wider MDT

<u>IT for renal</u>

It was agreed by all that bespoke IT support is vital for renal services to function effectively. Band 6 or above is usual. IT support is needed for:

- Ensuring all data is collected and submitted in timely manner for dialysis billing. Mistakes in the collection of this data can be very costly. Suggested that this should be used in any business case requirements for better IT support
- Ensuring all mandatory renal registry and NHS England dashboard returns are made and are correct. These data are externally representative of unit performance and need experienced and detailed review.
- Maximising use of IT in renal services to facilitate real-time data transfer from dialysis machines to bespoke renal IT and subsequent interaction with separate Trust systems. This frees up nursing and administration time and reduces error.

Psychological support

- Requirement for renal replacement therapy can be associated with depression and anxiety in up to a third of patients.
- Patients with these disorders have poorer outcomes than those without.
- It was agreed by all that psychological support is extremely helpful for dialysis patients, and indeed for all patients treated with, or approaching the need for renal replacement therapy (RRT). This is reflected in NHS England service specifications.
- Bespoke renal psychological support provides professionals who are fully cognisant of issues faced by RRT patients (an issue often brought up as an area of frustration by those seen outside of renal services), and far more rapid access to review than within general mental health services. It also allows for far more seamless MDT working than external psychological review. All present felt that this model should be provided in all renal units.
- Four out of seven units offer renal specific psychological support. Funding arrangements and exact support differ but all provide a service which is easily accessible to all renal patients within the unit. It was discussed that actually measuring how this affects patient outcomes is very difficult and is not easy to quantify for a business case model.

Suggestions to aid setting up of a service included:

- Citing NHS England Specifications
- Demonstrating patient need using survey of patient symptoms using a screening tool
- Exploring possible partnerships with third sector organisations
- Exploring with current mental health providers to establish whether specialised stream could be commenced in current service
- Exploring links with cancer services to see if any ‘piggy-backing’ of services could occur acknowledging that many renal patients have similar or worse outcomes than those under oncology care
- Recognising that psychology services would produce income from patient facing activity
- Upskilling of current staff with increased awareness of mental health issues facing dialysis patients and general sign posting. Certain staff identified for advanced communication skills training, approaching cancer services for possible funded course. Recognised by all that this would not be a replacement for a psychological professional but may aid recognition of issues and appropriate onward referral.

4.1.3 Dialysis capacity

A generalised discussion took place around challenges to dialysis capacity in hospital vs satellite units.

- Different criteria for acceptance of patients at satellite units across region. In some cases led by the private providers being reluctant to take frailer patients eg those requiring hoisting or pressure relieving equipment.
    - Discussed that private providers are able to hoist if trained. Provision of hoist will be according to individual contracts.
    - Pressure relieving equipment will depend on current set up particularly the presence of beds within the units. Again will be specified within contracts. Trusts are within their rights to supply beds into private provider units or negotiate provision. Pressure relieving equipment can be patient’s own from the community, loaned by Trust or provided by negotiation with provider.

- A difficulty of ‘letting go’ by hospital dialysis units was discussed. This culture delays or prevents patient transfer to satellite units.
    - In order to facilitate satellite transfer, it was suggested that patient expectations should be set from the commencement of dialysis.
    - Transfer to satellite should be as fast as possible, when appropriate. Some satellites are able to commence patients on dialysis rather than an in-centre start, where this is deemed appropriate.
    - All staff need to recognise the importance and convenience for patients dialysing as close to home as possible; problems with NEPT to non-local dialysis units was discussed.
- Discussion around the difference between ‘frail’ and ‘unstable’ patients. The unstable patient may well need in-centre dialysis, whereas the frail can probably be managed well in satellites as long as there is commitment to full integration with community services. The decrease in travel time can be particularly beneficial for the frail.
- Discussions about capacity issues for in-centre dialysis units around staffing models. Advice was shared. Differing methods of dialysis provision for inpatients and sick patients not in renal wards was discussed. This included:
    - Transfer of all patients to renal unit if at all possible to allow maximal staff efficiency
    - Ward nurses providing dialysis for renal inpatients, either at all times or just out of hours
    - An acute dialysis team providing ward dialysis for inpatients
    - Provision of dialysis for acutely sick at bedside in non-renal wards.
    - All agreed that models need to be adapted to Trust needs but ensuring balance between individual patient care and efficient nursing models in a very pressurised workforce.

4.1.4 Nursing challenges in Dialysis Units.

It was noted by all that there were difficulties with a number of unfilled nursing posts (at all levels) in the NHS and in Dialysis Units in particular. Discussion revealed that a number of centres have established Band 2 & 3 nursing staff who are working with the teams in delivering dialysis care. These individuals face restrictions in practice related to administering intravenous medications, including saline infusions and injections, and dialysis access cannulations.

A summary of discussion points around nursing care is as below:

- All centres had either training sister or professional development nurse roles.
- Most centres offered a period of supernumerary practise, where nursing skills were gained/enhanced whilst working in a dialysis centre.
- Mentorship of nursing staff, followed by regular review of skills, with competency assessments and training packs were available in various combinations in all centres
- A number of centres were utilising Band 2 & 3 staff in delivering HD patient care
- A number of centres supported Band 3 cannulation of arteriovenous fistulae with assistance from trained nursing staff.
- Concerns/ constraints have been raised due to the issues of administration of medications by Band 2/3 staff by Pharmacy Departments. However, these issues had been resolved successfully by several Trusts, particularly by the use of agreed training processes

supported by local Pharmacy departments, PGDs and support of Band 2/3 staff work by trained staff.

- A number of centres had developed non-medical prescriber roles as well as the use of dialysis unit specific drug prescription charts, easing difficulties experienced in dialysis units.
- One centre offered a period rotation between base and satellite units to maintain / enhance nursing skills.
- A number of centres had developed Access, Shared HD Care and Acute Kidney Care Nurse roles. Advanced Nurse Practitioner (ANP) roles were present in most centres. Several were undertaking business case processes to appoint ANPs.

5 Home Haemodialysis

See presentations in attachments

Issues arising from data submitted and discussion

All units show steady population over time period apart from RWT who have increased substantially over the last 3 years.

No other significant differences to highlight between units

Areas discussed

- Increasing patient numbers
- Infrastructure
- Holidays
- Patient concordance

5.1.1 Increasing Patient Numbers

- All units expressed the desire to continue to increase patient numbers. Sources identified are:
    - CKD population
    - Prevalent RRT patients

- Discussed that often tension within the CKD population as HHD cannot usefully be in ‘competition’ with PD and that many units encourage, or indeed adopt, a ‘PD first’ strategy. It was agreed that units needs to have a clear goal of the role of HHD in CKD population.

Most units have had a good deal of success recruiting from the in-centre population. Issues discussed were:

- Ensuring all in-centre staff were pro HHD. Recognised that staff may have anxiety around their jobs if HHD increased and pre-conceived ideas around suitability.
- Increasing knowledge and awareness of staff about HHD. Educational events for staff and ‘home therapy fayres’ had been helpful in some units. These can be open to all patients whether CKD or prevalent RRT

- Peer support. All patients present expressed the importance for them of contact with other patients when choosing the modality. This should be facilitated and encouraged at every opportunity.
- Shared care in-centre as transition to HHD had been adopted by several units with variable success. The main problems had been:
  - Consistency of support for shared care training and practice in the presence of stretched workforce
  - Filling of 'shared-care/self-care slots' within defined areas with patients not on the programme to aid capacity.
- All agreed that shared care should be encouraged, though it was thought a dedicated area may not be needed. One unit issues bronze, silver and gold certificates as encouragement with gold certificate highly coveted!
- Maintenance of the current programme is also a crucial part of increasing patient numbers and must never be overlooked when focussing on recruitment and training of new patients.
- Discussed how important provision of short term respite is to keep patients at home. Needs to be flexible. Some units have been able to provide this within the HHD set up and stated how beneficial they felt that this had been. Allows refreshment of staff-patient relationship and addressing of any training and support needs, by staff who know the patients. Some were able to offer regular, scheduled respite to patients which had allowed maintenance in the HHD system.

5.1.2 Infrastructure

- Presence of a dedicated and appropriate training area for HHD is felt to be very helpful. Allows a much better training environment with flexibility to offer respite and other services such as intravenous therapies away from impingement on in-centre capacity constraints.

<u>Staffing models</u>

- All agreed the importance of experienced nursing staff to support HHD patients and carers. Acknowledged that these are expert patients who need consistent and experienced support to engender confidence and ensure modality survival. One unit had been told they could only have a B5 nurse as programme lead and this was agreed by all as inappropriate.
- Staffing models varied but some units had combined PD and HHD teams into 'home therapies' team with good success. This was particularly effective in smaller units where the provision of separate fully functioning home therapy teams would be challenging. Some nursing staff were experts in both modalities whilst in other units there remained a modality split within the team but shared infrastructure could be utilised.
- Consistency in training and support was found to be very helpful with several programmes maintaining 'primary nursing' in the community where possible. Good handover was felt to be vital in these circumstances to ensure all of team aware of any important issues.

<u>Technology</u>

- Advanced technological solutions not yet widely available although felt by all to be desirable and to be encouraged. Patients felt ability to use Skype or equivalent would be extremely useful for wide spread trouble shooting. Trust IT issues discussed

5.1.3 Holidays

- All units, and patients, expressed frustration at difficulty encountered in arrangement of dialysis away from base within the UK. The inability to be able to plan ahead was mentioned in particular.

Holidays with NxStage

- Several trusts now utilise NxStage machines for HHD and have facilitated travel for these patients both within the UK and abroad. This requires use of a bag and warmer mode with the patient transporting the machine and the fluid either being transported by the patient or being shipped ahead. Fluid requirements are significant. This means that travel with this technology is very expensive and the units currently meet this cost.
- One unit has recently commenced a pilot of the NxStage system but has told patients up front that travel costs will not be supported. Another has recognised that they may no longer be able to afford funding travel as they have done and are trying to address.
- There was also some discussion around the lack of equity in travel funding in the current system; NxStage patients are able to have travel funded, often at significant expense, and throughout the world. However, in-centre patients, are limited to travel where there are reciprocal arrangements in place e.g. Europe or reimbursement to tariff value in private units in Europe only.

5.1.4 Concordance

- Most units were keen to explore ways of improving patient compliance. Some had already employed explicit patient contracts detailing activities expected to be undertaken. Enforcing these terms is however more difficult.
- Management of the patient at home where there are concerns about patient safety were discussed. Classification of ‘unsafe’ was agreed to be complex. Removal of a patient’s ‘privilege’ to dialyse at home as ‘punishment’ was felt to be difficult by all teams.
- It was agreed by all, particularly the patients present, that ultimately, in a patient with capacity, it is their decision to comply with a treatment plan or not. The role of the team is to do all that they can to facilitate engagement and to ensure that the patient is aware of the consequences of non-compliance with agreed treatment plan. However in some circumstances, for instance prolonged non-contact, it may be reasonable to take action to prevent supply delivery and write to the patient insisting on further contact to ensure safety.

6 Peritoneal Dialysis

See presentations in attachments

Issues arising from data submitted and discussion

- There remains variation in percentage of dialysis patients using PD across region. There is no defined target for this but increases in lower performing units is probably appropriate.
- Assisted APD is said to be established at all centres but there appears to be considerable variety in usage. Units with lower AAPD usage may wish to review if expansion is required taking advice from centres with higher usage. It is acknowledged that provision through external companies is expensive and that establishment of in-house solutions is not easy.
- There is variation across the region as to relative proportion of patients using CAPD vs APD. Unit practices may merit further exploration.

- Measurement of dialysis clearance, residual renal function and ultrafiltration is variable and units with lower performance need to address to meet national guidance. Staffing within each unit should allow for this time consuming evaluation.
- Catheter insertion complications showed variation across the region; DGH appeared to have significantly more primary non function than other units and this should be reviewed in the unit. UHNM did not provide data in this category and data should be collected and reviewed in the context of other units
- Peritonitis rates vary across the region and units with higher rates need to address this. Adequate staffing levels are important to ensure ongoing patient education and support around infection control measures. There may be some concerns around nature of data submitted indicating unlikely to be truly 'rolling years'.

Areas discussed

- Staffing levels and staff retention
- Staff education
- Infections
- Catheter insertion

6.1.1 Staffing levels and staff retention

- The group discussed the benefits of holding recruitment fairs not only to recruit but to raise profile for renal.
- Recognising that experienced staff extremely important within home therapy services to allow expert patients consistent and experienced advice. Often not recognised in a Trust generic model.
- An issue was raised regarding redeploying nurses out of PD into other areas within the Trust, it was agreed that a rotational approach should be put forward to the senior management team to prevent gaps in services.
- Having issues recruiting specialist trained PD nurses. Group discussed generalising adverts going forward and providing specialised training in house.
- To acknowledge that employing B5s is a national problem and to use existing staff more effectively, for example using B3 HCAs.
- Dieticians and Psychologists being stretched to full capacity and some units are without completely. Group agreed this was a big gap in service and has major impact on patient experience and quality of care.

6.1.2 Staff Education

- SpRs highlighted variation within the region of training and exposure to PD services. It was agreed that units need to prioritise rotation of clinics so SpRs are able to attend PD clinics.
- The geography of some PD units within the region was also discussed as an issue for SpRs to get knowledge and exposure of this service.
- Specialist knowledge and training was also raised as an issue, there is an online course that can be completed to provide this: http://www.pdacademy.org.uk/.
- Rotation of nursing staff as previously mentioned may help nursing knowledge of the service

6.1.3 Infection

- Infection remains an issue with all units across the West Midlands with varying rates of peritonitis and exit site infections

- Data is collection via the UKRR dashboard but there is still a concern that under or over reporting happens
- Infection rates are controlled by attention to detail and support by PD staff. Staffing pressures can make community visits more difficult and risk increase infection. This was raised as a current issue by one unit and as a concern by several
- The group felt that the ISPD guidelines for rates of peritonitis should be the floor as opposed to the ceiling we should be aiming for in the WM
- There is discrepancy in following ISPD guidelines across the WM and we should share good practice from units that have a low incidence of peritonitis
- Specifics discussed were gram negative exit site infection, duration of treatment and recurrent peritonitis.

6.1.4 Catheter Insertion

- Catheter insertion is carried out in a variety of manners across the WM
- Most units have surgical operators but the extent of this varies by unit – some have dedicated surgeons and some have to refer via the on call geberal surgery lists
- The rate of primary failure is extremely variable in units across the WM and should be reviewed in light of data presented. National collection is also now underway
- Some units have access to medical operators but several do not
- Pre procedural pre-meds and constipation treatment varies across the region
- Some centres are very innovative with their approach to catheter salvage in the case of primary failure and it was acknowledged that this is down to operator expertise
- The group welcomed the idea of WM PD forum to share good practice

6.1.5 Acute Kidney Injury (AKI)

It is also recognised that there is an ongoing issue regarding AKI and was agreed at the KQuIP/ UKRR Regional day that a West Midlands AKI Group should be formed to consider the local data, practices and policies to agree the regional approach and implement best practice in the regional units. This is therefore ongoing and being addressed separately from the peer review.

7 Transplant

See presentations in attachments

<u>Highlights of Good Practice</u>

- NHSE Transplant dashboard
- Improving pre-emptive listing and transplantation
- Post-transplant BP control in many units
- Preparations for RRT in failing transplants

<u>Areas most highlighted for improvement</u>

- Missing Data
- Significant variability in pre-emptive listing despite TF project
- Variation in access to SPK
- Variable post-transplant care

- Training for all in transplantation

Summary of Data presented

- All units except one (Coventry) are now achieving at or above England average in the NHSE dashboard for documented decision about transplantation at commencement of renal replacement therapy.
- There is still variability in transplant listing; 2 units (RWT and HEFT) appear to have lower rates of pre-emptive listing and higher median times to listing.
- There are still variable pre-emptive transplantation rates with HEFT, RWT and Dudley appearing low.
- Across most units 40-50% of listed patients are suspended (lower in Dudley)
- Across most units 40-60% of UHB annual review forms are filled in. However units are reporting much better with their in house annual review processes on the whole (except UHB).
- The number of post-transplant patients varies from 94-1217 with repatriation rates varying from 34% to 90%.
- Achievement of BP targets was variable although better than currently reported UKRR reports. HEFT and RWT did not return data.
- Complication rates are difficult to compare due to small numbers. UHNM appeared to have a high rate of BK, biopsy proven acute rejection (BPAR) and post transplant diabetes mellitus (PTDM) (although low rate of graft loss). Coventry did not return full data and RWT didn't return any.
- Across the region 50% or more of failing transplants had definitive access which is better than published elsewhere
- Some definitions gave highly variable results (e.g. assessment for ABOi) due to being non-specific.

Areas Discussed

- SPK rates: There appears to be variability in the numbers of patients from each unit receiving an SPK transplant. This needs further exploration locally where rates appear to be low.
- Post-transplant care: Access to specialist clinics, expertise and staff (e.g. post - transplant specialist nurses) was variable. It was agreed that all units looking after post-transplant patients should have a specialist nursing available.
- Training: There was general agreement that we needed to strengthen training as a network
- Tacrolimus turnaround times: Shrewsbury had turnaround times which were too long as they were dependent on another laboratory. Suggestion made to liaise with their dept and consider sending to a different laboratory
- Audit definitions: It was clear that some had caused confusion or were interpreted variably e.g. BP and % of patients assessed for ABOi and AI transplantation
- Emotional support/psychology and social work: There was widespread agreement that this was lacking and was very variable
- Tensions in relationships: the balance between Transplant Units working together and yet individual and competing was apparent in discussions
- Suspended patients: All units had high levels and it was agreed each unit needed to look into this (as nationally)

- Cardiology workup: There is variability in access to timely cardiology workup. The idea of referring to other units was discussed

Topics discussed in more detail

7.1.1 Repatriation of patients to parent units

- There is variable practice.
- With ever increasing transplant numbers the transplant units cannot continue to follow up all post-transplant patients.
- Patients generally prefer to be looked after close to home.
- Transplant units and patients need to feel there is sufficient local expertise to look after patients
- Optimal time for transfer may vary between units
- Most units should be able to take patients at 3 -6 months at latest with right infrastructure
- Some units could take patients at discharge or 6 weeks
- As a minimum each unit should have
  - A lead consultant and nurse for transplantation
  - Access to a specialist nursing team for patients to contact
  - A specialist transplant clinic
  - Mechanism of seeking advice from transplant centre as needed
- Further resources could include: rapid blood turnaround, histology, interventional radiology, etc
- It was agreed to develop a WM service specification for what would constitute a safe service for transfer at different time points.
- Referring units agreed to find out views of patients on the wait list as to what they would prefer
- Transplant units need to review how easy it is for units to get advice when needed
- When repatriating, transplant units need to send discharge letter and clinic letters
- As part of the on-going audit and education process individual unit outcomes should be monitored
- There was discussion that the new transplant tariff may impact on options available in terms of timing of transfer
- For units with large numbers of patients to be repatriated consideration needs to be given as to how to manage the increase in capacity
- Patient choice should be respected but patients given confidence to transfer if appropriate

7.1.2 Live Donor (LD)

- Noticed fall in numbers- which mirrors national picture
- Some themes noted e.g. recipient will not take from child, but barriers not understood
- Units have noticed high rate of donors not proceeding through process for various reasons.
- Discussion of balance of education and support i.e. making sure patients and donors aware of options and realistic risk
- Discussed psychological support
- Some units suggested that once LD suitable the patient is taken off list. Others felt this is individual patient decision.

- NHSBT funding for posts is coming to an end. Smaller units may struggle
- There was discussion that we could consider focusing LD workup on a few units rather than all.
- There was agreement to have further improvement event in spring around LD issues.

8 Miscellaneous

See presentations in attachments

(Missing Presentations from UHB, Dudley and UHNM)

Issues arising from data submitted and discussion

- Psychology and social work input. Psychology dealt with in HD section. Specific renal social work/welfare advice not available at UHNM, SATH or DGH.
- Formal patient feedback sought in all units. Five performed national PREM in 2016 with all doing so in 2017
- Specialised support areas lacking in some units: all units have access to plasma exchange. Pregnancy less well covered and should be addressed in areas without formal input. Transition from children's services patchy as often transitioned to UHB when live nearer to other units. Needs ongoing work.
- Transport discussed. Differing criteria for eligibility across region with different providers. All commissioned via CCG and not renal units. All had some concerns.
- Renal patient view uptake variable across region. Units need to ensure easily available for all who want and encourage usage.
- Patient letters; not routinely available to all patients. This should be the case.

Areas discussed

- Recruitment/ retention and succession planning for renal nursing
- Psychology and welfare services
- Transport

8.1.1 Recruitment/ retention and succession planning for renal nursing

- Issue raised about on-call dialysis staff, one unit reported finding it extremely hard to retain these members of staff
- Discussion about recruitment of international nurses and agreed that retaining these staff was sometimes an issue as they are a very mobile workforce and eventually move to London to work.
- It was agreed that a West Midlands wide recruitment day would be useful to promote vacancies and renal service for future nurses
- Group agreed that a 'support and buddy' system would be beneficial to further education. Need to ensure the member of staff is allocated the same shifts as mentor

8.1.2 Psychology and welfare services

- Requirement for psychology and welfare services to support kidney disease care is explicitly included in NHSE service specifications (A06/S/a, A06/S/c, A06/S/d, A06/S/e (https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-a/a06/)
- Currently no psychologists at HEFT, SaTH or UHMN (business case submitted at UHNM).
- May help to gather evidence of why this service is beneficial. Virginia Mason Institute to support? https://www.virginiamasoninstitute.org/
- In those trusts which do not currently provide psychology services for renal services, it was suggested that there might be scope for additional training of other staff (e.g. nursing) to give psychological support to patients as an interim measure
- Discussion also took place around whether access to psychologists for renal patients might be achievable via other services e.g. oncology
- SaTH Trust reported that it has no access to social workers or other welfare services for renal patients. UHNM also have no dedicated social work input or renal services.
- The importance of these services for renal patients was widely accepted with key roles in enabling discharge of in-patients with complex social care needs and in supporting out-patients, including patients on dialysis
- Novel models for welfare support including contracting third sector organisations were discussed. UHB contracts Auriga Services (https://www.aurigaservices.co.uk/)

8.1.3 Transport

- WMAS was contracted (by local CCGs) to provide NEPT for renal patients at most centres in the region. UHNM and SATH were exceptions where NEPT was delivered by other providers. At UHMN, E-Zec Medical Transport Services Ltd provide transport except for patients attending Crewe satellite dialysis unit which is served by WMAS.
- There were multiple reports of problems with NEPT for renal patients across the region.
- With the exception of UHNM and SaTH, eligibility to NEPT for renal patients is subject to restriction which is often problematic. Restrictions are implemented as part of the contract terms stipulated by CCGs.
- The group believed that patients using NEPT for travel to and from dialysis had significantly different needs to other users of NEPT (e.g. those attending OP appointments) which was not adequately recognized.
- Nick Flint from QEH Birmingham KPA gave an update on transport from the patient perspective and the role of KPAs in representing the patient voice in discussions with CCGs and ambulance services.

9 Summary/ Next Steps

CKD

Across the region models for advanced CKD care differ depending on size of cohort of patients and geographic location. There is however widespread availability of patient education programmes. Variation exists in uptake of home therapies and pre-emptive transplantation which will be addressed in other work streams. Units need to ensure methods in place to ensure timely referral but that care is organised so that it can be delivered efficiently to those most likely to have progressive renal disease.

Home therapies

There is variation in rates of home therapy use across the region. This also reflects national variation. All units valued the discussion possible on the peer review day and will be able to continue to learn from each other. This will be an ongoing focus of QI within the region. A regional home therapies day has been organised for February 15th 2018.

Transplantation

This review continues to highlight lower transplant rates in the region when compared to national rates. It also indicates differences in referral for pre-emptive transplantation, pancreas kidney transplantation and immunologically complex transplantation.

Repatriation of patients with kidney transplants for care close to home is variable. This needs addressing in the region to ensure effective transplant care close to home if this is what the patient desires. A WM wide service specification for effective repatriation of renal transplant patients will be produced.

There is ongoing QI work locally in the Transplant First programme which has now been nationally adopted

A regional transplant interest group (TIG) will also be formally established for QI purposes with meetings three times a year to include education and focused audit as well as ensuring appropriate specifications of care for all units. The first meeting is scheduled for April 26th and will focus on live donation.

Dialysis

Hepatitis B vaccination is very variable and a vital part of provision of control against blood borne virus. A regional working group will be set up to help co-ordinate and ensure all units are working as efficiently as possible in this area.

Dialysis patient transport remains a considerable issue for many patients. The region will continue to support patient groups and units to work with the relevant CCGs and providers to ensure a sensible service locally. In addition the region will support any national work in this area.

Vascular access rates within the region are generally very good with all units at national average or above. The two lower performing units may wish to engage with higher performing units and assess whether performance can be improved.

Infection is the major cause of death in dialysis patients. All units should record all bacteraemias in this group, not just MSSA/MRSA and work hard to limit.

Nursing roles and competencies differ across the region and discussion may enable differing methods of working within units.

Acute kidney injury

This was removed from the original areas to be reviewed in this process and is being addressed in a separate regional working group.

Patient feedback

This is now collected by all units via the national PREM for dialysis patients but not necessarily for all other categories. Such patient feedback should be routinely collected and analysed promptly with adjustment of service models if necessary.

Data

All units struggled to obtain aspects of data for this review, with more of a problem at some units and in some areas than others. All of the datasets were agreed by the units are being reflective of national guidance before collection. All units agreed that data is not as routinely reviewed as it could be and that this process has been very useful in highlighting this in specific areas

Future events

Feedback from the process was positive with an agreement that such a process will be held every two years, with the next event in 2019. Before this event there will be review of the suggested data sets with adjustment as needed, based on experience of this event. It was also noted that a larger organising group would be helpful reflecting the considerable workload.

10 Appendix

10.1 Appendix 1, Local policies, procedures and patient information

https://www.thinkkidneys.nhs.uk/kquip/west-midland-peer-review-day/

10.2 Appendix 2

Peer Review Terms of Reference

10.3 Appendix 3

KQuIP/ UKRR Regional day, West Midlands Region Agenda

10.4 Appendix 4

UKRR Data Presentation

All other presentations and information from the KQuIP/ UKRR Regional day, West Midlands Region can be found using the following link:
https://www.thinkkidneys.nhs.uk/kquip/west-midlands/

10.5 Appendix 5

Datasets submitted for Peer Review

10.6 Appendix 6

Example of real time feedback sheet

11 Glossary

AKI- Acute Kidney Injury

AAPD- Assisted automated peritoneal dialysis
APD-Automated peritoneal dialysis

ABOi- ABO incompatible

ANPs- Advanced Nurse Practitioners

BPAR- Biopsy Proven Acute Rejection

CAPD-Continuous Ambulatory Peritoneal Dialysis

CCGs- Clinical Commissioning Groups

CKD- Chronic Kidney Disease

DGH- Dudley Group Hospitals

eGFR- Estimated Glomerular Filtration Rate

ESA- Erythropoiesis Stimulating Agent

ESKD- End Stage Kidney Disease

Hb Level- Haemoglobin Level

HCAs- Health Care Assistants

HD- Haemodialysis

HEFT- Heart of England Foundation Trust

HHD- Home Haemodialysis

ISPD Guidelines-International Society for Peritoneal Dialysis

KPA- Kidney Patient Association

KQuIP- Kidney Quality Improvement Partnership

LD- Live Donor

MDT- Multi Disciplinary Team

National PREM- National Patient Report Experience Measures

NEPT- Non Emergency Patient Transport

NHSE- NHS England

NICE Guidance- National Institute for Clinical Excellence Guidance

PD- PeritonealDialysis

Peer Review- Peer review is the evaluation of work by one or more people of similar competence to the producers of the work (peers). It constitutes a form of self-regulation by qualified members of a profession within the relevant field. Peer review methods are employed to maintain standards of quality, improve performance, and provide credibility

PTDM- Post Transplant Diabetes Mellitus

QI- Quality Improvement

RRT- Renal Replacement Therapy

RWT- Royal Wolverhampton Trust

SATH- Shrewsbury and Telford Hospital

SPK- Simultaneous pancreas-kidney

SpRs- Specialist Registrars

Tangri risk equation- Using the patient's Urine, Sex, Age and GFR, the kidney failure risk equation provides the 2 and 5 year probability of treated kidney failure for a potential patient with CKD stage 3 to 5

UHB- University Hospital Birmingham

UHCW-University Hospital Coventry and Warwickshire

UHNM- University Hospital North Midlands

UKRR- UK Renal Registry

West Midlands Renal EAG- West Midlands Renal Expert Advisory Group

WM- West Midlands

WMQRS-West Midlands Quality Review Service