

Renal Services Peer Review Visit

Barts Health NHS Trust

Visit Date: 11th and 12th May 2016

Report Date: September 2016

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INTRODUCTION

This report presents the findings of the review of renal services at Barts Health NHS Trust that took place on 11th and 12th May 2016. The purpose of the visit was to review compliance with the West Midlands Quality Review Service (WMQRS) Quality Standards for Services for People with Progressive and Advanced Chronic Kidney Disease (Version 3).

The aim of the standards and the review programme is to help providers and commissioners of services to improve clinical outcomes and service users' and carers' experiences by improving the quality of services. The report also gives external assurance of the care, which can be used as part of organisations' Quality Accounts. For commissioners, the report gives assurance of the quality of services commissioned and identifies areas where developments may be needed.

The report reflects the situation at the time of the visit. The text of this report identifies the main issues raised during the course of the visit. Appendix 1 lists the visiting team which reviewed the services at Barts Health NHS Trust. Appendix 3 contains the details of compliance with each of the standards, and the percentage of standards met.

This report describes services provided or commissioned by the following organisations:

- Barts Health NHS Trust
- NHS England: Specialised Commissioning

Most of the issues identified by quality reviews can be resolved by providers' and commissioners' own governance arrangements. Many can be tackled by the use of appropriate service improvement approaches; some require commissioner input. Individual organisations are responsible for taking action and monitoring this through their usual governance mechanisms. The lead commissioner for the service concerned is responsible for ensuring action plans are in place and monitoring their implementation, liaising, as appropriate, with other commissioners, including commissioners of primary care. The lead commissioner in relation to this report is NHS England: Specialised Commissioning.

ACKNOWLEDGMENTS

West Midlands Quality Review Service would like to thank the staff and service users and carers of Barts Health NHS Trust for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. Thanks are also due to the visiting team and their employing organisations for the time and expertise they contributed to this review.

ABOUT WEST MIDLANDS QUALITY REVIEW SERVICE

WMQRS is a collaborative venture between NHS organisations in the West Midlands to help improve the quality of health services by developing evidence-based Quality Standards, carrying out developmental and supportive quality reviews – often through peer review visits, producing comparative information on the quality of services and providing development and learning for all involved.

Expected outcomes are better quality, safety and clinical outcomes, better patient and carer experience, organisations with better information about the quality of clinical services, and organisations with more confidence and competence in reviewing the quality of clinical services. More detail about the work of WMQRS is available on www.wmqrs.nhs.uk

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BACKGROUND

Renal services at Barts Health NHS Trust provided care for patients from across north east London, Essex and the surrounding areas. The Renal Centre at The Royal London Hospital formed the hub of the service, providing a full range of treatment options for patients with kidney disease, including haemodialysis, peritoneal dialysis and kidney transplantation, and including a 'blood group and Human leukocyte antigen (HLA) incompatible' programme. The renal service also provided support to a range of hospitals across the area, including the provision of six haemodialysis satellite units.

Service (as at May 2016)	No. Patients	No. Stations
Haemodialysis (HD)		
- Main Unit	434	88
- Satellite Units:		
Barts Health NHS Trust		
○ Whipps Cross University Hospital – Main	88	18
○ Whipps Cross University Hospital – Lister	77	17
○ Whipps Cross University Hospital – Patience	85	18
○ Newham University Hospital	94	18
Barking, Havering and Redbridge University Hospitals NHS Trust		
○ Queen’s Hospital, Romford	94	19
○ King George Hospital, Ilford	140	30
- Home HD	25	-
Total haemodialysis	1,037	
Peritoneal dialysis		
○ CAPD	17	
○ APD	187	
○ aAPD	21	
Total peritoneal dialysis	225	
Transplant follow up (local care)	1,106	
Number of transplants (previous 12 months)	119	
Permanent dialysis access	58%	
In-patients	No. Beds	
The Royal London Hospital – Wards 9E and 9F	44 beds 4 High dependency beds	

VISIT FINDINGS

This report describes the findings relating to renal services provided across Barts Health NHS Trust, including The Royal London Hospital. The visiting team met patients and carers, viewed facilities and talked to staff at The Royal London Hospital renal unit and satellite units at Whipps Cross University Hospital and Queen's Hospital, Romford (Barking, Havering and Redbridge University Hospitals NHS Trust). The 'renal services' findings are likely to apply to all satellite units managed by Barts Health. Additional issues in the satellite units not visited by the review team will not have been identified.

General Comments and Achievements

Renal services at Barts Health were provided by a friendly, welcoming and committed team of clinical staff who were clearly enthusiastic about providing the best possible care. Feedback from patients who met the review team was positive, especially about the care provided in the satellite units. Medical and nursing leadership was strong, and the team encouraged the development of the team members' skills. For example, a healthcare assistant was responsible for bed management – a role which would be taken by a registered nurse in many Trusts.

The Barts renal service was very large, with over 1,000 patients on dialysis at the time of the review. The number of patients was increasing significantly, because of the age profile of the local population and the high prevalence of diabetes, and new satellite units had to be opened regularly in order to manage capacity.

The service had a clear vision for personalised, patient-centred care, with a concentration on care of people with diabetes and renal disease and on the prevention of renal disease. The service had a strong commitment to research, and entry into clinical trials was high.

Two patient groups were running: the Kidney Patient Association worked to raise awareness and funds for the services and the Renal Patient Forum was involved with discussions about the running of the services.

The service was working hard to address the challenges it faced, including improving links with primary care by, for example, running a 'virtual clinic' using access to GP databases, improving the transport experience for renal patients and reducing waiting times for transport. Good competency-based training programmes for Allied Health Professionals (AHPs) and nurses had been developed and implemented. Despite staff turnover, the service had managed to retain experienced nurses within each specialist area.

Facilities at The Royal London Hospital and at Queen's Hospital, Romford were new and purpose-built (although see below in relation to some aspects of the facilities at The Royal London Hospital).

In relation to the satellite units visited, the three satellite units at Whipps Cross University Hospital were welcoming, all patients had a named nurse and patients were positive about the care they received. Patients at Queen's Hospital, Romford were also very pleased with their care and with the modern unit and facilities in which dialysis was provided. Reviewers were impressed by the strong leadership of the service at Queen's Hospital, Romford.

Good Practice

- 1 A 'virtual' chronic kidney disease (CKD) clinic took place for Tower Hamlets patients. A consultant nephrologist accessed GP records and monitored patients whose glomerular filtration rate (GFR) was decreasing. The management of these patients was then discussed with their GP. This service did not yet cover all the Barts Health catchment area, but there were plans to extend it beyond Tower Hamlets.
- 2 A very good database of information on renal patients was in place and was used for audit, for recording of governance meetings and protocols, and for research, as well as for patient care.
- 3 All satellite units had free parking for renal patients.
- 4 Patient involvement was embedded in the running of the service. The Renal Services Board included a patient representative. The Renal Patient Forum members visited all satellite units in order to get feedback

from patients. Senior managers from the Trust and the renal service attended meetings of the Patient Forum. A peer support programme was in development.

- 5 The dermatology service for renal transplant patients was excellent. Photographs of skin lesions were taken and sent to the dermatologist, and a response was received within one day. The number of clinic attendances had reduced because of the rapid access to dermatological opinion.
- 6 Two consultant-led biopsy lists were held each week for out-patients / day cases, and Monday to Friday consultant supervision of all in-patient biopsies was in place. This action had been taken in response to audit data showing a higher rate of complications following in-patient biopsies, which had previously not been a consultant-led procedure. Biopsy results were available quickly.
- 7 A rolling programme of audit was in place, which included a monthly presentation afternoon that all staff could attend because clinical commitments were not scheduled. This linked with a strong focus on team-building, service innovation and service re-design.
- 8 Consultant presence on the in-patient wards was very good. There were daily joint consultant ward rounds at patients' bedsides, and consultant board rounds in the afternoon. Transplant and all general nephrology patients had consultant review twice a day, seven days a week.
- 9 The four-bedded renal assessment unit ran very efficiently, with a proactive approach to patient management from highly trained and committed staff. This unit improved the patient experience, provided care more quickly and had a positive impact on the in-patient service. For example, radiological thrombectomy for treatment of access failure secondary to thrombosis was available within 24 hours, thereby avoiding in-patient admission.
- 10 Arrangements for transition from Great Ormond Street Hospital to adult services were robust. Guidelines had been agreed, 'ready, steady, go' information for young people was in use, the link nephrologist from The Royal London Hospital attended a joint clinic for children approaching transition to adult services and arrangements for shared care continued for two years after transfer to adult nephrology services.
- 11 Patients at the satellite unit of Queen's Hospital, Romford were all seen each month by the multi-disciplinary team (consultant, consultant nurse, anaemia nurse specialist and dietician) with the monthly blood results. Six-monthly holistic reviews were also undertaken.

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Immediate Risks

Whipps Cross University Hospital: Water bacterial levels and HDF treatment¹

Water bacterial levels at Whipps Cross were approximately 10 times higher than the recommended water quality standards. Despite the known high bacterial levels, the water treatment reverse osmosis (RO) equipment (CWP60 RO) was still being used to support haemodialfiltration (HDF) treatment, including the generation of on-line fluid. The service's Standard Operating Procedure said that HDF would not take place

¹ **Trust response:** 1. All machines are fitted with endotoxin retentive filters that are changed in accordance with the manufacturer's guidelines. 2. We have consistently tested post-endotoxin filter actual dialysate against the expected 2016 clinical practice guidelines prepared by the Renal Association and the Association of Renal Technologists standard for ultra-pure dialysate which states "ultra-pure dialysate shall contain a total viable count of less than 0.1 CFU/ml and an endotoxin concentration of less than 0.03 EU/ml". 3. We have taken random samples from the machines in the affected area and all samples taken have met the standards for ultra-pure dialysate. Please note we are not performing HDF on all machines. 4. Additionally we have taken water samples from the outlet of every R.O. and had a full chemical analysis performed (Group 1 & 2 according to renal association guidelines). All chemical results from the R.O.s have met the required standard for water used for dialysis. We will halt online haemodialfiltration until the lasting solution is enacted. Where on-going OL-HDF is necessary for clinical care, patients will transfer to Patience Dialysis Unit on the Whipps Cross site to receive care. We do not believe that any patient has come to harm. In addition to these immediate actions, we have a clear one month implementation plan that will resolve the risk (i.e., by June 19th 2016) until this point we will ensure repeat testing.

WMQRS Response: The actions address the immediate risk identified.

if there was a risk to water quality, however the treatment and generation of on-line fluid had continued. Regular testing of the water quality and dialysate fluid for endotoxins were in place, but the arrangements did not provide adequate protection against endotoxins and were not 'fail-safe'.

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Concerns

1 Pre-emptive transplantation rate

The pre-emptive transplantation rate was low (less than 10%). The pathway for referral had been audited some time ago and reviewers were given different views on the work-up time, with an average of 12 weeks. The main reasons given for the low rate were delays in donor work-up and a high rate of people presenting late and unknown to the renal service prior to the start of dialysis. Plans to achieve the 2020 Living Donor Kidney Transplantation Strategy were not yet in place.

Reviewers also noted that the first call from potential live donors was taken by an administrative member of staff who then went through a registration questionnaire. Quality assurance of this stage of the process was not clear. Live donors were only given a hospital patient record number when they were accepted by the unit. Reviewers considered that it may be helpful for calls to be directed to a more senior healthcare professional.

The Trust arrangements for overseas donors relied on the recipient identifying the donor, which may leave the agreement open to abuse. Also, if potential donors came from an area where there was no doctor then they would not be considered for donation. Reviewers acknowledged the challenges of exploring the suitability of overseas donors within a safe and ethical framework, but nonetheless suggested that the Trust policy on overseas donors may benefit from review.

2 Low rate of arteriovenous fistula / graft

The proportion of haemodialysis patients dialysing through arteriovenous fistula or graft was low (58%). This was of concern because it did not meet the Renal Association guideline of 80% of patients with arteriovenous fistula or graft and because the bacteraemia rate at dialysis units was reported to be high. The service was trying to increase vascular access rates and surgeons were visiting satellite units. Where this was working well prevalence rates were higher. Reviewers were given inconsistent versions of the vascular access pathway, with time from referral to surgical procedure ranging from four weeks (surgeons) to 12 weeks (nephrologists and specialist nurses). This issue may be related to comments (see 'further consideration' section below) about the surgical pathway, and links with surgical services.

3 Access to psychological support

Limited psychology support was available, with only one psychologist and one assistant psychologist with time allocated to the renal service. The waiting list for psychological therapy was nine to 12 months. Patients from satellite units were also signposted to their GPs for earlier community referrals, although support was variable. Priority was given to in-patients, especially 'new starters', and the liaison psychiatry service was contacted if the psychologist was not able to respond quickly. This issue affected staff as well as patients, and there was limited input into staff training about the care of patients with addiction or psychological problems or those who become distressed and disturbed.

4 Social work support

The service had no social work support with time allocated for work with renal patients. This may contribute to delays in the discharge of patients with renal disease. A social worker was available who would complete section 5/2 forms for people from the local area, but other patients had to be referred to the Trust discharge team, with long delays before a response was received. Satellite units were visited every six months by Citizens Advice for the provision of benefits advice and any patient could contact

Citizens Advice. Reviewers did not consider that this replaced the need for a social worker for renal patients.

5 Facilities at Whipps Cross University Hospital satellite units

Facilities at Whipps Cross satellite units were not fit for purpose. Space was insufficient, with dialysis stations too close together. The reviewers suggested that the available space was suitable for 14 stations rather than the 18 in use at the time of the visit. The environment was generally poor, including flooring that was lifting. Concerns about patient privacy and dignity were raised when reviewers observed a hospital in-patient waiting for dialysis in the middle of the unit in a hospital gown. Additional dialysis stations could not be curtained off and the unit relied on the use of screens. The windows were not frosted, but there was a plan for this to be done. Neither waiting room had space for wheelchairs, leaving patients waiting in corridors. The units were very hot, and reviewers were told of problems with pipes leaking into paediatric and cardiac services on the floor below. Reviewers were also told that the lift closest to the satellite units broke down on an approximately weekly basis, requiring patients to go a very long way round to access the units. A plan to re-develop the site was under discussion to consider the feasibility of relocating the service to a purpose built unit.

6 Satellite units: In-patient and out-patient dialysis together

Reviewers were concerned that in-patients and out-patients were dialysed together in both of the satellite units visited, leading to a lack of privacy and dignity for in-patients. Side rooms were available at Whipps Cross University Hospital that could be used for the dialysis of in-patients.

7 Equipment maintenance, calibration and water testing

Maintenance agreements with suppliers for planned preventive maintenance of reverse osmosis machines were in place for most machines. Some reverse osmosis machines did not have maintenance contracts, and the renal technology department did not undertake manufacturer-recommended maintenance on these machines. Electrical safety testers had not been calibrated for four years (rather than annual calibration which would be expected). Also, the water testing Standard Operating Procedure (SOP) did not reflect the latest national guidance on water testing. The SOP was drafted in 2012, did not have a review date and had not been reviewed since 2012.

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Further Consideration

1 Duration of dialysis

The service did not have a strong focus on duration of dialysis, and four hours of dialysis at each session was not routine, with many patients receiving only 3.5 hours. This was documented in individual patients' notes, but exception reporting and monitoring of the total number of patients not receiving four hours of dialysis was not yet in place. In the satellite units only approximately 50% of patients were receiving four hours of dialysis. Reviewers commented that there was general acceptance of dialysis sessions of less than four hours, rather than this being an exception.

2 Nurse staffing

The level of nursing vacancies on the in-patient wards was high, and difficulty recruiting nurses was reported. Some of the planned service developments were being hindered by a shortage of staff. The in-patient wards had a high number of agency nurses, which made it difficult to ensure all staff had and maintained appropriate competences. A recruitment drive was planned, and a local training programme had been developed to help to ensure that competences were in place. Reviewers considered that the high number of agency nurses must be having an impact on the quality of patient care, including the provision of advice and information for patients prior to discharge.

The nursing turnover rate on The Royal London Hospital in-patient wards and dialysis units was also high. Rotation of band 5 nurses through all areas of the renal service had been introduced to try and increase retention. Four practice development nurses had been employed with the aim of supporting staff training and development and improving retention.

There was some variation in skill mix within the satellite units. The nurse to patient ratio was 1:5 on all units, but at Whipps Cross University Hospital only one healthcare assistant (HCA) could put patients on dialysis whereas at Queen's Hospital, Romford all HCAs could do this. A more systematic approach to skill mix may be helpful in the main unit and the satellite units. Reviewers noted that the satellite units made little use of agency staff, with bank nurses being used to cover most shifts and with screening of agency nurses' competence before they started work on the units.

3 Patient education and involvement

In general, reviewers considered the service had the potential for a significant improvement in patient education and involvement. Relatively little patient information was available, and some of the information seen by reviewers was old (for example, some information at Whipps Cross University Hospital was over 10 years old), had little emphasis on self-care and was not written in plain English. Relatively little information was available in languages other than English. The Royal London Hospital was limited in where information could be displayed, but even in the display areas there was little information available. A clear process for review and replacement of patient information was not evident and reviewers saw little evidence of other patient information and education initiatives. Only about 10% patients were using Renal Patient View, and satellite unit patients who met the visiting team were not aware that this was available. Peer support and advocacy were beginning to be developed, and reviewers encouraged continuation of this work. Reviewers also noted that the dieticians had developed information for patients, some of which had been translated into other languages.

4 Surgical pathway

The pathway of care for renal patients needing surgery was not clear. Reviewers were given differing versions of the surgical pathway and the pressures on it, and inconsistent views on the waiting time for surgical vascular interventions in the event of the failure of an arteriovenous fistula / graft after radiological intervention. The role of the weekly multi-disciplinary team meeting was not clear. Similarly, reviewers were told both that there was lots of theatre space and that patients' operations were cancelled regularly unless their procedure could be done as a day case. Delays to surgery had resulted in alternative strategies being developed, for example, urokinase protocols for dysfunctional peritoneal dialysis catheters. This problem may be related to the 'lock down' of theatre lists three weeks in advance – this was challenging because of the unpredictable needs of renal patients. A dedicated theatre list was available for transplantation, but no other theatre time was specifically allocated to renal patients. The Trust protocol stated that all renal transplants should go to theatre within six hours, but this was not being achieved. Audit of the surgical pathway had not yet been undertaken and so audit data to confirm the length of any delays and the reasons for them were not available.

The amount of surgical time available to the renal service appeared insufficient for a haemodialysis population of over 1,000 patients. Responsibilities for the different aspects of the renal pathway were not clear. Reviewers were told that the pathway differed depending on which surgeon was involved. Arrangements for dealing with urological complications, such as ureteric strictures or previous urological complications, were not clear. Only one of the five transplant surgeons was available to meet reviewers on the day of the review visit, and a clearer picture may have emerged if more surgeons had been available. Reviewers were also aware that the number of surgical registrars in post at the time of the visit was only two, out of five, with a third appointment expected in the near future.

Reviewers suggested that the identification of a lead surgeon with responsibility for liaison with the renal service and for coordination of surgical services for renal patients may be helpful.

5 Transplant pathway and transplant coordinator time available

- a. Several aspects of the transplant pathway were not clear:
 - i. The process for the review of patients on the transplant list was not clear, particularly in relations to the availability of potential living related donors and consent for virology and storage for tissue typing. Only two hours was allocated in the surgeon's job plan for the review of patients on the transplant list. Reviewers supported the ongoing work to implement the Standard Operating Procedure of ensuring the documentation of annual reviews by nephrologists, and also the implementation of regular 'virtual reviews' by surgeons alongside the bi-annual face-to-face clinical reviews.
 - ii. The time needed for cardio-vascular work-up prior to transplantation was not clear. The protocol for cardiovascular work-up was brief and expected timescales were not clear. Audit data for this pathway were not available and patients who met the visiting team reported varying experiences. A dedicated renal cardiology clinic had been implemented, the pathway may therefore have improved and some of the patient experiences may have been out of date.
 - iii. Arrangements for transplant donor follow up were not robust. The Trust policy was that donor follow up should take place at two weeks, six weeks and one year. The two week and six week follow ups took place as planned. After the six week check, donors were sent a letter with a date for the annual follow up. Attendance rates for the annual check were very low despite the process of sending appointment reminders by text to patients nearer the time.
- b. Only 0.5 wte transplant coordinator was available to manage and maintain the transplant list. Reviewers considered that this was insufficient given the size of the service.

6 High number of patients presenting late to renal services

Approximately 40% of patients starting dialysis were known to renal services for fewer than three months before the start of treatment. Staff were aware of this problem and work with primary care (see good practice section of this report: 'virtual CKD clinic') was aiming to address this.

7 Facilities at The Royal London Hospital

Facilities for peritoneal dialysis patients at The Royal London Hospital comprised two clinic rooms, one treatment room, part of an office and part of the training room. The lack of facilities made it difficult to do group training. At the time of the review, 225 patients were on peritoneal dialysis.

Home haemodialysis training was provided using a shared facility at The Royal Free Hospital. Reviewers commented that this was a long way for patients to travel for an eight week intensive training programme, and wondered whether this training could be provided more locally.

8 Whipps Cross University Hospital satellite units: Frequency of patient review

The Trust self-assessment stated that patients on dialysis were reviewed every three months. Guidelines on the expected frequency of out-patient review were not yet available. Reviewers suggested that an audit of the frequency of review at Whipps Cross University Hospital satellite units may be helpful to ensure the expected frequency is being achieved.

9 Management of renal anaemia

The renal anaemia team used a range of policies, some of which were good and some of which were out of date. The team reviewed patients in the satellite units and had good administrative support. Significant improvement in anaemia management had been achieved. The Trust had an agreement to use a single product, which had the benefit of consistency but limited the therapeutic options available. The team relied on the home care company to inform them when a further prescription was required, and reviewers

suggested that it may be helpful for the team to keep their own records rather than relying on this notification. Reviewers were also told that prescriptions sent to pharmacy were processed for payment but were not reviewed by pharmacy, which did not comply with the recommendations of the Hackett Report.²

10 **Document control**

Policies, procedures and guidelines were in different formats and in draft form and most did not have review dates and were not in line with the Trust document control policy. Reviewers were aware that the renal service had plans to go through all documents after the peer review visit. Policies, procedures and guidelines would then be submitted to the Renal Services Board, standardised and, where required, submitted to the Trust document committee. Some staff were not aware of this process and it may be helpful to communicate the expected process to staff. Further work to ensure that all staff are aware of which policies and procedures they should be following and to support full implementation may also be helpful. Reviewers were also aware that this was the first of London's renal services to receive a peer review visit, and that some shared development of guidelines and policies may be indicated when all visits have taken place.

11 **Documentation of guidelines, policies and procedures**

Measures were in place to meet the requirements of the great majority of the standards in practice, but some written guidelines, protocols and policies were not yet in place (see Appendix 2 for details).

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² *Home care medicines: Towards a vision for the future*. Department of Health. 2011.

APPENDIX 1 MEMBERSHIP OF VISITING TEAM

Visiting Team

Sinead Burke	Clinical Lead Renal Dietician	Royal Free London NHS Foundation Trust
Dr Robert Elias	Consultant Nephrologist	King's College Hospital NHS Foundation Trust
Miss Sarah Heap	Consultant Transplant Surgeon	St George's University Hospitals NHS Foundation Trust
Roopkishor Hurril	Senior Nurse	Epsom and St Helier University Hospitals NHS Trust
Amanda Johnson	Patient Representative	Guy's and St Thomas' NHS Foundation Trust
Mr Nicos Kessarlis	Consultant Transplant Surgeon	Guy's and St Thomas' NHS Foundation Trust
Ian Morgan	Renal Technician	King's College Hospital NHS Foundation Trust
Rachel Mwansa	Senior Nurse	King's College Hospital NHS Foundation Trust
David Myers	Patient Representative	Royal Free Kidney Patient Association
Natasha Stubbs	Consultant Live Donor Transplant Nurse	Imperial College Healthcare NHS Trust
Dr Rebecca Suckling	Consultant Nephrologist / Associate Medical Director	Epsom and St Helier University Hospitals NHS Trust
Ros Tibbles	Senior Nurse	Guy's and St Thomas' NHS Foundation Trust
Hayley Wells	Renal Pharmacist	Guy's and St Thomas' NHS Foundation Trust

WMQRS Team

Jane Eminson	Director	West Midlands Quality Review Service
Carol Willis	Associate	West Midlands Quality Review Service

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APPENDIX 2 GUIDELINES NOT YET IN PLACE

Below lists the Quality Standards where written guidelines or protocols were not in place. The information in the table does not detail any practice or processes that were in place at the time of the review visit. For more detail please see the compliance section of the report.

Ref	Quality Standards	Comment
RN-501	Operational Policy	Many aspects of the Quality Standard were met - see report
RN-502	Guidelines: Lifestyle advice	Some aspects of the Quality Standard were not yet met. E.g. sexual health, contraception and pregnancy
RN-598	Referral to specialist palliative care	Guidelines for referral were not yet documented.
RN-507	Access surgery protocol	The protocol did not cover referral for surgery
RN-509	Acceptance on transplant list	A protocol was not yet in place
RN-510	Referral for combined kidney and pancreas transplantation	Guidelines were not yet available
RN-512	Annual review of patients on transplant list	Guidelines available did not yet include availability of potential living related donors and consent for virology and storage for tissue typing
RN-514	Cardiovascular work up pre-transplantation	See main report in relation to the pathway
RN-516	Monitoring	Guidelines were not yet available
RN-517	Six monthly holistic review	Guidelines were not yet available
RN-522	Haemodialysis: Regimes	Guidelines covered all but exception monitoring
RN-524	Haemodialysis: Access management	Guidelines were not yet available
RN-528	Post-transplant clinical guidelines	Guidelines were available but did not yet cover chronic allograft damage or chronic rejection.
RN-533	Post-operative care	Guidelines did not cover all the requirements of the Quality Standard
RN-535	Post-transplantation referral back to Renal Units	Guidelines did not cover all the requirements of the Quality Standard
RN-604	Liaison with diabetes services	Guidelines were not yet in place

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APPENDIX 3 COMPLIANCE WITH THE QUALITY STANDARDS

Analyses of percentage compliance with the Quality Standards should be viewed with caution as they give the same weight to each of the Quality Standards. Also, the number of Quality Standards applicable to each service varies depending on the nature of the service provided. Percentage compliance also takes no account of 'working towards' a particular Quality Standard. Reviewers often comment that it is better to have a 'No, but', where there is real commitment to achieving a particular standard, than a 'Yes, but' where a 'box has been ticked' but the commitment to implementation is lacking. With these caveats, table 1 summarises the percentage compliance for each of the services reviewed.

Table 1 - Percentage of Quality Standards met

Service	Number of Applicable QS	Number of QS Met	% met
Primary Care	2	2	100
Renal Services	102	63	62
Total	104	65	63

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PRIMARY CARE

Ref	Quality Standards	Met? Y/N	Reviewer Comments
RA-298	<p>Primary care training and development</p> <p>General practices should participate in the local programme of training and development in the care of people with end stage renal failure.</p>	Y	
RA-501	<p>Primary care guidelines</p> <p>Guidelines on the primary care management of patients with chronic kidney disease should be in use, covering at least:</p> <p>a. Information and advice for patients and their carers, including lifestyle advice in order to slow down the rate of kidney damage</p> <p>b. Indications for referral to the renal service</p>	Y	

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RENAL SERVICES

Ref	Quality Standards	Met? Y/N	Reviewer Comments
RN-101	<p>General Support for Service Users and Carers</p> <p>Service users and their carers should have easy access to the following services. Information about these services should be easily available:</p> <p>a. Interpreter services, including access to British Sign Language</p> <p>b. Independent advocacy services</p> <p>c. PALS</p> <p>d. Social workers</p> <p>e. Benefits advice</p> <p>f. Spiritual support</p> <p>g. HealthWatch or equivalent organisation</p>	N	<p>Many aspects of the Quality Standard were met. The aspects still requiring attention were: social workers were not available at either of the satellite units visited; Citizens Advice visits took place at Romford every six months and patients were referred to social services when necessary; and information about benefits advice was not easily available.</p> <p>See also main report in relation to availability of patient information.</p>

Ref	Quality Standards	Met? Y/N	Reviewer Comments
RN-102	<p>Information: All patients</p> <p>Information should be offered to all patients and, where appropriate, their carers covering:</p> <ul style="list-style-type: none"> a. Chronic kidney disease, including its causation, and physical, psychological, social and financial impact b. Treatment options available c. Pharmaceutical treatments and their side effects d. Promoting good health, including diet, fluid intake, exercise, smoking cessation and avoiding infections e. Symptoms and action to take if become unwell f. Support groups available, for example, Kidney Patients Association g. Expert Patients Programme (if available) h. Staff and facilities available, including facilities for relatives i. Who to contact with queries or for advice j. Where to go for further information, including useful websites 	Y	<p>Information was generally available, although see main report in relation to the quality of patient information. Information on the Kidney Patients Association was seen at Whipps Cross University Hospital but not at Queen's Hospital, Romford.</p>
RN-103	<p>Information: Pre-dialysis</p> <p>Information should be offered to all patients receiving pre-dialysis care covering at least:</p> <ul style="list-style-type: none"> a. What are the reasons for starting dialysis b. Conservative management c. Types of dialysis available and locations of these services d. Changing dialysis modality and possible consequences e. Self-care options f. Potential complications of each type of dialysis g. Access types and access surgery h. Transport options and eligibility for free transport i. Availability of, and eligibility for, temporary dialysis away from home j. Arrangements for six monthly holistic review with named nurse k. Who to contact with queries or for advice. <p>Where to go for further information, including useful websites</p>	Y	<p>Literature produced by the Kidney Patients Association was available. This information was not in a particularly user-friendly form, and further discussion with patients about what would be helpful to them may be useful. Some information from the dieticians was available, some of which was translated into other languages.</p>

Ref	Quality Standards	Met? Y/N	Reviewer Comments
RN-104	<p>Information: Patients with dialysis access</p> <p>Information should be offered to all patients with dialysis access covering at least:</p> <ul style="list-style-type: none"> a. Care of their dialysis access b. Management of pain and complications c. Emergency admission to hospital d. What to do if problems occur 	Y	Patients who met the visiting team commented that they felt well supported by staff. See main report in relation to information for patients.
RN-105	<p>Information: Patients considering transplantation</p> <p>Information should be offered to all patients being considered for transplantation covering at least:</p> <ul style="list-style-type: none"> a. Different types of transplantation available and locations of these services b. Potential complications of each type of transplantation, including the risks of infection and malignant disease c. Likely outcomes of each type of transplantation d. Tests and investigations that will be carried out e. What will happen if they are accepted for inclusion on the transplant list f. Annual review while on the transplant list g. What will happen if they are not accepted onto the transplant list h. Who to contact with queries or for advice. i. Where to go for further information, including useful websites 	N	Some information was available but did not cover all complications, annual reviews or what would happen if the patient was accepted onto the transplant list. The information was seven years out of date and was not worded positively about transplant as an option. New information was in draft form but was brief and used the same wording as the previous booklet.
RN-106	<p>Information: Patients considering live donation</p> <p>Information on kidney donation should be offered to all patients considering live donation and to all potential live donors covering at least:</p> <ul style="list-style-type: none"> a. What is live donation b. Antibody incompatible transplantation c. Potential complications for the donor d. Payment of expenses, including the time within which payment should be received and a contact point for queries over payments 	N	Information for potential live donors was not available. A claim form was available for payment of expenses but did not include a contact point for queries.
RN-107	<p>Information: Post-transplant patients</p> <p>In addition to the information in QS RN-105, information should be offered to all patients following transplantation covering at least:</p> <ul style="list-style-type: none"> a. Anti-rejection medication b. Symptoms and action to take if these occur, including what to do in an emergency c. Pregnancy and contraception 	N	Kidney Patient Association information on anti-rejection medication was available but was out of date. The list of medication was out of date. Information on pregnancy and contraception was not clear. Available information did not cover what to do in an emergency.

Ref	Quality Standards	Met? Y/N	Reviewer Comments
RN-108	<p>Information: Transition to adult care</p> <p>Information should be available on transition to adult care. This information should cover all aspects of the transition (QS RN-538).</p>	Y	'Ready, steady, go' information was in use.
RN-109	<p>Education and awareness: All patients</p> <p>An education and awareness programme should be offered to all patients with progressive and advanced chronic kidney disease and, where appropriate, their carers. In addition to a general programme appropriate to all patients and covering all points in QS RN-102, specific programmes for particular groups of patients should cover:</p> <p>a. Patients being considered for dialysis (QS RN-103) (Not applicable to Satellite Units)</p> <p>b. Patients needing immediate dialysis at presentation</p> <p>c. Patients with dialysis access (QS RN-104)</p> <p>d. Patients on the transplant list (QS RN-105)</p> <p>e. Education and training in the competences needed for self-care (for patients opting for self-care)</p>	Y	Patients at the satellite units said they felt well-informed. Patients at the satellite units also commented on a culture of self-care for patients on haemodialysis. A monthly pre-dialysis group was running.
RN-110	<p>Care plans and 'key worker'</p> <p>All patients and, where appropriate, their carer should discuss and agree their Care Plan, and should be offered a written record covering at least:</p> <p>a. A written individual care plan</p> <p>b. A permanent record of consultations at which changes to their care plan are discussed</p> <p>c. Access to clinical results and relevant clinical information through Renal Patient View (or an equivalent system)</p> <p>d. A key worker / named contact</p>	N	Only about 10% of patients were accessing Renal Patient View. Satellite unit patients were not aware that this was available. It was not clear that all transplant patients had a care plan. Staff were aware of this and were working on the issue.
RN-111	<p>Food</p> <p>Food should be offered to all patients who are away from home for more than six hours to attend clinic or receive dialysis.</p>	N	Patients were offered tea and biscuits, but arrangements for ensuring that patients who were away from home for more than six hours were offered food were not clear. Sandwiches and other refreshments were offered to patients who were in hospital all day.
RN-112	<p>Car parking</p> <p>Free or reduced price car parking should be available close to the dialysis unit for haemodialysis patients attending for dialysis.</p>	N	Good parking facilities were available at all satellite units. Parking was free at both of the satellite units visited but not at The Royal London Hospital.

Ref	Quality Standards	Met? Y/N	Reviewer Comments
RN-113	<p>Patient Transport</p> <p>Patients travelling by hospital transport should arrive within 30 minutes of their starting time for dialysis and should be picked up within 30 minutes of finishing dialysis. Adult patients should not travel for more than 30 minutes for dialysis unless by choice.</p>	N	Staff were committed to working with transport providers, but the 30 minutes 'door to door' times were not being achieved as several patients were being collected by the same vehicle.
RN-199	<p>Involving Patients and Carers</p> <p>The service should have:</p> <ul style="list-style-type: none"> a. Mechanisms for receiving feedback from patients and carers b. A rolling programme of audit of patients' and carers' experience c. Mechanisms for involving patients and, where appropriate, their carers in decisions about the organisation of the service 	Y	Results of patient surveys were displayed in both satellite units visited and at The Royal London Hospital. 'I want great care' was being used. Members of the Renal Forum were disappointed that they had not been involved in the design of the new hospital, but had been assured that they would be involved in future redevelopments.
RN-201	<p>Lead Consultant and Nurse</p> <p>The service should have a nominated lead consultant nephrologist and nominated lead nurse with responsibility for ensuring implementation of the Quality Standards for the Care of Patients with End Stage Renal Failure.</p>	Y	
RN-202	<p>Leads for particular aspects of care</p> <p>The service should have a nominated lead consultant and lead nurse / coordinator for:</p> <ul style="list-style-type: none"> a. Pre-dialysis care (Not applicable to Satellite Units) b. Dialysis care c. Transplant-related issues, including live kidney donation and Renal Unit / Transplant Centre liaison d. Transition to adult care (Not applicable to Satellite Units) e. End of life care 	Y	
RN-203	<p>Consultant Nephrologists</p> <p>A consultant nephrologist should be on call at all times and available to attend to care for patients within 30 minutes.</p>	Y	
RN-204	<p>Transplant Surgeons</p> <p>A consultant transplant surgeon should be available at all times for the care of patients in the Transplant Centre and for advice to Renal Units.</p>	Y	

Ref	Quality Standards	Met? Y/N	Reviewer Comments
RN-205	<p>Lead Consultant: Transition</p> <p>Transplant Centres with lead responsibility for the care of young people aged up to 25 years (QS RZ-601) should have a nominated lead nephrologist with responsibility for liaison with the network's Renal Service for Children (CRSs) in relation to transfer to adult care.</p>	Y	
RN-206	<p>Lead Surgeon and Urologist</p> <p>The service should have:</p> <p>a. A nominated lead surgeon for paediatric transplantation with responsibility for transplant-related issues, including coordination of all transplant surgeons involved with the care of children or living related donor transplants to children</p> <p>b. A nominated lead paediatric urologist with responsibility for liaison with the paediatric renal transplantation service in relation to the care of children with complex bladder anomalies</p>	N/A	
RN-207	<p>Staffing: In-patient wards</p> <p>The in-patient ward should have sufficient renal nurse and HCA staff with appropriate competences. Staffing levels should be based on a competence framework covering the skill mix, staffing levels and competences expected for the usual number and dependency of patients. The competence framework should cover, at least, care of patients with renal disease, procedures staff are expected to undertake and equipment they are expected to use.</p>	Y	See main report.
RN-208	<p>Staffing: Dialysis services</p> <p>The dialysis service should have sufficient renal nurse and HCA staff with appropriate competences. Staffing levels should be based on a competence framework covering the skill mix, staffing levels and competences expected for the usual number and dependency of patients. The competence framework should cover, at least, care of patients with renal disease, procedures staff are expected to undertake and equipment they are expected to use.</p>	Y	See main report.

Ref	Quality Standards	Met? Y/N	Reviewer Comments
RN-209	<p>Specialist Nurses</p> <p>The service should have an identified lead nurse with specialist expertise in each of the following areas:</p> <ul style="list-style-type: none"> a. Vascular access b. Anaemia management c. Home therapies d. Conservative management (Not applicable to Satellite Units) 	Y	Names of link nurses were clearly displayed on the ward notice board at Queen's Hospital, Romford.
RN-210	<p>Clinical Technologists</p> <p>Sufficient clinical technologist staff with appropriate competences should be available to support equipment maintenance, breakdown and replacement, including water treatment equipment. All clinical technologists should have regular assessment of competence in the maintenance of equipment appropriate to their role.</p>	N	The service had 9 technicians rather than the 20 recommended by the Association of Renal Technologists. In practice there were 1.5 technicians per site, who were carrying out the functions expected. The recommended levels were therefore met on a site basis but not per unit. Reviewers commented that more technicians may be needed as the home dialysis programme expands. All technicians had training on equipment but did not have regular assessments of their competence.
RN-211	<p>On-call Clinical Technologist</p> <p>A 24 hour clinical technologist on call service should be available.</p>	Y	
RN-212	<p>Support Staff</p> <p>The service should have:</p> <ul style="list-style-type: none"> a. A nominated lead for coordinating holiday haemodialysis b. Sufficient staff to ensure data collection as required for relevant QS RN-700s c. Administrative and clerical support 	Y	Arrangements for cover for absences of administrative staff were not clear. At Whipps Cross University Hospital one person provided administrative support to all three units. At Queen's Hospital, Romford one person provided administrative support for two units. Satellite units visited were therefore very dependent on individual members of staff for administrative support and it was not clear that cover for absences was available.

Ref	Quality Standards	Met? Y/N	Reviewer Comments
RN-301	<p>Support Services</p> <p>The following services should be available to provide support to patients with renal diseases:</p> <ul style="list-style-type: none"> a. Dietetics b. Pharmacy (Not applicable to Satellite Units) c. Psychological support d. Social worker e. Play specialist and youth worker (CRS only) <p>Staff providing these services should have specific time allocated in their weekly job plan to their work with the renal service and specific training or experience in caring for people with renal diseases.</p>	N	<p>'a'. A level of service was available for every treatment modality. Input varied but was generally appropriate.</p> <p>'b'. A new lead pharmacist had been appointed but was not yet involved multi-disciplinary team meetings. There was no pharmacy input to out-patient services. Pharmacy support for transplant patients had previously been very good but had been reduced. Consideration was being given to increasing it. A new polycystic disease pharmacist was in post and a polycystic disease clinic had been established. Transplant patients were counselled before discharge. There was no clinical pharmacy input to satellite units.</p> <p>'c'. Available psychology support was very limited. See main report. Good competency based training programmes were in place for AHPs and nurses</p> <p>'d'. See main report.</p>
RN-302	<p>Access surgery</p> <p>Emergency and elective surgical services should be available to provide:</p> <ul style="list-style-type: none"> a. Elective access surgery b. Emergency surgery for failed vascular access and removal of infected peritoneal dialysis catheters 	N	See main report.
RN-303	<p>Dermatology services</p> <p>Access to dermatology services with expertise in the management of patients on long-term immunosuppressive therapy should be available.</p>	Y	See main report (good practice section).
RN-304	<p>Transplant Coordinator: live kidney donors</p> <p>There should be a nominated transplant coordinator with lead responsibility for live kidney donors.</p>	Y	
RN-305	<p>Transplant Coordinator</p> <p>A renal recipient transplant coordinator should be available at all times.</p>	Y	The surgical registrar took the kidney offer. The nephrology registrar would prepare the patient ready for theatre. A 0.5 w.t.e. transplant coordinator maintained the list.
RN-306	<p>Expert advice on antibody incompatible transplantation</p> <p>The Transplant Centre should have arrangements for access to expert advice on antibody incompatible transplantation.</p>	Y	

Ref	Quality Standards	Met? Y/N	Reviewer Comments
RN-307	Histocompatibility service The Transplant Centre should have access within a two hour travel time to a consultant led, accredited histocompatibility service.	Y	
RN-308	Histopathology service The Transplant Centre should have access to a histopathology service with expertise in the interpretation of renal transplant biopsies.	Y	
RN-309	Theatres for transplantation The Transplant Centre should have 24 hour a day, 7 days a week access to operating theatres for renal transplantation.	Y	See main report (further consideration section) in relation to surgical pathway.
RN-310	Plasmapheresis The Transplant Centre should have 7 days a week access to plasmapheresis.	Y	Plasmapheresis was available six days a week, and cover for Sunday was provided so the service was available if required.
RN-311	Support Services: Transition Transplant Centres with lead responsibility for the care of young people aged up to 25 years (QS RN-601) should have the following services available: a. Youth worker service b. Psychological support service with expertise in the care of young people with renal disease	Y	See main report (good practice section).
RN-401	Haemodialysis facilities Appropriate facilities for the provision of haemodialysis should be available. All new facilities should meet the requirements of the latest HBN requirements and other services should be working towards these standards. In-patient services should ensure reasonable separation of patients receiving in-patient and out-patient care.	N	See main report in relation to a lack of separation of in-patients and out-patients, especially at Whipps Cross University Hospital where space between stations was very small.
RN-402	Equipment All equipment used in the delivery and monitoring of haemodialysis and peritoneal dialysis therapy should comply with the relevant standards for medical electrical equipment.	N	Records of equipment and of all work done on equipment were maintained. The service did not have any way of storing hard copies of service reports. Reviewers commented that this could leave the service vulnerable if an incident happened and evidence of maintenance needed to be provided. Meetings to discuss planned maintenance took place, but arrangements for review, to ensure nothing had been missed, did not appear to be robust. See also main report in relation to maintenance and calibration of equipment.

Ref	Quality Standards	Met? Y/N	Reviewer Comments
RN-403	Haemodialysis: Equipment replacement Each unit should have a programme of equipment replacement.	Y	
RN-404	Haemodialysis: Concentrates All haemodialysis concentrates should comply with European quality standards.	Y	
RN-405	Haemodialysis: Water A routine testing procedure for product and feed water should be in use which ensures water used in preparation of dialysis fluid meets the requirements of BS ISO 13959:2014	N	See main report in relation to water quality at Whipps Cross University Hospital and in relation to the water testing Standard Operating Procedure.
RN-406	Haemodialysis: Membranes A protocol on haemodialysis membranes should be in use covering: a. Use of low flux synthetic and modified cellulose membranes b. Membranes for patients at risk of developing symptoms of dialysis-related amyloidosis c. Membranes for patients with increased bleeding risk d. Membranes in patients on ACE inhibitor drugs	N/A	
RN-408	Isolation facilities Appropriate facilities for isolation of patients should be available.	N	Isolation facilities at Whipps Cross University Hospital satellite units were inadequate.
RN-409	Weighing scales All weighing scales should comply with Non-Automatic Weighing Instrument (NAWI) Regulations 2000, part III, section 38.	Y	
RN-410	Home therapy training facility Facilities for training patients in home therapies should be available.	Y	See main report (further consideration section).

Ref	Quality Standards	Met? Y/N	Reviewer Comments
RN-501	<p>Operational Policy</p> <p>The unit's operational policy should ensure:</p> <ul style="list-style-type: none"> a. Allocation of a key worker / named contact at each stage of the patient's care b. Arrangements for handover of key worker / named contact between stages of the patient's care c. Ensuring all patients and, where appropriate, their carers are offered information (QS RN-102) and education programmes (QS RN-109) d. Ensuring all patients have a written care plan that is discussed with the patient and, where appropriate, their carers: <ul style="list-style-type: none"> - following significant changes in circumstances - at least once a year e. Offering patients a copy of their care plan f. Offering patients a permanent record of consultations at which changes to their care plan are discussed g. Communicating changes to the care plan to the patient's GP, including information about changes in drug treatments and what to do in emergencies h. Arrangements for ensuring patients have up to date information on their blood results i. Arrangements for dealing with violent or aggressive patients j. Arrangements for providing care for prisoners 	N	<p>Many aspects of the Quality Standard were met. Particular aspects that were not yet being met were that transplant care plans were not in place in practice, satellite unit patients were not aware of Renal Patient View and little information was available for carers. Staff and patients had different views about whether patients received copies of GP letters. The monthly low clearance meeting did involve carers but there was little other evidence of carer involvement.</p>
RN-502	<p>Guidelines: Lifestyle advice</p> <p>Guidelines covering responsibilities, advice to be given and actions to be taken, including referral to other services, should be in use for:</p> <ul style="list-style-type: none"> a. Lifestyle advice and information, including: <ul style="list-style-type: none"> - Support for smoking cessation - Dietary advice, including salt reduction and alcohol - Programmes of physical activity and weight management - Sexual health, contraception and pregnancy - Travel and holidays - Risks and implications of having haemodialysis abroad b. Monitoring of growth and development (children and young people only) 	N	<p>Some aspects of the Quality Standard were not yet met, in particular, guidelines covering sexual health, contraception and pregnancy were not yet available.</p>

Ref	Quality Standards	Met? Y/N	Reviewer Comments
RN-503	<p>Clinical guidelines: Management of CHD risk factors, anaemia and diabetes</p> <p>Clinical guidelines should be in use covering:</p> <p>a. Monitoring and management of CHD risk factors, including:</p> <ul style="list-style-type: none"> - Anti-platelet therapy (where indicated) - Lipid reduction therapy - Control of hypertension - Calcium and phosphate control <p>b. Management of diabetes mellitus (adults only)</p> <p>c. Management of anaemia</p>	Y	
RN-504	<p>Referral for psychological support</p> <p>Clinical guidelines should be in use covering indications and arrangements for referral for psychological support.</p>	Y	See main report in relation to delays in access to psychological therapy.
RN-598	<p>Referral to specialist palliative care</p> <p>Guidelines, agreed with the specialist palliative care services serving the local population, should be in use covering, at least:</p> <p>a. Arrangements for accessing advice and support from the specialist palliative care team</p> <p>b. Arrangements for shared care between the renal service and palliative care services</p> <p>c. Indications for referral of patients to the specialist palliative care team for advice</p>	N	Patients were referred to Guy's Hospital using the Guy's proforma. Guidelines for referral were not yet documented.
RN-599	<p>End of life care guidelines</p> <p>The renal service should be aware of local guidelines for the end of life care of patients.</p>	Y	Guidelines were in place, but limited specialist palliative care support was available.

Ref	Quality Standards	Met? Y/N	Reviewer Comments
RN-505	<p>Operational Policy: Pre-dialysis care</p> <p>A policy should be in use cover pre-dialysis care. This policy should ensure:</p> <ul style="list-style-type: none"> a. Patients and, where appropriate, their carers, are offered information (QS RN-103), education programmes (QS RN-109) and psychological support to enable them to make an informed choice of dialysis modality b. Assessment of suitability for dialysis c. Assessment of home environment for those patients considering home dialysis (HD & CAPD) d. Assessment of the economic impact of dialysis and possible sources of financial support e. Discussion of transport arrangements with each patient f. Recording of the agreed transport arrangements in the patient's care plan g. The patient's preferred choice of dialysis modality is recorded in the patient's notes / electronic patient record and care plan <p>The policy should cover arrangements for patients:</p> <ul style="list-style-type: none"> i. With 12 months or more preparation ii. Presenting less than 12 months before starting treatment iii. Needing immediate dialysis at presentation iv. With failing transplants 	Y	
RN-506	<p>Control of infection</p> <p>Clinical guidelines should be in use covering:</p> <ul style="list-style-type: none"> a. Screening for blood born viruses b. Hepatitis vaccination if required c. Monitoring of hepatitis B and C antibodies d. Screening for staphylococcus aureus and MRSA carriage and treatment of carriers <p>The guidelines should cover arrangements for patients presenting less than 12 months before starting treatment and those needing immediate dialysis at presentation as well as arrangements for patients with 12 months or more preparation.</p>	Y	

Ref	Quality Standards	Met? Y/N	Reviewer Comments
RN-507	<p>Access surgery protocol</p> <p>Guidelines should be in use covering:</p> <ul style="list-style-type: none"> a. Referral for assessment and investigation of suitability for access surgery b. Referral for surgery c. Indications for antibiotic prophylaxis d. Ensuring patients are given information about their dialysis access (QS RN-104) <p>The guidelines should ensure that, whenever possible, access is established and functioning three months before haemodialysis and two weeks before peritoneal dialysis.</p>	N	A protocol was available but did not cover guidelines for referral for surgery. See also main report in relation to vascular access.
RN-508	<p>Referral for consideration of suitability for transplantation</p> <p>Guidelines should be in use covering referral to the Transplant Centre for consideration of suitability for transplantation. This protocol should ensure that:</p> <ul style="list-style-type: none"> a. A discussion with the patient, where appropriate their carer, and nephrologist takes place about their interest in and fitness for transplantation b. The patient is considered against agreed criteria for each type of transplantation (QS RY-502) c. The resulting decision is recorded in the patient's notes / electronic patient record and care plan d. Clinically appropriate patients are normally placed on the transplant list six months prior to the predicted start of dialysis 	Y	Guidelines were available, but were brief in relation to kidney-sharing ABO incompatibility and the kidney-sharing scheme.

Ref	Quality Standards	Met? Y/N	Reviewer Comments
RN-509	<p>Acceptance on transplant list</p> <p>A protocol should be in use covering acceptance onto the transplant list. This protocol should ensure that:</p> <ul style="list-style-type: none"> a. A discussion with the patient, where appropriate their carer, and a transplant nephrologist and / or transplant surgeon takes place about their fitness for transplantation b. The patient is considered against the network criteria for each type of transplantation (QS RY-502) c. A discussion takes place about the patient's suitability for and interest in: <ul style="list-style-type: none"> - Antibody incompatible transplantation - Combined kidney / pancreas transplantation (adults only) - Deceased donor transplantation d. The availability of potential living related donors is discussed e. Clinically appropriate patients are normally placed on the transplant list six months prior to the predicted start of dialysis f. The resulting decision is recorded in the patient's notes / electronic patient record and care plan, and communicated in writing to the patient and the referring Renal Unit (if applicable) within 10 working days 	N	A protocol covering acceptance onto the transplant list was not available.
RN-510	<p>Referral for combined kidney and pancreas transplantation</p> <p>Guidelines should be in use covering criteria and arrangements for referral of patients with diabetes for combined kidney and pancreas transplantation.</p>	N	Guidelines were not yet available.
RN-511	<p>Suspension and reinstatement on transplant list</p> <p>A protocol should be in use covering suspension and reinstatement of patients on the transplant list. This protocol should cover at least:</p> <ul style="list-style-type: none"> a. Regular review of patients suspended from the list b. Informing the Transplant Centre that a patient has been suspended c. Reinstatement of patients onto the list as soon as clinically appropriate d. Informing the Transplant Centre when a patient is to be reinstated onto the list 	Y	A short protocol was available. In practice it was not clear how patients were suspended, reviewed and reinstated. This may happen in practice, but staff were not clear about the arrangements.

Ref	Quality Standards	Met? Y/N	Reviewer Comments
RN-512	<p>Annual review of patients on transplant list</p> <p>Guidelines should be in use covering annual review of patients on the transplant list. The annual review should cover at least:</p> <ul style="list-style-type: none"> a. Current fitness for transplantation b. Risk factors for coronary heart disease c. Anaesthetic risk d. Co-morbidity e. Availability of potential living related donors f. Consent for virology and storage for tissue typing 	N	'a' to 'd' were covered in the available guidelines but there was no mention of 'e' or 'f'. See also main report in relation to surgical pathway.
RN-513	<p>Removal from transplant list</p> <p>A protocol should be in use covering removal from the transplant list. This protocol should ensure that:</p> <ul style="list-style-type: none"> a. A discussion takes place with the patient and, where appropriate, their family or carers about the reason for removal b. A decision to remove the patient from the transplant list temporarily or permanently is recorded in the patient's notes / electronic patient record c. The Transplant Centre is informed of the decision to remove the patient from the transplant list temporarily or permanently 	Y	
RN-514	<p>Cardiovascular work up pre-transplantation</p> <p>A protocol should be in use covering cardiovascular work-up prior to transplantation. This protocol should ensure that cardiac investigations are normally completed within six weeks of referral.</p>	N	See main report in relation to the transplant pathway.
RN-515	<p>Operational Policy: Self-care and home therapies</p> <p>A policy should be in use covering:</p> <ul style="list-style-type: none"> a. Self-care options offered by the service, including home haemodialysis, CAPD, self-care within a dialysis unit, APD and assisted PD b. Assessment of patient suitability for self-care and home therapies c. Training for self-care and home therapies d. Arrangements for assessing and monitoring competence of patients opting for self-care e. Assessment of home environment for patients choosing a home therapy f. Arrangements for water testing for patients on home haemodialysis 	Y	A good operational policy was in use.

Ref	Quality Standards	Met? Y/N	Reviewer Comments
RN-516	<p>Monitoring</p> <p>Guidelines should be in use which ensures:</p> <ul style="list-style-type: none"> a. Arrangements for multi-disciplinary review of blood results b. Monitoring of hepatitis B and C antibodies c. Frequency of out-patient review d. Arrangements for six monthly holistic review with named nurse e. Indications for change of dialysis modality f. Arrangements for changing dialysis modality 	N	Guidelines were not yet available. The Trust self-assessment was that patients were reviewed every three months. In practice, out-patient review of patients at Whipps Cross University Hospital satellite units was every four to six months.
RN-517	<p>Six monthly holistic review</p> <p>A protocol should be in use which ensures a six monthly holistic review with the patient's named nurse covering at least:</p> <ul style="list-style-type: none"> a. Review of biochemistry and referral to members of the multi-professional team if required b. Current medication, compliance and referral to the renal pharmacist if required c. Consideration of nutritional status and indications for referral to the dietician for assessment (QS RN-518 & RN-519) d. Psychological well-being and indications for referral for psychological support (QS RN-504) e. Lifestyle advice (QS RN-502) f. Transport arrangements g. Need for temporary dialysis away from home the outcome of the holistic review should be documented in the patient's care plan 	N	Six-monthly holistic reviews had not yet been implemented but plans were in place to achieve this. Arrangements for cover for absences of the patient's named nurse were not clear.
RN-518	<p>Nutrition while on dialysis (adults)</p> <p>A protocol should be in use which ensures that:</p> <ul style="list-style-type: none"> a. An interview with the dietician takes place within one month of starting dialysis b. An annual nutritional assessment is undertaken c. Indications for referral to the dietician at other times 	Y	
RN-519	<p>Nutrition while on dialysis (children and young people)</p> <p>A protocol should be in use which ensures that:</p> <ul style="list-style-type: none"> a. An interview with the dietician takes place within one week of starting dialysis b. A nutritional assessment is undertaken every three months c. Indications for referral to the dietician at other times 	N/A	

Ref	Quality Standards	Met? Y/N	Reviewer Comments
RN-520	<p>Dialysis away from 'base'</p> <p>A protocol on 'dialysis away from base' should be in use covering at least:</p> <ul style="list-style-type: none"> a. Isolation dialysis b. Use of dedicated machines c. Suspension from and re-instatement to the transplant list d. Informing the Transplant Centre of suspension from and re-instatement to the transplant list 	Y	
RN-521	<p>Withdrawal of dialysis</p> <p>A protocol should be in use covering withdrawal of dialysis. This protocol should ensure that:</p> <ul style="list-style-type: none"> a. A discussion takes place with the patient and, where appropriate, their family or carers about the reason for withdrawal b. A decision to withdraw dialysis is recorded in the patient's notes / electronic patient record / care plan c. Referral to palliative care services is made if appropriate (QS RN-598 & RN-599) 	Y	
RN-522	<p>Haemodialysis: Regimes</p> <p>Guidelines should be in use covering:</p> <ul style="list-style-type: none"> a. Frequency of haemodialysis b. Duration of haemodialysis c. Measurement of adequacy of haemodialysis d. Pre- and post-dialysis blood sampling e. Exception reporting arrangements for haemodialysis patients dialysing for less than four hours, three times a week 	N	Guidelines covering all except 'e' were in place: exception reporting arrangements were not in place (see main report in relation to duration of haemodialysis).
RN-523	<p>Haemodialysis: Control of infection</p> <p>Guidelines should be in use covering:</p> <ul style="list-style-type: none"> a. Care of temporary and cuffed dialysis lines and arterio-venous fistulae, including locking solutions and dressings b. Preparing vascular access for haemodialysis c. Decontamination of equipment after each treatment session d. Decontamination of equipment after use by patients with blood born viruses 	Y	

Ref	Quality Standards	Met? Y/N	Reviewer Comments
RN-524	<p>Haemodialysis: Access management</p> <p>Guidelines should be in use covering access care and performance. This should cover at least:</p> <ul style="list-style-type: none"> a. Arrangements for monitoring access performance b. Management of access infections c. Management of dysfunctional access d. Investigation of AV fistulae or grafts for evidence of stenosis e. Indications for secondary AV access after each episode of access failure f. Management of anxiety and pain 	N	Guidelines were not yet in place, although most aspects of the Quality Standard were met in practice. Draft guidelines on the management of anxiety and pain could be clearer. See also main report in relation to the proportion of patients dialysing through fistulae.
RN-525	<p>Peritoneal dialysis: Regimes</p> <p>Clinical guidelines should be in use covering:</p> <ul style="list-style-type: none"> a. Modality of dialysis used (CAPD, APD) b. Disconnect systems c. Type of fluid used including: <ul style="list-style-type: none"> - Solutions for patients experiencing infusion pain - Solutions for patients likely to remain on peritoneal dialysis for more than four years - Indications for use of specialist fluids d. Dialysis dose e. Monitoring dialysis adequacy, peritoneal dialysis function, residual urine and peritoneal ultra-filtration volume 	Y	
RN-526	<p>Peritoneal dialysis: Access management</p> <p>Clinical guidelines should be in use covering access care and performance. This should cover at least:</p> <ul style="list-style-type: none"> a. Peri-operative catheter care b. Care of peritoneal dialysis catheters c. Management of exit site and tunnel infections d. Management of catheter complications (leaks, obstruction) e. Management of anxiety and pain 	Y	The wording in relation to 'e' could be clearer.
RN-527	<p>Peritoneal dialysis: Management of complications</p> <p>Clinical guidelines should be in use covering management of:</p> <ul style="list-style-type: none"> a. Peritonitis b. Hernias c. Encapsulating peritoneal sclerosis 	Y	
RN-528	<p>Post-transplant clinical guidelines</p> <p>Clinical guidelines should be in use for patients who have had renal transplantation covering:</p> <ul style="list-style-type: none"> a. Treatment of acute rejection episodes b. Management of chronic allograft damage, including chronic rejection 	N	Guidelines were available but did not yet cover chronic allograft damage or chronic rejection.

Ref	Quality Standards	Met? Y/N	Reviewer Comments
RN-529	<p>Post-transplant follow up</p> <p>Clinical guidelines should be in use covering follow up of patients following transplantation, including at least:</p> <ul style="list-style-type: none"> a. Monitoring transplant function using eGFR b. Monitoring blood pressure c. Monitoring other CHD risk factors d. Skin surveillance e. Consideration of need for referral to pre-dialysis / pre-ESRF programmes f. Switching to a generic preparation g. Contraception and sexual health h. Care of mother and baby during pregnancy (adults only) i. Monitoring of growth (children and young people only) 	Y	
RN-530	<p>Live donor work-up</p> <p>A protocol should be in use covering:</p> <ul style="list-style-type: none"> a. Live donor work-up b. Arrangements for organising the transplant c. Communication with Renal Units about their patients <p>This protocol should ensure that transplantation takes place within three months of completion of the work-up.</p>	Y	See main report.
RN-531	<p>Pre-operative protocol</p> <p>Clinical guidelines should be in use covering pre-operative care of patients undergoing transplantation covering at least:</p> <ul style="list-style-type: none"> a. Psychological preparation b. Blood and tissue matching c. Antibody screening d. Pre-transplant vaccination e. Management of patients with blood born viruses f. Use of immunosuppressive therapy g. Counselling and advice for patients called for transplantation but where the operation does not take place (for whatever reason) 	Y	Some guidelines were well written but some were quite difficult to understand. The order of points in the guidelines also did not follow the patient pathway. The pre-transplant listing meeting decided on post-transplant immunosuppression.
RN-532	<p>Pre and peri-operative care: antibody incompatible transplantation</p> <p>Clinical guidelines should be in use covering pre- and peri- operative care of patients undergoing antibody incompatible transplantation.</p>	Y	Patient-specific pathways were in place but there was no overall protocol. The guidelines may benefit from review to ensure they fit with the patient pathway.

Ref	Quality Standards	Met? Y/N	Reviewer Comments
RN-533	<p>Post-operative care</p> <p>Clinical guidelines should be in use covering post-operative care of patients covering at least:</p> <ul style="list-style-type: none"> a. Pain control , including donor pain control b. Prevention of post-transplant CMV infection c. Use of immunosuppressive therapy d. Post-transplant vaccination e. Treatment of acute rejection episodes f. Antibody screening 	N	'a' : guidelines had been started but were not yet complete. 'b' was covered. 'd' and 'e' were available but were very brief. 'f' was not undertaken.
RN-534	<p>Discharge following transplantation</p> <p>A protocol should be in use covering discharge of patients following transplantation. This protocol should ensure that, immediately following discharge, the patient's GP has information on:</p> <ul style="list-style-type: none"> a. The type of transplantation undertaken b. The patient's medication and likely side effects c. Action to take should problems occur 	Y	Two protocols were available but were not easy to follow and it was not clear which was actually in use. In practice the arrangements worked well, although the discharge clinic had been operational only since April. Some staff were not aware of the discharge clinic.
RN-535	<p>Post-transplantation referral back to Renal Units</p> <p>A protocol should be in use for referral of patients back to Renal Units. This protocol should ensure that before the transfer of care takes place:</p> <ul style="list-style-type: none"> a. All patients have been offered a copy of their care plan b. All patients have a named contact for advice and support c. The Renal Unit and the patient's GP have received a copy of the patient's care plan 	N	The Standard Operating Procedure did not cover 'b'. The procedure suggested that plans were sent, but would benefit from stating specifically that the patient and GP would receive a copy of the care plan. Reviewers were told that most patients did not want to be referred back to renal units.
RN-536	<p>Live donor follow up</p> <p>A protocol should be in use covering follow up of live donors. This protocol should ensure that donors are followed up at least annually, including checks of blood pressure, urinalysis and renal function. There should be written hand-over from the Transplant Centre before live donor follow-up is undertaken by Renal Units.</p>	Y	See main report (further consideration section).
RN-537	<p>Payment of live donor expenses</p> <p>The network-agreed protocol (QS RY-509) for payment of expenses to living donors should be easily available within the Transplant Centre.</p>	Y	

Ref	Quality Standards	Met? Y/N	Reviewer Comments
RN-538	<p>Transfer to adult care</p> <p>The network-agreed guidelines for transition to adult care should be in use, covering:</p> <ul style="list-style-type: none"> a. Age guidelines for timing of the transfer b. Involvement of the young person in the decision about transfer c. Involvement of primary health care, social care and adult services in planning the transfer d. Joint meeting with the young person's paediatric and adult nephrologist and nursing representative e. Allocation of a named coordinator for the transfer of care f. A preparation period and education programme relating to transfer to adult care g. Arrangements for monitoring during the time immediately after transfer to adult care 	Y	
RN-601	<p>Multi-professional pre-dialysis care</p> <p>Arrangements should be in place to ensure effective communication and regular multi-disciplinary discussion to review the care of pre-dialysis patients. These arrangements should cover the involvement of, at least, consultant nephrologists, lead nurse for pre-dialysis care, dietician, renal pharmacist, clinical technologist (for home dialysis patients), renal social worker and vascular access surgeon.</p>	N	Weekly multi-disciplinary team meetings were held but did not involve a renal social worker, pharmacist or vascular access surgeon.
RN-602	<p>Dialysis quality monitoring</p> <p>Multi-disciplinary dialysis quality monitoring meetings should take place at an agreed frequency. These meetings should cover, at least:</p> <ul style="list-style-type: none"> a. Adequacy of dialysis b. Clinical parameters c. Dialysis access d. Water quality e. Significant events f. Patients on 'concerns register' (QS RN-605) g. Patients on the transplant list 	N	Multi-disciplinary team meetings took place, but 'd' was not considered at these meetings. A concerns register for each modality was not yet in place. However, water quality was discussed between the renal services and the Trust and was included on the Trust risk register.
RN-603	<p>Eligibility for free transport and temporary dialysis away from home</p> <p>Guidelines should be in use covering:</p> <ul style="list-style-type: none"> a. Eligibility for free transport b. Eligibility for temporary dialysis away from home 	Y	

Ref	Quality Standards	Met? Y/N	Reviewer Comments
RN-604	<p>Liaison with diabetes services</p> <p>Guidelines on the pro-active management of patients with diabetes should be in use, covering at least:</p> <ul style="list-style-type: none"> a. Indications for involvement of the renal service b. Arrangements for joint review with diabetologist and nephrologist c. Joint management / care of people with diabetes who are receiving renal replacement therapy or who have a renal transplant d. Monitoring of the number of patients with diabetes: <ul style="list-style-type: none"> - starting dialysis - with a renal transplant 	N	Guidelines were not yet in place, but a joint clinic was operational and the service was well-organised in practice. The multi-disciplinary team included all relevant specialties, and significant research had been undertaken.
RN-605	<p>'Concerns Register'</p> <p>The renal service should have arrangements for identifying and regularly reviewing patients approaching the end of life and those where there are concerns about their ability to cope with the expected dialysis regime.</p>	N	A concerns register was not yet in place.
RN-606	<p>Publicity of transplant successes</p> <p>The unit should have arrangements for taking advantage of local opportunities for publicising 'transplant successes'.</p>	N	Reviewers did not see any evidence of publicity about transplant successes.
RN-607	<p>Unit / Transplant Centre liaison 1</p> <p>Staff from the unit should meet with a representative of the team at the main Transplant Centre/s to which patients are referred at least three times a year in order to review transplant-related patients and issues.</p>	N/A	
RN-608	<p>Unit / Transplant Centre liaison 2</p> <p>A representative of the Transplant Centre team should meet with the renal team from each of its main referring units at least three times a year in order to review transplant-related patients and issues.</p>	Y	Outreach clinics took place five times a year. (Compliance based on self-assessment)
RN-609	<p>Transplant Centre coordination</p> <p>Representatives of the Transplant Centre should attend the twice yearly network transplantation meeting (QS RY-601) and contribute details of patients for discussion.</p>	Y	Local meetings were held but network transplantation meetings were not yet in place.

Ref	Quality Standards	Met? Y/N	Reviewer Comments
RN-610	<p>Transition: Joint clinic</p> <p>Transplant Centres with lead responsibility for the care of young people aged up to 25 years should hold a regular joint clinic with a paediatric nephrologist from the Renal Service for Children within the network.</p>	Y	
RN-701	<p>Renal Registry data submission</p> <p>The service should be submitting data to the Renal Registry and UK Transplant.</p>	Y	
RN-702	<p>Audit</p> <p>The service should have a rolling programme of audit, including:</p> <ul style="list-style-type: none"> a. Audit of implementation of evidence based guidelines (QS RN-500s) b. Participate in agreed network-wide audits 	Y	See main report (good practice section).
RN-703	<p>Unit audit: dialysis</p> <p>The unit should have undertaken regular audit of:</p> <ul style="list-style-type: none"> a. Travel times for dialysis patients, including waiting times for return journeys b. Relationship between timing of access surgery and start of dialysis 	N	'b' was not yet met.
RN-704	<p>Unit audit: transplantation</p> <p>The unit should have a programme of audit of compliance with its protocols for acceptance, suspension, annual review and removal of patients on the transplant list, including at least annual audit of:</p> <ul style="list-style-type: none"> a. Relationship between timing of dialysis and listing for transplantation b. Proportion of patients who have had an annual review c. Time from work-up to the transplantation for living related donors 	N	Reviewers did not see evidence of these audits.
RN-705	<p>Transplant Centre audit 1</p> <p>Transplant Centres should have undertaken an audit of the timeliness of communication of decisions about acceptance onto the transplant list to the patient and the referring Renal Unit.</p>	N	An audit of timeliness of communication had not yet been undertaken.
RN-706	<p>Transplant Centre audit 2</p> <p>Transplant Centres providing an antibody incompatible transplantation service should participate in the national AiT Registry Audit (when established)</p>	Y	Data were supplied to NHSBT. (Compliance based on self-assessment)

Ref	Quality Standards	Met? Y/N	Reviewer Comments
RN-707	Transplant surgeon minimum activity Transplant surgeons should normally undertake a minimum of 15 renal transplants each year.	Y	All transplant surgeons apart from the Locum Consultant (12 transplants in 2015/16) met the activity numbers required.
RN-708	Antibody incompatible transplantation service minimum activity Transplant Centres providing an antibody incompatible transplantation service should normally treat at least five patients per year.	Y	Compliance based on self-assessment.
RN-798	Review and learning The service should have appropriate arrangements for multidisciplinary review of positive feedback, complaints, morbidity, mortality, serious incidents and 'near misses'.	Y	
RN-799	Document Control All policies, procedures and guidelines should comply with the Trust (or equivalent host organisation's) document control procedures.	N	See main report (further consideration section).

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