Meeting Note

Title: Kidney Care Forum
Venue: H4 Seminar room, Salford Royal Hospital
Date & Time: Thursday 21 January 2010 @ 1130
Present: JMac Chair, HT, GB, BC, MC, HR, AB, AJB

Introductions were made and JMac welcomed AB and NC to the meeting. Stated the group's aims of looking at quality markers and how patients feel about the care they receive from the kidney service and being able to ask questions about that care.

<table>
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<tr>
<th>Item</th>
<th>Action</th>
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<tbody>
<tr>
<td>1 Apologies for absence</td>
<td>Apologies had been received from DT</td>
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<td>2 Agreement of previous meeting notes (221009)</td>
<td>Agreed as a correct record.</td>
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<td>3 Matters arising from the notes / updates (and not on agenda)</td>
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<td>Nocturnal dialysis</td>
<td>Had been discussed in a previous meeting with reference to Marion Higgins (NKF Chair) who had given several inspirational talks on the subject and suggested that Marion would be a good advocate for home haemodialysis for our patients. Thoughts were that patients are frightened of undertaken home care without the usual hospital/clinical input. Guys &amp; St Thomas's have a “sleep room” where trainees for nocturnal HHD are able to “practice” being left alone in a bedroom environment thus enabling them to become accustomed to sleeping whilst attached to the machine.</td>
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<td>Damaged kidney found during transplant</td>
<td>BC had asked this question at the previous meeting. Context being that if the kidney were damaged it would only be found during the transplant operation and thus, if the transplant had to be abandoned the donor kidney would be wasted. Mr Campbell had indicated it would be possible to remove the damaged kidney but that this would prolong the operation. It was suggested that pre-work could include more scans. JMac to make further enquiries.</td>
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<td>4 The patient experience:</td>
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<td>• Clinics update</td>
<td>HT pointed out that clinics had been posting a notice of how long waiting time was and how this was a simple but effective method of keeping the patient informed.</td>
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AKCS – clinic had been running for one year, had been successful and was running more smoothly as staff and patients became accustomed to the system. Multi-disciplinary team meetings took place each Thursday and discussion was ongoing extending the AKCS to an additional morning. There were plans to build into it a nurse led clinic to assist follow ups; this may enable patients to be taken from the main clinic to a nurse led clinic. Patient letters now included a named consultant and efforts were made to ensure continuity for consultations.
Greater Manchester Kidney Care Network
West Sector
Admin: Anne James-Burns  Tel 0161 20 61208/Fax 0161 20 65775
for better kidney care

Item  Action

- Training unit
  December 2009 saw the training stations move from the renal unit into 2 empty bed spaces on Ward G2. There had been some concerns (Infection Control Team) around mixing inpatient and outpatient activity but as each set of patients received their care from separate nursing teams the move was approved. The area is now dedicated and separate from the main renal unit, enables better training, is less disruptive and more accessible to the patient. With space at a premium the area is cramped with just enough room for 2 patients, and office facilities for nursing staff, however feedback was positive and generally it was considered an improvement.
  BC highlighted that potentially there were problems around the confined space and also privacy issues due to the proximity of the other person receiving training. It was felt that strategies could be examined to improve this aspect. These could include staggering of appointments and carefully matching trainers where possible. Additional staff would be recruited so that the training service could be extended (currently Mon, Wed, Fri) to other days and making evening training possible.
  Another potential problem had been that home dialysis patients had been asked to use Ward G2 for contact purposes in case of problems or questions. It was felt that it would be preferable to use the dedicated home training team and this was under discussion. A letter would be sent to each home dialysis patient to ensure the team held correct phone details and to notify patients of contact details for the hospital training team. There is currently phone support from the community patients’ in-house coordinator and after 17.00 in the renal unit, but the new training number would need to be added.
  With regard to urgent enquiries after being sent home from hospital the best number to call would be the Ward.

Discussion on home haemodialysis noted that NICE Guidance recommends 15% of dialysis population should be on home therapies (PD and haemodialysis). SRFT currently at 3.4% on home haemodialysis; over the past 5 years satellite usage had increased and this may have been to the detriment of home therapies since many patients could now dialyse closer to their home. In order to fulfil the right to patient choice, all patients approaching dialysis were provided full information on all modes of dialysis in conjunction with consideration of their social, economic and health circumstances.
  Payment by Results could incentivise home haemodialysis since monies would be provided per dialysis session whether at home or hospital based (and home haemo would not require direct input from clinical staff or acute facilities). Home haemodialysis also enables greater flexibility for dialysis; it may be taken more often or nocturnally and the patient may continue a normal job, with reduced medication and potentially no dietary restrictions.
  Notably, Ruth Shrigley, Curator of Manchester Museum home dialyses and her dialysis is fixed into her schedule as if part of her “job”; she has no dietary restrictions and no medicines.

Bernie raised an unrelated item where an unwell patient had been seen to arrive at the renal unit and nursing staff had asked why he hadn’t gone to A & E. JMac to
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raise with LC to ensure that all renal unit staff are aware of procedures.

5 Communication updates
Hope KPA
The Association would continue to ensure they were working within the Charity Commission Guidance and would continue to support and encourage all patients to take an interest/role in their care and treatment. Support to SRFT via research projects would continue as would promotion of the KPA holiday caravan in 2010.

SRT webpages
At the suggestion of Dr Hegarty Anne had revised some webpages to include links to NHS Choices. The website in turn provided more complete detail on kidney disease, its causes and effects and details of “information prescriptions” and how to get one. Anne would also be adding links to information videos showing patient “journeys”. NHS Choices also gave patients the opportunity to “speak” to each other via blogs. Update and revision of the site would continue.

- JMac suggested the group could read the report and discuss any items at the next meeting.
- NSF update
- NSF 5 year report
- Transport: noted that the snapshot survey revealed that the majority of West Sector patients were happy with transport but that the questionnaire related to one day only and not transport in general. It was recognised that transport was problematic with the limitations of the current service and that discussion was ongoing with NWAS.

Current pressures & strategy - quarterly update (circulated with Agenda)
- Home haemodialysis stats to be added to the update
- RPV – include the previous update’s numbers in brackets so that comparisons could be made

MRI Renal & Pancreas Transplant Unit 2008/09 Activity Report
- initiatives to increase transplant numbers
AB would attend the next meeting to talk about the initiatives and a transplant nursing rep would be invited to speak about the activity report.

AOB
Organ Donation Committee - as part of the group, GB confirmed the committee is now meeting and discussing the heart beating donation protocol, starting with ICUs. This will be rolled out to other areas once in place. It was noted that the Organ Donor Taskforce had recommended a 12% increase in live donation.
GB also sat on the The UK Donation Ethics Committee being the only lay-person on that group. The first meeting was yet to take place with all acute trusts
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being invited to put forward ideas on aspects of donation they would like to be considered. The current focus was on non heart beating donation. GB would report back to the next meeting.

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<td>Schedule of meetings for 2010</td>
<td>GB</td>
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<td>22 April, 15 July, 21 October</td>
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<td>H4 Seminar Room</td>
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