Renal Association Clinical Affairs Board Teleconference
Tuesday 3rd December 5-6pm, 2013
Minutes

Attendees: Graham Lipkin (Chair), Richard Fluck (NCD), Alastair Hutchinson (Chair CSC), Andrew Lewington (Chair Guidelines), Fergus Caskey (Medical Director UKRR), Neil Turner (Chair RPV), Mike Robson (Elected Member), Mark Taylor (Rare Disease Chair). Afzal Chaudhry (Terminology Chair).

Apologies: Claire Sharpe (Chair EO Committee).

Introductions/Overview: Graham Lipkin welcomed all with plan for Committee to meet quarterly-alternate meetings by telecon. TOR of CAB adjusted to incorporate NCD which Chair and Trustees agreed important. CAB Committee reflects committed role of RA groups in striving to improve renal service delivery, patient safety and Quality Improvement. Most Trusts currently do not allow time for this major commitment. GWL Chairmanship will focus on improving patient safety agenda, QI, **Multi-professional team input and patient engagement**. Focus on meaningful improvements in patient care.
The august group act as important Professional advisors to NHS England, NICE, NCD.

RA Website goes live December. Committee Chairs asked to update pages. Major upgrade on old site (paid for by RA from Subscription fees).

1. **NCD Overview** of key issues in NHSE: Turbulent time following NHS reorganisation. NCD role different from prior NCD position. Role is with NHSE rather than DH-shorter sessional commitment. Covers only NHS England not devolved nations. Delivery based on NHS Outcomes Framework.

   4 Key stands of Renal Focus.
   a. AKI-program board established and manager appointed. UKRR closely working with NHSE, funded.
   b. CKD: done deal, supported by Primary Care QoFF. Some concerns (BMJ Article), Requirement for education by Renal Community for Primary Care. PH England input?
   c. Specialised Commissioning: Service Specifications for Dialysis and Transplant-clinically led (Chas Newstead and Keith Rigg). CAB group felt good documents.
   d. Patient involvement and measure patients relevant outcomes (PROMS/PREMS/Intrusion scores).

   Clinical Service Specifications (under Renal Clinical Reference Group) are seen as a key lever in generating high quality care.

   Work on going on with Renal Data Set/Collaboration (UKRR-Keith Simpson). It is recognised that Commissioners pay for UKRR via capitation fee. RF expressed requirement for UKRR to report simplified patient-relevant measures with greater patient input, perhaps via RPV as proportion of patients increase (already 33, 000 registrations).

   Quality Assurance/Peer Review/Accreditation was discussed (Raised by Bruce Kehoe report). There was general support for a structure that would improve quality and be deliverable. AH commented that an O&G project in Manchester took 3 days and involved 15 people. GWL commented that Wmids Peer review was also resource hungry on Commissioner and provider Unit time. Nevertheless many positives came out. It was flt that RA should be closely involved to optimise any development by NHSE. This could be further discussed at RCP Renal Meetings.

   Francis and Don Berwick reports briefly mentioned. UKRR, CSC, RPV all willing and able to contribute. Patient safety/Quality assurance to be discussed at CD Forum.

   Actions; GWL/Charlie Tomson to raise Peer Review/Accreditation at RCP Renal Meet.

The CAB expressed wish to continue close collaboration with NCD/NHSE and offer support/advice where required. Many of the CAB Committees where strongly placed as Professional Organisations to support and help implementation,

2. **Clinical Services Committee (New Chair Alastair Hutchinson):** TOR for membership changed by Trustees to reflect new NHS England Regions (ie Chair, plus 4 English Regions reps, plus 3 reps from devolved nations, plus BAPN Rep plus Patient safety lead (Paul Rylance) plus BRS nominated members (Senior nurse and Technologist).

Annual CD Forum planned for 21st March in Manchester. NCD invited. CAB asked for topic suggestions to go to AH.

Patient safety project discussed. Led by Paul Rylance (Within CSC). Inputs of issues from MHRA, Clinicians alerts and in past from MPSA (Now defunct). PR working with NRLS. Web page for Renal on MHRA Website. Output: emails to list of CDs, Senior nurses and posted on BRS and RA Website. New RA Website goes live in December. Twice yearly report to Br J Renal Medicine. Consideration of 3 monthly slide set on safety issues. Discussion took place regarding risk of statutory responsibility. The RA activities in patient safety are purely additional to existing statutory authorities. Whilst RA can be very effective in drawing out safety issues from Clinicians and effectively communicating issues, it does not replace any existing legal structure. Some care needs to be exercised in putting out comment on early reports of issues so as not to risk legal issues (although this ahs not occurred over 5+ years). Need for succession plans for PR and support for him. AH working on this.
GWL to ask UKRR if full list of CDs, Renal Nurse and technologist can be maintained by UKRR fior use by CSC Chair, Trustees.
Actions: To feed suggestions to AH re topics for CD Forum (All)
AH to work with PR to develop patient safety project further.

3. **UK Renal Registry (Fergus Caskey).** Fergus is first UKRR Medical Director-post has 5 sessions/week. He described focus on timiely UKRR reports. UKRR keen to work with NHSE via Renal data collaboration to update national Renal Data Set which at present ahs >800 data points. All discussed need reduce number of mandatory data points focusing on those which are clinically/patient relevant.

From January 1st UKRR will code aetiology of CKD under EDTA-ERA primary Renal Diagnosis Codes. Key issue was inclusion of co-morbidity data from Renal Units to enable corrected mortality reports. No co-morbidity entry will be interpreted as non existing (at present co-morbidity is recorded in 60% patients only). Large amount or positive work going on at UKRR.

Discussion on how variation identified in UKRR can be used for quality Assurance in outlying Renal Units. First step must be to be ensure data is valid (Co-morbidity as a major example). Any process must be supportive. Discussions have taken place with RCP as there is a mechanism in existence. RF commented that Commissioners would wish to see these data, hence need for clear validation
Actions; FC-ongoing.

4. **Guidelines Committee (Andy Lewington).** RA guidelines are now approved by NICE and appear on NHS Evidence, a major achievement by AL.
   Some guidelines coming up for review-AL encouraging guideline authors. Focus on including patient representatives and Renal SpR on guideline groups had full support.

   Guidelines now uploaded in much more user friendly format on RA website.

   Discussion about audit measures which come with each guideline. Could these be refined to a core minimum and form basis of useful data collection by UKRR?

   2 guidelines have been developed with other professional Societies. Any new guideline can be accommodated if following the NICE-agreed process. New report being developed for HHD. Commentaries of KDIGO guidelines being considered.

   Actions: AL to further encourage guideline authors to update.
   AL to explore patient SpR input.

AL to discuss audit measures in guidelines.

5. **Equal Opportunities (Claire Sharpe).** Report at next meeting.

6. **Renal Patient View (Neil Turner).** NT congratulated on extremely successful developments. 33,000 people now registered. Group meets twice monthly. Only 4 Units not recruited patients, There is a high level of engagement. 1/3 of patients are pre-dialysis an 2/3 of patient log in each month. Potential for direct patient input to be used in collecting PREMS/PROMS discussed. As numbers increase further becomes even more valid. RPV might be a route for validated data to be submitted to Commissioners as part of Quality assurance (validation routines included in RPV)?

   The RPV platform is applicable to other specialities. It is being trialled for Diabetes and Inflammatory bowel disease. Governance issues surrounding this are being explored. Key focus must clearly remain as Renal unless additional resource made available.

7. **Rare Diseases (RaDar) (Mark Taylor). (**Report attached). All radar groups are making progress. Patient information is held on rare Disease.org. Many groups have held patient/national study days. Work is ongoing to ensure all groups can register patients onto radar. Technical support being discussed. 500 patients registered, predominantly adult.

Actions: Further work on enabling registration of patients. Succession planning (Trustees)

8. **Renal Terminology Committee ((Afzal Choudhry).**

Date of next Renal Association CAB Meetings:

- Monday 10th February 2:30 to 5-00 Meeting Birmingham or telecon
- TB Discussed Glasgow (During Renal Week)
- Tuesday 8th July 5pm Telecon/Webex
- Tuesday 21st October 2-30 to 5 Birmingham

Date of next Executive Committee meeting: 28/04/14
Date of next-but-one Executive Committee meeting: 15/09/14