Renal Association Executive Meeting

07/09/11

Webex virtual meeting

Attendants Lorraine Harper, Charlie Tomson, Peter Mathieson, Damian Fogarty(DF) Mary McGraw, Jonathan Fox, Martin Raftery, Claire Sharp, Alison Brown, Jonathan Barratt, David Wheeler, Alastair Hutchinson, Mark Taylor, Peter Drew, Graham Lipkin, Abraham Abraham, Albert Ong, Neil Turner, Bruce Hendry, Simon Davies, Peter Choi, Jane MacDonald, Fiona Karet, Phil Mason, Liz Lightstone, Donal O'Donoghue, Mark MacGregor, Mark Brady, Andy Lewington.

Mark Macgregor was unable to join the meeting due to technical difficulties

Agenda

1. Apologies – John Reynolds, Fiona Loud, Billy Nelson, John Williams, Andy Connor, Sue Carr, Sunil Bhandari
2. Previous Minutes – approved
3. Matters raised not on agenda –
    a. Information relating to one year free membership for SpRs has been distributed to renal programme directors. There has been a very positive response with programme directors writing to their SpRs informing them of offer. 15 new enquires to MCI about membership so far from SpRs not currently members. There was some debate at last executive meeting about whether this should also be offered to PhD students. Bruce Hendry and Fiona Karet supportive. Executive agreed the offer should apply to PhD students. This needs to be advertised widely via RSWP, website and through academic affairs board
    b. Terminology committee Chair job description distributed for expressions of interest in eNews
    c. Listing documents from partner organisations
    d. Webex pilot underway. Comments about the meeting and the way it progressed were requested by CT. DF noted that he couldn't look at other documents other than those seen by the presenter. Phil Mason noted that it is possible to have personal documents open on one's own computer which solves this problem.
    e. Martin Raftery had fed back to the Newcastle team comments on the atypical HUS application. The full application has now been submitted with RA support.
    f. Neil Turner thought that further thought needed to be given as to how the rare diseases initiative integrates with RPV. The diseases cystinosis and Alport's Syndrome have been chosen as pilots to move this integration forward.

g. Peter Mathieson is moving the joint meeting with RCP and RA on end of life care forward.

4. President's report- see attached
    a. Graham Lipkin noted that there is a QIPP teleconference next week to look at quality markers which he will join on behalf of RA. CT notes that this is an important document that will drive provision of renal services so needs comment from the Renal Association members.
    b. Rest of report accepted without comment.
5. Treasurer report
    a. The joint meeting with the BRS in Birmingham had made a loss: the likely liability for RA is approximately £30K: this takes into account BRS running costs which have been reduced by £25K in recognition of the financially unsuccessful meeting. The RA had not yet settled the invoice for this amount, but had agreed to do so. The excess spend was mainly due to high costs of venue. Birmingham ICC was £100K more expensive than previous meetings, also there was reduced corporate income. Attendance was similar to previous years but there was reduced income from registration, due to shorter registration of delegates and increased numbers of lower fee registration brackets. Unlikely to return to Birmingham as too expensive. Liz Lightstone asked whether loss was due to BRS costs or meeting costs. CT noted that annual budget of BRS was approved after negotiation to reduce costs to satisfaction of RA trustees. Agreement for financial sharing was approved some years previously. Jane Macdonald also noted that more people were applying for early registration. JF noted the offer to reduce costs of annual running costs of BRS was appreciated by the RA. Abraham Abraham suggested that specific sessions within the annual meeting can be conjoint with other specialist societies to improve registration numbers and income. Also, this can reduce the number of stand alone meetings through the year that sometimes struggle to attract a large enough audience. CT responded that this needed to be explored by David Wheeler, the next President
6. Secretary Report –
    a. Meetings
        i. The next annual meeting is on track for delivery. The science programme is more or less finalised and formal invitations are being sent out.
        ii. The joint meeting in February with the ABCD group should be very exciting. Executive encouraged to attend.
        iii. Joint meeting with BTS in Bournemouth in 11-14th June 2013. No progress on programme: this will need to be a priority for next Secretary and President.
    b. ASN membership
    Abraham Abraham not sure that this should be endorsed by RA. Neil Turner supportive of approach. Alison Brown suggested that it might allow submission of abstracts as an RA member rather than as a ASN member. Simon Davies wished to know if the ASN wished access to the RA membership list, if this was the case he was not supportive of the venture. Neil Turner noted that standard way would be for RA

to distribute email for JASN. Needs further investigation. The consensus was that the RA membership lists should not be shared with the ASN. If it was decided to proceed, the offer would be routed through the RA rather than directly from the ASN. Any response to the offer would be determined by what they were offering and what they expected in return.

   c. Call for Secretary re-appointment. LH will demit from post at June Annual meeting. A hand over period should be arranged prior to this. Plan to announce call eNews September.

7. Clinical Vice President
   a. Payment by results – discussions between RA and the DoH has resulted in an improvement in the tariff. However, there remain issues around holiday dialysis that are not resolved. Holiday dialysis patients will only allowed to invoice at best practice tariff. Most units that offer holiday dialysis have invested in spare capacity to allow this and will therefore run at a loss due to the move to payment on a per dialysis tariff. This may result in patients not being able to move around the UK on holiday or family visits. The issue needs to be flagged with commissioners. Peter Drew works in a unit that does a lot of holiday dialysis and noted holiday dialysis is associated with significantly increased costs. Phil Mason notes that funding for holiday dialysis needs to be recovered from the local commissioners and this is very bureaucratic. There is also an issue which applies to patients who go off out of country for prolonged periods of time. Units are unable to recover costs for these patients as need to keep slot which means still need to cover cost of nurses etc. Graham Lipkin noted a further problem with these patients was the need to isolate patients on their return but funding for isolation dialysis only provided when patients are formally identified as carrying BBV. MR suggested that this issue needs to be discussed extensively at next CAB with a robust response submitted to DoH.
   b. Robert MacTier to step down as guidelines committee chair. Andy Lewington takes over at this meeting. 14 guideline modules completed and published in Nephron Clinical Practice. Future - 4 joint specialty guidelines in preparation to be published later this year. MR formally thanked Robert for all his help and leadership on this committee.
   c. Clinical Services Committee Strategic document presented by Graham Lipkin within the plan
      i. Document includes succession planning for Paul Rylance to take on his work on patient safety. Additional support by the clinical services committee has been put in place to help to support Paul currently. The committee should expand the work on patient safety with the Clinical Services Committee acting as a champion for quality and safety working with the MDT. This is an important and significant role for CSC to promote safety but the role needs to be deliverable and sustainable. DF noted that it may be possible to use systems similar to that used for the RADAR system to help record safety issues which in general are rare events. Graham Lipkin noted that there is a need not only to record events but also deliver on improvements and promote best practice solutions. This needs the engagement of the MDT to

allow proactive reporting and change implementation. Jane Macdonald agreed that the MDT needs to be involved in learning from safety issues and reporting of safety issues likely to improve change implementation. This is also a communication issue which needs improved. The BRS hope to do this. Lessons could be learned from the experiences of the Green Nephrology Network model which aims to improve awareness on green issues. DF noted that better use of eNews and website needs to be made to address safety issues with regular updates.

ii. There is a need to increase utility of clinical services page on the RA website. The members of the committee should be encouraged to report local issues. Abraham Abraham suggests that an archive of problems/solutions could be held on website. GL agrees this is the plan and will be linked to the BRS website. Most units are all doing the same thing with limited information sharing, this needs to change to allow greater collaboration. Need a swap shop of sharing processes.

iii. Clinical Services Committee currently meets once a year at annual meeting and also supports a Clinical Directors meeting. Graham Lipkin proposes increase in number of meetings which will be via WebEx. This will allow committee to focus on one particular problem and drive forward the agenda on this issue. Information from the renal registry may be able to support this initiative dependent on the area.

iv. The Clinical Services Committee needs to expand its quality remit via peer visiting of units. This is not formal peer review but just learning from other units.

d. Renal Registry –

i. The full annual report is now available on the web. Hard copies will be available soon.

ii. A new RR director, Ron Cullen, has been appointed. He has considerable experience, including board level Department of Health and Quality Improvement roles. He will bring a number of important new skills to the Registry.

iii. Data management difficulties – It has been identified that there are large amounts of redundancy in data validation processes which have created unnecessary delay and work over time. Much of the validation work is now automated and will improve delivery of reports. Two new data mangers have been employed.

iv. Reports returning to units have changed. The RR needs feedback on the utility of these reports.

v. It is unlikely that there will be full integration of reporting of paediatric and adult data soon. This is in part due to a different dataset and approach to using IT systems for RRT in children compared to adults.

vi. Vascular access audit needs to be repeated. There have been many lessons learned from completion of the previous audit. However concern remains

about the readiness of Renal IT systems to capture access data for both haemodialysis and peritoneal dialysis.

vii. HES linkage project moving forward. James Fotheringham(based in Sheffield) is working on the HES linkage project and now has a full data set.

e. Rare Diseases Committee – Mark Taylor had noted that the first meeting occurred and minutes approved. The rare disease initiative is rolling out quickly. 12 applications to KRUK for pump priming funding were received; 5 new rare disease groups were awarded funding, the vasculitis group application was approved was not given funding as group already had funding. A Rare Diseases workshop will be held in London for all coordinators of each group. To ensure that the initiative is implemented and delivered successfully there is a need for good project management. MT asked for approval to use some of the funding pump priming money to employ a project manager to deliver the project to secure future growth. The project manager would also need to deliver advice on set up and management. All similar sorts of RA initiatives need to amalgamate under a registry umbrella as part of the RA strategy. **Executive approved.** Albert Ong requested clarification from the Executive as to how to move forward for ADPKD since this falls outside the official remit of the Rare Diseases Committee. The original application had been unsuccessful since it did not qualify as a rare disease. However, its main aim had been to seek approval as a grouping in order to utilise APKD as the RPV platform to establish a UK PKD cohort. The PKD Charity was part of the application and had provisionally agreed to pump-prime the project once approved. DF noted that the Registry wishes to support the PKD initiative and had a large number of patients (7,000) already registered although these were mainly with later stage CKD. Bruce Hendry supportive of ADPKD initiative and suggested BKPA might also be approached to fund as an initiative. MT and NT noted that things needed to be managed in a stepwise way and not all groups could be accommodated at once. NT noted that rare disease committee will keep an eye on progress and roll out registry platforms as sure of success. MT noted that success needs to be seen, which is why pilots have been undertaken. Once sure of success will then apply to other disease groups. Albert Ong asked for an indication of time frame when this would be done and also feedback on how the initial pilot groups had performed. MT said that the MRC pilot of childhood nephrotic syndrome patients has recruited well. The MPGN group had stalled but was now on track since infrastructure support has been provided by Newcastle. MRC initiative envisaged standalone registries; this is not sustainable. There needs to be a move to greater involvement with Renal Registry and RPV. This will make things more sustainable and allow role out to other diseases.

8. Academic Vice President report

   a. UKKRC met on 15th July. Updates from 10 of 12 CSGs. Discussion was had on a focused initiative of one or 2 national projects with support from NIHR and DO’D. 2 programmes of work were supported on phosphate and CKD progression. Phosphate work exciting as strong possibilities of co-funding with Shire and

collaboration with Australians. However an HTA application on dialysis and Bicarbonate was rejected. Alistair Hutchinson agreed that the phosphate study is essential as no evidence case to underpin guidelines on phosphate management. Jonathan Barratt asked what support available to renal community from NIHR. BH responded that there was no commitment to renal call. The UKKRC needs to work with HTA with suggestions of work that needs to be to undertaken. Approved approach by executive

b. Training and education – A Shire supported elearning project by the ET&C is taking place. Thought needs to be given as to how to make this sustainable and may require some funding. Needs involvement by members to contribute new material. A business case will be submitted by Sue Carr. Neil noted that the initiative is in early days and will require initial intense input but will then become sustainable. Liz Lightstone asked how the initiative overlapped with Meguid El-Nahas's online academy. NT noted that the on-line academy is currently dominated by material contributed by previous graduates from the Sheffield Renal MSc and there is little overlap.

c. International committee –

    i. Albert Ong requested approval of Dick Banks and Diana Chiu as new members of the committee to replace Robert Unwin and Meguis El-Nahas. **Approved by executive**.
    ii. Joint session with ISN at next RA meeting will be held. The ISN will co-sponsor a speaker. Albert proposed that this should be a regular feature of each annual meeting in view of the increasing involvement of the RA members in international nephrology through the ISN. Support from Graham Lipkin and Charlie Tomson was voiced. **Approved by executive**.
    iii. Albert proposed that there could be a regular news feed from the ISN website to the RA website. This should not be technically difficult. Jonathan Fox noted that there should not be any advertising and Lorraine Harper commented that other society meetings including ISN and ASN already feature in the RA web diary. Supported by Bruce Hendry and Charlie Tomson.– **Approved by executive**.
    iv. Bruce Hendry asked for an update on the new joint RA-ISN fellowship. Albert commented that 5 applicants were eligible for up to 3 UK-linked fellowships (including 2 KRUK funded ones) in the last round (July 2011).. The decision will be made soon by the ISN committee and the process will be administered through KRUK. Albert to feedback the result to the Exec at the next meeting.
    v. Albert Ong suggested the development of informal groupings of RA members focussed around different regions of the world to increase involvement especially of younger members. Embryonic proposals but should improve links with different regions. The proposal in principle was approved by the executive. **Action: Albert Ong to return with formal proposal.**

d. Research committee –New members to the committee, Claire Sharpe, Emanuele de l'Angelantonio, Jill Norman and Rachel Lennon were approved by executive. Tim Johnson, although an outgoing member of the committee, will see through the research database project to its conclusion. FK thanked him for his efforts. Research training document needs to go back on website. The website needs to promote success of UKKRC. PM noted that the BKPA have significant funds to spend. He had suggested to the BKPA that they should support research. The RA needs to make links with the BKPA. NT noted that the BKPA are supporting the rare disease initiative but this project needs to show success before approaching them again for additional funds. FK felt that as a small team from the RA should arrange talks with the BKPA re a formal approach on supporting research funding. BKPA has small research committee. Bruce Hendry to approach BKPA research committee chair. DF noted that the BKPA will be keen to see patient benefit. Need to understand what patients want from research and what their priorities are. Charlie noted that work on this issue is on-going focussing on shared decision making in renal medicine

e. Equal opportunities committee

    i. At the last meeting of the committee discussions about making contact with new consultants and offering mentoring sessions and how this should be achieved practically had taken place. CT not sure how to identify new consultants. College are notified of new posts, this would at least trigger awareness of a new appointment. RCP assessor should provide report on who is be appointed. President should send letter to new consultants inviting them to join and offer mentoring. JB concerned not enough mentors. AB did not feel this would be a problem. **Executive approved proposal**. **Action CT to contact Royal College for notification of new posts**

    ii. AB proposed the RA should support specialty specific mentoring training session. Minimum useful session is 4 hours which would cost £2250. Will survey membership to see what take up would be like. Alison noted that many of those who responded to her survey and offered to mentor had no training. She felt that important to get people trained. Liz Lightstone suggested using the deanery mentoring training may be an option. Fiona Karet also suggested on-line mentoring training.Executive felt more information required before approving spend. **Action AB to submit formal proposal with funding implications and data on how many likely to take up training.**

9. NSF update – DO'D wishes feedback on QIPP. Responses should be sent to DO'D. AKI consensus conference occurring in October. Need input from membership to shape meeting. AKI delivery board will meet to develop. RA happy to be active partnership in this initiative. Feedback to DO'D about PBR and dialysis away from base. MR asked for a representation from Department of Health at the next Clinical Affairs Board meeting.

10. Report on revalidation – not a lot of changes compared to previous reports in terms of the process, with multi-source feedback and evidence of performance will be required. Revalidation will occur every 5 years. Remediation process may change. Webpage open for comment

11. Workforce planning – centre for workforce intelligence recommend further reduction in posts suggesting almost 100 posts to be lost over next 4 years. It is unclear how reduction will be allocated but likely to be based on weighted capitation which would have a major impact on London and West Midlands but committee may be open to other alternatives. PM noted that the changes should be based on number of RRT patients and on number of posts rather than actual trainees. PM actively working to support changes in manpower. Registry done a lot of work on patient numbers. Need to ensure that hospitals are assigned to correct region for this to work. The recommendations of the centre for workforce intelligence are likely to be accepted by DoH and implemented by Deaneries. Comments required from executive. Martin Raftery noted that major issues are there is a difference between number of training posts and actual numbers of trainees as many trainees are out of programme doing research. He also felt that training numbers should be based on number of patients on RRT. The executive needs to support Phil's approach to workforce intelligence. Jonathan Barratt notes that the number of trainees should be the same as posts trainees going into research should be backfilled by LATS and not inflated by another numbered post. P Mason noted that consultant expansion was predicted to double but most expect this is unlikely. Likely that a large number of current trainees are unlikely to get consultant jobs. SD noted that nephrology has a poor ratio of consultant to trainees and the specialty needs to promote appointment of trained doctors. NT noted that Clinical Directors suggest conservative expansion in Scotland of nephrology consultants. Need to accommodate trainees currently in training. The specialty is currently under represented by consultants compared to other countries. Alastair Hutchison notes expansion needs to happen in district general hospitals. DF notes we need to support and appoint trainees as CKD, AKI and specialist clinics initiatives require additional consultants. Much of this activity is not registered if RRT numbers is the sole metric and is not recognised by chief executives. Martin Raftery notes that the RRT programme does reflect activity. MR noted that once a posts was lost, Trusts lose MADEL funding and therefore cannot replace trainee with another type of appointment. Phil Mason agreed that RRT is a good measure of overall activity but need to use AKI agenda to promote renal consultant expansion. Do'D noted that need to change model of delivery of care with increased presence of nephrologists in district hospitals to allow employment of trainees.
12. SpR Club Report –Mark Brady taken over from Andy Fry. SpR club now has differential costs for RA members. Need to have transparency on accounts held by RA. SpR club needs to see accounts. Little representation of SpRs as members of the club from Wales or the Southwest. The SpR club meetings will allow submission of abstracts and presentations by members to increase its utility. SpR club would like to thank Phil Mason for all his hard work on workforce planning. This is much appreciated by the club.
13. BAPN report – see attached
14. RPV – 8 renal units have >50% of patients enrolled in RPV. 17000 patients registered. Working well
15. No devolved nation representation
16. RSWP report – John Reynolds informed the executive by email that they are due to have a teleconference soon

17. SAC report – Simon Davies reported a joint curriculum in renal/ICU medicine is now approved. Renal medicine is represented as a partner specialty. Curriculum will be available for this year's recruitment. Dual accreditation would take 8.5 years from ST1.There will be flexibility in level of appointment. Annual recruitment progresses without problems with appointment and trainees are similar level of quality to other specialties.
18. Green nephrology report – Andy Connor was unable to attend the meeting due to on call commitments and the fact that he had not received early notice of the meeting. He informed the executive by email that The Centre for Sustainable Healthcare are very grateful for the financial support provided by the RA towards the Green Nephrology Network. Over the last 2 months the IT infrastructure has been put in place and tested. The focus will now be on getting it up and running, with the aim of creating a medium through which the Local Representatives can more readily communicate. The progress in this regard will be reported at the next RA Exec Committee meeting, considering the lessons learnt and the possibilities for such strategies elsewhere in renal medicine.
19. AOB
    a. Webex pilot – need feedback. In general appears to have worked well. Need understanding of how much saved financially
20. Next meeting 11th January in Birmingham venue to be arranged.