

# RENAL INFORMATION EXCHANGE GROUP

## Notes of Meeting held Friday 20 March 2009 Department of Health, London

### PRESENT

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### APOLOGIES

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### ACTION

- 1 The notes of the last meeting were reviewed and accepted as an accurate record.
- 2 **RIXG Membership**  
Decision to invite a Specialised Commissioner to join the group confirmed. After some delays Afzal Chaudhry due to meet Specialised Commissioner in the East of England and will extend an invitation to her to join the group if that meeting goes well. AC
- 3 **CURRENT STATUS OF UK RENAL IT**
  - 3[a] **Increasing influence of Renal IT Advocates**  
  
DOD to write in the near future to Chairs of Renal Networks strongly recommending that Renal IT Advocates are given a voice and position in Network structures. DOD
  - 3[b] **Verbal updates by Renal IT Advocates on progress in their own patches**

- i) Generic issue of effecting the culture change necessary when moving to a paper-free environment (eg as at Guy's in the last few months in the outpatient setting). Cormac Breen reported uptake and enthusiasm high by both nurses and doctors, and patient satisfaction also high. Sean Fenwick noted that the inpatient environment can be much more challenging. Stan Fan emphasised the critical need for reliable and effective wireless technology to ensure that the paper free environment did not pull staff away from patients on the wards and dialysis units.
- ii) Challenges of ensuring reliable data returns from commercial satellite haemodialysis units. Discussion largely about Fresenius units, but issues relevant to all commercially run units. Several different discussions in different parts of the country with Fresenius were reported and the need for a coherent approach was emphasised.
- iii) KS confirmed that the new West of Scotland IT System contract has been awarded to Vitalpulse, and that with the exception of Inverness (which had recently bought a new system) it was anticipated that within a few years the whole of Scotland may be on the system.
- iv) KS reported a problem with laboratory data in Scotland which presently goes from GP systems into SCI data warehouses, one for each health board with no uniformity of data collection or messaging formats. KS's view was that this urgently needed a Scotland-wide solution, and that the approach in England was preferable. It was suggested that the new Information Partnership Board might consider offering an invitation to SCI representatives to facilitate discussions.

**Decisions:**

- a). Renal IT Advocates will be asked to report back (within the limits of commercial confidentiality) about contractual obligations on private providers to deliver IT solutions to ensure Registry returns.
- b). JF would write on behalf of RIXG to Nick Richards, Medical Director of Fresenius seeking a co-ordinated and efficient approach. JF
- c). This will be an Agenda item with a short presentation at the next meeting, JF will identify a Renal IT Advocate to lead this discussion [post-meeting note: Cormac Breen has 'volunteered'] JF

**5[c] Renal Unit Informatics Staff**

Kate Harris and Cherry Bartlett reported interim findings from 21 survey responses so far received. Very striking variations in the range of responsibilities and resources, as well as the grading of staff.

**Next Steps:**

- a) Agreed that present survey size was informative, but one more attempt will be made to increase the number of returns.
- b) An interim report would be made available to inform the BRS Workforce Planning Meeting on 23<sup>rd</sup> March. Nicki Thomas would speak on behalf of the informatics issue at that meeting. KH,CB,  
NT
- c) DOD would feed the same document into the DH Workforce Review Team process DOD
- d) A further final report on the survey would be completed before the next RIXG meeting in June. KH,CB

**5[d] Disseminating information about Renal IT via the RA Website**

Afzal Chaudhry reported that he had developed a page on the RA Website where documents could be uploaded and an email discussion could begin under his moderation. Agreed that all past RIXG Minutes would be posted, as well as other key documents such as the forthcoming Informatics Staff Survey. AC

## **5[e] The East Kent System – SEIK (System for Early Identification of Kidney Disease)**

Chris Farmer presented this system established and tested over four years in East Kent which accesses data on GP systems through MIQUEST and provides algorithm-driven advice to GPs about further investigation or referral of people identified as having CKD3-5. Now being modified to be compliant with NICE CKD Guidelines. The system was strongly approved and endorsed by RIXG, JF will provide a letter to facilitate Chris Farmer's discussions with PCTs.

JF

Noted that NHS Kidney Care and DH are taking this system forward to field test in four other PCTs (chosen because they have kidney units within their boundaries) and then intend to "industrialise" the system.

Continuing issues to be considered include

- information governance if anonymised data is de-anonymised; is an NHS number appropriate?
- deciding the precise language to use in advising GPs – eg recommend referral, suggest referral, etc.
- whether ultimately this should be a "push" or "pull" system. i.e. will a flag on a primary care system offer the GP the opportunity to invoke the algorithm whenever a blood test identifies a patient with CKD 3-5? Or will the GP be presented with the algorithm and recommendations automatically whether or not requested?

## **6 CONNECTING FOR HEALTH FOR ENGLAND**

### **6[a] Renal Specialty Systems Scoping Document**

This document had been submitted to CfH before RIXG's last meeting and continues to be considered by their Requirements Team.

### **6[b] Update on Local Service Providers**

Cormac Breen and Chris Farmer both reported that they had been invited to meetings within the next few weeks at which LSPs are meant to be making presentations to clinicians and managers about the most recent iterations of their generic systems. It was agreed that they would feed back at the next meeting.

CB,CF

### **6[c] Southern Renal Clinical Content Project**

CfH had responded following the letter from RIXG pointing out the many good features but nevertheless incompleteness of the renal clinical content originally developed for the southern cluster. JF had taken Chairman's Action with DOD and advised OCCO (Office of the Chief Clinical Officer) at CfH that the renal content could be signed off as a 'professional standard', implicit in that decision being ongoing work to turn it into an ideal specification.

A paper from Helen Hood (Project Manager, OCCO, CfH) was tabled and is attached. The proposed programme of work invites professional help in a number of steps. James Medcalf has agreed to be renal representative on a Logical Record Architecture User Group – RIXG agreed in principle to offer necessary support to LRA development, assessment of clinical safety of the content, and further piloting of the content through definitional testing and implementation/conformance testing.

Agreed that Helen Hood would be invited to the next meeting to talk further to this project. She would also be asked to present before our meeting a programme implementation document with clear scope and timelines.

JF

RIXG recognised that this is critically important work, and that its complexity should not be understated, but RIXG will engage fully in giving this the best chance of success.

#### **6[d] Existing Systems Programme**

JF reported that OCCO had responded to his letter to the Chief Clinical Officer which had been critical of the process by which approved suppliers had been identified, and expressed concern that the approved list narrowed options for Trusts tendering for new renal IT systems.

A telephone call between JF and senior staff at OCCO had provided reassurance that the list was not restrictive and any organisation tendering for a renal IT system was free to use the tendering procedure going beyond the list of approved suppliers. However written confirmation of this discussion while promised had not yet been forthcoming – JF to pursue.

JF

#### **6[e] National Renal Dataset**

Confirmed by DOD that the National Renal Dataset has been signed off by the Information Standards Board and now has a ROCAR number. Current issues are

- i) Implementation – Trusts are obliged to provide systems which allow the National Renal Dataset to be returned, but are typically passing this responsibility directly down to renal units' systems managers and indirectly therefore to the Registry, whose assistance is being sought. This is creating considerable work and it is recognised that implementation will take time.
- ii) Updates – it is recognised that the National Renal Dataset will continue to change (some new terms will need to be introduced – eg albumin creatinine ratio ) and others will become redundant. The process for these regular updates is under discussion.

#### **6[f] SNOMED-CT Renal Subset**

KS reported

- i) that the new ERA-EDTA codes for primary renal diagnosis (now extended to include all diagnoses not only those resulting in ESRD) is out for final consultation and will be presented at the World Congress of Nephrology in Milan, May 2009.
- ii) The SNOMED-CT Renal Subset is close to completion. The ERA-EDTA codes will match SNOMED. The National Renal Dataset will map to SNOMED.
- iii) EUNEPHRON (a Europe wide group studying rare kidney diseases) is reviewing the codes to ensure they are fit for purpose. New codes are mapped to old ERA-EDTA codes.

#### **6[g] Data Communication Standards**

KS had taken forward the suggestion at the last meeting that progress was required in establishing a data communications standard to ensure efficient messaging between all renal IT systems. Clinicians and commercial suppliers were enthusiastic about this project, but after some discussion it was agreed to leave this as an issue for the new NHS Kidney Care Information Centre Partnership Board.

#### **6[i] Choose & Book**

No Renal IT Advocate had anything new or encouraging to report. In some systems a continuing problem was inability to load attachments to a referral (eg ultrasound reports and so on). DOD is pursuing this issue centrally.

DOD

DOD reported on progress with the establishment of this Board and a first meeting in May 2009. JF presented a slide (attached) showing the many different organisations which hold data relevant to quality improvement, audit, research, training. The challenge for RIXG and the new Partnership Board is to improve data flows and deliver real gain.

Agreement that RIXG continued to have an important independent voice despite the establishment of a Partnership Board. It would meet regularly. DOD suggested the possibility that in future RIXG and the Partnership Board might meet morning and afternoon on the same day – no decision made.

Recognition that the Partnership Board initially was for England only, but DOD affirmed that wherever possible UK-wide solutions would be sought.

## **8 INFORMATION FOR PATIENTS, CARERS & NON-SPECIALISTS**

### **8[A] RenalPatientView**

- KS reported steady progress with patient registrations and new units taking up the system. Some concern that Clinical Vision, although claiming functionality, had not yet registered patients but that aside all systems fully operable.
- Capitation fee for 2009 £2.50 per RRT patient.
- RPV administration moving to the Registry in Bristol within the next few months.
- >12,000 patients registered nationwide, but question asked about how many of these are regular users, and as yet no data available.
- New modules in RPV will test opportunities for patients to input their own data (eg blood pressure) or make their own comments on care.
- Some are ambitious for RPV to be available to all kidney patients including those who have never attended a renal unit but the enormous technical challenges in this are recognised; majority view was that this cannot be developed until integration of primary and secondary care IT systems for direct clinical care has been achieved.

### **8[c] Map of Medicine**

JF reported that the CKD Pathway had now been updated to be consistent with NICE Guidelines, and would be signed off by the RA-RCP Joint Specialty Committee in the near future.

A new Pathway led by John Stoves is being started; this will provide a pathway for the assessment of abnormal blood and urine results.

Difficulty in engaging GP colleagues in the groups working on the Pathways was noted. RCP has been working with RCGP to improve this; RIXG members with individual contacts of enthusiastic and committed GPs should pass these on to JF.

**All**

### **8[d] National Library for Health – Renal Specialist Library**

David Goldsmith had asked for two representatives from RIXG to join his new External Reference Group for the Renal Specialist Library. Regrettably no volunteers from RIXG were forthcoming. JF will recommend that David Goldsmith approach RA and BRS and seek nominees.

**JF**

## **9. TRAINING AND EDUCATION**

Discussion about the importance of the whole information agenda within the curriculum for nephrology trainees. JF to write to Sue Carr who is chairing the RA Curriculum Review Group to emphasise the importance of this.

**JF**

## **10 PAEDIATRIC RETURNS TO UK RENAL REGISTRY**

Chris Reid reported on slow and steady progress by the BAPN Registry Group chaired by Carol Inward. Seven of the 13 paediatric units in the UK have PROTON systems or immediate access to PROTON systems in adjacent adult units and electronic returns should start in 2009. These are Birmingham, Bristol, Cardiff, Glasgow, Leeds, Manchester, Nottingham.

Work is required to create paediatric-specific screens within PROTON, this requires Registry staff time, and there is residual money from a previous DH grant to facilitate this.

In other units progress and solutions are as follows:

Liverpool – Will be integrated in the new Cybernius adult system in the next one to two years

Southampton – ?

**12 A O B**

**12[a]** Other information issues raised by member organisations

UK Renal Registry – Afzal Chaudhry reported that on World Kidney Day new interactive maps had been launched on the RA website allowing units to access substantial local data.

**12[b]** “Dashboards” are being introduced across the NHS with the goal of improving quality of care. Pilot site for a renal dashboard is in Salford led by Janet Hegarty and is focussing on the year before renal replacement therapy. Agreed that Janet would be asked to a future RIXG meeting to present her work.

**JF**

**13 DATES OF NEXT MEETINGS**

Friday 19 June 2009, London

Friday 18 September 2009, London

Friday 27 November 2009, London

# RENAL INFORMATION EXCHANGE GROUP

## Notes of Meeting held Friday 19 June 2009 Department of Health, London

### PRESENT

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### ACTION

- 1 The notes of the last meeting were reviewed and accepted as an accurate record.
- 2 **RIXG Membership**  
The Group welcomed Catherine Turner, a Specialised Commissioner in the East of England. It was noted that the representatives from the NKF and BTS had resigned and JF was to investigate the appointment of replacements

JF

### 5 **CURRENT STATUS OF UK RENAL IT**

#### 5[b] **Increasing Influence of Renal IT advocates**

DOD had written to Chairs of Renal Networks strongly recommending that Renal IT Advocates are given a voice and position in Network structures.

#### 5[a] **Verbal updates by Renal IT Advocates on progress in their own patches**

- i) Cormac Breen reported that meetings had taken place with CSC re Lorenzo, but that little was on offer at this stage. Most Trusts were continuing with iCM. The area was looking for

a long-term approach. St Helier had looked at the new Guys system and were considering it for a possible move from their well-developed Proton system.

- ii) Afzal Chaudhry reported that the Cambridge Renal and Transplant system was to be extended to Papworth. The Fresenius Euclid system could now be accessed from Addenbrooke's and they would soon be able to retrieve Fresenius data for return to the Registry. Issues at Colchester were being developed in conjunction with Catherine Turner.
- iii) Keith Simpson confirmed that the new West of Scotland IT System (excluding Inverness) supplied by Vitalpulse was progressing well with a predicted go-live in November. The problems with the Scottish central results store continued.
- iv) Hameed Anijeet reported that the Cheshire and Merseyside system was well advanced and links between Euclid and the Cybernus system were being established. He was planning to visit Preston to discuss their system and no problems had been reported from Manchester.
- v) Sean Fenwick confirmed that the Freeman and Newcastle were soon to be upgraded to CV5. James Cook were acting as a pilot for vascular access audit. Sunderland were experiencing problems at PCT level in implementing RPV.
- vi) John Stoves reported that the Yorkshire and Humberside network was being redeveloped. Tendering for a system for Leeds, Bradford, Hull and York continued with demonstrations planned in the autumn. Staff had been trained to use System One links with primary care. He had met with CfH about a pilot within the SHA of a renal system; JF reported he thought this was intended to be a pilot focusing on primary-secondary care interface being led by Sarah Peart-Benthamn, CfH; however JS noted that he had been asked by CfH staff who met him about renal secondary care issues.  
There was some concern in the region about the workload around the national dataset.
- vii). Kate Harris confirmed that Oxford were staying with the proposed Cerner development being implemented there by Paul Altmann, and Reading were to be a CV5 site. Portsmouth had no plans or money to move from Proton. There was no renal network in South Central and Bev Matthews (NHS Kidney Care) was pursuing this.
- viii). Chris Farmer had nothing to report from Brighton. Kent and Surrey had no LSP and had stalled as far as Primary care systems were concerned. It was hoped there would be a central results server for Renal, but this was still experiencing problems. The East of the patch were reluctant to allow primary care access to results and there were problems getting results into renal systems.
- ix) Andrew Williams reported most of South Wales was now covered by Vital Data. Links to Euclid had yet to be established. North Wales was considering whether to link with Liverpool.

#### **5[c] Renal Unit Informatics Staff**

Kate Harris and Cherry Bartlett presented detailed findings from staff survey responses from 19 units and a framework of knowledge and skills for renal informatics staff linked into the functionality spreadsheet. Again the striking variations in the range of responsibilities and resources, as well as the grading of staff were noted. Data had been fed into the BRS workforce planning group. There was a wide ranging discussion about the findings and the difficulties posed in the wider NHS IT context. It was thought that similar types of roles may be found in Cancer or Primary care practice managers. The next stage will be to map the linkages to the AFC banding levels.

**KH, CB**

#### **5[d] Disseminating information about Renal IT via the RA Website**

Afzal Chaudhry reported that he had added material to the website, and would continue to keep it updated, for example with the work on informatics staff. The discussion forum was being developed and David Ansell had agreed to provide some material, but it was important to keep the debate lively. Examples of achievements by the Renal advocates would also be added to the site.

**AC**

**5[e] Interactions with private dialysis providers**

John Feehally had written to Nick Richards (Fresenius) who had agreed to meet Cormac Breen and then attend RIXG if that was thought necessary. Cormac Breen would lead for RIXG on this issue; he reported some progress with other manufacturers such as Diaverum. He emphasised how important it was to write linkages into contracts for satellite centres that were clear about what data would be transferred. It was felt that a framework was needed to guide Units contemplating using private providers.

**CBr**

**6 CONNECTING FOR HEALTH FOR ENGLAND**

**6[a] Renal Specialty Systems Scoping Document**

This document had been submitted to CfH and continues to be considered by their Requirements Team.

**6[b] Update on Local Service Providers**

Chris Farmer reported that there was no prospect of a new LSP in the South. Worthing were reverting to iSoft from Fujitsu. Local solutions were being investigated. In Kent and Canterbury they were planning to use System One in Primary care.

**6[c] Renal Clinical Content Assurance + Logical record Architecture Renal Domain**

**6[d]**

Bev Havard and colleagues from the OCCO section of CfH gave presentations on the Clinical Content Assurance/Pathways group and the Logical Record Architecture (LRA) renal domain. They described the work that already been done and emphasised that they would like to continue to work with the Renal Group through RIXG to progress to a completed LRA for Renal, but within a fairly tight deadline.

RIXG discussed the presentations and the request for support from the CfH group. The feeling of the group was:

**JF  
JM**

The Renal LRA described so far was encouraging  
It was good that renal content was the first domain to be developed, but that carried extra work  
RIXG are willing to engage, but were concerned about the timescales, and preferred the concept of workshops rather than RXIG members working individually with the LRA team  
James Medcalf would continue to be the contact point

JF would respond formally

**6[e] National Renal Dataset**

Trusts are obliged to provide systems which allow the National Renal Dataset to be returned, but are typically passing this responsibility directly down to renal units' systems managers and indirectly therefore to the Registry, whose assistance is being sought. JF would follow up with the Registry for clarification as to whether the IC was now receiving data via the Registry.

**JF**

Requirements for new systems should be built up around the Dataset.

**SNOMED-CT Renal Subset & New ERA-EDTA Diagnostic codes**

**6[f]** KS reported there were no new developments. The Renal subset was being completed and there had been no recent request for help from the IC team working on it. The new ERA-EDTA diagnostic codes had been launched at the WCN in Milan. The codes would soon be on the EDTA website and then available through national renal societies. Mapping was available from the old EDTA codes, and contact had been made

**KS**

with the CEO of SNOMED-CT International to progress mapping of new EDTA codes to SNOMED.

#### **6[i] Choose & Book**

No Renal IT Advocate had anything new or encouraging to report. Problems were still being reported concerning the inability to load attachments to a referral (eg ultrasound reports). Some referrals were very late arriving in Renal Departments resulting in some inappropriate patients being seen just because it was too late to stop them attending.

#### **NHS KIDNEY CARE – INFORMATION CENTRE PARTNERSHIP BOARD**

DOD was away on leave so no report, but a first meeting of the Board was scheduled for July 1<sup>st</sup> with John Feehally and Catherine Turner from RIXG attending and Charlie Tomson representing the Registry

### **8 INFORMATION FOR PATIENTS, CARERS & NON-SPECIALISTS**

#### **8[a] RenalPatientView**

- RPV administration had moved to the Registry in Bristol and an administrator had been appointed.
- Worth Solutions were working on new modules in RPV for patients to input their own blood pressure with a view to extending this facility to other patient entered items.
- Consideration was being given to the feasibility of returning data items from RPV to Renal databases
- Requests have been received to include unusual tests and it was proposed to use a letter format to enable these to be reported without creating new fields on the system
- Software has been commissioned to examine activity data
- An application to use RPV for research was being worked up

**KS**

#### **8[b] Map of Medicine**

Work continues on renal aspects of MoM. Andrew Williams reported that there was evidence from Wales that use of MoM led to fewer and better referrals to renal services

### **9 NEPHROLOGY CURRICULUM**

- 9[a]** A document describing the requirements and levels had been circulated by AC and sent to Sue Carr, chair of the Renal Association curriculum review group. It was agreed that this was a very comprehensive description of the requirements and that it would be expected that SpRs would reach level 4. It may need to be made more renal specific, and additional levels may be added for those wishing to be more IT specialist in their role.

**AC**

### **10 PAEDIATRIC RETURNS TO UK RENAL REGISTRY**

There was no paediatric representative, but it was expected that all Proton based paediatric centres would be making electronic returns to the Registry for 2009.

### **12 A O B**

UK Renal Registry – more interactive maps were to be launched including public health data. The first centre specific reports were being sent out for comment and then would be made available to all centres

**AC**

Hameed Anijeet reported that they had been requested to delete electronic records over a

certain age to meet local information governance advice. It was agreed that this was incorrect and the records should be maintained.

JF

#### **DATES OF NEXT MEETINGS**

Friday 18 September 2009, DH Wellington House, London

**PLEASE NOTE CHANGE OF DATE FOR FINAL MEETING OF 2009:  
NOW FRIDAY 27<sup>TH</sup> NOVEMBER** (originally 4<sup>th</sup> December)

# RENAL INFORMATION EXCHANGE GROUP

## Notes of Meeting held Friday 18 September 2009 Department of Health, London

### PRESENT

John Feehally (Chair)	<a href="mailto:jf27@le.ac.uk">jf27@le.ac.uk</a>
Cherry Bartlett (Minutes)	<a href="mailto:cb203@york.ac.uk">cb203@york.ac.uk</a>
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Mike Sandell, Information Centre	
Nick Richards, Medical Director, Fresenius UK (for presentation)	

### APOLOGIES

Chris Rudge	<a href="mailto:mrcjrudge@aol.com">mrcjrudge@aol.com</a>
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Neil Turner, Renal Patient View	<a href="mailto:neil.turner@ed.ac.uk">neil.turner@ed.ac.uk</a>
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Stan Fan, Renal IT Advocate, London	<a href="mailto:Fan.Stanley@bartsandthelondon.nhs.uk">Fan.Stanley@bartsandthelondon.nhs.uk</a>

### **ACTION**

- 2+3** The notes of the last meeting were reviewed and accepted as an accurate record.
- 4** **RIXG Membership**  
Richard Baker has replaced Rob Higgins as the BTS representative and Tim Statham has agreed to continue representing the NKF at RIXG.  
*Post-meeting note: Nitin KOLhe [Derby] is the new East Midlands IT advocate [replacing Maarten Taal].*
- 5** **Renal IT Provision in Private Provider Dialysis Units**  
Presentation by Nick Richards, Medical Director, Fresenius UK  
Nick indicated that he was presenting the perspective of Fresenius. The company intends to run 50 to 60 units in the UK and in the last 18 months has moved to having a single IT system across its units, with integration to the local system with two way flows of lab and treatment data. Their intention is to move to paperless centres including the care record. There are still some issues regarding remote prescribing, but Fresenius are looking at systems to overcome these. Nick emphasised that Fresenius deliver against a tender and

that the quality of delivery equates to the quality of tender submitted. He would like to see a combination of requirements from Nephrologists and the local IT staff. Some Trusts are anxious about interfacing with a private company. Fresenius do provide downloads to the Renal Registry, but only of the data from their satellite centre. The data collected is used only for audit purposes and comply with Data Protection legislation. Quarterly reports are produced within the Company for service level monitoring and participation with international data requests is only undertaken with local agreement.

## **6 CURRENT STATUS OF UK RENAL IT**

### **6[a] Verbal updates by Renal IT Advocates on progress in their own patches**

- i) Catherine Turner reported in Afzal Chaudhry's absence that issues at Colchester were being addressed to improve their service.
- iii Keith Simpson indicated that Inverness were to implement RenalPlus and RPV. VitalPulse was progressing in the West of Scotland, covering more than 50% of the Scottish population and the Scottish Renal Registry would be moving over next year.
- iii) JF reported in Hameed Anijeet's absence that the Cheshire and Merseyside system was well advanced and links between Euclid and the Cybernius system were now established, but there were still some issues with links to Gambro equipment. There was some discussion regarding the standards that need to be written into contracts and Peter Rowe agreed to lead a RIXG group to produce recommendations of key elements to be included. **PR**
- iv) Sean Fenwick confirmed that the Freeman and Newcastle have been upgraded to CV5 allowing links to RPV and enabling the renal dataset to be collected. Sunderland's RPV issues had now been resolved and patients were being registered. Contact had been made with the Chief Information Officer and Renal IT was on the agenda for Specialised Commissioning meetings with feedback to the SHA.
- v) Cherry Bartlett on behalf of John Stoves reported that four companies had been shortlisted for the new IT system in Yorkshire and three demos had been held with one more in the following week. No new issues had been raised from the local Trusts. DOD questioned whether JS included Sheffield and Doncaster within his remit. (to be followed up by JS). Representatives were being sent to the MORRIS dialysis prediction toolkit event organised by NHS Kidney Care. **JS**
- vi). Kate Harris confirmed that Oxford were staying with the proposed Cerner development, and Reading were to be a CV5 site. Portsmouth were continuing with Proton. A Renal Network in South Central had been established with the first meeting on 15<sup>th</sup> Oct and contact would subsequently be made with the SHA Chief Information Officer.
- vii). Chris Farmer reported no change from Brighton. Kent were to use RenalPlus, and Sussex CCL. In East Kent data were being collected on acute kidney injury for identifying at risk individuals; an approach was being explored for enabling information from GP records which predicted AKI risk [e.g. medication, co-morbidities] to be available in the acute trusts to emergency admitting staff. Discussions were being held with SHA re Acute Care and IT involvement in the Renal Network.
- viii) John Smith indicated that NI had six dialysis units all running Emed on a regional basis and making returns to the Renal Registry. The system was run in Belfast giving smaller units little control over it. The drug prescribing module was considered to be very good. RPV is available but needs a local appointment to be made to be implemented. Emed was also being used in the Irish Republic.
- ix) Peter Rowe reported that a contract had not yet been signed with VitalPulse for Plymouth, but a Dialysis Unit manager was to act as project manager and it was hoped the project would go ahead soon. Exeter had been included in discussion about an integrated SW system and they and Truro were considering the proposal. Work continued to develop links to the Renal Network and SHA.

### **6[b] Plans to disseminate information about renal IT via RA website**

1	Afzal Choudhry had given late apologies and would update at the next meeting, but was considering a blog approach.	AC
6[c]	<b>Renal Unit Informatics Staff</b> KH and CB would report to the next meeting.	KH, CB
7	<b>CONNECTING FOR HEALTH FOR ENGLAND</b>	
7[a]	<b>Update on Local Service Providers</b> Chris Farmer reported that in his region all decommissioned IT equipment and data were being stored pending any legal action. No new LSP had been appointed. No RIXG member was aware of significant relevant developments in Lorenzo.	
7[b]	<b>Renal Clinical Content Assurance + Logical record Architecture Renal Domain</b>	
1	The first workshop had been cancelled owing to lack of numbers. Other workshops were to be held on 8 <sup>th</sup> Oct, 6 <sup>th</sup> Nov, 25 <sup>th</sup> Nov with a fourth one to be held in January. There was now some confusion among RIXG members as to the purpose of the LRA as it was not about context.	KS
7[c]	<b>Choose &amp; Book</b> Little had changed, and some aspects were better depending whether 'advice and guidance' was switched on or off. In Sunderland it was switched off. Plymouth were not using C & B but were setting up their own system. Portsmouth had restructured clinics, which had caused some problems and the Trust was concerned re the effect on income. In the SE advice was switched off and no tariff was agreed.	
8	<b>NHS KIDNEY CARE – KIDNEY QUALITY INFORMATION BOARD</b>  The first meeting had taken place on 1 <sup>st</sup> July bringing together custodians of kidney data with the aim of sharing and extending their use and analysis that would lead to improving quality of delivery of service. Minutes from this meeting had been circulated. A number of priorities had been identified that the next meeting would consider for prioritisation. KS suggested that standardisation of data transfer methods should be added to point 9.	DoD BM
9	<b>National Kidney Care Audit, Coding and Data Collection</b>  Mike Sandell from the Information Centre gave a presentation and demonstration of the IC's analysis tool – iView. This tool had been used for the Renal Transport Audit and a report was now available of the findings. This audit would be repeated in 2010. iView is available via the IC website and Mike demonstrated the types of analysis that could be accessed. Workshops are to be made available on iView's use and staff could register for access to use it. Many datasets held by the IC can be interrogated using it. IT advocates were asked to disseminate information about iView and its functionality in their own patches.	All
9[a]	<b>National Renal Dataset</b> This has now been approved by the ISB. Clarification has been given on what is collected by various organisations including the Registry and NHS Blood and Transplant. Trusts were mandated to create the environment to collect and to subsequently collect the dataset. A FAQ was being planned by Department of Health and the IC which was expected in the next few weeks. IT advocates were asked to report to progress at future meetings.	
9[b]	<b>SNOMED-CT Renal Subset</b>	
1	The Renal subset was completed and lodged with CfH. Links to LRA was being investigated by CfH. It was important to ensure the work wasn't lost, but the codes had not yet been released for use.	
9[c]	<b>New ERA-EDTA diagnostic codes</b> The codes were launched at EDTA this year. KS is working on mapping them to SNOMED-CT and help had been offered by CfH. The Chief Executive of SNOMED was keen to see	

them on a proper footing and it was hoped that SNOMED would have a renal group in the future. There had been no interest from Pharmacy or Renal IT suppliers in meeting to explain the new codes.

## 10 INFORMATION FOR PATIENTS, CARERS & NON-SPECIALISTS

### 10[ RenalPatientView a]

- New servers had been purchased resulting in RPV being much faster
- Worth Solutions were working on new modules in RPV for patients to input their own blood pressure with a view to extending this facility to other patient entered items.
- Consideration was being given to the feasibility of returning data items from RPV to Renal databases
- Registrations were increasing steadily
- An application to use RPV for research was being worked up
- Cancer, Diabetes and HIV Aids were interested in using a similar system
- It was hoped that usage statistics would be available from the new server

KS, NT

### 10[ Map of Medicine b]

Work continues on renal aspects of MoM.

JF

## 11 NEPHROLOGY CURRICULUM

AFC's work had been fed into the Curriculum Review Group.  
RIXG emphasised that the importance of including this new aspect of the curriculum in question setting for the Specialty Certificate Examination.

AC

JF

## 12 UK RENAL REGISTRY

### 12[ Appointment of new Registry Chair a]

Damian Fogarty would take over as Chair from May 2010

### 12[ Paediatric Returns b]

Six units had now submitted returns electronically. A review would be carried out of quality and completeness. All but one Unit (Great Ormond Street) would submit electronically next year. The paediatric registry database is now held by the RR.

### 12[ Rare Renal Disease Registry – RaDaR c]

A MRC funded pilot programme was being developed within the RR. Guidance for genetic testing would be very helpful. The intention was to provide support for staff with patients with rare diseases.

The context is a RA BAPN strategy for management for management, education, research & audit of rare renal diseases in the UK, which should be released before the end of 2009.

## 13 AOB

TS indicated that the NKF were promoting more frequent dialysis and looking to achieve more than 30% of patients dialysing at home (inc PD). He was keen that plans for IT developments included consideration of more home based dialysis. RIXG were keen to support the NKF in this regard and it would become an agenda item. KS indicated that the developments in RPV would help pave the way for expansion of home based dialysis.

## 14 DATES OF NEXT MEETINGS

Friday 27<sup>th</sup> November 2009, London  
Friday 26<sup>th</sup> March 2010  
Friday 18<sup>th</sup> June 2010

Friday 24<sup>th</sup> September 2010  
Friday 17<sup>th</sup> December 2010

**PLEASE NOTE CHANGE OF DATE FOR FINAL MEETING OF 2009:  
NOW FRIDAY 27<sup>TH</sup> NOVEMBER** (originally 4<sup>th</sup> December)

# RENAL INFORMATION EXCHANGE GROUP

## Notes of Meeting held Friday 27<sup>th</sup> November 2009 Department of Health, London

### **PRESENT**

John Feehally (Chair)  
Keith Simpson, Scottish Renal Registry  
Nicki Thomas, BRS  
John Smyth, Renal IT Advocate, N Ireland  
Es Will  
Cherry Bartlett, NHS Kidney Care  
John Stoves, Renal IT Advocate, Yorks & Humber  
Nitin Kolhe, Renal IT Advocate, East Midlands  
Hameed Anijeet, Renal IT Advocate, North West  
Afzal Chaudhry, Renal IT Advocate, East of England  
Paul Altmann  
Sean Fenwick, Renal IT Advocate, North East  
Donal O'Donoghue, National Clinical Director [item 5]  
Bev Matthews, NHS Kidney Care [item 5]

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### **APOLOGIES**

Kate Harris, Renal IT Advocate, South Central  
Catherine Turner, Specialised Commissioner  
Tim Statham, NKF  
Charles Kernahan, KRUK  
Chris Reid, BAPN  
Donal O'Donoghue, National Clinical Director  
Peter Rowe, Renal IT Advocate, South West  
Chris Farmer, Renal IT Advocate, SE Coast  
Chris Rudge  
James Medcalf  
Andrew Williams, UK Renal Registry  
Cormac Breen, Guy's Hospital  
Kieran Donovan, Renal IT Wales  
Richard Baker, British Transplantation Society  
Neil Turner, Renal Patient View  
Simon Ball, Renal IT Advocate, West Midlands  
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### **ACTION**

#### **1. Welcome and Apologies**

##### **Introductions**

Cherry Bartlett was congratulated on her new role as Programme Lead for NHS Kidney Care with a portfolio which includes informatics matters.

The BRS has proposed that its second representative (in addition to Nicki Thomas) to RIXG should be a representative of the Association of Renal Managers. Rani Prue will take this role but could not attend this meeting.

It was agreed that the notes of the last meeting were an accurate record and there were no matters arising other than those in the meeting agenda.

#### **4 CURRENT STATUS OF RENAL IT**

##### **4a East of England**

Cambridge has identified a funding stream to establish RenalPatientView. There has been a continuing problem with accessibility of data from Fresenius but remarks made by the Fresenius Medical Director at the last RIXG meeting had been helpful in progressing this.

Colchester – there had been an agreement since May 2009 to provide a clinical information

system for dialysis patients only. AC and CT have been supporting this but progress is slow.

Ipswich – the old Baxter system now taken on by BBraun is not yet fit for purpose in delivering the necessary aspects of the National Renal Dataset.

#### **North West**

There are issues in Preston where four different systems are being used in various satellite units although PROTON remains the system for the main unit.

#### **Cheshire/Merseyside**

The Cybernius system is now live at Arrow Park and making its first Registry returns. This will be followed by Aintree and then Royal Liverpool live by May 2010.

#### **East Midlands**

Derby's VitalPulse system is now well established for haemodialysis but not yet for PD. Baxter have promised an interface for their PD system but this has not yet emerged.

#### **Yorkshire**

A preferred bidder has been identified for the new Leeds-Bradford-Hull-York system and a final decision will be announced soon. System 1 is now being adopted by 90% of GP practices in Bradford and Airedale allowing extension of the work developed by John Stoves and colleagues. There is interest from other specialties in Yorkshire in adapting the system. System 1 is increasingly used around the country (driven in part by it being announced as the preferred partner for Lorenzo) although there is still great variety with many parts of the country having EMIS as its majority GP system.

#### **Northern Ireland**

A business case has now been developed for RenalPatientView and it is thought likely this will be available soon. There is no progress with Primary Care-Secondary Care interfaces.

#### **Scotland**

The new West of Scotland system with VitalPulse is expected to go live in early 2010.

#### **North East**

Newcastle have been delayed in the implementation of ClinicalVision because of delays in moving into their new renal unit. Sunderland have identified ring-fenced money for an update of their system.

In the absence of their IT advocates, there were no updates from other geographical patches. IT Advocates reported limited progress in establishing working relationships with SHA Chief Information Officers, and variable success in becoming involved with renal networks.

#### **4b Plans to disseminate information about renal IT via RA website.**

AC led a discussion about a variety of options including posting additional information, highlighting new updates, E-awareness, and discussion. He will continue to progress this.

#### **4c Renal Unit Informatics Staff**

In the absence of Kate Harris it was agreed to defer a further report on this item until the next meeting.

#### **4d Interfaces with Private Dialysis Providers**

In the absence of Cormac Breen and Peter Rowe this was not discussed in detail. However JF reported that PR is drafting some standard paragraphs which RIXG will recommend become part of future contracts.

**PR**

### **5 JOINT MEETING WITH RENAL NETWORK MANAGERS FOR ENGLAND**

RIXG was joined by eight of the ten Renal Network Managers for England as well as the National Clinical Director and Director of NHS Kidney Care. The objective of this interface meeting was to develop effective contacts, introduce Renal Network Managers to the current informatics achievements and challenges, and make plans for future closer working.

JF gave a short presentation on the current renal IT situation in the UK and the opportunities for progress. Informed discussion followed and contacts were made.

The Renal Network Managers Group will identify a representative to become a member of RIXG

JF

## 6 NHS INFORMATION STANDARDS BOARD

Professor Martin Severs gave a presentation about information standards, criteria used by ISB to judge such standards, and processes of implementation.

## 7 CONNECTING FOR HEALTH FOR ENGLAND

### 7a *Local service providers*

It was noted that Lorenzo had had a recent “go live” in Bury, Lancashire, which had delivered PAS and administrative systems rather than clinical systems. Cerner is live with some aspects of a clinical system including electronic prescribing, most notably in Newcastle where there are up to 30,000 users. The BT Cerner product including a generic clinical information system is now being agreed to go live in “green field sites” in North Bristol, Oxford and Bath. However no new substantial new progress by LSPs for renal specialist systems was reported.

### 7b *Clinical Content Assurance and Logical Record Architecture Renal Domain*

KS reported on the recent LRA Workshop. It was agreed that the principle stated by LRA that they wished to make clinically valuable information available in a logical environment was to be welcomed. Inevitably the LRA underestimated the complexity of process, presenting it in 2D when it was at least 3D in its applicability.

The importance of integrating SNOMED-CT into the LRA was emphasised.

One more workshop is planned. It was agreed that RIXG could not realistically support the LRA work beyond that on a volunteer basis. JF and James Medcalf were in discussion with the LRA team to see if they would support a part-time clinician post to help this work progress.

### 7c *Choose & Book*

IT Advocates reported no significant progress in improving functionality and usability of Choose & Book

## 8 KIDNEY QUALITY INFORMATION PARTNERSHIP BOARD

The Minutes of the recent KQIP board meeting and draft Terms of Reference were reviewed. Proposed recruitment of a Clinical Advisor for Informatics part-time secondment was welcomed. RIXG was concerned that the Terms of Reference for KQIP remain somewhat ill-defined and EW agreed to draft some proposed modifications for JF to forward.

EW, JF

It was agreed by RIXG that the KQIP needed to move from notional collaboration to effective action. The proposed work programme was not yet available for review and this was seen as critical to success. It was agreed that if JF is unavailable, another RIXG member would attend KQIP.

## 10 CODING AND DATA COLLECTION

### 10a *National Renal Dataset*

No specific new issues in NRD collection were reported.

### 10b *SNOMED-CT*

KS reported that mapping of SNOMED codes to the new ERA-EDTA codes was almost complete and publication was expected soon.

## 11 INFORMATION FOR PATIENTS, CARERS AND NON-SPECIALISTS

### 11a *RenalPatientView*

KS reported continuing progress with increasing numbers of patients and centres involved. All UK centres had now indicated their desire to be involved in RPV and there were no residual technical problems, although some implementations were still outstanding.

DH has recently provided further financial support for the RPV project developing the facility for patients to enter their own data (in the first instance blood pressure). For the purposes of evaluation of this project a DH representative will sit on the RPV Committee.

### 11b *NHS Choices and NHS Direct*

NT reported continuing involvement in refining and improving renal content.

### 11c *Map of Medicine*

JF reported that John Stoves is taking over the lead from Richard Fluck in the RCP/Renal Association review process for Map of Medicine pathways.

## 12 INFORMATICS IN NEPHROLOGY CURRICULUM

AC is working with the RA Curriculum Review Group chaired by Sue Carr to develop proposals for the teaching and assessment of informatics in the new nephrology curriculum. It was noted that appropriate teaching programmes should be available to be accessed by other members of the renal multiprofessional team as well as doctors. Proposed tools for assessment are being pursued including questions in the Specialty Certificate Examination, evidence of the trainee using informatics in clinical practice (for example chairing a satellite dialysis unit review meeting), inclusion of informatics in the Advanced Nephrology Course. AC will continue these discussions

## 13 UK RENAL REGISTRY

AC has taken over from Andrew Williams as Registry representative on RIXG. He reported steady progress on electronic returns from paediatric units, and also on early implementation of the Rare Disease Registry.

## 14 RIXG APPOINTMENT OF VICE-CHAIR

RIXG supported the proposals in JF's memo. It was agreed that a vice-chair would be appointed by summer 2010 to take over as chair from JF whose last meeting in the chair would be March 2011.

It was agreed that RIXG did not wish to create a formal Constitution and Terms of Reference. The agreed process for succession planning is that JF will write to all organisations who are members of RIXG asking for nominations and in the event of more than one nominee coming forward, offering each member organisation a single vote in selecting the new vice-chair.

## 15 AOB

It was noted that the BRS Workforce Planning Document is still awaited, that it was very important that informatics staff were properly represented in that document, and that it would be valuable to renal units in pressing for staff improvements. Nicki Thomas will liaise with Kate Harris to ensure available data are incorporated.

**DATE OF NEXT MEETING:** Friday 26<sup>th</sup> March 2010, London

### **Other dates for 2010**

Friday 25<sup>th</sup> June

Friday 24<sup>th</sup> September

Friday 17<sup>th</sup> December