

RENAL INFORMATION EXCHANGE GROUP

Notes of Meeting held Friday 14 March 2008 Prospero House, London

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ACTION

1 Change in Membership

- Cormac Breen was welcomed to his first meeting. He has been invited to join the group to bring his experience in developing a specialist renal IT system within the new hospital-wide EPR at Guy's & Thomas's.
- Paul Altmann was a guest at this meeting to present his experience in developing the Millenium software, but it was agreed that he should become an established member of the group.
- JF noted that, as agreed at the last meeting, he had asked CDs on the Renal Association Clinical Services Committee (representing all SHAs in England) to each nominate an "IT advocate" who would interact with RIXG and promote the Renal IT agenda locally. As soon as all nominees have been identified JF would establish a network and offer all these individuals the opportunity to come to RIXG if they so wished.

JF

2 Notes the last meeting were accepted as accurate record.

4 4a) Connecting for Health

EW reported on an approach from CfH asking if a renal IT system (perhaps using the Registry as an example) could be part of a demonstration CfH had been asked to prepare for the new Medical Director of the NHS to demonstrate the efficacy and potential of IT development. EW had agreed to take this forward since it was thought to offer an opportunity for the expertise and reputation of renal IT to be advanced in the higher echelons of NHS, but in due course this had come to naught, some other demonstration of functions within Lorenzo being preferred.

4b) Clinical Interface with Local Service Providers

MILLENIUM

Paul Altmann, who works half-time on IT development for the Southern Cluster LSP and Oxford

Radcliffe NHS Trust, gave a detailed presentation of the progress made in Millenium's generic EPR product now close to roll-out in a number of Trusts in the south, as well as renal specialty IT developments currently focussing on work in the Bristol renal unit. RIXG indicated its appreciation of this update, and the extent of progress, and it was agreed that Paul Altmann should become a regular member of RIXG.

4c) Clinical Interface with Local Service Providers

LORENZO

AN reported that the early adopter sites for Lorenzo had now been deferred from Spring 08 to June/July 08. It was also noted that the number of clinical advisers actively involved in development of the Lorenzo product had been significantly reduced, raising further concerns about continuing clinical engagement.

1. it was agreed that the network being developed of IT advocates across the country would provide an ideal opportunity to get full information on local developments, a report on this should be brought to the next meeting
2. it was agreed that transfer of data between developing renal IT systems was a vital function, and that its early testing should be a priority for CfH. JF to write to the Chief Clinical Officer on this point

JF

JF

4e) Existing Systems Programme

JF confirmed that renal system tenders submitted to CfH within its Additional Services Catalogue had recently been reviewed by three nephrologists – Es Will, Rob Higgins, David Ansell. Confidentiality matters precluded any further sharing of information. RIXG's present understanding is that contracts have not been offered to any of the tendering companies, although it is presumed that names may be on a "preferred provider" list if capacity is required. RIXG once again noted its concern that the very prolonged process of CfH development meant that specialist renal IT providers were at risk and may not survive commercially long enough to be able to contribute their expertise to eventual developments.

4f) Renal Dataset Development Project

The project has reached a critical phase with "road testing" being undertaken over the next two to three months in six testing renal units using two different IT systems. This has required significant development work by the Registry.

4g) SNOMED-CT Renal Sub-set

KS reported that work was nearly complete on development of a renal sub-set within SNOMED-CT. However

1. as yet chosen terms do not have precise definitions. To provide definitions for all terms was potentially a formidable piece of work and outside the remit of RIXG. It was agreed that KS and JF would review the terms when finalised, considering whether there were particular areas of ambiguity where definition might be of special importance (for example, overlap and uncertainty between the terms "fluid overload", "congestive heart failure", "pulmonary oedema").
2. RIXG indicated its disappointment that there was as yet no facility within SNOMED-CT to provide links to clinical decision support or relevant literature. This was contrary to an initial understanding that such developments were not only possible but planned.

KS/ JF

5 Information for Patients, Carers and Non-Specialists

5a) RenalPatientView

The latest newsletter provided by NeilT was welcomed. RIXG agreed in principle that it was appropriate for RPV's future to lie within the Renal Association for financial and governance reasons. NT will prepare a paper to go to the Trustees of the Renal Association (and also for approval by appropriate member organisations of RIXG). This paper would cover

- (a) Agreement to collect a capitation fee from 2009 with the Renal Registry capitation fee. The fee likely to be £2-£3 per RRT patient per year in 2009 with the potential for it to reduce further as numbers increase.
- (b) A business case for the recruitment of one or more permanent staff members from the achieved budget to support RenalPatientView.
- (c) A description for the governance of RPV within the Renal Association's structures (by analogy TO the relationship between the UK Renal Registry and the Renal Association). RPV to have a separate Management Board with representation including RA members, patient representatives, multiprofessional membership from other RIXG represented organisations.
- (d) The proposal that RPV-employed staff would work in Bristol alongside Registry staff for reasons of cross-cover, line management, human resource support, and so on.

NeilT

5b) Patient Information DVD Project

RIXG noted and accepted the letter from Steve Smith providing cogent reasons for the current financial structuring of the DVD project.

5c) NHS Choices

It was noted that Muir Gray had indicated the possibility that funding would be available for secondment of a nephrologist probably for one day a week to support the specialist information environment within NHS Choices. RIXG agreed that if it materialised, this would be warmly welcomed. JF to watch and act if necessary.

JF

NickiT and SS have assisted in writing the CKD content of the NHS Choices site which went live on 10 March 2008. They will review the content of the site and send any comments to the NHS Choices team in due course.

NickiT
SS

5d) NHS Direct

NickiT reported that there had been some further changes in the material posted within NHS Direct. RIXG agreed that she should take this further if it still fell short of expectations.

NickiT

5e) NLH Renal Specialist Library and NHS Renal Knowledge Week

DG provided an update on the Renal Specialist Library launched on World Kidney Day, March 2007. This was receiving a modest 2000 hits per month which was slowly increasing. Further progress had been somewhat stultified by the need for DG and his librarian team to re-tender for the work which they had now successfully done.

It was noted that an annual "Knowledge Week" was a statutory requirement for each Specialist Library. RIXG supported DG's proposal that the Renal Knowledge Week to be held in June/July 2008 should focus on assembling and presenting recent literature on issues related to chronic kidney disease, measurement of proteinuria, and eGFR. DG was in discussion with the DUET organisation led by Ian Chalmers which focuses on an approach to clinical areas characterised by lack of evidence.

RIXG strongly supported the notion that the Knowledge Week should focus not only on developments within the Specialist Library but should also take the opportunity to showcase the achievements of RenalPatientView, the patient information DVD, and so on. NT and SS agreed to support DG in providing review of his developing proposals on CKD, and it was agreed that Roger Gadsby should be approached to identify a GP reviewer.

DG to keep JF informed invoking RIXG Chair's action where necessary to push forward the Knowledge Week.

DG/JF

6 Review of DH Renal IT Workshop held on 14th March 2008

RIXG welcomed the preceding DH Workshop as evidence of real movement within CfH to resolve the specialty issues which have concerned RIXG over the last three years. There was some concern that the level of detail required had not been sufficiently achieved in a single workshop morning; the report to be prepared by James Medcalf may therefore require further work.

KS reported that a similar exercise had resulted in a document in Scotland which he would circulate as soon as it had received the necessary approvals.

KS

7 Any Other Business

7a) KVJ had recently circulated to all RIXG members a survey inviting views on some aspects of the CfH Clinical User Interface for which she is a clinical lead. All agreed to make every effort to complete the survey.

7b) BAPN

It was noted that Carol Inward has recently been appointed Chair of the BAPN Registry Committee. It is understood that BAPN may also appoint an Informatics Officer to take a broad overview of all informatics issues. RIXG welcomed this development. It was agreed that JF would contact the President of BAPN for further details.

JF

8. Date of Next Meeting:

Friday 20th June 2008 - VENUE TBC

Friday 19th September 2008

Friday 12th December 2008

RENAL INFORMATION EXCHANGE GROUP

Notes of Meeting held Friday 20 June 2008 Leicester General Hospital

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ACTION

1. CHANGES IN MEMBERSHIP

The expanded membership of RIXG now including Renal IT Advocates for ten SHAs in England was noted. As they only received short notice of this meeting, it was not surprising that a number were unable to attend.

2. Notes of last meeting of RIXG dated 14th March 2008 accepted as accurate.

4. CONNECTING FOR HEALTH FOR ENGLAND

4a Renal Specialty Systems

Renal Specialty Systems Requirements Project – Final Report

RIXG approved this report introduced by DOD and JM. Agreement that it provided a clear description, at a relatively high level, of renal and IT system requirements. RIXG was enthusiastic about this document moving through Connecting for Health welcoming the

opportunity to emphasise renal IT requirements.

4b

4c Progress in Local Renal IT Systems

Returns received so far from six of ten Renal IT Advocates were reviewed demonstrating a striking patchwork of progress (and lack of progress) in different SHAs, indeed in different Trusts. Evidence is emerging of some new investment in renal IT systems, compared to the stagnation over recent years. This appears to reflect increasing scepticism that a CfH product is imminent, and increasing energy within Trusts to develop their own IT solutions, albeit designed to be compatible with eventual CfH solutions. Success in York of establishing an interface between the hospital IT system and EMIS, the locally used GP system, was noted, as was a successful interface between primary and secondary care systems in Salford.

It was agreed that review of progress in each SHA, with sharing of ideas, opportunities and risks, would be a major agenda item at the next RIXG meeting.

4d Choose and Book

Anecdotal information continues to identify a remarkable variation in the implementation of Choose and Book in renal units. Only a minority of nephrologists seem to be able to use the system on line. Reports have been received of inappropriate referrals of 'out of catchment' patients with advanced kidney disease, driven by "next available appointment". Patient and carer concerns include difficulty in obtaining appointments with consultants previously involved in care of a chronic condition, again limited by "next available appointment". It appears there should be a facility within Choose and Book to allow consultant-specific appointments to be requested, and in a number of Trusts this part of the system has been turned off.

Agreement that this wide variation in practice and experience should be documented through the Renal IT Advocates in order to accelerate improvement.

4e Existing Systems Programme

Results of the Additional Services Catalogue tendering process were apparently in the public domain, although there had been no direct communication with RIXG. It appeared that a number of providers had been "authorised" through this process as being competent according to CfH to tender for renal IT systems in the future. It was reported that some established renal IT system providers had not been considered, as their business turnover did not meet a minimum threshold to enter the tendering process. It was agreed that further information would be sought.

JF

4f Renal Dataset Development Project

Testing of collection of a range of items in the National Renal Dataset had now been completed in a number of renal units with the support of the Registry. The National Renal Dataset Project Board are continuing the process to achieve full recognition of the dataset by the Information Standards Board. RIXG noted some uncertainty about the eventual process by which data would reach the Secondary Uses Service from Trusts, especially the mechanism by which data would be appropriately "cleaned" and validated. RIXG noted that rigorous standards of data verification were needed to support high quality audits such as that delivered by the Registry; and these could be somewhat different that the standards of data "cleanliness" needed for more routine NHS reporting. RIXG supported the potential benefits to the Registry of being freed from a data cleaning role, since this might allow Registry staff more time for appropriate audit and research. On the other hand RIXG was concerned that withdrawal of the Registry from a data validation role, without proper alternative arrangements, could compromise data quality.

4g SNOMED-CT Renal Subset

Progress has been slow in developing a renal subset of SNOMED-CT terminology, but recent appointment of an informaticist [Yongsheng Gao] working on renal aspects of SNOMED-CT (including the National Renal Dataset) should be a launching pad for accelerated progress.

(6) ERA-EDTA Diagnostic Coding

It was noted that the longstanding renal diagnostic codes developed by ERA-EDTA, and used

by the UK Renal Registry were being reviewed. RIXG was pleased to know that Keith Simpson, Charlie Tomson, and Venkat Raman were all involved in this European initiative.

4h Communication with CfH Clinical Team

No reply had yet been received from the CfH Chief Clinical Officer to the letter from RIXG emphasising the need to achieve effective electronic communication across LSP boundaries for the care of renal patients and others with complex disease.

5 DEVELOPMENTS ELSEWHERE IN THE UK

The current tender for a new renal IT system in the west of Scotland was noted, and the possibility that this might become a Scotland-wide system. The very high quality and detail of the spec was commended by those who had seen it. It would be circulated to RIXG as soon as confidentiality allowed. The indication from its authors that it could be adapted for use elsewhere in the UK was warmly welcomed.

There were no reports on progress in Wales and Northern Ireland.

The importance of RIXG seeking to influence renal IT issues throughout the UK was emphasised. It was agreed that further efforts should be made to obtain Wales and Northern Ireland representation on RIXG for future meetings. **JF**

Paediatric IT Issues

Efforts continue to achieve Registry returns from paediatric units. RIXG welcomed the news that members of BAPN had received MRC funding to establish a Renal Rare Diseases Registry, and noted the proposal that this should be sited within the Registry. RIXG supported the view that it would not be logical for the Registry to host such an initiative when it was not in a position to receive routine data on the generality of paediatric RRT patients. RIXG emphasised that access to RenalPatientView should be a powerful lever to expedite the establishment of effective IT systems in paediatric renal units, and hope that the patient and family voice might drive this.

6 INFORMATION FOR PATIENTS AND CARERS & NON-SPECIALISTS

6a RenalPatientView

RIXG supported the paper describing future governance arrangements for RenalPatientView within the Renal Association and the Registry. A minority of renal units still do not provide access to RenalPatientView for their patients. It was anticipated that the patient and carer voice would be a powerful mover to expedite resolution of any local issues limiting introduction of RenalPatientView.

6c NLH Renal Specialist Library & Knowledge Week 9-13 June 2008

The efforts were acknowledged of SS and others in reviewing literature on proteinuria and CKD which was posted on the Renal Specialist Library during the recent Knowledge Week.

6b/d NHS Direct and NHS Choices

The improved quality of information on NHS Direct and NHS Choices was noted. There was discussion of a risk stratification tool for CKD which had been offered for posting on NHS Choices. Although the concept was welcomed in principle, there was general agreement that the tool itself was not yet fit for purpose and should not at the present time be posted.

7. AOB

Department of Health Kidney Care

DOD reported on his Kidney Care Programme supporting implementation of the NSF. He briefly described that modest resources available would be used to identify initiatives best developed nationally, or locally in partnership with clinical renal networks. Information management would be a key element in the implementation programme. A further description

of his plans would be available at the next meeting.

It was noted that NHS Choices may provide some short term funding for a renal clinician to be seconded to support increasing integration of the many strands of information and knowledge management emerging for the renal community. It was agreed there was sense in integrating this as well as possible with Kidney Care.

Information Prescriptions

There was some discussion about the possible implications of this DH initiative designed to encourage provision of appropriate information for patients with longterm conditions. RIXG noted the wealth of information and expertise within the renal community. TS indicated that NKF had volunteered to be a pilot organisation testing a proposed DH model for the accreditation of information. RIXG was encouraged that accreditation of organisations rather than individual pieces of information was being suggested, strongly believing that any more detailed system would be unworkable. The risk of unnecessary bureaucratisation was noted. Any other opportunities to benefit from early interaction with information prescriptions would be taken.

National Kidney Federation

TS reminded RIXG that it delivered large numbers of information leaflets free to patients, but that it charged kidney units for bulk orders of leaflets. Charges were to cover costs and not for profit. TS reported his disappointment that some kidney units were asking Kidney Patients Associations to order large numbers of leaflets to circumvent this charging process. RIXG agreed that this was not within the spirit of the renal community's support for NKF, and it would be unfortunate if increasing use of this approach by kidney units compromised the viability of NKF's extensive and highly regarded information programme.

Next Meeting

Friday 19th September 2008 in London

An all-day meeting with a major agenda item being sharing of progress and challenges by renal IT advocates from the ten SHAs in England as well as devolved parts of the UK

RENAL INFORMATION EXCHANGE GROUP

Notes of Meeting held Friday 19 September 2008 Department of Health, London

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ACTION

2. The notes of the last meeting were reviewed and accepted as accurate
3. No matters arising
4. **CURRENT STATUS OF UK RENAL IT**

England

The six Renal IT Advocates for England who were present each summarised the current situation in their patch. The following themes emerged:

There had been some initial contacts with Chief Information Officers in SHAs but none had produced substantial progress.

A number of renal units are updating their renal information systems (for example replacing PROTON) and funds are becoming available for this from a variety of sources.

Support for renal systems from Trust IT departments is typically slight or non-existent, and the insecure position of renal informatics staff, particularly with regard to professional development, back up and support, and succession planning remains a major concern.

Solutions originating from LSPs are still little in evidence.

With few exceptions there is no real progress in effective electronic communication across the primary care/secondary care interface.

Nevertheless there were many excellent initiatives underway, although individual renal units and SHA patches were taking varied approaches.

It was agreed we must find a better way of making this wealth of information available to the whole renal community in order that experiences can be shared and duplication of effort avoided. Afzal Choudhry agreed to discuss with Mark McGregor (Renal Association website manager) ways in which this might be achieved in an easily accessible way.

AC

The following concerns emerged from these discussions.

- The need for effective joined up thinking throughout Connecting for Health
- The need for proper clinical engagement
- Avoiding duplication of data entry
- Avoiding duplication of new initiatives
- The need for a single sign-on process
- Likely loss of functionality moving to newer systems
- Lack of progress in proper primary/secondary care electronic interfaces in real time
- Concern about the multiplicity of coding initiatives which are not yet producing coherence
- The need to use IT developments to improve Registry returns, particularly co-morbidity, and other newer Registry elements

Wales

Kieran Donovan's submitted report was noted; including the likelihood that two renal IT systems in Wales – one in the north, one in the south – will emerge in the near future.

Scotland

RIXG congratulated Keith Simpson for the superb tendering document [circulated with the RIXG papers] presently being used to award a new renal IT contract in the west of Scotland, probably extending across much of Scotland in due course. This is now in the public domain, and all agreed it would save much future effort for others who may need to tender.

Northern Ireland

There was no report from Northern Ireland, and JF undertook to secure representation from the province on RIXG.

JF

5 CONNECTING FOR HEALTH FOR ENGLAND

5a Renal Specialty Systems Scoping Document

James Medcalf updated RIXG on progress within CfH of this document approved by RIXG in June 2008. James Medcalf and Keith Simpson with the National Clinical Director for England had attended a useful meeting with the development team at CfH whose role appeared to be to identify which elements of the renal specialty systems requirements were already being met elsewhere in CfH. Progress appeared to be good, although KS expressed concern that the CfH team did not yet understand the complexities of renal systems.

5b LSPs

There is still no evidence of Lorenzo providing any renal-specific systems. The withdrawal of Fujitsu from the southern cluster contract has created great uncertainty about

the future of the Cerner Millennium product and it seems that “discussions continue”.

Southern Renal Clinical Content Project

RIXG discussed in detail this work presented for content assurance. It was noted that this work had emerged from a project originally designed to provide content within the context of the Cerner Millennium software solution, the work originally being led by Paul Altmann. Following the withdrawal of Fujitsu the Office of the Chief Clinical Officer (OCCO) at CfH had taken on and completed the work. The following points emerged in the discussion

- When content is presented in Excel spreadsheets, it is very difficult to be confident that the content is either appropriate or complete. Ideally it needs to be seen in the context of the proposed software solution (which had apparently been the intention in the original Cerner project).
- The proposed data items included a number which should not be in a renal specialty system, but should be available in the generic system from which they could be drawn. This goes against a fundamental principle that data should never be collected twice.
- While the content proposed is all useful and should be part of a final renal systems solution, it is not a description of a complete renal system.
- RIXG was very concerned that any statement about content assurance should not be misunderstood. It would be very unfortunate if this content was made available through the OCCO “filing cabinet” and misinterpreted by suppliers and NHS organisations seeking renal IT systems as a sufficient and complete description of a proper renal specialty system. In line with the agreed process, this feedback will be provided to RAG who will in turn inform OCCO.

JF

The “Guy’s System”

Cormac Breen gave an impressive presentation of his work developing a renal-specific EPR within the context of an iSoft based EPR being developed across Guy’s and St Thomas’s. He emphasised that these developments are open source and he will gladly share any aspect of them with those for whom it would be useful. Presentation attached to these notes.

5c Choose and Book

Two of 10 Renal IT Advocates for England had provided specific written feedback on the issues arising from Choose & Book. Problems were many, the good points few. It was agreed that all patches should provide specific feedback since this would make it much easier for JF and Paul Rylance (representing nephrology on the CfH National Specialty Reference Group where Choose & Book issues are discussed) to make their points.

5d Existing Systems Programme

RIXG expressed concern about the process and results of the tendering for the Additional Services Catalogue. The list now approved by CfH included four companies designated competent to produce renal specialty systems and who therefore could be approached by Trusts seeking to purchase such systems without needing to go through OJEU. Two of the four companies had no previous track record in producing renal specialty systems. Furthermore the “rules” of the process appeared to have excluded a number of companies with a track record in renal specialty systems; these were excluded by virtue of size, a minimum annual turnover of £1m for a small or medium enterprise being required for eligibility. Furthermore the nominees of RIXG who had contributed to the evaluation had indicated that the final list did not necessarily bear close relation to the advice they had been giving. It was agreed that JF would write to CfH expressing these concerns and distancing itself from the final recommendations. Furthermore Clinical Directors of renal units in England would be informed.

JF

5e Dataset and Coding Developments

The National Renal Dataset for England is now awaiting final improvement by the Information Standards Board.

A working group developing a renal subset within SNOMED-CT is making steady but rather slow progress. A recently appointed informaticist working on SNOMED-CT is now developing better co-ordination with the Dataset.

The EDTA-ERA diagnostic codes have been reviewed and will be available for consultation in the near future. It is intended they will map to SNOMED.

5g Communications with CfH Clinical Team including Chief Clinical Officer

These remain at best fragmentary. JF still awaits a reply to his letter of May 14th to the Chief Clinical Officer pointing out the critical problem which will emerge if there is no requirement for systems developing in different clusters in England to 'talk' to each other.

6 INFORMATION FOR PATIENTS, CARERS AND NON-SPECIALISTS

6a RenalPatientView

It is anticipated that the arrangements for RenalPatientView to be run by the Renal Association in parallel with the Renal Registry will be implemented before the end of 2008.

6b NHS Direct & NHS Choices

- &**
c Nicki Thomas and Steve Smith continue to liaise with NHS Choices to upgrade their information. NHS Direct information is now much improved. Nicki Thomas continues to watch carefully.

6d Map of Medicine

A solid process for review and updating of Map of Medicine pathways is now established, a partnership between the Renal Association and RCP London, led for RA by Richard Fluck. The CKD Pathway has been completely rewritten. Other pathways have received rapid editing sufficient to make them "safe" and one inappropriate pathway has been withdrawn. The programme of further pathway revision continues through the coming year.

8 PAEDIATRIC ISSUES

RIXG noted gradual progress with the key issues of establishing electronic data returns to the Registry from paediatric units and effective handling and analysis of paediatric data. Carol Inward is presently leading this project on behalf of BAPN, and RIXG will continue to give any support as required.

9 Any Other Business raised by member organisations

BRS

The BRS is undertaking a renal workforce review, and Nicki Thomas agreed to ensure that renal informatics staff are part of that review.

NTh

10 Date and place of next meeting:

There was general agreement that the Department of Health is a preferred venue although a slightly later start time would be helpful. **The next meeting of RIXG will therefore be Friday 12th December, 10.30am – 4.30pm at the Department of Health.**

Meeting dates for 2009 are

Friday 13 March 2009
Friday 19 June 2009
Friday 18 September 2009
Friday 4 December 2009

RENAL INFORMATION EXCHANGE GROUP

Notes of Meeting held Friday 12 December 2008 Department of Health, London

PRESENT

John Feehally (Chair)
 Donal O'Donoghue, National Clinical Director
 David Goldsmith, National Specialist Library
 Es Will
 Cherry Bartlett
 Charles Kernahan, KRUK
 Peter Rowe, Renal IT Advocate, South West
 Kate Harris, Renal IT Advocate, South Central
 Neil Turner, Renal Patient View
 Keith Simpson, Scottish Renal Registry
 Afzal Chaudhry, Renal IT Advocate, East of England
 Cormac Breen, Guy's Hospital
 Hameed Anijeet, Renal IT Advocate North West
 Chris Farmer, Renal IT Advocate, SE Coast
 John Stoves, Renal IT Advocate Yorks & Humber

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APOLOGIES

Rob Higgins, British Transplantation Society
 Kieran Donovan, Renal IT Wales
 Chris Rudge
 Charlie Tomson, UK Renal Registry
 Paul Altmann
 Annette Neary
 Sean Fenwick, Renal IT Advocate North East
 Simon Ball, Renal IT Advocate West Midlands
 Tim Statham, NKF
 Steve Smith, BRS
 Mark Forrest, BRS
 James Medcalf, Renal Specialty System Scoping Project
 Maarten Taal, Renal IT Advocate East Midlands
 Donald Richardson, Yorks & Humber Renal IT Advocate
 Stan Fan, Renal IT Advocate, London
 Chris Reid, BAPN
 Nicki Thomas, BRS
 Andrew Williams, UK Renal Registry

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		ACTION
2.	The notes of the last meeting on Friday 19th September 2008 were accepted as accurate	
3.	Membership	
	<p>John Stoves was welcomed as Renal IT Advocate for Yorks and Humber, replacing Donald Richardson.</p> <p>John Smyth just identified as representative for Northern Ireland and will be invited to the next meeting.</p> <p>Agreement that it would be appropriate to invite a specialised commissioner involved in commissioning of renal services to become a member of RIXG. JF will seek an appropriate name.</p>	JF

4.	CURRENT STATUS OF UK RENAL IT	
	4[a] Progress in Local IT systems Most recent reports from Renal IT Advocates noted and discussed.	
	4 [b] Plans to disseminate information about renal IT systems Proposal by Afzal Chaudhry discussed. Agreement that he would (1) customise the available information and post it on the Renal Association website. (2) establish on the RA website an electronic discussion group, initial membership to be Renal IT Advocates only. Once discussion group established and successful and covering substantial topics, plan a change to open membership. Although RA website being used as the main portal for RIXG, discussion again emphasised that RIXG is <u>not</u> an RA group; non-RA members of RIXG expressed no concern that using this portal might create misunderstanding.	
	4[c] Renal Unit Informatics Staff Returns from Renal IT Advocates confirmed the wide range of local arrangements, frequently involving staff for whom support, cover for absence, and succession planning were inadequate. The roles typically involved both routine informatics and IT development. The latter were of proven importance but had proved difficult to recognise in Agenda for Change, often resulting in lower grading for these posts than reflected the role and experience of the incumbents. Es Will commented on precedent in oncology where informatics staff had become part of MDTs making it easier to emphasise the clinical quality benefits which emerged from their role. Cormac Breen emphasised that in his Foundation Trust he had been successful in securing a high-grade post by emphasising the financial gains to be had from strong renal unit information. Donal O'Donoghue pointed out the current work led by Professor Susan Hill seeking to improve the position of scientific staff within the NHS, and agreed to bring the role of renal informaticists to their attention. The importance of renal informaticists in the verification of the National Renal Dataset could also be emphasised. Agreement that a proper description of the role of renal infomaticists sat well alongside the Renal Specialty Systems Scoping Document written by James Medcalf. Agreement that Kate Harris and Cherry Bartlett would begin to develop a document describing the renal informaticist role. Possible role for NHS Institute for Innovation and Improvement in assisting the development of these proposals was also discussed. Michelle Webb a potential contact.	CB, KH
	4[d] Increasing Influence of Renal IT Advocates DOD proposed that Renal IT Advocates should be offered a defined role in each Renal Network as part of the core team. He will work with JF to draft a suitable communication to Network Chairs. Agreement that it would be very useful for a generic powerpoint presentation to be available to Advocates, which described briefly the origins of RIXG, the national renal IT landscape, and achievements so far. JF agreed to prepare this.	JF
	4[e] Report on the Bradford System – working with primary care John Stoves gave an impressive report on the Bradford CKD Electronic Advisory Service. A key element in the success of this system is that the use of a single GP electronic system (System One) has been mandated throughout the SHA and has >85% uptake within Bradford and Airedale PCT. Discussion on the challenges of proving the apparently self-evident benefits of this system – fewer referrals to nephrology? more appropriate referrals to nephrology? better use of nephrology specialist time? John Stoves estimated 15 minutes of consultant time for a typical piece of virtual advice to a GP. The issue of costing and charging appropriately for this time was discussed as a possible means of resourcing further work and a sustained infrastructure. Contrast and comparisons noted with the NEOERICA work in Kent described briefly by Chris Farmer in which GP systems are interrogated to identify people with undetected CKD, and advice given to GPs. Agreement that Chris Farmer would present his system to the next meeting of RIXG.	CF

5.	CONNECTING FOR HEALTH FOR ENGLAND	
	<p>5[a] Cross-Boundary information flows, communications with the Chief Clinical Officer</p> <p>RIXG viewed the response from the Chief Clinical Officer to JF's letter of May 2008 as disappointing. No guarantees were given that it will be possible to share information across LSP boundaries or national boundaries. The major clinical disadvantages of this system weakness were again rehearsed.</p> <p>Agreement that RIXG should push for a requirement in all newly procured renal IT systems to collect and/or store data using a common language which would ensure transferability between different renal unit IT systems. Keith Simpson will draft a proposal and when this is approved by RIXG, a meeting will be sought with representatives of all renal IT suppliers to discuss this further.</p>	KS
	<p>5[b] Renal Specialty Systems Scoping Document</p> <p>Noted that this document was still being discussed by the Requirements Team within CfH, no further progress to report.</p>	
	<p>5[c] Local Service Providers</p> <p>No new information available about significant progress with either Lorenzo or Cerner Millenium products.</p>	
	<p>5[d] Southern Renal Clinical Content Project</p> <p>DOD confirmed receipt of RIXG's report and we await further progress.</p>	
	<p>5[e] 'Routines'</p> <p>Es Will led a discussion (based on the BMJ 2008;337:1269-71 article and responses) emphasising the need to develop renal IT systems that incorporated the largely implicit routines which underpin renal units' day-to-day clinical activity, as demonstrated in current unit informatics practice. This approach provided the opportunity to develop systems which did more than simply present electronic versions of traditional paper records. There were some limited IT models in development and he was in discussion to advance recognition of the issues and the possibilities.</p>	
	<p>5[f] Existing Systems Programme</p> <p>Chief Clinical Officer CfH has acknowledged receipt of RIXG's letter expressing concerns about the appraisal process for ASCC Lot2, and has so far given only a holding reply.</p>	
	<p>5[g] Renal Dataset Development Project</p> <p>Confirmation of Information Standards Board approval and issuing of a "change note" was welcomed by RIXG.</p>	
	<p>5[g] Coding</p> <p>Work to complete the SNOMED-CT renal subset is close to completion. At the same time a revision of the primary renal diagnosis codes of ERA-EDTA is soon coming out for review. Availability of mapping between Read codes, SNOMED codes and ERA codes was noted and welcomed.</p> <p>A meeting on 19th December 2008 has been called to ensure the best possible integration between the National Renal Dataset and SNOMED-CT. KS and JF will attend.</p> <p>KS pointed out that SNOMED does not contain definitions for each term. If RIXG chose to expend effort in providing definitions for renal terms in SNOMED these would almost certainly be welcomed nationally if not internationally. However it was agreed that this is a formidable task and no commitment should be given at this stage. The concept of Logical Record Architecture is emerging and may be crucial to the most effective use of coded information as appropriate to clinical context. KS and JF will report back after the 19th December meeting.</p>	

6	PROPOSAL FOR A NEW NHS KIDNEY CARE INFORMATION PARTNERSHIP BOARD	
	<p>DOD reported on the recent Kidney Care Workshop on information (18 November 2008) from which had emerged a proposal to establish a Partnership Board between NHS Kidney Care, the Information Centre, Connecting for Health, other agencies with crucial data to share, eg. The Health Protection Agency.</p> <p>DOD to chair, RIXG to be represented by JF. RIXG welcomed this initiative as an opportunity to achieve the sharing of information crucial to improvement in renal services. It was noted that the rhetoric of sharing has not yet yielded real benefits, but there was optimism that this new Board would achieve the practical and cultural changes necessary to take things forward. The critical importance of a properly established renal informatics environment in secondary care was again emphasised.</p>	
7	INFORMATION FOR PATIENTS AND CARERS AND NON-SPECIALISTS	
	<p>7[a] RenalPatientView</p> <p>NT and KS reported on a very successful user meeting in Edinburgh in September attended by >100 people. More than half UK renal units have now adopted RenalPatientView, and all renal IT systems have established capacity so to do. Very few units remain in which there is scepticism (typically from senior nephrologists) about the value of RenalPatientView. New organisational arrangements within the Renal Association will be established from 1st January 2009. Capitation fee for 2009 will be confirmed within the next few weeks but will not be >£2.50 per RRT patient.</p>	
	<p>7[b] NHS Direct and NHS Choices</p> <p>Nikki Thomas could not attend the meeting but had reported no new progress. Charles Kernahan raised the concern of continuing confusion about the respective roles of NHS Direct and NHS Choices. JF will seek clarification on this point.</p>	JF
	<p>7[c] Map of Medicine</p> <p>Review of Map of Medicine pathways led by Richard Fluck on behalf of RCP/Renal Association continues. Agreement that RF would be asked to provide a brief report to the next meeting.</p>	
	<p>7[d] National Library for Health – Renal Specialist Library</p> <p>David Goldsmith, Clinical Lead for the project, attended for this item accompanied by Niamh Leonard, NLH Specialist Library Information Manager, Linda Atkinson, Project Manager, Eli Bastin, Information Specialist. DG provided a brief history of the Specialist Library and the following points were noted.</p> <ul style="list-style-type: none"> • The renal library has now been integrated into the Kidney and Male Uro-genital Diseases Specialist Library. • The number of visits to the site was respectable given the rather small nature of the specialty, with a satisfying surge in visits at the time of the information release on proteinuria and eGFR in June 2008. • Topic for the next information release under discussion but probably malignancy and renal transplantation. • RIXG is willing to continue as external reference group, but it was suggested that the Library consider establishing a user group with wider professional representation than RIXG which by virtue of its individual organisation representation, was somewhat dominated by nephrologists rather than other health professional groups. RIXG members for are asked to suggest names for a NLH Kidney Disease Library users group.; especially names to ensure multi-disciplinary multi-professional representation. Suggestions to David.Goldsmith@gstt.nhs.uk components especially important and welcome. Please forward me both any suggestions for this, and, any comments on the 	

	<p>attached documents (in the original meeting bundle) to do with the Library content and strategy</p> <ul style="list-style-type: none"> • Ed Sharples (Oxford) expected to take over from David Goldsmith as Clinical Lead within the next one to two years. • RIXG members agreed to review the content development strategy and taxonomy for the Library and give any comments within two weeks to David.Goldsmith@gstt.nhs.uk 	<p>All</p> <p>All</p>
8	PAEDIATRIC ISSUES	
	Noted that the remaining Paediatric Registry data still held in Manchester would be transferred to the UK Renal Registry in Bristol in the near future. Discussions to improve paediatric returns to the UK Renal Registry continue. Discussions between the new Rare Diseases Registry (led by Moin Saleem) and the UK Renal Registry continue.	
9.	A O B	
	<p>Renal Association Noted that the Renal Association website section on RIXG was only thinly populated mainly by previous RIXG three year reports. Agreement that RIXG Minutes should be posted.</p>	JF
	<p>UK Renal Registry Afzal Chaudhry reported on his work, which will soon provide unit-specific reporting, mapping software etc. A sample can be seen at <registry.glomerulous.net>.</p>	
	<p>Nephrology Training and Informatics Es Will expressed his longstanding concern about the lack of formal training in this area for specialist registrars, which was shared generally. It was noted that a committee to review the nephrology curriculum has recently been established chaired by Sue Carr (Chair, RA Education & Training Committee) and she will be informed of RIXG's concerns.</p>	JF
	<p>E-Teaching and E-Learning It was noted that this very substantial area of activity was not represented on RIXG. There was inconclusive discussion on the value of incorporating such work, and it was agreed that this would be an Agenda item for the next meeting.</p>	
	<p>DATE OF NEXT MEETING Friday 13 March 2009, 10.30-4.30, Room 412, Wellington House, London. (It was agreed that Wellington House preferable to Richmond House if a suitable room can be booked – NB – all meetings in 2009 booked in Room 412, Wellington House)</p>	