

RENAL INFORMATION EXCHANGE GROUP

Notes of the 7th Meeting held on Friday 4th February 2005
Leicester General Hospital

PRESENT

Renal Association

John Feehally

British Renal Society

Steve Smith

Mark Forrest

National Kidney Research Fund

Diana Blass

Renal Association UK Renal Registry

Es Will

Cherry Bartlett Information Manager, St James's Hospital, Leeds

APOLOGIES

British Transplantation Society

Rob Higgins

Department of Health

Jane Verity

NSF for Wales

Kieran Donovan

NHS Information Authority (and BAPN)

Kate Verrier-Jones

National Kidney Federation

Tim Statham

Renal Association

Neil Turner

David Wheeler

Nursing Representative

Nicki Thomas

Scottish Renal Association

Keith Simpson

		Action
1.	We agreed that the notes of our previous meeting were accurate.	
2.	Matter Arising from the Notes <u>NHS Direct On-Line</u> There was discussion about the quality of information on kidney disease available through NHS Direct On-Line. Nicki Thomas had expressed some concern by email about this, although Diana Blass from a carer perspective was a little more positive. If however, staff answering calls to NHS Direct are using NHS Direct On-Line as their immediate source of information support, this was thought to be inadequate. It was agreed that RIXG should write to NHS Direct On-Line asking about planned improvements to information on kidney disease and offering our support.	JF

3	<p>National Electronic Library for Health – Renal Specialist Library</p> <p>The complete lack of progress was noted. It was agreed that RIXG should write to Muir Gray expressing their disappointment and asking for a timetable for implementation of the Renal Specialist Library. It was agreed that this letter should also enquire whether the new “Map of Medicine” seen by some members was thought to be a potential replacement for specialist libraries.</p>	JF
4.	<p>RenalPatientView</p> <p>RIXG gave its continuing support to the development work on RenalPatientView which is seen to be progressing satisfactorily and close to schedule. A number of specific points were made</p> <ul style="list-style-type: none"> • The considerable amount of time taken to register individual patients with RenalPatientView was noted and should be made explicit in the information given to units prospectively joining the scheme. • It was agreed that RenalPatientView should soon be offered to PROTON units for a fixed joining fee of £2000. Joining units would need to meet the criteria circulated in draft. • It was agreed that RenalPatientView would ideally be offered to non-PROTON units for the same joining fee. RIXG welcomed an indication from Jane Verity that further financial support may be forthcoming to assure roll out into non-PROTON units. <ul style="list-style-type: none"> ○ A bid with the necessary supporting information would be sent to Jane Verity within the next two weeks. <p>Note after meeting: This additional funding £25k now confirmed.</p> <ul style="list-style-type: none"> ○ It was also noted that companies owning non-PROTON systems may wish to ensure RenalPatientView was available to their customers at low cost, and it was agreed that the RenalPatientView team should meet with them soon to discuss this. • Concern was expressed that, although indication of support had been given in Wales, funding had apparently not yet been secured. It was agreed that this should be pursued through Kate Verrier-Jones, perhaps seeking support from Kieran Donovan in his role as IT lead for the Renal NSF in Wales. • The expertise of David Ansell and the Renal Registry in resolving technical issues with non-PROTON systems was noted, and the RenalPatientView team are asked to contact him. • There was discussion about the possibility of manipulating data within RenalPatientView after it had been downloaded from PROTON or similar systems. RIXG took the view that RenalPatientView should be a conduit to patients of data which is held in the unit’s clinical information system. For example there should be no attempt made to rationalise different systems for estimated GFR between units, but the value held in the unit’s system should be shown to the patient. • The proposal for the RIXG Information Review Panel was supported, but it was proposed that a DGH nephrologist should be added to the group, and it was suggested that Colin Jones (York) should be approached. 	<p>JF</p> <p>JF</p> <p>NT</p>

5.	<p>Patient Information DVD Project RIXG supported this new project being led by NKRF and BRS, but with support from other member organisations of RIXG. The importance of the full support of other organisations to make this venture a success was particularly noted. Funding is not yet secure, but RIXG emphasised as soon as the project is viable it would be important to inform all renal units of this development to minimise the risk of local duplication of effort.</p>	
6.	<p>NSF Information Issues A steady increase in national Renal Registry coverage was noted, but concern was expressed that a small number of adult units, and the majority of paediatric units are still not returning data. RIXG supported JF's continuing efforts through a variety of channels to progress this.</p>	JF
	<p>Part 2 of the NSF for England has just been published, the accompanying Renal Information Strategy is not yet available but it was hoped that it would be on the DH website within a few weeks. There was general discussion about key information issues within Part 2, in particular moves towards universal reporting of estimated GFR, and the need for appropriate information support to non-renal clinicians for this to have value. The broad issue of electronic communication between primary, secondary and tertiary care was also discussed, and the potential value of a national CKD register was aired, although there was no consensus on this. No action points emerged, and it was agreed to watch progress carefully</p>	
7.	<p>Any Other Business</p> <p>Criteria for Success – this document is now open for consultation, and it is recognised that it will need further expansion to take into Part 2 as well as Part 1 of the NSF.</p> <p>Work continues on questionnaires which will become a national Renal Patient Satisfaction Survey as part of Criteria for Success. RIXG's discussion emphasised the importance of distinguishing two elements in such a questionnaire – the collection of information, and the collection of opinion.</p> <p>EDTNA/ERCA Initiative “www.renalpatient.org” – RIXG noted this developing web based initiative designed to provide objective evaluations of the various information web sites available for kidney patients.</p> <p>Attendance at RIXG – concern was expressed at the relatively small attendance on this occasion, asking whether this reflected any sense that the Group had diminishing value. This does not seem to be the case, but should be watched carefully.</p>	
8.	<p>Date and time of next meeting:</p> <p>Friday 13 May 2005, 2.00 – 6.00pm : Seminar Rooms A + B, Education Centre, Leicester General Hospital</p>	

RENAL INFORMATION EXCHANGE GROUP

Notes of Meeting held on Friday 13th May 2005

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Pam Darcy [RenalPatientView]

Renal Unit Information Manager, Heartlands Hospital, Birmingham

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		ACTION
1.	The notes of the last meeting on 4 th February 2005 were reviewed and those present confirmed their accuracy.	
2.	Review of RIXG progress and planning	
	<p>The paper circulated by JF was discussed. There was general consensus that RIXG remained an effective and important group and there was strong support for its continuing work.</p> <p>It was agreed that each organisation should continually review its representation on RIXG, in case “new blood” could bring additional insights.</p> <p>David Wheeler, a founder member of the group who had not managed to attend a single meeting, had written apologising and tendering his resignation and this was accepted.</p> <p>It was agreed that a representative from the Northern Ireland renal community should be invited to join and John Woods would be approached.</p>	JF
3.	RenalPatientView	
	<p>NT reviewed progress. There are now about 100 patients registered in a number of units. It was agreed that further work was needed on the administrative functions, for example systems for maintaining lists of users and enabling patients to change password.</p> <p>The principle was affirmed that RPV should only show information held on the local clinical information system. This meant that some patients would not have eGFR available for view until their unit had implemented this. It also required that the supporting information should not at this stage explicitly relate clinical developments to CKD classification based on eGFR, but it was recognised that this would be an evolving field as eGFR was nationally implemented.</p> <p>KVJ emphasised that she was carefully reviewing supporting information shown on RPV to be sure it was appropriate for children.</p> <p>NT agreed to circulate a mock up prepared to show how information support developed from the forthcoming RCP/RCGP guidelines could be developed in RPV based on eGFR.</p> <p>It was reported that Keith Simpson is holding a meeting soon with those who run non-PROTON renal unit information systems; there appeared to be enthusiasm from them for embracing RPV.</p> <p>The OTIS system developed by Roche and being used in a number of transplant units was discussed. This uses a different information approach than RPV, since it requires additional work from unit staff to download information into OTIS which then becomes available to patients on the unit, or by taking away a memory stick or disc. It was noted that the patient information aspects of OTIS, for example including video clips of transplant patients discussing issues, were well liked by patients. TS reported that NKF are making available their patient information for OTIS. It was thought that the limitations of OTIS would become more apparent as RPV becomes widely available.</p> <p>Although all renal unit clinical directors have been informed about RPV, this information may not have reached all transplant units. NT agreed that he would write to transplant unit directors, and to all paediatric unit directors, to be sure everyone was fully informed of RPV and its potential.</p>	NT

4.	Patient Information DVD Project	
	SS and DB reported steady but encouraging progress. There was considerable commercial interest in joint funding of the project although no final sign up yet. It was hoped that a project manager would be appointed later this year and that the first product would be available for view next year. A questionnaire seeking patients' views on the content of the DVDs was going out through 20 units and it is hoped will reach more than 1000 patients.	
5.	NHS Direct On-Line	
	There had been little progress, mainly because it had not been possible given many recent changes of personnel to identify the key leaders who we should approach to offer our support. KVJ indicated she had appropriate contacts and JF agreed to write to them.	KVJ, JF
6.	Renal Information Strategy	
	The Renal Information Strategy for Part 2 of the NSF was as yet unpublished, in part because of unavoidable delays relating to the recent general election. Final approval from new ministers was required, and JV was optimistic this would be forthcoming soon.	
7.	Renal Dataset Development Project	
	This work appeared to be progressing steadily. Es Will was unable to be at RIXG on this occasion as he was at the first meeting of the Dataset Reference Group.	
8.	Categorisation of Disease and Healthcare Episodes	
	In the absence of Es Will, who has most involvement in this work, this item was held over until the next meeting.	
9.	NEIH Renal Specialist Library	
	There was at last evidence that funding had become available and optimism that this project would now move forward under David Goldsmith's leadership.	
9.	Do Once and Share Project	
	<p>James Medcalf (Consultant Nephrologist, Leicester) had been invited to join RIXG through his involvement as Project Leader for the "Do Once and Share" Project being established in Leicester with funding from Muir Gray, Director of Knowledge & Information for the NHS. The project, based in the East Midlands Renal Network, will develop a description of the IT services required by a renal community to inform NHS Connecting for Health as it oversees implementation of the National Programme for IT. The project has a 6 month time scale reflecting the need to move rapidly before Local Service Providers have advanced their development plans beyond the possibility of including our requirements.</p> <p>RIXG has been asked to provide a national perspective and input to the project.</p> <p>RIXG agreed that this is potentially an extremely important project, the key opportunity for the renal community to make clear its expectations and requirements from to NPfIT. JM agreed to circulate the relevant part of the output based specification for LSPs relating to renal services: Section 167 – to be found at http://www.dh.gov.uk/assetRoot/04/07/16/32/04071632.pdf</p> <p>All RIXG members would add to this outline other proposals and</p>	JM

	requirements to assist the development of the scoping document for the project. The importance was noted of ensuring that all relevant links to primary care and other specialties were identified, and that the implications of the whole range of the NSF were taken into account.	All
10.	UK Renal Registry	
	RIXG registered its disappointment that a small number of renal units in England are still unable to return to the Registry despite this being mandated in the NSF. Local reasons differ in each case. JV confirmed that she is applying appropriate pressure through Commissioners. The possibility that this requirement should be registered as a performance indicator for Trusts was discussed and supported if this were possible.	
11.	Date of Next Meeting Friday 2 nd September 2005, 2pm, Leicester General Hospital	

RENAL INFORMATION EXCHANGE GROUP

Notes of Meeting held Friday 2nd September 2005

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IN ATTENDANCE

NHS "Do Once & Share" Project

Bernie Stribling

Anne Keogh

APOLOGIES

British Transplantation Society

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NHS "Do Once and Share" Project

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		ACTION
	It was agreed that the notes of the previous meeting on 13 th May 2005 were an accurate record.	
	Matters arising not covered elsewhere in the Agenda	
	John Woods had provisionally accepted an invitation to represent the Northern Ireland renal community on RIXG. However there was still some uncertainty that he would be released by his Trust to attend meetings; clarification is awaited.	
	It was noted that the Renal Information Strategy for Part 2 of the NSF was now published.	
3a	RenalPatientView	
	<p>NT gave a live demonstration of the current format of RenalPatientView [RPV] which received strong support from RIXG. Roll out among PROTON units continues satisfactorily. KS reported on slow progress with non-PROTON units. Unfortunately the suppliers of Clinical Vision have indicated they do not wish to commit the necessary development costs to make their system compatible with RPV. Responses from other non-PROTON suppliers are still awaited. It was agreed that KS should press for such responses and an indication of suppliers proposed development costs. It was agreed that units planning to invest in Clinical Vision should be made aware that at present they will not have access to RPV. KS was mandated by RIXG to continue negotiations.</p> <p>Options for the launch of RenalPatientView were discussed. JV indicated that the Minister would be speaking at the one-day conference on October 19th organised by SW Thames Renal Unit, and it was likely the Minister's speech could highlight RenalPatientView accompanied by a press release; in addition NT is speaking at the conference about it.</p> <p>It was also agreed that the RA/BRS conference at Harrogate in May 2006 was an important opportunity to demonstrate RPV to a large number of renal health professionals; it is expected by the time of Harrogate that coverage should have reached more than half the country.</p>	<p>KS</p> <p>JV, NT</p>
3b	Patient Information DVD Project	
	SS and DB reported encouraging progress in identifying funding. It was expected that a project manager would be in post by the end of the year and a project completion date of early 2006 was still anticipated.	
3c	NHS Direct On-Line	
	JF and NTh have recently met Mike Sadler, Medical Director of NHS Direct and NHS Direct On-Line. He welcomed input from the renal community to improve information about kidney disease on their website; and also to work with NHS Direct staff in refining algorithms used during telephone contact. NHS Direct had particularly welcomed an approach which ensured that there was a single point of contact between them and the renal community. RIXG have agreed to provide that point of contact and a working group was agreed led by NTh and also including Diana Blass, an NKF representative (to be identified by TS), a former renal nurse now working with NHS Direct who has been in contact with NTh – Anne Hughes - and Rob Higgins (who in his absence was identified as the appropriate nephrologist to join the group given his experience in working with NKF to provide patient information).	NTh
	TS reported NHS Direct will continue to work closely with NKF as its provider	

	of patient information; NKF would become an “accredited partner” when the process for that had been defined.	
4a	Renal Dataset Development Project	
	The reference group is now meeting under the chairmanship of Terry Feest. Others from RIXG on the group are EW and KS. The project is on time.	
4b	Categorisation of disease and healthcare episodes	
	EW continues to chair the group leading this work. He reported on slow progress and outlined the difficulties in defining the complex healthcare episodes which are part of renal care. It was noted that the Vascular Society had nominated David Mitchell (Bristol) to provide input to his group on definitions for vascular access surgery.	
4c	NeLH Renal Specialist Library	
	JF has received further assurance from Muir Gray that funding is about to be released for this project.	
4d	Do Once and Share Project	
	<p>Bernie Stribling (Project Manager) and Anne Keogh (external advisor) reported on progress and shared some draft pathways. A wide ranging discussion emphasised concerns about the project including</p> <ul style="list-style-type: none"> • The level of detail required • The need to integrate with other chronic disease pathways • The need for the patient to be the focus of the pathway throughout • The need to emphasise acquisition and display of the necessary and appropriate information at every point of interaction between health professional and patient. <p>RIXG recognised the challenges but also the great importance of the project and gave its continuing support.</p>	
5	UK Renal Registry Universal Coverage	
	Encouraging progress towards universal coverage of adult renal units was reported. Plans seem to be in place in all outstanding units. However concern that a number of units planning to invest in Clinical Vision were at some risk of being unable to access RenalPatientView.	
	KVJ reported that in some cases it seemed that business cases for new renal unit clinical information systems had not taken account of adjacent paediatric units even within the same Trust. It was also noted that those paediatric units remote from an adult unit were still encountering difficulties in gaining support or investment from local Trust IT departments. JV had unfortunately left the meeting by this time, but JF will highlight these issues with her to see what additional pressures can be applied.	JF
8	Any Other Business	
8a	“Map of Medicine”	
	It was understood that the anticipated contract between the NHS and the developers of the “Map of Medicine” had not yet been finalised. Once this has occurred, Mike Stein will be invited to RIXG to discuss “Map of Medicine” and its implications.	
8b	JV was thanked for her excellent contributions to RIXG, her strong support for the renal community, and wished every success in her forthcoming career	

RENAL INFORMATION EXCHANGE GROUP

Notes of Meeting held Friday 9 December 2005

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		ACTION
1	The Notes of the previous meeting dated 2 nd September 2005 were accepted as an accurate record.	
2	Matters Arising not discussed elsewhere	

	Map of Medicine	
	JF reported that it had still not proved possible to engage with Mike Stein, who had not replied to invitations asking him to come to an RIXG meeting to discuss the Map of Medicine. Attempts to contact him would continue.	JF
3	Information for Patients and Carers	
	a) RenalPatientView	
	<p>The most recent newsletter was circulated. KS reported no major negative feedback so far from approximately 700 patients who were signed up in different units. Likewise renal unit staff had not expressed any major new concerns. A small risk was noted that investigations arranged by other departments in the hospital but downloaded onto PROTON may be viewed by patients before they had been seen by renal unit staff; this was accepted as an inevitable consequence of the system at work.</p> <p>KS reported positive contact with all suppliers of non-PROTON systems who had received a detailed specification showing the requirements for making RenalPatientView available on their system. Responses were awaited.</p> <p>Budget – the project remains within budget. It was noted that modest longterm funding will be required to maintain the server but no final conclusion was reached about how this would be provided.</p> <p>Evaluation – CB reported that MREC approval for the evaluation programme had been obtained and NHS R&D approval from various centres was awaited. She is expecting to send out questionnaires in January.</p>	CB
	b) Renal Information DVD Project	
	SS and DB reported that £110,000 had been secured from pharmaceutical companies. There was a possibility of funding from the Big Lottery Fund, and it had been decided to defer implementation of the project until the final Lottery decision was made. The job description is ready for the Project Manager and a multi-professional patient steering group has been identified. The potential to link the DVD modules to RenalPatientView was recognised. The value was agreed of linking in other DVD projects – for example the live donor transplant DVD which had been made at Guys, and the ABLE DVD for education and awareness among South Asians made in Leicester.	
	c) NHS Direct On-line	
	i) Health encyclopaedia – RH agreed to build on other work in which he is involved to provide CKD information. The modifications of the dialysis and transplantation information made by NT would be tested and returned to NHS Direct On-Line for implementation. The importance of maintaining short text, with adequate links to approved and proven information was emphasised.	RH, NT
	ii) NHS Direct algorithms. A meeting had been set for February at NHS Direct to work through the algorithms. This will be attended by Nicki Thomas, Diana Blass, Tim Statham, former renal nurse now working at NHS Direct, a nephrologist - probably from within London for convenience, plus a paediatric nephrologist to be identified,.	NT, DB, TS
4	National Programme for IT	
	a) Renal Dataset Development Project	
	The very good progress of this project was reported by JF who is a member of the project board. The working group chaired by Terry Feest is close to	

	completing the proposed national renal dataset.	
	b) NELH Renal Specialist Library	
	JF reported that David Goldsmith has now received definite funding for this project from Connecting for Health. He has requested that part of the next RIXG meeting should serve as a scoping meeting for the Renal Specialist Library. This was agreed.	
	c) Do Once and Share	
	James Medcalf, Bernie Stribling and Anne Keogh reported excellent progress, the project is completed in December with a report to be submitting to Connecting for Health probably in early January. The many opportunities for sharing work from this project and many other related projects were discussed. In particular, in the field of CKD management, developing work in a number of centres should now be shared to avoid duplication and ensure coherent effort. It was noted that Muir Gray and Donal O'Donoghue had agreed to resource a meeting in February/March 2006 at which the wide renal community could be updated on IT matters. It was anticipated that the agenda for this meeting would include reports on Do Once and Share as well as most other information projects in which RIXG is engaged. It was hoped that RIXG would have the opportunity to shape the agenda for that meeting. JF agreed to talk to DOD	JF
5	Scoping National Renal Audit – Healthcare Commission	
	JF updated RIXG on the scoping work for national renal audit now being undertaken by a group including the Renal Association, BRS, BTS with an external consultant. It was expected that the group would make proposals for national renal audit building on the Registry, and make recommendations about interface with other national clinical audits relevant to renal disease.	
6	Renal Informatics Expertise	
	RIXG again raised concern that the high level of expertise among informatics staff in renal units remained unrecognised, and was being put at risk by a number of developments including Agenda for Change. It was agreed that Do Once and Share should emphasise this crucial group of staff. Concern was raised that their role was not understood in many areas of Connecting for Health.	JM
7	Defining Functionality of Renal Clinical Information System	
	KS reported excellent progress in drawing together a description of nationally available current functionality. It was agreed that this should remain in "broad headlines" rather than become a technical IT specification. It was agreed to circulate the document further among clinical directors and renal informatics staff in time for a product to be included in the Do Once and Share report. The value of this document to positively influence current practice by sharing the wide range of functionality currently available was emphasised. Discussion on how best to engage with local service providers or other appropriate echelons of Connecting for Health to emphasise the functional needs of renal units did not lead to a clear path for action. It was hoped that the Do Once and Share report might be one vehicle for this.	
9	Any Other Business	
	i) The need to provide translation into multiple languages of nationally prepared renal information was emphasised. Gerry Lynch indicated that it may be possible to arrange some funding through the Department of Health, but he also emphasised the importance of seeking local resources where specific languages were highly relevant to one local health economy.	

	<p>ii) SNOMED and Other Coding Systems</p> <p>There was a discussion about the need for a compatible system of coding that could be used both in an electronic patient record and in literature retrieval systems. This would allow the introduction of decision support engines and would help to remove the block between the two domains which is currently bridged by free text.</p>	
10	<p>Next Meeting:</p> <p>17th March 2006 was provisionally noted for the next meeting. If however the National Renal IT meeting was held around that time, the possibility of holding RIXG on the day of the national meeting would be considered. However JF agreed to discuss with David Goldsmith his requirements for Renal Specialist Library Scoping.</p>	<p>JF</p>