

# RENAL INFORMATION EXCHANGE GROUP

Notes of 3<sup>rd</sup> Meeting held on 23<sup>rd</sup> January 2004  
Leicester General Hospital

## Present:

### **British Renal Society**

Steve Smith

Steve.Smith@heartsol.wmids.nhs.uk

### **British Transplantation Society**

Rob Higgins

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### **Department of Health**

Paul Richardson

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### **NHS Information Authority**

Andrew Scott

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Kate Verrier-Jones (and BAPN)

verrier-jones@cf.ac.uk

### **NHS Information Policy Unit**

Simon Pearson

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### **Renal Association**

John Feehally (Chair)

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Neil Turner

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### **Scottish Renal Association**

Keith Simpson

Keith\_Simpson@compuserve.com

### **National Kidney Federation**

Tim Statham

tim.statham@btinternet.com

## Apologies:

### **British Renal Society**

Gareth Murcutt

gareth.murcutt@royalfree.nhs.uk

### **Department of Health**

Jane Verity

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### **National Kidney Research Fund**

Stephen Chan

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### **Renal Association**

David Wheeler

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David Goldsmith

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### **Renal Association UK Renal Registry**

Es Will

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### **UK Transplant**

Chris Rudge

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### **cfi:**

### **National Kidney Research Fund**

Diana Blass

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The notes of our meeting on 31<sup>st</sup> October 2003 were accepted as an accurate record.

## Membership

It was noted that Kate Verrier-Jones (KVJ) had now been asked by BAPN to represent their views on the group as well as her position working on the Renal Information Strategy.

## ACTION

### **Presentation by Andrew Scott**

Andrew Scott (AS) gave a very informative presentation with three elements

- Description of the national programmes for IT, providing a framework within which the group could understand the position of the Renal Information Strategy.
- An outline of the Renal Information Strategy (RIS) which had been published the previous week with NSF Part 1.
- An outline of short to middle term plans for implementation of RIS.

The value of strengthening working relationships between RIXG and NHSIA was discussed and supported. RIXG unanimously agreed to invite AS to join the group. AS indicated that he would recommend to the next meeting of the RIS Project Board that RIXG became an Advisory Group to that Project Board.

AS

Data protection issues were discussed. It was noted that AS has been supporting the UK Renal Registry in completing their application to PIAG (Patient Information Advisory Group) and it is expected that approval may be forthcoming within a few months.

### **Renal Interface – Pilot Proposal for a Renal Information System**

There was a wide ranging discussion about the best approach to take this pilot forward. The following were agreed

1. The importance of gaining the support of the Advisory Group for Implementation of the Renal NSF, which is being established. John Feehally (JF) agreed to take a slightly modified version of the present proposal to the first meeting of that Advisory Group in early February. The proposal would be slightly re-drafted by Neil Turner (NT) to strengthen further the key messages behind the proposal. Ideally with the support of the Advisory Group the pilot will come to the attention of the NHS Information “Top Team” and obtain their approval. It was felt this was most likely to be achieved by emphasising three features of the pilot which were a great attraction to the NHS IT Strategy – direct patient access to records; strengthening interactions between primary, secondary and tertiary care; the provision of decision support systems for patients and health professionals. JF  
NT
2. It was also agreed that an approach should be made to the new National Clinical Advisory Board (NCAB) through Professor Mike Richards, who leads on NSF issues at that Board. AS/JF
3. It was also hoped that this would lead to the opportunity to test the pilot in the “sandpit” of the National Design Authority (NDA).
4. It was expected that these approaches would help to ensure that the local service providers (LSPs) would be supportive of the pilot when it was being developed.

## 5 Testing patient preference, and patient acceptability

- [a] Keith Simpson (KS) agreed to seek approval for the pilot to be discussed and demonstrated at a forthcoming Focus Group of patients to be held in Glasgow on February 17<sup>th</sup>. **KS**

It was agreed that a questionnaire should be ready for use at that meeting. Rob Higgins (RH) and Kate Verrier-Jones (KVJ) offered to prepare a questionnaire (first draft RH). This will be circulated among RIXG for rapid approval and sent to KS in time for printing for the Glasgow meeting. Returns will be forwarded to JF for analysis. **RH, KVJ, KS, JF**

NT would show a mock-up at the Glasgow meeting, the exact content of that mock-up depending on other progress. **NT**

- [b] The group warmly welcomed Tim Statham's proposal that the NKF Annual Conference in September 2004 be used as an opportunity to continue testing the progress of the pilot from the patient perspective.

- [c] Paul Richardson (PR) reported briefly on a development group he had convened before Christmas exploring renal patient perspectives on the development of care plans. A draft report of that meeting is circulated with these notes – members of RIXG should note that this is a draft report for their own information and **not** for wider circulation

6. It was agreed that RIXG should continue work to develop the pilot within an indicative budget of £20,000. RIXG took the view that for this modest funding, an open process of tendering was unnecessarily cumbersome; rather the expertise within RIXG itself should be used to develop the pilot further. NT and KS (supported by AS) agreed to develop the pilot further as follows:

1. NT will look into the technicalities of importing information into, and then setting up and running a suitable database/Internet server. **NT**
2. KS will consider how best to extract information from PROTON with suitable field descriptors. **KS**
3. KS will ask an XML expert if we can use XML for the field descriptors, even for the pilot. **KS**

### **Tasks and Targets**

KVJ agreed to prepare a table outlining the tasks and targets for RIXG through 2004 (attached)

### **Information from Member Organisations**

There was an opportunity to share other relevant information from member organisations but no specific points were raised.

### **Date of Next Meeting**

Friday 23<sup>rd</sup> April 2004, 2pm, Leicester General Hospital

**All**

# RENAL INFORMATION EXCHANGE GROUP

Notes of 4<sup>th</sup> Meeting held on 23<sup>rd</sup> April 2004  
Leicester General Hospital

## Present:

### **NHS Information Authority**

Andrew Scott

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### **National Electronic Library for Health**

Muir Gray

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### **Renal Association**

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### **Renal Association UK Renal Registry**

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### **Scottish Renal Association**

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### **National Kidney Federation**

Tim Statham

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### **National Kidney Research Fund**

Diana Blass

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### **Department of Health**

Paul Richardson

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### **NHS Information Policy Unit**

Simon Pearson

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### **National Kidney Research Fund**

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David Wheeler

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### **Welsh Renal Association**

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		Action
1.	<b>National Electronic Library for Health – Renal Specialist Library</b>	
	RIXG welcomed Muir Gray, who introduced this topic by describing the approach which he is championing within the NHS on the role of knowledge and the use of knowledge. In particular he emphasised the value of specialist libraries within NeLH and their value in providing core knowledge for non-specialists. He emphasised that such knowledge would include knowledge from research, from data, and from experience. He emphasised that many of the problems in developing this work were not technical, but cultural and managerial. He confirmed that David Goldsmith was being appointed as Clinical Editor of the Renal Specialist Library and would be supported by an information scientist. It was confirmed that RIXG will provide multidisciplinary quality assurance for the developing Renal Specialist Library.	
2.	<b>Patient Questionnaire</b>	
	Following its pilot use in Glasgow, it was agreed that the Patient Questionnaire should be further refined before being used widely on a national basis. It was agreed to ask Cherry Bartlett, renal information manager at St James' Leeds, to take the lead on this. (She is presently undertaking a PhD on the evaluation of information systems, and has considerable expertise in this field).	JF
3.	<b>Renal Patient View</b>	
	<p>A meeting had been held on 16<sup>th</sup> April 2004 at which a sub-group of RIXG had evaluated bids for technical aspects of the renal patient view pilot proposal. The recommendations of that meeting were accepted: preferred suppliers are VitalPulse Limited and Worth Solutions.</p> <p>Muir Gray gave strong support to the Renal Patient View development and the work of RIXG. He indicated that the strong clinical involvement of the renal community, its coherence, and commitment to implementation of the Renal Information Strategy put the renal community significantly ahead of most other clinical groups. He emphasised the importance of ensuring that Renal Patient View was fully integrated into the National Programme for IT as a development project.</p> <p>After detailed discussion the following actions were agreed:</p>	
	<ul style="list-style-type: none"> <li>Renal Patient View would in future be described as a technical feasibility project providing proof of concept for patient access to key clinical information. JF would write to Aidan Halligan indicating that Renal Patient View had been developed with full awareness of the National Programme and indicating that we wished it to become a Development Project of the Programme. Andrew Scott would contact the Design Team through Mike Bainbridge to ensure Renal Patient View was integrated into their plans (Muir Gray had already discussed the project with Mike Bainbridge). RIXG warmly welcomed the email from Paul Richardson indicating in principle that the DH Renal Policy Team would find £20-30k to allow the first year of Renal Patient View to get under way. He had asked for some minor modifications in the written proposal which he had already received and JF will ensure this is done.</li> </ul>	<p>JF</p> <p>AS</p> <p>JF</p>

	<ul style="list-style-type: none"> <li>On May 14<sup>th</sup> Neil Turner, Keith Simpson and Andrew Scott will meet with the preferred suppliers VitalPulse Limited and Worth Solutions. Andrew Scott would also ensure the presence at that meeting of an individual for NHSIA with sufficient seniority to give definitive recommendations on the security issues of the project.</li> </ul>	<b>NT</b> <b>KS</b> <b>AS</b>
	<ul style="list-style-type: none"> <li>Two renal units were identified for the initial feasibility study. Since no resources were being provided for these units, and rapid roll out to other units was envisaged, it was not thought that any formal bidding process was appropriate. It was necessary for the first units to use PROTON, to have local energy and expertise, and at least one to be a transplant unit. It was unanimously agreed to start with St James' University Hospital Leeds (Es Will as lead) and Heartlands Hospital Birmingham (Steve Smith as lead).</li> </ul>	
	<ul style="list-style-type: none"> <li>It was agreed that the project should also be developed in Wales and Scotland as soon as possible provided that appropriate resources could be found.</li> </ul>	
	<ul style="list-style-type: none"> <li><u>Project Management Arrangements</u></li> </ul>	
	<p>The core project team would be chaired by Neil Turner and also include Keith Simpson and Andrew Scott. A Patient &amp; User Panel would support this team and would be eight strong (the four members of the NKF "Web Team", two members of NKRF's Patient Advisory Group, two members of the Scottish Patient Group). Tim Statham, Diana Blass and Keith Simpson respectively would approach these individuals as soon as a description of the workload being asked of them had been agreed, and this would be drafted by Neil Turner.</p>	<b>KS,</b> <b>NT,</b> <b>DS, DB</b>
	<p>The core team would also call on the expertise of Kate Verrier-Jones and Cherry Bartlett whenever necessary.</p>	
<b>4.</b>	<b>NHSIA Renal Information Strategy</b>	
	<p>Kate Verrier-Jones and Andrew Scott tabled an update on progress with the Renal Information Strategy, particularly emphasising issues where RIXG would provide positive support to speed progress. The following were noted:</p>	
	<p>The posting of the Renal Information Strategy on the DH website had been technically flawed, unreliable, and had substantially weakened the impact of the Strategy within the renal community. RIXG registered its strong disappointment about this and it was agreed that JF would write to Jane Verity to confirm our disappointment. It was hoped that the technical issues were now resolved but Kate Verrier-Jones would liaise with Neil Turner to test whether links to the Renal Association website were working properly.</p>	<b>JF</b> <b>NT,</b> <b>KVJ</b>
	<p>RIXG should provide further encouragement and support to those units who do not have adequate electronic systems in place. Andrew Scott confirmed that it was written in the LSP contract that PROTON or its equivalent should be provided for those units not yet supported. It was recognised that each of these units had distinct technical, cultural and resource issues delaying their progress. It was agreed that JF would check with David Ansell at the UK Renal Registry which adult and paediatric units still lacked electronic systems and would write to the relevant Clinical Directors asking for their action plan.</p>	<b>JF</b>

	<p>RIXG expressed concern about the number of groups working on different elements of data set definition relevant to the renal community. These include work on the Renal Data Set to prepare it for Information Standards Board approval, HSG4 and Spectre RIXG would like reassurance that these programmes were linked through their common aims and that each has adequate input from appropriate clinicians. After discussion it was agreed that the new Renal Advisory Group [RAG] at DH was the place where these issues should be discussed and influence brought to bear. JF will write to the RAG leaders about this.</p> <p>KVJ will contact David Nelson who is co-ordinating the dataset work to confirm the level of interaction between these groups.</p>	<p><b>JF</b></p> <p><b>KVJ</b></p>
	<p>The renal community itself was also initiating work which would have substantial information implications. Criteria for Success by which the NSF Standards and Markers of Best Practice could be judged were being developed – BRS, Renal Association and BTS are all involved in this work. The Health Care Commission have been made aware that this work is under way and it seems probable that it will form the basis for an agreed model for monitoring of renal services by the Health Care Commission in due course. RIXG noted this work, and felt that it indicated again the need for co-ordination of the NHSIA activities discussed above.</p>	
	<p>Kate Verrier-Jones and Andrew Scott are now writing Part 2 of the Renal Information Strategy to support Part 2 of the NSF. RIXG recognises the crucial role of IT in ensuring that Module 3 of the NSF concerned with early detection and management in primary care, could be delivered. JF would bring these issues to the attention of the Renal Advisory Group.</p>	<p><b>JF</b></p>
<p>5.</p>	<p><b>DATE OF NEXT MEETING</b></p>	
	<p>Suggested dates: Friday 30 July or Friday 6 August . Please advise your availability on these two dates.</p>	

## RENAL INFORMATION EXCHANGE GROUP

Notes of the 6<sup>th</sup> Meeting held on 5<sup>th</sup> November 2004  
Leicester General Hospital

### **British Renal Society**

Steve Smith

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### **British Transplantation Society**

Rob Higgins

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### **NHS Information Authority (and BAPN)**

Kate Verrier-Jones

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### **National Kidney Research Fund**

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### **Renal Association**

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Neil Turner

neil.turner@ed.ac.uk

### **Renal Association UK Renal Registry**

Es Will

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### **Scottish Renal Association**

Keith Simpson

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### **National Kidney Federation**

Tim Statham

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### **Nursing Representative**

Nicki Thomas

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## **In Attendance**

Cherry Bartlett, St James's Hospital, Leeds

Pam D'Arcy, IT Manager, Heartlands Hospital, Birmingham

## **Apologies:**

### **British Renal Society**

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### **Department of Health**

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### **NSF for Wales**

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### **UK Transplant**

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		<b>Action</b>
	Notes of the previous meeting were accepted as an accurate record of our discussions. The following topics were discussed.	
<b>1</b>	<b>Renal Information Strategy – Implementation</b>	
	KVJ tabled an extremely helpful paper summarising the present situation for a number of implementation issues for the Renal Information Strategy. A number of specific issues were discussed under “other agenda items”. However RIXG expressed overall concern that implementation of the strategy was at some risk. This was in part the result of changing arrangements with the dissolution of the NHS Information Authority, the movement of some staff into the new Information Centre in different roles, and the loss of the specific focus on the Renal Information Strategy which thus far had been provided by KVJ and Andrew Scott. It was recognised that many of these responsibilities had been re-aligned to the Renal Policy Group at the Department of Health, but RIXG was aware of the very large agenda facing the Renal Policy Group. RIXG expressed concern that ineffective implementation of the Information Strategy would seriously jeopardise implementation of the NSF. RIXG will make representations that the Renal Advisory Group at the Department of Health consider expanding its membership to include an individual with a substantial grasp of information issues who could promote implementation of the information strategy.	<b>JF</b>
<b>2</b>	<b>National Electronic Library for Health – Renal Specialist Library</b>	
	Regrettably there was no further progress to report. KVJ would discuss this further with David Goldsmith to establish where further pressure might be applied, given that meetings earlier in 2004 appeared to show continuing commitment from Muir Gray and Ann Brice. This will also be discussed further with Jane Verity.	<b>KVJ/ JF</b>
<b>3</b>	<b>RenalPatientView</b>	
	RIXG was satisfied that progress remained very good in Phase 1 of RenalPatientView. The timeline was only a week or two behind the very aggressive schedule which had been established. In Leeds real patients were now testing live information on line, and technical problems were being resolved. Publicity material was now available for use on roll out to other units. NT and JF had presented the project at a workshop at the NKF National Conference and it had been well received with useful feedback. Additional funds had been committed in both Scotland and Wales proportionate to population size to allow pilots in those two countries. (At the time of the meeting final confirmation from Wales had not yet been received by KVJ). After St James’s Leeds and Heartlands Birmingham, it was agreed that the next two units would be Glasgow Western (chosen because it has clinic letters on PROTON which can therefore be shown on RenalPatientView) and Cardiff Paediatric Unit (where given the small patient population, clinicians had committed to testing a more extensive individualised electronic care plan). KVJ would circulate to RIXG for comment her early proposals on the content of that care plan.	<b>KVJ</b>
	KS reported very positive discussions with UK Transplant who will make available at no cost current transplant status to be shown on RenalPatientView.	
	Future roll out to PROTON and non-PROTON units was discussed, as well as possible stable funding streams but no decisions were made. RIXG noted the experience of the Renal Registry in dealing with problems of interactivity	

	with non-PROTON systems, and it was agreed that this resource should be tapped into at the right stage to avoid duplication of technical effort . RIXG will write formally to Jane Verity confirming satisfaction with progress in Phase 1 and raising an invoice for the second tranche of £50,000.	<b>JF</b>
	There was also discussion about the impact of inaccuracies in information held within PROTON in each unit, and at UK Transplant. It was recognised that one effect of RenalPatientView would be to highlight such inaccuracies, and this would likely generate work within units in reviewing and correcting data. RIXG regarded this as a positive outcome of this initiative.	
<b>4</b>	<b>Renal Registry</b>	
	National coverage remains incomplete although this is mandated by the NSF. JF reported that he had been active in writing letters and giving support to those units not yet linked, particularly all paediatric units and the units at Manchester Royal Infirmary and Salford. The great majority of delaying problems were within Trust IT departments rather than within renal units. RIXG took the view that the Department of Health should provide additional central pressure through Strategic Health Authorities for resolution of these problems as a matter of some urgency since units not linked by the end of December 2005 would not be able to contribute data fully in time to satisfy the NSF mandate. This will be discussed with Jane Verity	<b>JF</b>
<b>5</b>	<b>National Renal Dataset Development Project</b>	
	JF reported that himself, Terry Feest, and a representative from UK Transplant had all been invited to join the Project Board for the development of the National Renal Dataset. First meeting of the Project Board is in late November. The full remit of this Board was not yet clear, but RIXG expressed concern that there were still significant elements of data definition relevant to renal disease which were occurring outside this project, and not always with coherent activity. The discussion centred on vascular access data as an exemplar of the issue. As well as the National Renal Dataset Project, the Renal Registry was planning some straightforward vascular access data collection in 2005, the two Modernisation Agency projects were considering definitions of vascular access, among others. RIXG decided to approach Donal O'Donoghue, as co-Chair of the Renal Advisory Group, to request that he take the initiative in drawing together all those involved in vascular access definitions at the earliest opportunity to avoid duplication and ensure agreement.	<b>JF</b>
	RIXG expressed some concern that UK Transplant was not regularly represented at its meetings, and KVJ reported her concern that UK Transplant was still less engaged with the National Programme for IT than was ideal. Jane Verity had indicated by email that all appropriate steps were being taken at present.	
<b>6</b>	<b>NHS Direct and NHS Direct On-Line</b>	
	RIXG has major concerns at the lack of information and expertise relevant to renal patients within NHS Direct and NHS Direct On-Line. Anecdotal reports around the table suggested concerns that information might be at best unhelpful, at worst misleading, and possibly carrying risk for patients. TS reported that early discussions for an information partnership between NKF and NHS Direct On-Line had not made progress. It was agreed that all RIXG members would review these two facilities and report back their assessment in order that RIXG could push for appropriate developments.	<b>ALL</b>
<b>7</b>	<b>Other Information Issues</b>	
	TS reported that NKF had recently modified its website using "Betsy" [?]	

	software which provides colour and other functional enhancement to improve usability for the visually impaired. This had been very well received. He recommended that this development be considered for RenalPatientView. NT agreed that this should be looked into, but commented that such adaptation was particularly difficult for screens which held much numerical information (for example the results screen on RenalPatientView).	
<b>8</b>	<b>Chair of RIXG</b>	
	JF indicated that he felt the time had come for a change of Chair. RIXG had now been established for nearly 18 months and was remaining an effective forum which appeared to be fulfilling its terms of reference, and should certainly continue in its present form. Because of other time commitments, JF would prefer to hand on the Chair, particularly because there were others with greater information expertise among the membership who might lead more appropriately. It was agreed that the membership would consider this and a decision be made at the next meeting.	
<b>9</b>	<b>Date of Next Meeting</b>	
	Friday 4 <sup>th</sup> February 2005, 2pm, Leicester General Hospital.	