

RENAL INFORMATION EXCHANGE GROUP

Notes of Telephone Conference held Friday 23 March 2007

PRESENT ON CALL

Renal Association

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A face to face meeting had been planned. In view of small attendance it was agreed at 24 hours notice to change to a phone call which enabled EW and NT to join having previously given apologies.

Apologies were noted from other members of RIXG

Notes prepared by John Feehally - 28 March 2007

		ACTION
1	Notes of the previous telephone conference held on 8 th December 2006 accepted as an accurate record.	
3.	Information for Patients and Carers	
3a	RenalPatientView	
	A draft newsletter was reviewed and endorsed. Important points discussed included	
	a) rapid progress with patient recruitment, but marked variations in uptake in different units. NT undertook to explore with one high-achieving unit (Dunfermline) some possible explanations.	NT
	b) agreement that there should be links to the NKF and BRS websites to ensure that the widest range of patients and professionals had access the news and could see continuing success.	NT
	c) the successful link in Salford was seen as of great strategic importance, demonstrating the ability to link directly to one of the chosen software platforms for Connecting for Health.	
	d) concern was expressed that CCL who had previously indicated they were offering an RPV interface, had not yet done so. It was agreed to pursue this with some urgency to see if an alternative message could be in the newsletter.	KS, NT
	e) it was noted that Cherry's evaluation work is now being prepared for submission to the BMJ. It was agreed that this should be expedited if at all possible which required a face-to-face meeting - Cherry, Keith and Neil - in the near future.	NT, KS, CB

	f) JF to talk to the National Clinical Director to see if he can improve our access to strategic individuals within Connecting for Health so that we can indicate the scale of our success.	JF
3b	Patient Information DVD Project The first module of the DVD had been launched on World Kidney Day. It concentrates on CKD. A second module on renal replacement therapy is expected in the Autumn. Preview copies are now available but translated editions are awaited. JF agreed to circulate preview copies.	JF
3c	NHS Direct JF reported on behalf of Nicki Thomas. a) Progress continues to be painfully slow. We had made suggestions for updating renal elements of the NHS Direct website in early 2006 but these had not yet been actioned by NHS Direct. b) The clinical algorithms had been updated in late 2006 by NHS Direct in response to our advice. c) JF had written to NHS Direct's Clinical Director proposing that "special notes" be added to caller's details so that they could be flagged as patients with known CKD and appropriate direct referrals made to renal units. A reply is awaited d) educational packages had been offered by Nicki Thomas to update NHS Direct nurses on renal care but there had been no response to this offer. It was agreed that we should continue to press NHS Direct for response and action.	JF
3d	CCL have been in touch with NT & KS to say that a link from Clinal Vision to RPV is now underway again. They hope that it will be ready for testing by mid year	
	CONNECTING FOR HEALTH	
4a	Renal Dataset Development Project The Renal Dataset awaits approval by the Information Standards Board.	
4b	SNOMED CT RIXG noted that an action team to develop a renal subset within SNOMED CT had been assembled by JF in response to an approach from the SNOMED team at Connecting for Health. The group includes KS and EW and there is a first meeting on 1 st May 2007.	
4c	Map of Medicine RIXG supports the Renal Association in entering further discussions with Map of Medicine, despite the extremely disappointing care pathways which were the early product of Map of Medicine. A meeting is planned within the next few weeks.	
5	Scoping National Renal Audit – Healthcare Commission It was noted that the Healthcare Commission has now identified funds to implement renal audits in 2007 in the areas of vascular access, patient transport for dialysis, and management of early CKD. It was agreed to ask the National Clinical Director for a summary of his proposals for ensuring robust audits involving all appropriate expertise.	JF
6.	NHS Institute for Innovation and Improvement – new website RIXG was aware of the new website and its potential role as the setting for web-based elements of continuous quality improvement collaboratives being led by Charlie Tomson.	

	There was some uncertainty about any additional scope or value of the new website, and it was agreed to approach the National Clinical Director for an additional brief.	JF
7	Independent Sector Treatment Centres – IT requirements and expectations	
	Some reassurances have been received that IT functionality and proper links into renal unit information systems were embedded features of the developing ISTC contracts. NT reported that a number of potential bidders had approached him to ask for information about RenalPatientView interfaces while developing their bids. It was agreed that JF would write to the three clinical directors involved in the first wave of renal ISTCs to understand what contractual expectations were in place.	JF
8.	Restructuring of RIXG	
	It was agreed that a lack of direct links with staff in LSPs was limiting the ability of RIXG to influence developments, but there was no clarity about how such links might develop. It was agreed that JF would write to clinical directors asking them if they were content with the links in their own patches with strategic health authorities and LSPs, and identifying any individual in positions of real influence who we might co-opt to RIXG.	JF
	Chair of RIXG	
	Although JF has been in the chair for three years, there was general support for his continuation in the role. It would be reviewed in twelve months.	
9.	Perspectives from other member organisations	
	NKF - TS reported a very successful initiative whereby MPs had received information from NKF about the range of travelling times of renal patients in their constituencies. This had apparently provoked a flurry of activity from MPs seeking explanations of long travelling times from PCTs. He was congratulated on this initiative. It was noted that the UK Transplant representative on RIXG, Chris Rudge, had not been able to attend meetings. Some disappointment was expressed that the potential for UK Transplant to contribute to our discussions and add to useful information flows was not really being maximised. RH, who has recently joined the Kidney Pancreas Advisory Group at UKT, agreed to engage with their staff to see if we could strengthen our links.	RH
10	Any Other Business	
	It was noted that a submission had been made on behalf of RIXG and the Renal Association by JF to the Parliamentary Health Committee as a contribution to the Committee's review of the Connecting for Health initiative to introduce a National Care Record Service. It was not yet clear whether it would be among the evidence the Health Committee chose to put in the public domain.	
11	Date of next meeting: It was agreed by all that telephone conferences were proving a time and cost effective way of conducting RIXG business. It was still agreed that from time to time face-to-face meetings might be valuable especially when there were new members joining the group. It was agreed that if at all possible such face-to-face meetings should be during other gatherings such as the Renal Association or BRS annual conferences. The next meeting would be a phone conference on Friday 15 June 2007 at 2.00pm.	

RENAL INFORMATION EXCHANGE GROUP

Notes of Telephone Conference held Friday 15 June 2007

PRESENT ON CALL

British Renal Society

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Department of Health

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		ACTION
1	Notes of previous telephone conference accepted as accurate. No matters arising other than those all covered elsewhere in the agenda	
3	INFORMATION FOR PATIENTS AND CARERS	
3a	RenalPatientView	
	JF reported that 3850 patients are now registered nationwide using three different IT systems. There is encouraging progress with six other systems and optimism that they will be functional by later this year: KS maintains contact with these other system providers to encourage progress. Feedback continues to be positive. KS and NT alternate monthly in receiving all e-queries from patients. These typically relate to occasional delays in downloading of results, or in uploading altered patient contact information, but that aside no new problems have been revealed. It was agreed to write to all CDs with patients now registered confirming plans for a	

	<p>capitation fee based on the size of the RRT population in the unit (regardless of the number of RRT or non-RRT patients actually registered).</p> <p>It was agreed that capitation for RPV should be administered independently of capitation for the Registry.</p>	
3b	<p>Patient Information DVD Project</p> <p>The first module is now published and well received. A second module is expected in October 2007. The development work for this module is being led by Fiona Loud (transplant patient, recently appointed Chair, Kidney Alliance) and is expected to focus on information directed at helping patients come to terms with a chronic condition, rather than specific information about dialysis and transplantation. The possibility for a third module later in the year remains. RIXG continues to be very supportive of this project but has no direct input into its management.</p> <p>One new feature for RenalPatientView being discussed would be a space where patients could make their own annotations (for example to prepare for a clinic appointment). It was noted that this bore increasing similarity to the CfH proposal "My Health Space" and it was agreed that JF should raise this with the CfH Chief Clinical Officer at a forthcoming meeting.</p>	JF
3c	<p>NHS Direct On-Line</p> <p>Regrettably there is no progress at all to report. NT and JF have both sent further reminder emails to various staff at NHS Direct, but there has been no feedback. It was concluded that no further effort should be made at this stage.</p>	
4	<p>CONNECTING FOR HEALTH</p>	
4a	<p>Renal Dataset Development Project</p> <p>The Dataset have now been approved by the Information Standards Board. It is being road tested in selected units across the UK; the Registry is also involved in this work in developing software modifications necessary for downloading the full dataset. SS reported that his own unit had been reluctant to get involved in the "road testing" because of the scale of work required; JF indicated that sufficient other units of varying types (eg PROTON and non-PROTON, transplant and non-transplant) had been identified.</p>	
4b	<p>SNOMED-CT Renal Subset</p> <p>KS reported on progress. The work is led by David Crook from the Information Centre who has received information from a number of units who have been using their own bespoke classification systems over recent years. David Crook is now establishing how best to integrate into the existing SNOMED-CT terminology, and further meetings of the Action Team will be called. RIXG noted that if renal units in the meantime were involved in procuring or updating electronic systems it would be important to ensure that they came with software making them compatible with SNOMED-CT. It was again noted that there was no final commitment of the NHS in England, Wales and Northern Ireland to adopt SNOMED-CT (as is already the case in Scotland) but there was seen to be no realistic competitor and RIXG supported continuation of this work.</p>	
	<p>"Map of Medicine"</p> <p>There has been further contact between the Renal Association, Royal College of Physicians (London) and "Map of Medicine". JF is due to meet the RCP Chief Executive in the near future to discuss a possible business plan. It is understood there may be resource available from Map of Medicine to fund work undertaken by the renal community ensuring that these care pathways are in the end fit for purpose. RIXG agreed that this was an important task that should be pursued.</p>	
4c	<p>"Existing Systems" Programme</p> <p>A current tendering process initiated by CfH seeks proposals over a wide portfolio of "additional services" including a clinical renal information system. A brief description of the required functionality in the tendering document is compatible with a survey of</p>	

	<p>current functionality in PROTON and allied systems undertaken by RIXG. JF would continue to press for a role for RIXG in evaluating bids over the next few months.</p> <p>It was agreed that RIXG should now activate its inquiry to Clinical Directors (and other key staff including Clinical Information Managers) to identify ideal additional functionality which should be considered. KS has circulated this through Clinical Directors and through the available list of Clinical Information Managers.</p>	KS
4e	Evidence to Health Select Committee on Electronic Care Record	
	<p>Written evidence (correct document attached, RCP evidence to the Committee having been previously circulated in error) was followed by verbal evidence by JF given on 14th June 2007. Some coverage on BBC Radio 4 "Yesterday in Parliament" ensued. Apart from the generic points about CfH's failure to engage effectively with clinicians, the opportunity to raise specific issues on behalf of the renal community had arisen. A member of the Health Committee required an answer on a specific point from the National Clinical Lead for Hospital Directors, Simon Eccles. JF had the opportunity to meet Dr Eccles immediately after the Health Committee and it would appear this has given a new opportunity for the voice of the renal community to be properly heard by CfH Clinical Leaders. A meeting with the Chief Clinical Officer of CfH is already planned for late June.</p>	
6.	Any Other Business	
6a	<p>DOD updated RIXG on slow progress with a website hosted by the NHS Institute for Innovation and Improvement which had been intended to host the Quality Improvement Collaborative initiative led by Charlie Tomson and the Registry. This website had not proved fit for purpose and the web elements of the collaborative were now being hosted on the Renal Association website. An overall goal remains to have a single website portal for the whole renal community through which entry can be obtained to all relevant sites. As yet this is not close to fruition.</p>	
6b	<p>It was agreed that an annual report be published by RIXG, and it was suggested that this report should be prepared after the September 2007 meeting.</p>	
6c	<p>There was some discussion about the possibility of identifying an individual within each LSP who could be a member of RIXG and help to give us local intelligence on variations in implementation progress. There was some concern that it may be difficult to correctly identify these individuals, and it was agreed to discuss this in light of any further progress made in talking with CfH National Clinical Leads.</p>	
7	Date of Next Meeting	
	<p>Friday 21st September 2007. It was agreed that this should be a face-to-face meeting held at Leicester General Hospital, but that the three subsequent quarterly meetings would be phone conferences. If possible facilities will be arranged for those unable to travel to Leicester to join in by phone.</p>	

RENAL INFORMATION EXCHANGE GROUP

Notes of Meeting held Friday 21 September 2007

PRESENT

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		ACTION
1	Notes of previous telephone conference on 15 th June were accepted as accurate by those who were on the call.	
2	No matters arising other than those all covered elsewhere in the agenda	
3	INFORMATION FOR PATIENTS AND CARERS	
	3a. RenalPatientView	
	KS provided an update. 32 units now have some patients using RenalPatientView and the number continues to increase. There are now three non-Proton units live with RPV - Hope Hospital Salford [iSoft], Derby [Vitalpulse EPR], Norfolk & Norwich [Mediqual]. All other non-Proton systems seem to be making excellent progress and are anticipating availability of RenalPatientView by Q1 2008 – Cybernius, Renal Plus, Clinical Vision, Kings, UHB Birmingham. Paediatric progress is slow with only 2 units (Bristol, Cardiff) presently using RPV. CR agreed to work to progress this further. It was also agreed that paediatric-specific information would be welcomed within RPV and CR agreed to ask BAPN to take this forward.	CR
	<u>Evaluation</u> Regrettably the paper reporting on the evaluation of RPV is still not yet ready for submission and RIXG asked that NT and KS progress this as soon as possible	NT/KS
	There was discussion about securing the long-term future of RPV in organisational and financial terms. EW pointed out that it could be regarded as an archetype of a 'Patient Information Project' and it might be expected that others would follow in other specialty areas, given that such dissemination of knowledge is mandated in some NSFs and seems to be a current NHS priority. After discussion with DOD it was agreed that KS would prepare a brief business case [max 3 paras] for the long-term implementation of RPV within renal unit budgets, which DOD could use to make the case within DH. Submission target for this document end of October 2007.	KS
	3b. Patient Information DVD Project	
	SS reported the successful dissemination of the first DVD, now sent to all GPs in the UK.	

	Individual purchases of the DVD through the website continue. The second module is just completed and publication will follow soon. There is discussion whether a third model will be pursued.	
	3c. NHS Direct On-Line	
	<p>There has been no significant progress. The NHS Direct website has recently been significantly revamped but there has been no upgrading with the improved information on kidney disease which we had supplied. There has been no further communication between NHS Direct and Nicki Thomas with regard to the educational material on CKD which she had developed for NHS Direct staff. There has been no further feedback about the RIXG proposal of Special Notes for renal patients.</p> <p>Although there has been a consistent lack of progress, we had received a strong request from DB, representing patient and carer interests that we continue to pursue this issue which is perceived to be very important by them. It was agreed that JF would again write to the Medical Director of NHS Direct, copy to the National Clinical Director.</p>	JF
4	CONNECTING FOR HEALTH	
	4a. Renal Dataset Development Project	
	Collection of the Renal Dataset is now being 'road tested' in selected units in collaboration with the Registry. The understanding was that those items which would prove collectable in this exercise would next year become part of a mandatory dataset with further data to be added in due course when it became collectable. The apparently shifting philosophy and strategy behind the implementation of the Dataset was discussed in some detail but no additional actions were agreed.	
	4b. SNOMED CT Renal Subset	
	KS expressed concern that the SNOMED-CT work was not developing in the most productive way. Presently the ERA-EDTA diagnostic codes which were being refreshed by a European group (chaired by KS) were being mapped to SNOMED-CT. However the broader vision that SNOMED-CT would cover all aspects of our work including procedures, complications and co-morbidities as well as underlying renal diagnoses, seems to be slipping from the focus. It was agreed that KS would discuss this with David Crooks (Project Lead for SNOMED-CT).	KS
	4c. Clinical Interface with Connecting for Health	
	The concerns rose by JF and others, including evidence to the Health Select Committee, had resulted in some improved access to senior clinical leadership in CfH. JF had an informative meeting with Michael Thick, Chief Clinical Officer for CfH, and was now a member of the National Specialty Reference Group.	
	4d. Specialty Renal Systems	
	<p>Although no formal request has yet been received, it is anticipated that CfH will ask all specialties for a description of their specialty requirements in light of the recognition that specialty systems will need to continue alongside the main CfH EPR solution.</p> <p>The results of the recent RIXG survey of renal units were reviewed. It was agreed that KS and JM would upgrade the current draft document providing a more accessible introduction for non-specialists. This would need to be circulated within the renal community for comment and confirmation, and also made available to the National Clinical Director.</p> <p>Many of the requirements for a renal EPR indicated by renal units are generic and should ideally be provided by a powerful generic EPR solution. Nevertheless RIXG maintains the view at this stage that there are specialty system requirements both for data collection and analysis which must be regarded as a minimum requirement for the renal community, and whose value have been proven by the history of successful local solutions over many years.</p>	KS JM
	4e. Existing Systems Programme	
	This programme seemed to have been stalled after the tendering stage, and as yet RIXG has not been asked to provide any clinical comment on bids for the "additional services catalogue". The relationship of this programme to the CfH request for specialty system advice [4d.] remains unclear.	
	4f. Clinical Interface with Local Service Providers	

	<p>Concerns remain that the Despite considerable effort JF has made no worthwhile progress in engaging with developers of the Lorenzo solution for the EPR being produced by CSC Alliance in the North and Midlands. Efforts continue.</p> <p>In London and the South there is the advantage that Paul Altmann (nephrologist in Oxford) has a part-time secondment as a Clinical Officer for the Millennium solution being provided by Cerna.</p> <p><i>(Note after the meeting: a phone conversation between JF and Paul Altmann suggests significant disparity in rate of progress and possibly strategy between the development of the LORENZO and Millennium products). Paul Altmann will be invited to come to share his experience with RIXG as soon as possible, ideally at our December 2007 meeting</i></p>	JF
	4g. IT Interface Between Primary Care And Secondary Care	
	DOD reported on the meeting planned for 15 th October 2007 where representatives of the renal community, Connecting for Health, and primary care will meet to seek ways to solve the primary-secondary care interface limitations which so much restrict the efficiency of care for longterm conditions such as CKD.	
5.	OTHER RENAL INFORMATION ISSUES	
	5a. NHS Choices	
	<p>DOD reported on a new NHS knowledge website – NHS Choices – which seeks to provide information under three broad headings</p> <ol style="list-style-type: none"> 1. Staying Healthy 2. An A-Z of conditions 3. Information about healthcare provider units <p>He requested that RIXG act as “gate keeper” and provider of quality assurance for the information posted on that website. RIXG agreed to do this. Material RIXG had already offered to NHS Direct would be entirely suitable for posting also on NHS Choices</p>	
	5b. MAP OF MEDICINE	
	RIXG noted progress of the shared project between the Renal Association and RCP London to provide specialist review and editing of Map of Medicine pathways. The first chosen pathway being that for CKD. There was no specific progress to report at this time.	
6	ANY OTHER BUSINESS	
	The continuing lack of representation from UKT and from nephrology colleagues in Wales and Northern Ireland was again noted, but it was concluded that there were no other available steps to remedy this.	
7	<p>DATE OF NEXT MEETING - Friday 14th December 2007</p> <p>Though planned as a phone conference, there was post-meeting consensus that should instead be a face-to-face meeting in Leicester, inviting Paul Altmann to join us and give an update on the Millennium software.</p>	-
	<p>Dates for 2008</p> <p>Friday 21 March</p> <p>Friday 20 June</p> <p>Friday 19 September</p> <p>Friday 12 December</p>	

RENAL INFORMATION EXCHANGE GROUP

Notes of Meeting held Friday 14 December 2007

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Annette Neary	Lorenzo	

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		ACTION
1	Notes the last meeting were accepted as accurate record.	
4.	Connecting for Health	
	<p>RIXG had a wide ranging discussion about the current Connecting for Health situation following a brief Powerpoint presentation by JF outlining the goals and strategy of CfH as currently understood, and its interactions with other central information initiatives including the activities of the Information Centre.</p> <p>Paul Altmann [nephrologist, Oxford] had planned to attend but gave apologies during the week. He is seconded on a part time basis to work on the CERNER MILLENIUM software product, the electronic care record being developed for London and the south of England. He was intending to present aspects of MILLENIUM he has been developing to meet the needs of the renal community, but owing to ongoing "contract refresh" between CfH and the local service providers [LSPs] which he had expected to end in November he felt unable to give worthwhile current and future perspective of plans for MILLENIUM.</p> <p>Since Annette Neary, currently completing a one year secondment to the core team of LORENZO, the software product for the North, Midlands and east, was at the meeting it was inevitable that product-specific discussion revolved around LORENZO rather than MILLENIUM.</p> <p>The following main points were discussed.</p> <ul style="list-style-type: none"> • The clinical interface with Connecting for Health centrally had improved this year following the appointment of Michael Thick as Chief Clinical Officer. JF reported useful conversations with Michael Thick, and Mark Dancy (Cardiologist, St George's) who is in Michael Thick's team. • The verbal assurance previously received from Michael Thick that specialty systems would be required, respected, and developed with professional input was much appreciated by RIXG. However there was concern that CfH did not yet feel it possible to put this on paper. 	

	<ul style="list-style-type: none"> • Nevertheless it is anticipated that CfH will soon ask for a content specification for such specialty systems. It is understood that the delay in this request relates to debate with LSPs about the format in which the content should be presented for technical development. • JF reported on his first attendance at the National Specialty Reference Group (NSRG) of CfH in November 2007. The focus thus far of that group has been on the information implications of the Choose and Book initiative for which Paul Rylance has been leading for the renal community. NSRG only briefly discussed the development of specialist systems. Chair of NSRG expressed concern that the group should not promote the development of proposed content for specialty systems until CfH centrally could guarantee there would be resource for the proper development of these systems. • Nevertheless RIXG agreed that a content proposal for a renal specialist system should now be developed taking the functionality described in the RIXG survey of renal units and developing textual description of these functions to a form which could rapidly be adapted to any specific technical requirement from CfH. Before tasks were allocated it was agreed to await the outcome of the next bullet point. • DOD reminded RIXG that as National Clinical Director he was engaging with CfH to acquire project management support which had been primarily intended to focus on developing primary-secondary interface issues relevant to the renal community. DOD offered, assuming this resource became available, that it could also support content development work for the specialist system. RIXG gladly accepted his offer and awaits developments. • Annette Neary shared her own experience of developing content for LORENZO in another specialty setting (emergency medicine), and offered her expertise as part of the RIXG writing group. This offer is warmly welcomed. • It remains unclear how this emerging support for specialist systems from Connecting for Health relates to the ongoing work of the Existing Systems Programme within CfH which is tendering for an Additional Services Catalogue which includes a renal system tender. RIXG is aware that a number of commercial providers of renal systems has bid for this aspect of the catalogue. After a period of inactivity, JF has been informed that this tendering process is being reactivated, and RIXG's offer to assist in evaluation of any bids is apparently still welcome although specific details are lacking. JF will pursue this. • CfH is devolving responsibility for the leadership of development programmes to Strategic Health Authorities. Each SHA now has a Chief Information Officer who is a key individual. RIXG agreed that the time had now come to establish a network of information leads for the renal community, one in each SHA. Such an individual could be a nephrologist or another health professional with the necessary expertise and energy. JF agreed to approach the Renal Association Clinical Services Committee to make contact with CDs representing each SHA, and ask them to assist in identification of key individuals in each area. • The Renal Dataset Project moves steadily forward. Acquisition of the Dataset is now being 'road tested' in a number of renal units. Support for the necessary software reconfiguration is provided by the Renal Registry. This work is expected to complete in the first half of 2008. • Part of the 'road testing' is to demonstrate the technical ability to download data from renal unit systems through the Registry to the Secondary Uses Service (SUS). RIXG noted the concerns of the Registry that its relationship with SUS has not yet been properly defined. A request earlier this year for a project board with appropriate representation to oversee these emerging arrangements and their implications had not yet been met, and supported the Registry in continuing to make very strong representation that this was a necessary basis on which any further discussion with SUS could continue. • It was noted that current "roll outs" of new IT systems by LORENZO and MILLENIUM appeared to be somewhat piecemeal and reflect the commercial need to demonstrate 	<p>DOD</p> <p>JF</p> <p>JF</p>
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	<p>benefit to the health community, rather than being part of definitive final IT solutions.</p> <ul style="list-style-type: none"> Coding: JF reported that the SNOMED-CT action team was continuing its work and it is hoped that there may be sign-off on a renal subset of SNOMED-CT by February 2008. 	
5	Information for Patients and Carers	
	5a RenalPatientView	
	<p>RIXG again endorsed its view that the time had come for RenalPatientView [RPV] to be regarded as a routine part of clinical care for patients in renal units and therefore to be a commissioned service.</p> <p>NT reported on the continuing steady expansion of RPV. There are now no technical restrictions to all units having it available for their patients. CB and NT reported that CB's paper on evaluation of RenalPatientView was close to submission.</p> <p>Ongoing support and funding for RPV were again discussed. Following the last meeting KS had prepared a brief description of RPV sent to DOD which he has now circulated within DH where discussions continue. RIXG agreed that the time had now come where a capitation funding approach to RPV was entirely appropriate; this had been discussed earlier but dismissed because of the patchy coverage of RPV at that stage. NT agreed to provide the Registry a proposed capitation fee based on expected costs for maintenance and development. It is still anticipated that a part time employee will be needed to deal with queries and to support RPV. The possibility that such an individual might be physically located in the Registry was discussed, and not regarded as mandatory. Likely alternatives would be in Glasgow with the Scottish Renal Registry, or in Edinburgh.</p> <p>Registry representatives raised concern that placement of this individual within the Registry building might be misinterpreted as "a Bristol takeover" and RIXG gave assurances that no-one around the table would misconstrue things in this way.</p> <p>A further paper describing the capitation fee proposal will be forwarded to DOD following these discussions.</p>	<p>CB/NT/KS</p> <p>CT/NT/JF</p>
	5b Patient Information DVD Project	
	<p>This was discussed in the absence of Steve Smith and Nicki Thomas, the two RIXG members who have been most actively involved. RIXG's role in this project is one of support and comment rather than any specific line management, although the initiative first emerged at RIXG before it was taken forward by Steve Smith and others at Kidney Research UK.</p> <p>There was very strong support for the high quality of the two DVDs which have been produced and their value to the whole renal community is recognised. There was some lack of clarity about the continuing status of the project. RIXG recognised that ongoing resource may be needed for appropriate updating of the current products, but was unclear about the goal of any further DVDs, the production of which is apparently being considered.</p> <p>RIXG also had significant concerns about the current strategy of charging individual patients for a DVD. Both patient and professional representatives around the table had assumed from the preliminary discussions that DVDs would be freely available to all who would need them. A strategy whereby they are distributed free to General Practitioners and therefore might reach some patients without cost when others were charged, seemed uncomfortable. RIXG decided to write formally to Steve Smith and KRUK asking for a description of their current and future plans and their perspective on the issue of charging to patients.</p>	JF
	5c NHS Direct On-line and NHS Choices	
	<p>DOD reported on encouraging progress at NHS Choices. NT had also sent a brief report describing progress with NHS Direct. A key point is that any material posted by NHS Choices on a specific topic must be identical with that held by NHS Direct and that material relevant to kidney disease has now been significantly improved. NT and SS had provided DOD with some rapid help to develop and assure the quality of new material being posted on NHS Choices. It was agreed that RIXG will in future identify a sub group of its membership to support the production and quality assurance of further new material presented on NHS Choices.</p>	JF
	Any Other Business	
	National Library for Health – Renal Specialist Library	
	<p>The recent communication from David Goldsmith was noted with the news that he and his team were re-tendering for continuing supply of the Renal Specialist Library, and that sufficient</p>	

	recurrent resource appeared to have been identified to make this a viable project.	
	NHS Knowledge Week	
	RIXG supported DG's proposal that there should be an NHS Knowledge Week probably in June 2008 which would not only serve to highlight the quality of the Renal Specialist Library, but also to give the opportunity to demonstrate the wide information successes of the renal community including RenalPatientView, material about kidney disease on NHS Choices and NHS Direct, the patient information DVD and other nationally available sources of information for patients and carers, and the powerful information impact of the Renal Registry. DG will attend the next meeting of RIXG in March 2008 to discuss plans for NHS Knowledge Week.	
	Response to Lord Darzi's letter "NHS Next Stage Review – Invitation to submit policy ideas"	
	JF will draft a response on behalf of RIXG which will be circulated for comment.	JF
	Date of next Meeting:	
	Friday 14 th March 2008 at LGH – <i>note after meeting; venue now changed to London to coincide with a workshop on renal IT issues convened by the National Clinical Director</i> Major agenda items at that meeting will included a presentation by Paul Altmann and planning for Knowledge Week 2008	