

# RENAL INTERFACE GROUP

## Notes of a meeting to discuss renal information issues convened by the Renal Association

3 July 2003 – Heartlands Hospital, Birmingham

### Present

#### **British Renal Society**

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#### **British Transplantation Society**

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#### **NHS Information Authority**

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#### **National Kidney Research Fund**

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#### **Renal Association**

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### Apologies

Tim Statham [National Kidney Federation]  
Chris Rudge [UK Transplant]  
Jane Verity, Anne-Marie Campbell [Department of Health]  
Simon Pearson [NHS Information Authority]  
Neil Turner [Renal Association]  
David Wheeler [Renal Association]

## **Introduction**

John Feehally [JF] welcomed everyone to the meeting and appropriate introductions were made.

JF emphasised that the meeting had been convened by the Renal Association [RA] with the goal of achieving representation from all key professional and patient groups in the renal community, and the response was extremely encouraging.

JF also made clear that the meeting had been convened without commercial support, that RA had met the catering costs, and it was assumed that individual organisations would meet travel costs. Steve Smith, Heartlands & British Renal Society [BRS], was thanked for his hospitality.

## **Goals**

JF emphasised three main goals for the meeting:

1. To ensure that all the organisations represented were well informed about current developments on the renal information scene particularly including the implications of the NSF Information Strategy and also the National Electronic Library for Renal Disease.
2. To consider whether the time is right to develop a web based communication system to improve:
  - communication between renal units
  - communication between renal units and local primary care professionals
  - communication between individual renal patients and their units, facilitating access to personal health information
1. To consider whether the *ad hoc* group convened on this occasion should continue to meet regularly and have an ongoing defined role in providing patient and professional specialist input to information developments.

## **GOAL 1: The Current Information Scene**

### **NHS Renal NSF Information Strategy Presentation by Kate Verrier-Jones**

Kate Verrier-Jones [KVJ] emphasised the work done so far in the development of the NSF Information Strategy and the very tight timescale required since the Strategy was to be published alongside Modules 1 and 2 of the NSF in autumn 2003. Among a number of policy drivers, she emphasised the Renal NSF, the Transplant Framework (a forthcoming DH response to the current shortfall in transplantation programmes), and the policy goal of patient empowerment.

Information needs include

- Information required for direct patient care – e.g. ICRS (Integrated Care Record System)
- Information required for secondary purposes – including audit and other benchmarking activities, for example the work of the Renal Association UK Renal Registry
- Access to a knowledge base for patients and professionals – national programmes include the National Electronic Library for Health, NHS Direct and NHS Online.

#### Discussion:

- It was noted that the rapid rate of progress in individual national information programmes risked loss of coherence and unnecessary overlap.
- It was noted that the important role of the UK Renal Registry might demand of the Registry increased accountability (although how this would be defined was not at all clear).
- There was concern that managers of national programmes may not understand local renal information systems nor appreciate the high quality work currently available.
- Concern was expressed that a number of the individual DH projects were “idealisations” whose deliverability had not yet been tested.

#### National Electronic Library for Renal Disease Presentation by David Goldsmith

RA has been commissioned to establish a National Electronic Library for Renal Disease [NELRD] and David Goldsmith [DG] is leading this work. DG briefly presented the principles behind NELs - that they should provide accurate and timely information which was useful and reliable for patients, carers and professionals. They should also interface properly with other information providers.

DG's early work has developed the notion of three portals of entry to the NELRD, one for the patient, one for the generalist, one for the specialist, with relevant levels of information through each portal.

Start up funds (probably providing a salary and some support for two years) were available and David was planning a scoping meeting in autumn 2003 to which all relevant bodies would be invited.

#### Discussion:

- the difficulty of distinguishing between fact and opinion was emphasised
- it was also pointed out that the mantra that “everybody needs to know” should more correctly be read as “everybody needs to know something ...” and this would have a significant impact on the way NELRD would be established
- there was concern about the different indexing structures in libraries (for example MESH) compared to those used for clinical information (SnoMed, ICD and Read) which made cross-referencing particularly difficult.

#### General Discussion on Goal 1

The group discussion strongly emphasised the need for renal services to be regarded as a special case from an information perspective. There was a strong feeling around the table that renal health professionals were real experts in this field and had a long track record of using information in direct patient care and also to derive secondary information. There was a strong feeling that the group should continue to meet in order to ensure that this expertise was heard and properly involved in current developments.

## **Goal 2: Communication System for Patients and Health Professionals**

Peter Calcraft (PraxisMed Ltd) supported by David Deakin and Glen Griffiths (InteractivHealth Ltd) presented their proposal for a web based communication system in which each renal unit would retain local control over a wide range of information access provided centrally. They demonstrated a means by which individual patient access could be obtained to relevant specific clinical information and personal data. They emphasised that a system using similar principles had been commissioned and established by a PCT in Southampton by them, and a second PCT system was being introduced in London. They emphasised their familiarity and background in the renal field. Following some discussion of their presentation, those three individuals withdrew and the remainder of the meeting continued in their absence.

### Discussion of Goal 2

- There was broad support for the need to develop such a system at this time. The rapid information developments discussed in Goal 1 required effective communication. The group felt that such a development would be powerful in demonstrating the “renal community” did exist and was an effective collaborative grouping of patients and professionals, an approach which should strengthen the relationship with the DH.
- There was concern that failure to develop things at this stage might lead to the imposition of a national system of generic design which did not necessarily meet the particular needs of the renal community
- The risk was noted that a two-tier system would develop with much superior information access for the patients who had computer access compared to those who did not. However it was felt that this was an unavoidable consequence of current global IT developments and it was necessary to go with the system.
- The importance of not duplicating existing information access established by organisations around the table was emphasised.
- The potential of such a web-based platform not only to provide information access, but to facilitate education and training, as well as research, was appreciated, but this discussion focused on the establishment of the platform.
- The means by which information would be controlled was discussed; including the amount of person power which would be needed either centrally, for example a central web master, or locally to ensure effectiveness.
- The potential complexity of developing local working arrangements with individual Trust and PCT Intranets was aired
- A view was expressed by a minority that the model presented was technically less complex than was implied in the presentation. Stephen Chan agreed to use his contacts to explore this issue further
- Although individual units had developed local systems with some of these features, the lack of an integrated system despite appreciation of its value was attributed to the lack of dedicated resources

Cost could be divided between a substantial start up cost and running costs.

- Start up costs. If an appropriate brief were prepared it was hoped that DH would contribute to the start up costs since the proposal met so many current DH goals

and aspirations. An alternative approach would be to seek pharmaceutical company support – some members of the group preferred to avoid this, but funding from a consortium of companies avoiding over-reliance on any one area of industry was thought acceptable by others.

- Running Costs Once established, maintenance of such a system was most likely to be successful if costs were integrated into patient care budgets and therefore borne by commissioners. One model which found favour with the group was that the running costs should be added on a per capita basis to the current UK Renal Registry annual fee. It was thought this would likely be acceptable to units and commissioners if the benefits of the system were demonstrated.

#### Need for a Pilot Study

There was thought to be a substantial risk in attempting the introduction of such a large and complex system across some 80 renal units in the UK. The group strongly favoured a pilot programme in which the benefits of the system were tested and demonstrated probably on a regional basis. An appropriate region/regions should be chosen in which there was a major tertiary unit with transplantation as well as other substantial dialysis units without transplantation and also satellite units.

#### 'Due Process'

PraxisMed and InteractivHealth had shown commitment to the renal area, and had done considerable groundwork in demonstrating their expertise to the renal community. No one on the group was aware of other commercial organisations with a product at a similar stage of development. However there was unanimous agreement that these companies should not be further involved in these developments without an appropriate and transparent process. It was agreed that the process should be as follows:

1. The group would prepare a brief describing the kind of web-based system should be developed, and an appropriate pilot study. This brief would initially be prepared by Es Will, Keith Simpson, Rob Higgins, Stephen Chan; Es Will to prepare the first outline. It would then be circulated by e-mail to the whole group for comment and ratified at the group's next meeting.
2. This brief should be used to seek DH funding for the pilot. KVJ agreed to explore which contact points in DH might best be approached for pilot funding. An approach to consortium industry funding would also be considered.
3. The funded brief would then go out to tender for the pilot study. Ideally this would occur before the end of 2003.

#### **Goal 3: The Future of this Group**

There was a strong consensus for the group to continue. It was felt that it provided a considerable voice by which the renal community could impact on the current information agenda. KVJ in particular indicated she valued the opportunity to use such a group as a sounding board for the renal community in developing the NSF Information Strategy further.

- The group agreed that JF should remain in the Chair for the present and he offered to convene the next meeting in early October 2003.
- It was agreed that formal support for the existence of the group should now be sought by JF from the leaders of each of the involved organisations.
- It was also suggested that the relationship of the group to the Kidney Alliance should be considered, some saw considerable "political" value in this. It was agreed that JF brief Roger Greenwood, Chairman of the Kidney Alliance.

Notes prepared by John Feehally, 17 July 2003

# RENAL INFORMATION EXCHANGE GROUP

Notes of 2<sup>nd</sup> Meeting held on 31<sup>st</sup> October 2003  
Leicester General Hospital

## Present:

### British Renal Society

Steve Smith

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### British Transplantation Society

Rob Higgins

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### NHS Information Authority

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### National Kidney Research Fund

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Neil Turner

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### Scottish Renal Association

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### National Kidney Federation

Tim Statham

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### Department of Health

Paul Richardson (1<sup>st</sup> part of meeting only)

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## Apologies:

### UK Transplant

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### British Renal Society

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### National Kidney Research Fund

Stephen Chan

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### Renal Association UK Renal Registry

Es Will

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The meeting consisted of two parts. The first was a scoping meeting for the proposed Renal Diseases Specialist Library being developed as part of the National Electronic Library for Health. This was chaired by David Goldsmith and separate notes will be circulated.

The second part of the meeting was chaired by John Feehally. The notes of the first meeting of the Group on 3<sup>rd</sup> July 2003 were reviewed and accepted as accurate.

## Goals and Scope of the Group

The goals laid out at our first meeting in July were affirmed by the group. These were

1. To ensure that all the organisations represented are well informed about current developments on the renal information scene.

It is recognised that there are three main elements to current information developments.

- Information required for direct patient care
- Information required for secondary purposes, including audit and other benchmarking activities
- Access to a knowledge base for patients and professionals

The group aims for information sharing which will minimise duplication of effort and energy. The group recognises the excellent work being undertaken to develop the knowledge base and user information required for secondary purposes. The particular focus of this group's immediate planning is to strengthen the information handling required to improve the care of patients with kidney disease.

## Authorisation of the Group

As agreed at the last meeting John Feehally (JF) had written to organisations invited to the Group seeking a more official recognition of this group and its goals. Positive letters of support (each raising a number of different perspectives) had been received from British Renal Society, National Kidney Federation, UK Transplant. No letter had been received from British Transplantation Society (BTS) but Rob Higgins (RH) indicated to the group that BTS was supportive of the group's development and goals. It was agreed that JF should write to British Association for Paediatric Nephrology seeking their support and offering them full group membership, if so wished, in addition to the paediatric perspective offered by Kate Verrier-Jones (KVJ).

The group discussed offering membership to the Association of Renal Industries. The increasing value of the role of ARI as part of the renal community was recognised, as well as their considerable expertise in information handling and education. It was agreed to discuss again at a future meeting ARI's potential role.

**(Note added after the meeting:** outside the meeting JF as Chair of the group had been approached with concern over the sufficiency of patient representation on the group. In addition to Tim Statham (TS) representing NKF, it should be noted that the NKRF representation offered this perspective. Stephen Chan representing NKRF is a patient. On this occasion Stephen was unable to join us and his substitute Diana Blass, as well as being an NKRF Trustee is a former carer for a renal patient. It is hoped that the group sees this level of patient and carer representation as sufficient.)

## Group Title

It was agreed that the title of the group should be finalised, and should be chosen to reflect the range of its activities.

From now on the group will be known as the **“Renal Information Exchange Group”**

## Review of Renal Information Strategy

KVJ gave an excellent update of the current Renal Information Strategy which is expected to be published alongside Modules 1 and 2 of the NSF in the near future. Progress and plans are summarised in the table at Appendix 1.

The very positive progress achieved in the Renal Information Strategy was warmly welcomed by the group. However it was noted that this was predominantly a middle to long term strategy describing a seven year programme working to completion of the NCRS Spine with appropriate LSPs. A focus of the work would be a “levelling up “ to ensure that all renal units had sufficient electronic systems to work effectively at the local level, and also to integrate with the NCRS Spine. The group noted that many renal units around the country already had very robust electronic systems to this level. So the opportunity to develop a beacon proposal testing the potential of an electronic patient care plan was discussed in detail (see below).

## Other Renal Information Updates

NKF. TS emphasised the established role of NKF as a supporter of the knowledge base for patients through their website, telephone helpline, and the extensive provision of patient information leaflets.

NKRF. It was noted that NKRF also has a patient helpline and a range of patient information literature.

Renal Association UK Renal Registry/ UK Transplant. JF reported briefly on continuing work to improve integration and data sharing between the UK Renal Registry and the database of UK Transplant. RA and BTS are also involved in these discussions with a further meeting in November.

## Pilot Study for an Electronic Patient Care Plan

The proposal for an electronic renal information system developed after the group’s last meeting in July was reviewed in the light of new developments in the Renal Information Strategy.

The group strongly endorsed the need for such a proposal, the importance of a pilot study, and the great potential this offered for progressing the Information Strategy.

The established excellence in information handling of the renal community allows a unique opportunity to test many of the principles in the Information Strategy; at the same time as the overall strategy seeks to “level up” the electronic base for the care of all patients with kidney disease.

The proposal will have two main goals

1. Testing and establishing a system for patients to have direct electronic access to appropriate information held in their electronic patient record by their renal unit. This could include for example appropriate blood results, indications of transplant status, current dialysis schedule, next clinic appointment, etc. The information should be supported by sufficient education and information to empower patients to interpret this information to their greatest benefit.

**(Note after the meeting:** Neil Turner has done a mock up of a potential site which can be viewed at [www.renal.org/patientview.html](http://www.renal.org/patientview.html) ).

2. A process for the identification of significant abnormal blood results or other pointers to kidney disease in both secondary care and primary care. The process should identify abnormal results and provide a sufficient decision support system based on nationally agreed guidance. This process would focus not only on the care of patients with chronic kidney disease known to renal units, but also would be a model for the early detection and prevention of chronic kidney disease in line with the developing module 3 of the NSF.

It was agreed that both processes, which are very closely linked, should appear in a pilot proposal, but the primary emphasis should be on patient access thus developing an electronic patient care plan.

Other relevant products and developments in this field were discussed briefly. The "OTIS" Programme developed by Roche Pharmaceuticals had been assessed by some members of the group. Some limitations of this system were noted – the OTIS system apparently required additional inputting of data onto a secondary electronic database held by the renal unit, focussed only on transplantation, and required the patient to attend the units to be able to take their information away in a hand-held system for review at home. This contrasted with our pilot proposal which would require only handling of data already held by the local electronic database, and would assure the patient remote access with appropriate safeguards.

The group felt strongly that it was ideally placed to develop this proposal, which should be very attractive to the Department of Health given its relevance to many elements of the Information Strategy and the NSF, particularly patient empowerment and the development of an electronic care plan of true practical value. The following actions were agreed

1. RH will re-draft the pilot proposal within the next two-three weeks for circulation to the group as a whole, with further editing by email.
2. JF and KVJ to discuss this proposal with relevant colleagues at NHS Information Authority and Department of Health to ensure that the goals of the pilot study were well understood, other potential interactions had been maximised, and that any funding opportunity was identified.

Ideally all these discussions should be completed by Christmas.

**Date of next meeting:           Friday 23<sup>rd</sup> January 2004, 2.00pm.  
Seminar Rooms A and B, Education Centre  
Leicester General Hospital**