Renal Association Short Life Clinical Affairs Working Party

Report to the Renal Association Executive

20th February 2004

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Renal Association Short Life Clinical Affairs Working Party

1 The Remit

"The remit of the Working Party is to consider the future role of the Renal Association in the development of clinical standards for renal units, in promoting the conditions needed to attain them, and auditing the success with which this is done. The Working Party will make specific recommendations to the Executive within the overall context of the changing Health Service."

Terms of Reference

1) The Working Party has been established by the Executive Committee of the Renal Association and will report back to it.

2) The Working Party will consider the current roles of the Standards and Service Provision and Delivery Subcommittees of the RA, and of the Renal Association UKRR, and make recommendations about their (or their successors) future roles.

3) These recommendations will be made in the context of current developments within the Health Service including the Renal NSF, NICE, CHI and the NHS Information Strategy.

4) The recommendations will take account of the expanding role of patients in decision making within the NHS.

5) They will consider the best way to work within the multidisciplinary workforce required for treating patients with renal disease.

6) The Working Party will be drawn from the membership of the Association selected on the basis of their expertise in the relevant areas.

Timescale

The Working Party will present a short discussion paper to the Autumn Meeting of the Renal Association in order to initiate the wider consultation process with the membership. It will present its report to the November Meeting of the Renal Association.

AJ Rees
President

April 2003

2 Members of the Working Party (alphabetical)

Prof John Feehally	(President-elect and formerly Treasurer)
Prof Terry Feest	(Chairman of the RA UKRR Subcommittee)
Dr Donal O'Donoghue	(Treasurer and link with the BRS)
Prof Alison Macleod	(Chairman Standards and Audit Subcommittee)
Prof Steven Powis	(Formerly on Executive, and link with the BTS)
Dr Stuart Rodger	(Chairman Service Provision and Delivery Subcommittee)
Dr Kate Verrier-Jones	(Representing NHS IT policy and the BAPN)
Dr Es Will	(Hon Secretary of the RA UKRR Subcommittee)
Dr Christopher Winearls	**Chairman** (formerly Hon Secretary RA)

The Working party met twice: on 24/9/2003 and 19/1/2004. It presented its preliminary findings and recommendations to the Autumn Meeting of the Association, the Trustees of the RA and the full Executive. The draft recommendations were mailed to all members of the RA and posted on the website. Responses to the Chairman were invited.

3 Organisations invited to submit opinions

British Renal Society (BRS)	Appendix 1
British Transplantation Society (BTS)	Appendix 2
British Association for Paediatric Nephrology (BAPN)	Appendix 3
Department of Health (DoH)	Appendix 4
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4 Introduction

The Renal Association (RA) has evolved from a small scientific club to an organisation providing a forum for, and leadership in, both academic nephrology and clinical practice. In the 1980s a political function was thrust upon it by the overwhelming problems being experienced by its members who were practising clinical nephrologists. Three of the RA's subcommittees are responsible for clinical and service issues. Although these subcommittees have a record of achievement and a reputation for rigour, a Working Party was asked to consider the present and future roles and functioning of these, taking into account the changes in the national health landscape and the emergence of a number of other bodies whose work overlaps and impinges on these subcommittees. Examples include: the *BRS*, the *BTS*, *NICE*, and the *ERG of the NSF*.

We considered first the overall role of the RA as a body providing policy and other advice on clinical and service matters. We agreed that although the RA is largely an association of *medically* qualified individuals and scientists it had, in addition to its scientific function, a continuing leadership rôle in many aspects of renal disease and its treatment. Responsibility for directing, planning and delivery of renal services is usually placed upon clinical nephrologists as clinical directors. They are almost all members of the RA and have a career-long commitment to the specialty. However, service provision is absolutely dependent on a multi-disciplinary team of which nephrologists are but one part. We therefore agreed from the outset that: 1) The Association should, when preparing policies and guidance in its own right, always collaborate with other bodies with an interest in, or responsibility for, the care of patients with renal disease. This includes creating channels of communication with the representatives of patients. 2) It should build on its relationship with the DoH which values the expertise of the RA. 3) It should maintain a consistent high level of involvement in clinical issues and seek to communicate its views clearly and widely.

The subcommittees should where appropriate have paediatric representation.

5 Standards and Audit Subcommittee

Membership of the subcommittee was constituted as follows. There were twenty-five members, including those who took the lead in writing each of the major chapters. In addition to consultant nephrologists, paediatric nephrology and intensive care were represented. The chapter on transplantation was written in conjunction with the British Transplantation Society and the committee had representation from nursing staff and from the federation of Kidney Patients Associations, (the NKF). A Public Health physician with particular interest in renal disease was included. Members of health care management and of the four Departments of Health within the UK attended as observers.

The Working Party agreed that the RA Standards Subcommittee has been highly successful in producing useful documents that have been well-received by the renal community and other health professionals. The recommendations contained within the Standards Documents are considered by most organisations

including the DoH to be the de facto standards for renal medicine within the United Kingdom.

The Working Party felt strongly that the RA should continue to produce clinical standards for the UK, and that the standards should be produced and "owned" by the profession. The scope of the NSF and limited number of specific issues dealt with by NICE are such that an overall Standards Document remains a necessity. Indeed the Renal Standards document is one of the cornerstones of the NSF and Information Strategy.

However, the Working Party also agreed that a number of issues should be taken into account when plans are made to produce further RA standards documents.

1) Where possible, duplication of the efforts of other organisations should be avoided. The RA should ensure (and acknowledge) the full participation of other organisations. For example, standards on renal transplantation should continue to be produced jointly with the British Transplantation Society. Such a single standards document would be issued by both organisations *but the same numbered and dated version should be extant on individual websites or within published policy documents.* There should be liaison with those organisations producing European and International guidelines but their recommendations should not be binding on the RA.

2) Future documents should always clearly distinguish between recommendations that are based on evidence and those that are based on opinion and consensus.

3) Future standards should be produced in a modular form, which can be updated regularly. Chapters on standards (e.g. in peritoneal dialysis) should be produced by small “Expert Groups” working at the behest of the subcommittee. These “Expert Groups” should include other health professionals who form the multi-disciplinary team, as well as patients representatives. This would reduce the need for the Standards and Audit Subcommittee to meet as frequently as it has hitherto. There should still be review of the proposals of the “Expert Groups” by the full Standards and Audit subcommittee.

4) Standards Documents (or chapters) should be updated on the web at regular intervals, but the Working Party believes that there will still be a need for a complete paper document to be produced (at intervals to be decided). This would collate the latest versions of each stand-alone chapter.

5) The Standards Document should extend its scope to clinical problems other than End Stage Renal Failure (ESRF), e.g. Acute Renal Failure, management of pre-ESRF and vascular access. It should give guidance on broader issues of practice, e.g. standards of facilities and resources including e.g. pathology and laboratory support of renal services.

6) Future Standards Documents should highlight or prioritise those standards to be audited by the RA UKRR and those for which regular monitoring may be mandatory e.g. the requirements of the NSF. Identifying the standards to

be audited should be the responsibility of the proposed Clinical Affairs Board (*vide infra)* and the mechanism, then delegated to the subcommittees.

7) The Subcommittee will have to decide whether it is able itself to conduct formal searches of literature in an attempt to synthesise standards, or rely on the findings of organisations specifically committed to this work e.g. NICE. It is unlikely the individual members of the "Expert Groups" would have the time or expertise to conduct such searches but they should suggest the commissioning of them for important questions in clinical care.

8) There was a majority view that the RA Standards Committee should not attempt to provide guidelines on the standard management of common renal diseases or conditions. [See paragraph 13 of Registry section].

9) The RA should not itself take administrative responsibility for the conducting of peer reviews of units nor should it alone undertake invited visits. A review of a unit would necessarily be multi-disciplinary so the RA should offer to assist if invited by a unit, CHAI or the Royal Colleges. The President would nominate the Association's representatives.

6 The Renal Association UK Renal Registry (RA UKRR) (Appendix 8)

The Working Party believes that the RA UKRR is an outstandingly successful initiative of the RA. Its strengths are its financial independence based on capitation, allowing it to determine its policies; its electronic data gathering; its increasing coverage of England and Wales, Northern Ireland and Scotland as a whole, and its ability to focus on both quality and quantity of treatment of renal failure using innovative methodologies. It is a unique resource internationally for the audit of renal services.

It was recognised that rapid growth had created some management problems within the RA UKRR, but these had been acknowledged and a solution had been adopted through restructuring of the management arrangements including the appointment of a part-time general manager.

There remain a number of challenges for the RA UKRR.

1 Coverage of England remains incomplete. The Renal Information Strategy (IS) states that, "…. it is essential that all Trusts with renal services are adequately served by electronic renal data management systems capable of transferring data to the ***Renal Association UK Renal Registry*** and ***UK Transplant*** at the earliest opportunity." This aspiration is supported by the NSF.

2 The quality of the data remains variable and submission of datasets is incomplete for some important fields such as co-morbidity. The data acquisition at unit level requires improvement to which the NSF IT strategy should contribute. Senior clinical commitment supported by dedicated informatics staff is essential for this to be achieved. Ideally units should be required to vouch formally for the accuracy of their returns.

3 Although paediatric data have been transferred to the Paediatric Registry, the Renal IS makes no provision for a separate registry and expects that all data will be held on a continuous database for adults and children. It is anticipated that the two registries will merge through transfer of the paediatric data to the RA UKRR. The Working Party supports this proposed development.

4 There is a heavy reliance on the efforts of the Chairman, the RA UKRR Director and other members of the committee. Succession planning will be essential to maintain the momentum of the RA UKRR.

5 For practical and personnel reasons the physical siting of the RA UKRR is fixed but consideration should be given to linking the Registry to a university department. To allow the chairmanship of the RA UKRR to change without disruption of its working we recommend that the Chairman be funded to oversee the running of the RA UKRR one day a week (two programmed activities). This would be a supervisory and co-ordinating role, which could be exercised without the need to be resident near the RA UKRR headquarters.

6 Regular audit of the NSF's "5 Standards and Markers of Good Practice" should, when these have been translated into measurable criteria and audit measures, take priority. There is a particular need to gather non-numerical data e.g. on vascular access, given the recommendations of the NSF. This poses problems for the acquisition of data in a uniform format from subscribing/member units.

7 Sharing of data with UK Transplant could be improved to allow continuous monitoring of patients on Renal Replacement Treatment (RRT). Although there is collaboration between UKT and the RA UKRR, there should ideally be a formal partnership of the two organisations. This would need the authorisation of the DoH and will depend on the requirements of the Data Protection Act.

8 The NSF part 1 and the Renal Services Information Implementation Strategy require that the Registry will work with the DoH and the NHSIA Information Strategy Development Programme. Ultimately it is expected that the National Programme for IT through the National Clinical Record Service (NCRS) and the Local Service Providers (LSPs) will generate data directly from the clinical patient record and facilities for analysis will be available through the National Patient Record Analysis Service, so that the role of the RA UKRR will be more concerned with planning data analysis and interpretation than with data collection.

9 It needs to set up mechanisms for canvassing a wider spectrum of topics for occasional audit and should consider, with the appropriate safeguards, providing data, but not access to the database, to independent researchers. Any such projects would have to be agreed by the subcommittee.

10 The links with the Standards Committee should be strengthened. There needs to be formal feedback and analysis of unit results to inform the Standards. This could be achieved by regular open fora attended by the representatives of the Standards and RA UKRR subcommittees and the units, which subscribe to the RA UKRR. A decision on the timing of these in relation to the RA meetings requires consultation.

11 Original work from the RA UKRR database should be used to create the scientific literature of clinical effectiveness and thereby actually help to define standards.

12 The duties of the RA UKRR Committee to act on findings of poor performance by individual units should be defined. The WP recommended that the RA UKRR Chairman should in the first instance alert the unit and suggest audit of the submitted data to ensure that the findings were real. If confirmed performance was deemed a matter for concern, the President of the RA would be informed. The unit itself, not the RA UKRR should then inform its Clinical Governance Department. The RA UKRR would expect to co-operate with any internal or external investigation e.g. by CHAI. This has been mandated in the NSF and the Renal Information Strategy.

13 The RA UKRR should also identify units with consistent high performance and invite them to submit descriptions of their systems and protocols and make these available for consideration by other renal units.

7 The Service Provision and Delivery Subcommittee

The Service subcommittee first met in April 2001 after meetings of Clinical Directors of Renal Units arranged by the RA. It has a representative, who is usually a clinical director or lead clinician, for Northern Ireland, Scotland, Wales and each region in England, and its Chairman sits on the Executive. Members of the Subcommittee are elected or nominated by the nephrologists in each region or country. Its terms of reference are to organise the Clinical Directors Forum, to collaborate with agencies involved in the provision of renal services, to examine the adequacy and inequalities in the provision of renal services and to recommend best practice in contracting and delivery. Following the publication of the NSF, its main task will be to monitor implementation, focusing on the following three related areas.

Inequality in service provision

The Subcommittee's 2001 pilot dialysis study led to the 2002 NKRF/SCHARR survey, which clearly documented that most Renal Units were working at, or over capacity. Of particular concern were those units with excessive use of twice weekly haemodialysis (HD), or peritoneal dialysis, rather that HD, and where patient choice of dialysis modality was restricted. A preliminary report of a follow up survey by the RA UKRR in 2003 has been reported to the January 2004 Clinical Directors Forum and will be made more widely available when the data have been checked. This important interaction with the RA UKRR should continue and the Subcommittee should resolve how it would assist those units,

which through the commissioning process, remain under-resourced. Although monitoring dialysis provision is the priority initially, inequalities in all aspects of renal replacement therapy including transplantation should be examined.

Consideration should be given to mechanisms by which this committee addresses the issues of service delivery to children.

Workforce Planning

There is a major shortfall in the specialist workforce needed to deliver renal services. The BRS Workforce Planning Document clearly outlines the staffing requirements now and with the predicted increase in the prevalence of ESRF. It is also clear that this shortfall cannot be met without a change in working practices and this is currently being assessed by the "Skills for Health" project. The Subcommittee has met with this group and is providing feedback on their draft proposals, which have been presented to the Clinical Directors Forum. The Subcommittee should also work with the Joint Specialty Committee [JSC] (of the Royal College of Physicians of London and the RA), and other agencies to redefine the role of the nephrologist in light of these changes, and reassess the future medical workforce requirements accordingly. It will rely on the RA UKRR to monitor both the medical and other workforce numbers annually but should, via the JSC, have access to the RCP annual census and trainee numbers. In addition, The Renal Information Strategy has identified a need for specialist renal IT staff who require training and career development. This will be supported through the National Health Informatics Development (NHID) Programme.

Commissioning/Planning

There is a wide variation and general lack of specificity in the commissioning processes for renal services nationally. This has been documented in the surveys conducted by the Subcommittee and NKRF/SCHARR, and has been discussed at the Clinical Directors Forum. Deficiencies in the commissioning process and the associated lack of planning are responsible for many of the longstanding problems of inadequate provision of dialysis and other renal services. Although the NSF does make recommendations about the route and method of commissioning, the lack of definition, specification and quantum of clinical contract currencies is problematic. Responsibility for making proposals for clear and nationally consistent definitions of renal services has been placed on the JSC of the Royal College of Physicians of London and the RA. A member of the JSC, Dr Paul Stevens, has been invited to lead this work and the subcommittee is ready to provide support.

8. Reorganisation of the Renal Association Sub-committee Structure

The three sub-committees whose work is integral to the Association's contribution to clinical affairs and the well being of patients with renal disease are:

RA UKRR Subcommittee
Standards and Audit Subcommittee
Service Provision and Delivery Subcommittee.

We propose that all *Subcommittees* of the RA are in future termed *Committees* (of the Executive).

To strengthen and integrate the work of these committees it is recommended that the Association establish a Clinical Affairs Board. A Clinical Vice-President, a new position with a key role in the Association, would chair this Board.

The Clinical Affairs Board would advise the President and the Executive Committee on all aspects of clinical affairs relevant to the work of the members of the Association, and in particular would oversee and integrate the work of the three committees on behalf of the Executive Committee. The committees themselves would then remain more involved in operational matters within their area, but the Clinical Affairs Board would set the broad agenda, for example prioritising topics for RA UKRR data analysis, setting a timetable for the updating of various modules of the Renal Association Standards, and recommending actions to 'close the audit loop'.

The Clinical Affairs Board would provide the planning to assist the President and the Executive Committee to ensure that the RA is strategically influential in the national scene, and that appropriate patterns of collaboration and symbiosis can be developed by the RA with patient groups, other key renal organisations, including BRS, BAPN, BTS, NKRF, the NKF, and the DoH, in influencing the national planning of renal services.

We believe that this board should be small and the Chairs of the Committees be balanced by two elected members of the Executive. We do not recommend that there be any statutory representatives of subgroups of the RA. The views of such groups would be fed into the Board from the Committees and the advice of the Board would be subject to scrutiny by the full Executive on which these groups already have representation.

Proposed membership of the Clinical Affairs Board

Clinical Vice-President [chair]
Chair, RA UKRR Committee
Chair, Standards Committee
Chair, Service Provision & Delivery Committee
Two elected members of the Executive Committee

Reporting

The Clinical Affairs Board would report to the President and Executive and its activities would be a standing item on the Executive Committee and Trustee agendas. The Clinical Affairs Board would also provide regular reports of its work to the RA membership.

Clinical Vice-President

The Clinical Vice-President would be elected by the membership to serve for a minimum of 3, and maximum of 5 years. Expressions of interest in the post

would be sought from the membership of the RA. Prospective candidates would be asked to provide a statement of their qualifications for the role and their proposals for action during their tenure. If there was a single candidate, the Executive would decide whether he/she was appointed, otherwise election would by ballot of the membership of the RA. The Clinical Vice-President would usually become a Trustee.

The Clinical Vice-President would be a member of the Executive and attend its meetings; oversee the work of the clinical committees; co-ordinate their activities; foster relationships with other clinical organisations; advise the President on RA responses to clinical issues that are matters of public discussion; represent the President when he/she is unavailable.

Committees

The terms of reference of each of the committees should be reviewed, agreeing the duration of tenure of the chair and providing job descriptions to define more precisely the roles and responsibilities of both chair and subcommittee members.

There should be positions for at least one elected member of the Executive on each Committee.

Elected members of the Executive

Increasing the committee involvement of elected members of the Executive Committee will result in the need to increase the number of elected members of the Executive. All elected members should serve on *a* committee.

To broaden representation we propose that consideration should be given to electing to the Executive a member who has been a consultant for less than five years.

9 Relationships with outside bodies

The goal of this restructuring is to ensure RA is equipped to take its proper place alongside other organisations, in influencing and leading national strategy, policy and planning to ensure that renal services in the UK develop to their maximum potential over the next 10 years.

This work will often require collaboration and partnership with other organisations – including NKF, BTS, BRS, BAPN, and NKRF. The complementary nature of these organisations in reflecting the multidisciplinary, multiprofessional nature of the clinical renal team is recognised and supported by the RA. Bilateral and multilateral arrangements should be sought on a task-by-task basis with partner organisations; the goal being to avoid duplication, and to ensure the lead is taken by the most appropriate organisation for each task. It should be the RA's aim to promote partnerships built on mutual trust and respect by strengthening informal contacts between the Presidents/Chairs of these organisations. The Kidney Alliance provides a potential forum for more formal ratification of such partnership working, and the Working Party supports the development of this function for the Alliance.

The function of the Joint Specialty Committee of the Royal College of Physicians of London and the RA, has been clarified to our satisfaction by the Registrar of the RCP and the Chairman of the Committee, Dr Charlie Tomson. (Appendices 6 and 9)

There was a suggestion from some members and Clinical Directors that the RA become a broadly based multidisciplinary organisation catering for the interests of *all* those involved in renal care. Although consideration of this proposal was not part of our remit, the majority of the Working Party did not favour it. We nevertheless, draw attention of the Executive to it. However in recognition of the widening remit of the RA, the Executive should consider modifying the constitution to allow membership to any individuals interested in, and supporting its aims, irrespective of whether they have a medical or scientific qualification (a current requirement). Abstracts for presentation at the RA meetings by non-members are already considered but they should continue to be introduced by an existing member. Attendance at the RA meetings should be open. We welcome the suggestion of holding joint meetings with the BRS and suggest that a CAB could represent the RA in choosing the clinical content of such meetings.

The Association should seek collaboration with international bodies involved in the drafting of standards and continue working with other registries.

The views of patients should be sought from organisations such as the National Kidney Federation (NKF). Consideration should be given to appointing patient advisers to the RA who may be patients themselves or their advocates. One role would be to contribute to the various modules of the Standards documents. We do not believe that patients should be invited to be members of the Renal Association nor should they be represented on its committees.

List of Appendices

1 Response from Dr D O'Donoghue on behalf of the ***British Renal Society.***

2 Response from Dr Philip Dyer President of the ***BTS.***

3 Response from Dr Lesley Rees on behalf of the ***BAPN.***

4 Response from Dr Jane Verity on behalf of the ***DoH.***

5 Response from Prof R Wilkinson ***(Chairman ERG of the NSF).***

6 Correspondence with Prof Ian Gilmore, Registrar of ***the Royal College of Physicians of London.***

7 Names of members of the RA who submitted opinions to the Working Party.

8 Draft Terms of Reference of the Renal Association UK Renal Registry.

9 Dr Charlie Tomson, Chairman of the ***JSC of the Royal College of Physicians and the Renal Association***

Appendix 1

British Renal Society
response from Donal O'Donoghue

15/9/2003

We discussed the Clinical Affairs Working Party at the council meeting on Friday.

As you will be aware the majority of BRS Council Members are not Renal Association members and they felt it was inappropriate for them to comment in detail about the internal workings of the Renal Association.

I was however pleased that the matter was received so positively.

The Council felt that if a Clinical Affairs Board is constituted a major challenge will be to achieve multi-professional consensus and legitimacy.

There was a genuine desire to work closely with the Renal Association in trying to meet that challenge.

I look forward to seeing you on the 24th.

Kind regards

Appendix 2

British Transplantation Society

Please reply to:

Philip A DYER PhD FRCPath
BTS President
Transplantation Laboratory
Manchester Royal Infirmary
Oxford Road
Manchester M13 9WL

☎ 0161 276 6397
0161 276 6148
president@bts.org.uk

Dr Chris Winearls
Renal Association Clinical Affairs Working Group
Oxford Kidney Unit
The Churchill Hospital
OXFORD OX3 7LJ

15 December 2003.

Dear Chris,

Thank you for sending me the Renal Association Clinical Affairs Working Group report. The Society Treasurer, Steve Powis, has represented the views of this Society at meetings of the Working Party and will continue to do so. Here are comments on the report which are the views of the Society Executive.

4. The willingess of the RA to collaborate with other bodies is welcomed, particularly with this Society which will reciprocate.

5. 1) We support the need to continue to work in a collaborative way on developing standards. They should be produced jointly as stated.

5. 3) Future development and production of standards should be done by electronic means (website & email discussion) and there should be an open electronic document library.

5. 7) Standards for closely associated professionals should be included. This Society is already doing this with the Immunosuppression Pharmacists and the BSHI.

5. 8) Audit of standards is essential. There must be efforts to progress such audit and funding of audit support staff is essential. A list of topics for audit should accompany all standards.

/continued

5. 11) Peer review is a complex and expensive task. There is significant liability associated and this cannot be assumed by a professional body. This Society supports the RA position.

6. 1) The need for dedicated IT support staff for Registry work cannot be over-stated.

6. 5) The RA, Renal Registry, UK Transplant and this Society recently met to discuss integrated data collection and analysis. There was agreement of the pressing need to make progress towards an integrated system.

6. 7) The same meeting agreed there was a need to involve data contributors in analysis and publication.

6. 9) A unified database must form the evidence base to define standards for best practice.

7 Any review of inequality in service provision for transplantation should be conducted jointly with this Society.

8 This Society seeks to work closely with the Renal Association and could provide input to the Clinical Affairs Board. The RA is asked to consider how this can best be achieved.

9 A relationship with the British Society for Histocompatibility & Immunogenetics should be considered.

Thank you for the opportunity to comment.

With best wishes,
Yours sincerely,

Signed PA Dyer

On behalf of the Executive.

cc Prof A Rees, RA President.

Appendix 3

British Association for Paediatric Nephrology

Dear Chris, the points from the BAPN are as follows:

1) It is vital that there is a paediatric representative on all RA committees. We need to be fully integrated with the adult services but also to be able to demonstrate where standards and services inevitably have to differ from adults ones.
2) These reps should be appointed by the BAPN and report back to the BAPN.
3) Future clinical standards might be best undertaken on a European level as there are currently many groups trying to do the same thing
4) The critical aspect of any body producing guidelines is its membership which should extend beyond professional membership and should be multiprofessional with lay and user representation.

With Best wishes,
Lesley Rees.
Secretary of the BAPN

16/10/2003

e-mail from Dr Lesley Rees

Dear Chris, I am hoping that The BAPN will have a place on this committee. As an isolated body we can have little influence but if joined with you we can be fully integrated with the adult services but also are able to demonstrate where standards and services inevitably have to differ from adults ones.

Best wishes,

Lesley
Secretary of the BAPN

Disclaimer: Great Ormond Street Hospital for Children NHS Trust

Appendix 4

Department of Health

Thank you for you email of 13 June about the role of the Renal Association in setting clinical standards. I welcome the opportunity to comment and apologise for the delay in doing so.

The NHS Plan in July 2000 stated that national standards for the NHS would be set by National Service Frameworks (NSFs) and by the National Institute for Clinical Excellence (NICE). This policy is still current. New style NSFs, such as the Renal NSF, will continue to set out the vision and challenging aims for modernising a particular service or care group over a period of 10 years. The ways to achieve these aims will be described in a limited number of standards, focused as far as possible on the needs of patients and good outcomes, which are underpinned by:

- rationale and a clear statement of the evidence base;
- good practice: markers of good practice and service models which have worked in practice (linked, whenever possible to NICE guidelines and appraisals)
- performance indicators to measure local and national progress.

Targets are set out in the Planning and Priorities Framework (Improvement, Expansion and Reform) and are expected to be revisited as priorities change. New targets may be introduced for NSF areas depending on the overall funding available for the NHS, and local capacity to deliver change.

You will appreciate that NSFs only set a few standards to provide national direction for a particular service or care group. They do not lay down detailed clinical guidelines like those in the Renal Association's document – *Treatment of adults and children with renal failure*. Clinicians find the Renal Association guidelines particularly valuable in setting out the consensus of clinical standards for high quality renal care. As Professor Wilkinson pointed out in his response to your enquiry there is a role for the Renal Association Standards Committee in considering the evidence for a particular clinical issue, publishing the evidence and setting out expert opinion on which to base current practice. With the introduction of NICE and the Cochrane reviews there is still going to be a need for a consensus of clinical opinion.

NICE will consider appraising particular areas of practice or setting out clinical guidelines however, their work programme is extensive and has been set for the next few years. I cannot imagine that NICE will be able to provide guidance as comprehensive as the current RA clinical guidelines for many years. There may also be a case for uniform standards across Europe through the adoption of European Best Practice Guidelines, but there needs to be a consensus among Nephrologists in this country that this is the path they want to tread. In the meantime we will continue to suggest topics for the NICE programme to support the renal NSF. You will I am sure be aware that NICE published an appraisal on home haemodialysis last December and that they are expected to publish the results of the work on immunosuppressive for transplantation in April 2004.

Other areas that are being considered for the future include GP referral guidelines and the management of anaemia among people with Established Renal Failure.

Implementation and monitoring are important to the ensuring that NSFs are on track and delivering change. The monitoring regime will differ from NSF to NSF however we will expect local services to participate in national comparative audit. The UK Renal Registry's coverage is improving rapidly and UKT also have a good national database. I would be interested to hear about any proposal that your review might make to strengthen the links between the two organisations.

In addition the Health and Social Care (Community Health and Standards) Bill currently before Parliament provides for the Secretary of State to "prepare and publish statements of standards in relation to the provision of health care by and for English NHS bodies and cross-border SHAs". The Health Care Standards Team in Department of Health is currently working to develop draft standards for the Secretary of State for implementation in 2004. Although the standards are in development it is very likely that they will encompass statutory requirements, the NSFs and NICE guidance. A public consultation on the standards will take place later this year.

The Renal Association has a track record of working collaboratively with other professional bodies and renal organisations. I would like to support this collaboration and feel that it would be inappropriate to set barriers or guidelines for these relationships that would restrict participation. My view is that depending on the issue in hand the collaborating groups may differ. Good examples that come instantly to mind are the collaboration with the RCGP about the development of referral guidelines and with the Kidney Alliance in setting out the 'End Stage Renal Failure - A Framework for Planning and Service Delivery'. As a Department we appreciate the different views that each of the professional bodies and renal associations bring to the table and recognise that it is not always possible for a consensus view to be presented.

Once again I would like to apologise for the delay in responding and to wish your review well.

Yours Sincerely

Jane Verity
Renal NSF Team Leader
Email address: jane.verity@doh.gsi.gov.uk

Appendix 5

Prof Robert Wilkinson (Chairman ERG of the NSF)

10/6/2003

Thank you for your e-mail regarding the Renal Association Short Life Clinical Affairs Working Party.

The main question seems to me is what is the role of the Renal Association Standards Document in the future and of the Renal Registry. I can give you my view but cannot say that it is the official view of the External Reference Group of the National Service Framework and you would of course need to discuss this with Jane Verity as you indicate in your e-mail.

The ERG of the NSF does not itself instruct guidelines but does suggest topics to NICE whose task it is to provide the guidelines. In an ideal world I think that NICE would give guidelines on all aspects of renal work but in practice the process is very slow because each guideline has to be based on very thorough analysis of the literature. It seems to me therefore that there will be a role for the Renal Association Standards Committee for some time to come since often standards have to be set on the basis of the opinions of expert groups especially when there is insufficient published evidence to base decisions on firmer ground.

In line with the multidisciplinary approach to standards, I think it may be important to have a greater representation from other professions related to medicine in the preparation of future standards documents.

Appendix 6

Correspondence with the Registrar of the Royal College of Physicians of London

-----Original Message-----
From: Winearls, Chris [mailto:Chris.Winearls@orh.nhs.uk]
Sent: 15 October 2003 15:28
To: Ian Gilmore

Subject: Renal Association

Dear Ian,

As a former Secretary of the RA I am chairing a Working Party on the future of the Standards, Registry, and Service Provision and Delivery Subcommittees (3) of the Association's Executive. We have been asked to deal with the relationship of the RA with the RCP Committee on Renal Disease. Please could you tell me what the specific remit of the Committee is? I had taken it to be advisory. I would value your comments too on collaboration with the RA (The Standards Document is a good example). Are there problems? Is there overlap and duplication? Can the boundaries of responsibility be defined? How can the College help the RA and vice versa? An example is the College's central role in speaking on behalf of all physicians - The RCP is better placed and organised than the RA to issue authorative statements on, and responses to, issues that have become of public and political interest.

The remit given to us by the President of the RA, Prof Andrew Rees is attached.

The College response will be forwarded to the other members of the Working Party and published as an appendix to the Report.

Yours,

Christopher

Dr CG Winearls,

REPLY 16/10/2003

-----Original Message-----
From: Ian Gilmore [mailto:Ian.Gilmore@rcplondon.ac.uk]
Sent: 15 October 2003 18:54
To: 'Winearls, Chris'
Cc: Clive Constable
Subject: RE: Renal Association

Dear Chris
I will ask Clive, through copy of this email, to send you details of the composition, terms of ref etc of the JSC in renal medicine. But in a nutshell, since I reviewed and revised the College specialty committees in 1999 they have been truly joint with the specialist society, and Andy Rees chaired it as President of the RA until the summer (the chairmanship has rotated back to the RCP and is with Charlie Thomson at our request). Hence the idea is that the specialty speaks with one voice and responds jointly whenever possible on issues such as NICE, workforce planning, training etc. While there remain concerns about duplication, most specialties find that by alternating the executive or equivalent of the spec soc with the Joint Specialty Committees (JSCs) held with the RCP it works quite well.

As you imply, the secret is for the specialties to play to the College's strengths (which, as you know, are manyfold!). We have regular meetings with Government Ministers and DoH and have, for instance, undoubtedly got the issue of sexual health (or lack of it) right up the government agenda recently. Also the Specialties Board, on which all JSC chairmen sit, give the spec socs a chance to learn from the experiences of other specialties and what is going on in the wider world of medicine. We (the College) should play to the RA strengths, which include a strong allegiance from nephrologists, much excellent work done on standards,etc

Incidentally we modified the basic structure of the JSC to accommodate a broad church of renal advice at Andy's request, and again Clive will give detail.

I've typed myself to a standstill but do give me a ring if you want to discuss it further - it is obviously crucial to the College (and to the future of Medicine) that there is a strong, symbiotic relationship between the association and the RCP

kind regards
Ian

Tel: 44- (0)1865 225803/4
Fax: 44- (0)1865 225773
e-mail Chris.Winearls@orh.nhs.uk

Appendix 7

List of members who submitted comments, questions and opinions

1 Dr Christopher Burton
2 Dr Peter McClelland
3 Dr Robert Higgins
4 Prof Caroline Savage (Member of the Executive)
5 Dr Peter Garrett
6 Dr Charlie Tomson
7 Dr Andrew Stein
8 Dr John Scoble
9 Dr Tim Goodship (formerly Secretary of the RA)
10 Dr David Bennett-Jones

Appendix 8

October 2003
DRAFT 2

Terms of Reference - UK Renal Registry

1 The awareness of data demonstrating results that are well out of range, arising in the course of data analysis, creates a problem for the Renal Registry.

2 The Registry wishes to have a positive role with all the client groups, and in no sense wishes to 'police' the activity that it reflects. That is not the Registry (or Renal Association) mandate, but there is a natural concern that the absence of other agencies may lead matters in that direction.

3 It is important that the confidence of reporting units is maintained through the transparency of Registry activity, among other things.

4 However, a responsibility rests with medical professionals to bring to attention results that might imply inadequate clinical practice. This derives from GMC guidelines on professional behaviour.

5 In addition, the philosophy of Clinical Governance implies a need to bring to attention any major deviation of clinical performance. Trust chief executives are 'accountable officers', who are mandated, through the Trust Boards and Chairmen, to deal with any issue of anomalous performance as if it were a financial irregularity (Corporate Governance).

6 The position of agencies such as the Renal Registry is not entirely clear given these two imperatives.

7 It is apparent that an awareness of potential irregularity requires some action on the part of the Registry.

8 On the one hand there must be conviction, or as near conviction as possible, that an irregularity is present. This may be through validation of the data input, the demonstration of a repeating pattern in time, and initial exploration of the reliability of the material.

9 The analysis of the data may need to demonstrate by various statistical techniques the degree to which the data are irregular, for example the use of Shewhart diagrams rather than distributions. A declared deviance of data may be then established, so as to define 'irregularity'.

10 It seems sensible to discuss the findings with the registry lead at the Unit concerned, to validate the data and ensure that there is no prima facie explanation. The lead must have confidence in the way that data have been handled by the Registry. This step might be considered by some beyond the remit of the Registry already.

11 The Annual Report is forwarded to chief executives. It would seem necessary to indicate whether a unit is demonstrating any irregular behaviour when communicating with the chief executive. It would seem only appropriate that the local registry lead clinician was also informed.

12 The extent of Renal Registry (and Renal Association) responsibility beyond the above should be debated. The Registry must take some responsibility by virtue of the data analysis and contact with the chief executive.

13 The responsibility for establishing the nature and degree of possible irregularity in clinical performance would seem to remain with the chief executive and his officers, as does any necessary remedy.

14 The Renal Registry will need to accept contact with any agencies that are requested to explore clinical performance brought to attention in this way and may need to justify the data analysis and presentation.

15 The Renal Registry may be vulnerable to criticism at both ends of the critical spectrum. On the one hand, excessive anxiety about clinical results may be generated from the registry interpretation and notification. Alternatively, the registry data and analysis may not reveal what comes to be seen as significant and unacceptable clinical performance from another source.

16 The analytical approach of the registry needs to be proof against the latter criticism as far as possible, through established methods of data analysis. Both potential criticisms imply a need to explore and employ the most up-to-date methods of data analysis and presentation. This may be seen as an inevitable consequence of the registry activity (as data held in trust for analysis and presentation) and a responsibility to users and the health service generally.

17 The issue of consent to holding computer records with identification of the individual implies the right of access to the material. The degree to which Unit records should be available at individual behest remains to be seen. There would also seem to be a difference between raw data and data that have been validated, categorised, analysed and presented.

18 The Renal Registry should consider how it might respond to any such criticisms and prepare a strategy for doing so. This may mean specific delegation to individuals and the development of considered text, particularly so that no important issues are left unexplained in the heat of the moment.

19 Some experience is already available in this area and should be carefully reviewed, so that practical lessons may be learned from previous intuitive responses.

20 The Registry has no formal role in investigating the specifics of irregular data, once validated for analysis.

21 The Registry has no obligation to inform the Renal Association Trustees or Executive about particular data unless the Association is expected to become involved in comment, or formally, with subsequent events. The chairman, as a Trustee, is well–placed to discriminate the relevant circumstances.

22 Unit agreement to the identification of local activity data might be reconsidered in the light of Registry responses to irregularity – little discussion has occurred over these circumstances in the absence of particular examples.

EJW 8.10.02

Appendix 9

Received October 2003

Dr Charlie Tomson

The Joint Specialty Committee on Renal Disease is a standing committee between the Royal College of Physicians of London and the Renal Association. It meets three times a year. Its terms of reference are "to advise its parent bodies, or other organisations on their behalf, on matters including:

- Workforce and training
- Setting national standards and agreeing joint guidelines and policy statements
- Drawing up specifications for clinical governance in relation to the practice of the specialty
- Continuing professional development for the specialist, including general medicine if necessary
- Reviewing ethnic minority health issues on an annual basis
- Any other specific matter or particular relevance to a specialty
- Advice to College or other Working Parties".

Its major function is to ensure that the RCPL has adequate advice, with the minimum of duplication of effort, on all relevant aspects of renal medicine. Although other bodies including the Renal Association, the Kidney Alliance, and the British Renal Society also represent renal medicine, there are numerous areas in which the RCPL has major influence. These include:

- Advice on manpower planning
- Setting clinical standards
- Setting educational standards.

In these areas the RCPL, representing 25 specialties, can be seen to be unbiased in a way in which a single-specialty organisation cannot. Many organisations – for example, NICE - also look to the RCP for clinical input; wherever possible this is supplied jointly with the Renal Association

Membership of the committee is composed of three nominees from the Royal College (currently Dr Charlie Tomson (chair), Dr John Bradley, and Dr Paul Stevens (representing the District General Hospitals Nephrologists); three nominees from the Renal Association (currently Professor A Rees, Dr Donal O'Donoghue, and Steve Smith as President of the British Renal Society); Dr Les Sellars (co-opted for input on manpower planning); Dr David Carmichael (as Chair of the SAC); Dr Alex Crowe (representing the RCP New Consultants Committee); and an SpR representative (currently unfilled). The Scottish Colleges send an observer (Dr Brian Junor), as do the renal section of the Department of Health (Dr Peter Doyle or Ms Jane Verity), the British Transplantation Society (currently Mr Murat Akyol) and the British Association for Paediatric Nephrology (currently Dr Robert Postlethwaite). The possibility of including a member of the National Kidney Federation is currently being explored. The meetings are also attended either by the President of the RCPL (Professor

Carol Black) or the Registrar (Dr Ian Gilmore). The RCP nominees get onto the committee by nominating themselves to the College in response to requests for nominations in the College Commentary, or by invitation in the absence of any nominations. Chairmanship alternates between the RCP and the Renal Association on a 2-year rotation.

Recent and current agenda items include:

- Drafting a specialty-specific section in "Good Medical Practice for Physicians", an RCP document modelled on the GMC document "Good Medical Practice"
- An initiative jointly with the RCGP to develop management and referral guidelines for chronic kidney disease to ensure appropriate and timely referral of those patients most likely to benefit from specialist management while ensuring improved management of cardiovascular/progression risk factors in all patients with renal disease in primary and secondary care (chaired by Dr Charlie Tomson)
- Drafting guidance to commissioners on purchasing renal services (Dr Paul Stevens)
- Re-drafting the renal section for the 4th edition of the RCP publication "Consultant Physicians working with patients" (Dr John Bradley)
- Advice to the College Committee on Ethical Issues in Medicine on areas to develop guidance on – possibly to include management of disruptive dialysis patients, paired organ exchange, and end-of life decisions in dialysis patients
- Advice to the RCP on College Lecturers and Conferences
- Input to the 2nd phase of the Wanless report on funding of the NHS – this phase concentrates on public health measures. We propose to submit a document summarising the huge costs of renal replacement therapy and the opportunities for prevention of end-stage renal failure.
- Manpower planning – including the planned expansion of SpR numbers to ensure that by 2010 we have somewhere near adequate numbers of consultant nephrologists to manage the expanding population of patients with ESRF (a subgroup of the RCP Committee, meeting mostly by teleconference or email, including Prof Andy Rees, Dr Les Sellars, Prof Steve Powis, drDonal O'Donoghue, and Dr David Carmichael).

We plan to include a short paragraph on the Committee's activities in the Renal Association mailshots in future, and to publish minutes of meetings on the Renal Association website.

CRV Tomson

Charlie.tomson@north-bristol.swest.nhs.uk