Appendix E: Renal National Service Framework IS Support Strategy

This document was commissioned from the NHSIA by the Department of Health, as the IS support document for the renal NSF in England.

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Executive Summary

1. Implementation of the Renal Services Information Strategy will help deliver the National Service Framework (NSF) for Renal Services through the provision of tools and resources. In particular, the Information Strategy supports the NSF around national comparative audit and provision of nationally available data to support planning and identify local priorities.

2. The Information Strategy consists of a series of tables containing National and related Local Actions developed to support Part 1 of the NSF which addresses kidney transplantation and dialysis for people with established renal failure. Each action, where appropriate, is linked to further information that explains the background to and the reasoning behind the action.

3. The tables are divided into themed sections as follows:

Section1: Information for Direct Care of the Patient

1. The National and Local Actions in Section 1 have been developed to take into account the plans of the National Programme for Information Technology (NPfIT), in particular the plans for a national spine record (National Actions 1.1 to 1.3). Trusts with Renal Services are encouraged to work with the Local Service Providers (LSP) under the National Care Records Service programme (Local Actions 1.1 and 1.2).

2. The National and Local Actions in Section 1 also pick up the theme of the development of care plans (National Action 1.4 and Local Actions 1.3 and 1.4).

3. Patients will be able to see their registration to receive a transplant on the transplant list and to check their status (National Action 1.5).

4. Trusts with Renal Services are encouraged to examine the issues surrounding the sharing of information and to use the results to ensure that the interests of patients, donors and care professionals are recognised and properly safeguarded (Local Action 1.5).

5. Trusts with Renal Services are encouraged to provide care professionals with decision support at the point of care (Local Action 1.6).

Section 2: Information for Secondary Purposes

9. The data that will reach the national spine record will be derived from datasets approved by the NHS Information 3.Standards Board (National Actions 2.1 and 2.2). Trusts with Renal Services are encouraged to ensure that data required for secondary purposes can be collected and submitted electronically and in accordance with the approved datasets (Local Action 2.1 and 2.2).

10. National comparative audit and national data to support planning and to identify local priorities are addressed in National Actions 2.3 to 2.6 and Local Actions 2.3 to 2.5.

Section 3: Access to Knowledge

11. The National Actions in this section discuss the provision by the Department of Health of a national website of information links (National Action 3.1) and a series of actions for the National electronic Library for Health, NHS Direct Online and NHS Direct (National Actions 3.2 to 3.8).

12. The Local Actions in this section encourage the development and provision of information for patients, carers and the public (Local Action 3.1) together with the necessary IT infrastructure to make this possible (Local Action 3.5).

Section 4: Training and Developm#ent

13. The National Health Informatics Development (NHID) programme of the NHS Information Authority will lead on the development of a renal informatics special interest group (National Action 4.1) and a series of educational packages in the use of systems and for career development in support of staff within the renal community (National Actions 4.2 and 4.3).

14. Locally Trusts with Renal Services are encouraged to offer their staff appropriate training and support in developing their skills and knowledge (Local Action 4.1) and to ensure that patients understand how to access and use the information that they receive (Local Action 4.2). Similarly PCTs are encouraged to ensure that GP surgeries provide online access to information for their patients (Local Action 4.3).

1 Information for Direct Care of the Patient

National Actions

Implementation of the Renal NSF Core Service

1.1 Under the National Care Records Service (NCRS) programme Cluster Management Boards will instruct Local Service Providers (LSP) as they are appointed to implement the Renal NSF Core Service.

Support for Renal Data on the NCRS Spine Record

1.2 The Spine Project of the National Programme for Information Technology (NPfIT) will ensure that the NCRS Spine Record will support a National Renal Dataset in Phase 2 of its programme.

NHSIA NSF Implementation Information Strategy Implementation Programme

1.3 The NHS Information Authority (NHSIA) NSF Implementation Strategy Programme has the remit to advise the NPfIT Clinical Advisory Board of the specific needs of Renal Services (clinicians, renal patients and donors) during the period of implementation of National Actions 1.1 and 1.2 and to monitor progress on behalf of the Department of Health.

Care Plans

1.4 By 2004 the Department of Health will initiate the development of a care plan to support all people with chronic renal failure in managing their condition as an interim solution in advance of its inclusion within the NCRS.

Status on the Transplant List

1.5 Pending the likely provision of this function by My HealthSpace, the Department of Health will work with UK Transplant and other possible partners, such as NHS Direct Online, to make arrangements for a nationally agreed mechanism to enable patients to see their registration, to receive a transplant on the transplant list and to check their status as to whether they are active or suspended. There will be clear guidelines on how their status can be changed where this is necessary.

1 Information for Direct Care of the Patient

Local Actions

Use of Electronic Clinical Information Systems

1.1 Local Service Providers (LSP) will work with Trusts with Renal Services through the National Care Records Service (NCRS) programme Cluster Management Boards to ensure that the electronic clinical information systems (ECIS) are embedded in the management and care of patients with established renal failure

Access to Information for Primary Care Teams

1.2 PCTs should work with their Cluster Management Boards and LSP to ensure that primary care teams can access the records of patients with ERF, including a facility to view the patient's registration and status on the national transplant list.

Introduction of Care Plans in Trusts with Renal Services

1.3 Trusts with Renal Services will be able to draw upon the national care plan model developed by the Department of Health to meet the needs of their patients and to encourage its use by both patients and health professionals.

Support for Care Plans by PCTs

1.4 PCTs are encouraged to work with local renal units to access their care plan model, in order that primary care teams can promote its use by both health professionals and patients in the community.

Information Sharing

1.5 Trusts with Renal Services are encouraged to lead a formal examination of the issues relating to information sharing for all relevant stakeholders including those in primary care and to use the results to ensure that the interests of patients, donors and care professionals are recognised and properly safeguarded.

Decision Support

1.6 Trusts with Renal Services are encouraged to provide care professionals treating patients with ERF with access to decision support at the point of care in advance of this functionality being provided in the Renal NSF Core Service.

2 Information for Secondary Purposes

National Actions

UK Renal Registry and UK Transplant

2.1 In recognition of the work that has been and is currently being undertaken and planned by the UK Renal Registry and UK Transplant, the Department of Health and the Commission for Healthcare Audit & Inspection (CHAI) will include both these organisations together with all other key renal stakeholders in future developments for the definition, collection and reporting of data on patients with ERF.

National Dataset for Dialysis and Transplantation Services

2.2 The Department of Health and CHAI will commission the UK Renal Registry and UK Transplant to develop a National Dataset to cover both dialysis and transplantation services. The UK Renal Registry and UK Transplant will commission the NHSIA Datasets Development Programme to achieve Information Standards Board (ISB) approval. The work will start in April 2004 and be completed by April 2005 to fit with National Action 1.2. In preparation for the development of a national dataset, a steering group with representation from Department of Health, CHAI, UK Renal Registry, UK Transplant and NHS Information Authority will establish the requirement and then cost and schedule the development of a national dataset prior to April 2004.

National Analytical Services (NAS)

2.3 The NHS Information Authority is developing a National Analytical Service (NAS) to support national secondary information requirements, e.g. activity and outcome for epidemiology, clinical governance, public health and service planning based on the Secondary Uses System under development by the NPfIT Spine Project. The renal services community will call upon the services of the NAS as they become available.

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2 Information for Secondary Purposes

Local Actions

Clinical Information Systems

2.1 In order to submit the required data for secondary purposes, Trusts with Renal Services may use the agreed procedure to extract the data used by UK Transplant and the UK Renal Registry electronically.

Datasets

2.2 Trusts with Renal Services should collaborate with the LSP to implement the National Dataset upgrade to their electronic clinical information systems when available.

Analytical Capacity

2.3 Access to the analytical and epidemiological skills required to handle and interpret the data required for audit and other purposes is essential if data are to be handled and interpreted correctly. It is good practice to use such services for data interpretation locally and nationally.

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2 Information for Secondary Purposes

National Actions (cont'd)

Renal National Survey

2.4 The Department of Health has commissioned a national survey of renal treatment facilities in England for the year 2002. This survey will continue subject to approval by the Committee for Review of Central Information Requirements (ROCR) until the data can be provided automatically through the implementation of the actions in this Information Strategy.

Performance Indicators

2.5 CHAI will work with the Department of Health and other key stakeholders to develop suitable performance indicators for national and local use.

Information for Audit

2.6 CHAI will work with the Department of Health, the Renal Association, the UK Renal Registry, UK Transplant and the renal services community to develop national comparative clinical audit plans within a framework of standards for national audit as a matter of priority.

2 Information for Secondary Purposes

Local Actions (cont'd)

Information about Services

2.4 Renal collaborative commissioning groups are advised to use information including local population demographic data and information about staffing, facilities and current capacity in renal services provided by Trusts with Renal Services to identify gaps and inequalities and plan future services to meet demand. National Survey data (see National Action 3.4) will be available as a baseline for comparison and improvement.

Information for Audit

2.5 It is good practice for Trusts with Renal Services to participate in national comparative audit of the structure, process and outcome of their work. This could include, for example, patients' opinions, suggestions, transport arrangements, as well as audit of activity, outcomes, waiting lists and admissions to non-renal wards with feedback used to inform change.

3 Access to Knowledge

National Actions

National Website of Information Links

3.1 The Department of Health Renal NSF website will act as a central link to supporting programmes of work including links to the NeLH, NHS Direct Online, the UK Renal Registry, UK Transplant, professional organisations such as the Renal Association and the British Transplantation Society as well as charitable organisations such as the National Kidney Federation and the National Kidney Research Fund.

National electronic Library for Health (NeLH) – Central Repository

3.2 Whilst designed primarily for the use of health professionals, the NeLH will act as the central repository for information from accredited organisations and sources about end-stage renal failure and its treatment and management, whether for patients and their carers, the public or health professionals. Their information resource will be used by NHS Direct and NHS Direct Online to develop information suitable for the needs of patients, their carers and the public.

National electronic Library for Health (NeLH) – Renal Specialist Library

3.3 The NeLH, along with key stakeholders, will develop a Renal Specialist Library designed for the use of health professionals. It will provide access to the evidence base where this exists, and identify areas where research is required to strengthen the evidence where it is lacking.

National electronic Library for Health (NeLH) – Information from National Agencies

3.4 The NeLH will incorporate knowledge about end-stage renal failure and its treatment from all the national agencies such as NICE, UK Transplant and the Modernisation Agency and present this as a single interoperable source for healthcare professionals and interested members of the public.

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3 Access to Knowledge

Local Actions

Information for Patients, Carers and the Public

3.1 Trusts with Renal Services could, by using the services described in National Actions 3.1 to 3.7, make available a full range of information for patients, carers and the public about renal failure, its treatment and management and services available locally.

Information for Third Parties

3.2 Trusts with Renal Services should ensure that patients are aware of how to obtain information, such as through the services described in National Action 3.6, about renal failure and its treatment that has been written for use by third parties, for example educational establishments, employers and insurance companies.

Information for Children and Young People

3.3 Trusts with Renal Services should ensure that children and young people, as well as their parents and carers, are aware of how to find the information and advice, such as through the services described in National Action 3.7, about the problems of adjusting to their disease and how they might have a greater say in managing their disease as they grow up.

Information for Transferring to Other Units

3.4 Trusts with Renal Services should give patients transferring to other units either within or outside their local renal network information about the receiving unit before they are transferred in order to ensure smooth transition.

Access to the IT Infrastructure

3.5 Trusts with Renal Services need to consider how to ensure that professional staff and patients have ready access to the knowledge base through implementation of the necessary IT infrastructure.

3 Access to Knowledge

National Actions (cont'd)

NHS Direct Online – General Information for Patients, Carers and the Public

3.5 Drawing on information from the National electronic Library for Health (NeLH), NHS Direct Online will provide a web-based service giving access to recognised sources of high quality information about established renal failure and its treatment and management, designed primarily for use by patients and their carers and members of the public, as well as access to information about organ donation for the public and potential live donors.

NHS Direct Online – Information for Third Parties

3.6 Drawing on information from the National electronic Library for Health (NeLH), NHS Direct Online will make available information about renal failure and its treatment written for use by third parties such as educational establishments, employers and insurance companies.

NHS Direct Online – Information for Children and Young People

3.7 Drawing on information from the National electronic Library for Health (NeLH), NHS Direct Online will make available information and advice for children and young people with renal failure about the problems of adjusting to their disease and how they might have a greater say in managing their disease as they grow up.

NHS Direct – Provision of Information and Advice for the Public

3.8 Working with all the appropriate stakeholders and sources of medical knowledge NHS Direct will undertake the necessary actions to enable it to become a safe source of information and advice for people with renal failure and members of the public enquiring over the telephone about issues relating to established renal failure and about the possibility of becoming kidney donors.

4 Training and Development

National Actions

Renal Informatics Special Interest Group

4.1 The NHSIA in partnership with the renal community, UK Renal Registry and UK Transplant will develop a renal informatics special interest group through the Informatics Learning Network available from the National Health Informatics Development (NHID) programme of the NHSIA. The first step will be to establish a web site and moderator.

Educational Packages for Use of Systems

4.2 NHID, in partnership with the renal community, the UK Renal Registry and UK Transplant, will develop an educational package for units embarking on electronic data collection and for units who have systems not yet fully utilised, to provide a practical guide on how to embed an electronic clinical information system in the delivery of direct care.

Educational Packages for Career Development

4.3 NHID, in partnership with the renal community, the UK Renal Registry and UK Transplant, will develop an educational package to support Trusts with Renal Services in providing career development and succession planning.

4 Training and Development

Local Actions

Training and Support for Staff

4.1 Trusts with Renal Services are encouraged to give staff with responsibilities for data and the preparation of information the appropriate training and support in developing their skills and knowledge.

Support for Patients at Trust Premises

4.2 Trusts with Renal Services are encouraged to ensure that, wherever access to information is given to patients via, for example, a workstation located on their premises, help and support as well as sufficient material are readily available so that patients can use the IT system appropriately and understand the information they receive.

Support for Patients at GP Surgeries

4.3 PCTs are encouraged to ensure that GP surgeries provide online access for patients to information about renal disease, renal failure, its management, local services and organ donation possibly by accessing the services described in National Actions 3.1 to 3.7, with appropriate support from staff.

Supporting Information For The National Actions

Information for the Direct Care of the Patient

Implementation of the Renal NSF Core Service

1.1 Under the National Care Records Service (NCRS) programme Cluster Management Boards will instruct Local Service Providers (LSP) as they are appointed to implement the Renal NSF Core Service.

The National Care Records Service (NCRS) programme, initiated by the National Programme for Information Technology (NPfIT) will support the availability of electronic patient records enabling timely and accurate delivery of results and communication between health professionals and care sectors and between the patient and the renal multi-skilled team through the development and use of care plans. Through the NHS Direct Online My Health Space portal it will also provide the means for patients to view their own health records and thereby encourage them to participate in the management of their own care.

The NCRS will implement its programme across the country in regions known as 'clusters'. Each cluster will be overseen by a 'Cluster Management Board' whose role, amongst other things, will be to ensure that the implementation runs to time and to budget and to ensure that all required resources are made available.

The Cluster Management Boards will instruct the local suppliers of the service, known as Local Service Providers (LSP), to proceed with the implementation of the services that have been specified in the Output Based Specification Contract (OBSC) Section 167. These contractual requirements have been prepared based on the Output Based Specification (OBS) for the NCRS that was developed to enable LSP and National Application Service Providers (NASP) to understand the requirements and to quote for and carry out the work of developing the necessary systems. The OBS includes the requirements for the published Information Strategies as well as information for those under development.

In essence the Core Service requirement for Renal Services consists of the following steps for implementation by each LSP:

- To maintain and upgrade as required electronic clinical information systems (ECIS) hardware and software, e.g. Proton etc. in use in Trusts with Renal Services for children, young people and adults
- To deploy ECIS in any Trusts with Renal Services that do not have them
- To send donor and recipient data to UK Transplant for organ allocation and transplantation
- To deploy the Renal National Dataset (scheduled for April 2005), working as required with the renal software package vendors to modify their packages to support the new dataset and deploy any such upgrades
- To deploy an extract programme to send data to UK Transplant and the UK Renal Registry for the National Dataset
- To deploy a set of renal messages based on the National Dataset to populate the national Spine Record

The limitations of conventional records are well known. Problems are related to completeness, accuracy, and volume of notes, indexing and accessibility. Patients with established renal failure (ERF) have a lifetime dependent on medical and nursing care. They attend primary, secondary and tertiary care centres for diagnosis and treatment by dialysis and transplantation and for accompanying problems and complications. They require the services of several members of the renal multi-skilled team and frequently access other health services such as those for diabetes or coronary heart disease both in hospital and in primary care. Important information is often unavailable when required because treatment has taken place at another location or because the notes are unavailable due to loss, miniaturisation, storage or recent consultation. Notes become very large, disintegrate, are split into several folders and may ultimately become separated. It becomes increasingly difficult to locate the information required.

Through the NCRS paper records and conventional X-rays will eventually be replaced by electronic information. Electronic records are capable of being organised in such a way that information can be readily filed and extracted as required and the record can be easily shared with appropriate parties, including the patient, using information sharing protocols agreed with the local Caldicott Guardian and local clinicians. These should ensure that patients are adequately prepared and supported when accessing their notes, that there are no surprises and that confidential information on third parties is appropriately protected. Data required for management and audit should be derived from the electronic record with minimal need for keying in data a second time. This will improve efficiency and accuracy.

Local clinical information systems have been evolving over the past two decades to meet the local needs for patient care and to aid management and audit. In the management of patients with ERF local systems have been particularly important because of the need to monitor a large number of biochemical and physiological parameters in every patient on a recurring basis for life. These systems have generally been developed and run from within renal units to meet the specific requirements of patients with renal failure and other renal diseases. Use of systems that receive results directly from the laboratory has been combined with the ability to transform data to assess renal function, dialysis adequacy or to correlate functions. These numeric functions can be combined with records of dialysis treatment sessions, the facility for free text and the ability to transfer data to (and from) national organisations for clinical care (UK Transplant) or audit (UK Renal Registry and UK Transplant) has further enhanced the value of such systems in some units. This functionality must not be lost in the development of the NCRS and the national actions seek to ensure that the needs of Renal Services in these respects will not be neglected. However, ultimately the success of the NCRS will be determined at local level through participation by Trusts in the development and implementation process with the LSP.

Generic requirements of clinical information systems that are particularly relevant to renal Services include:

- Generation of the data required for secondary purposes described in National Action 3 including data on kidney donors
- The ability for professionals to share information in an accurate and timely way when patients are seen in primary and secondary care or when they transfer from one unit to another, for example when young people transfer to an adult unit.
- The need to ensure that patient-related data, wherever clinically appropriate, is recorded once only in order to minimise the frustration often experienced by patients of repeating details of, for example, family history to different care professionals at different times
- Functionality to enable patients to access their own records through the NHS Direct Online web site
- The ability to share information within the constraints of safety and confidentiality for the patient and third parties and with adequate preparation and support for the patient. For further information visit the data protection website at http://www.dataprotection.gov.uk/

Specific requirements to support the direct care and management of children, young people and adults with ERF in primary and secondary care should include, but not be limited to, the following:

- Ability to support serial online biochemical and other tests, X-rays and biopsies with electronic links to laboratories. This should include alerts for abnormal results.
- Ability to transform and collate data for estimation of functions such as glomerular filtration rate and dialysis adequacy
- Ability to provide decision support systems based on national guidelines or protocols, e.g. NICE.
- Remote monitoring of home haemodialysis treatment
- Information to monitor the standards of the Renal Association, the British Transplantation Society and other relevant professional bodies.
- Information to monitor the standards outlined in the Renal National Service Framework and other NSFs such as Diabetes, CHD and Children's & Maternity Services when published.
- Functionality to support prescribing for patients with impaired renal function, on dialysis and with renal transplants
- Provision of a facility for patients to view their own records and participate in the development and management of their own care plan including the ability for patients to review their status on the transplant list through NHS Direct Online's 'Health Space' facility or other agreed mechanisms
- Functionality to transmit the recipient dataset to UK Transplant for patients wishing to receive a transplant
- Information to meet the requirements of live and cadaveric kidney donation including:
  - Functionality to support secure and confidential links for authorised health professionals to the Organ Donor Register in order to establish the status and wishes of a potential donor.
  - Functionality to enable authorised health professionals secure access to view the medical records of potential non-heart beating and heart beating donors to inform decisions about proceeding with organ donation
  - Functionality to support UK Transplant in the process of organ allocation and statutory duties related to organ donation
  - Functionality to enable health professionals to view the records of deceased kidney donors if the recipient has a subsequent problem or to research newly identified problems and to identify the recipients if the donor is later found to have an unexpected problem (e.g. cancer found at post mortem or CJD)
  - The ability of live donors to see the results of their tests and participate in shared decision-making.
  - The need to ensure that the information required by the national potential donor audit, primarily but not exclusively patient

information from intensive care units, is routinely recorded and transmitted to UK Transplant so that ongoing potential for organ donation in the UK is understood and maximised.

– Information to enable monitoring of the Human Organ Transplant (HOT) Act and the requirements of ULTRA (Unrelated Live Transplant Regulatory Authority).

Support for Renal Data on the NCRS Spine Record

1.2 The Spine Project of the National Programme for Information Technology (NPfIT) will ensure that the NCRS Spine Record will support a National Renal Dataset in Phase 2 of its programme.

The specific functions to support the direct care and management of children, young people and adults with ERF in primary and secondary care which will need to be present in electronic clinical information systems as implemented by the LSP under the Core Service (see the supporting information for National Action 1.1 above) must also be capable of providing all the data needed for secondary analysis purposes both for local and national use.

At the centre of the NCRS is the ‘Spine Record’, the collection of data and information for each patient for whom data are collected through the medium of national datasets approved by the NHS Information Standards Board (ISB). The Spine Record is to be designed and implemented at national level by the selected National Application Service Provider (NASP) and the work is to be overseen by the Spine Project of the National Programme for Information Technology (NPfIT).

In order for the Spine Record to be maintained for patients within Renal Services a National Dataset for dialysis and transplantation services (including the donor dataset) will be developed (See National Action 2.2) during Phase 2 of the NPfIT and the project within the National Programme for Information Technology (NPfIT) known as the Spine Project has agreed that the Spine Record will be capable of being updated by the data collected by this dataset once it has been approved by the ISB and implemented in local electronic clinical information systems.

NHSIA NSF Implementation Strategy Programme

1.3 The NHS Information Authority (NHSIA) NSF Implementation Strategy Programme has the remit to advise the NPfIT Clinical Advisory Board of the specific needs of Renal Services (clinicians, renal patients and donors) during the period of implementation of National Actions 1.1 and 1.2 and to monitor progress on behalf of the Department of Health.

The work of the Cluster Management Boards and the Spine Project in fulfilling their roles as set out in National Actions 1.1 and 1.2 will be informed by the knowledge and expertise of the NHS Information Authority (NHSIA) NSF Implementation Programme via the NPfIT Clinical Advisory Board. The Programme is resourced by clinical and information specialists across the whole spectrum of NSF Information Strategies and is able to take the broader view of information needs within the NHS as well as being able to reflect the needs of particular conditions and client groups.

Care Plans

1.4 By 2004 the Department of Health will initiate the development of a care plan to support all people with chronic renal failure in managing their condition as an interim solution in advance of its inclusion within the NCRS.

Care plans have long been a feature of nurse-led patient care on wards but have not necessarily been shared or seen as a tool for promoting a multi-skilled team environment and self-management of long-term disease by patients.

The NSF has set out a role for the care plan and the NCRS will need to accommodate this facility in the future in order to help both to achieve the standards laid down in the NSF and to go some way towards addressing the standardisation of information for exchange within the multi-skilled team.

In the meantime professionals caring for people with ERF, and indeed with other conditions, would benefit from having available a model of such a plan as a basis for local development in advance of the feature becoming available as part of the NCRS. The Department of Health will initiate the development of a care plan for local development for use in the short to medium term.

Local Action 1.3 encourages Trusts with Renal Services to tailor the model, once it becomes available, to meet the needs of their patients and to encourage its use by both patients and health professionals. Local Action 1.4 encourages Primary Care Trusts to promote the use of care plans in primary care. Part of the development of care plans should include the facility for patients to hold their own records electronically. Patients should be able to have access to sources of knowledge to help them manage their own condition.

The action to develop a care plan is referred to as part of the modernisation programme in the Renal Services National Service Framework.

Status on the Transplant List

1.5 Pending the likely provision of this function by My HealthSpace, the Department of Health will work with UK Transplant and other possible partners, such as NHS Direct Online, to make arrangements for a nationally agreed mechanism to enable patients to see their registration to receive a transplant on the transplant list and to check their status as to whether they are active or suspended. There will be clear guidelines on how their status can be changed where this is necessary.

UK Transplant is a Special Health Authority with responsibility to support solid organ and corneal transplantation across the United Kingdom. As part of that responsibility UK Transplant:

- Maintains a national list of all patients registered to receive a transplant
- Matches and allocates organs as they become available according to a set of rules that ensure the best use of scarce organs whilst trying to achieve equity of access for all patients
- Transfers data to recipient units
- Maintains the National Transplant Database as a central, up-to-date, and accurate computer record of transplantation from donation to the death of the recipient
- Manages the NHS organ donor register.
- Has measures in place to increase the number of organs available for transplant

In a national system such as organ allocation it can be difficult for patients to know whether they are active or suspended from the list of those registered for transplant at any moment in time and of course some patients may be included on the list for many years before a suitable organ becomes available, making the opportunity for multiple suspensions (e.g. for holidays or inter-current illness) greater.

It is envisaged that the health professionals will be able to register patients for transplantation electronically via their local renal IT system and subsequently amend the patient's status from 'active' to 'suspended' or vice versa through links to UK Transplant.

In the interim, UK Transplant should make arrangements with local units to ensure that there are satisfactory arrangements for patients to ensure that they know whether or not they are registered and that they can check their status and are not suspended for longer than necessary. There should be clear guidance for patients and health professionals on the correct route to take to ensure that their patient status is changed quickly when this is appropriate.

The Department of Health and UK Transplant will work together to find a national solution that will allow patients, subject to security and confidentiality safeguards, to gain access to information about their status on the transplant list with the minimum of difficulty until such time as the National Care Records Service can provide the functionality.

2 Information for Secondary Purposes

UK Renal Registry and UK Transplant

2.1 In recognition of the work that has been and is currently being undertaken and planned by the UK Renal Registry and UK Transplant, the Department of Health and the Commission for Healthcare Audit & Inspection (CHAI) will include both these organisations together with all other key renal stakeholders in future developments for the definition, collection and reporting of data on patients with ERF.

For a short description of the UK Renal Registry and UK Transplant please see the Glossary of Terms. More information on these organisations can be found at:

- http://www.renalreg.com/) and
- http://www.uktransplant.org.uk/default.htm.

Other key stakeholders for renal data include, but will not necessarily be limited to, the following organisations:

- Association of Clinical Biochemists
- British Association for Paediatric Nephrology
- British Transplant Society
- Charities, e.g. National Kidney Federation, National Kidney Research Federation
- Commission for Health Improvement (CHI)
- Commission for Healthcare Audit & Inspection (CHAI) (from 2004)
- Department of Health
- Intensive Care National Audit & Research Centre (ICNARC)
- National Institute for Clinical Effectiveness (NICE)
- National Patient Record Analysis Service (NPRAS)
- Patient Information Advisory Group (PIAG)
- Proton Users' Group
- NHS Information Authority
- Renal Association
- Renal Collaborative Commissioning Groups
- Royal College of Anaesthetists
- Royal College of Nursing (Nephrology Nursing Network)
- Royal College of Paediatrics and Child Health
- Royal Colleges of Physicians
- Royal College of Surgeons
- Strategic Health Authorities

- Trust Chief Executives and Medical Directors of Trusts with Renal Services and of Trusts which commission renal services

In addition, national coverage of renal units will enable English data to be included in the Registry of the European Dialysis and Transplantation Society

National Dataset for Dialysis and Transplantation Services

2.2 The Department of Health and CHAI will commission the UK Renal Registry and UK Transplant to develop a National Dataset to cover both dialysis and transplantation services. The UK Renal Registry and UK Transplant will commission the NHSIA Datasets Development Programme to achieve Information Standards Board (ISB) approval. The work will start in April 2004 and be completed by April 2005 to fit with National Action 1.2. In preparation for the development of a national dataset, a steering group with representation from Department of Health, CHAI, UK Renal Registry, UK Transplant and NHS Information Authority will establish the requirement and then cost and schedule the development of a national dataset prior to April 2004.

The UK Renal Registry is central to the collection of data about patients on Renal Replacement Therapy and contribution to this registry is essential in order to support national audit and to provide information on renal patients and their treatment nationally for management and planning.

UK Transplant has the leading role in overseeing and monitoring the activity and outcome of organ transplantation.

The Department of Health and CHAI will commission the UK Renal Registry and UK Transplant to develop a National Dataset which will cover both dialysis and transplantation services. Much work to develop datasets has already been undertaken by both these organisations and it will be important, in developing a national dataset, to be aware that datasets such as those for CHD and Diabetes will already contain some of the data items needed.

The approval of datasets by the Information Standards Board is a pre-requisite for the NPfIT to allow patient data to pass onto the national Spine Record within the NCRS. The NHS Information Authority through its Datasets Development Programme has the expertise and the experience of ensuring that data items in the many datasets that it has developed meet the required NHS standards and also that the processes required by the NHS Information Standards Board to gain their formal approval for use in the NHS are fully complied with.

The NHS Information Authority is, therefore, well placed to work alongside renal stakeholders both to help them define their needs in terms of data for secondary purposes and to ensure that the resulting datasets and collection, verification and transfer methods are implemented with the full approval of the NHS Information Standards Board.

Information about the NHS Information Standards Board approval processes, including ISB Draft Standards Submission Guidance, may be found on the ISB website at http://www.isb.nhs.uk/pages/default.asp

National Analytical Services (NAS)

2.3 The NHS Information Authority is developing a National Analytical Service (NAS) to support national secondary information requirements, e.g. activity and outcome for epidemiology, clinical governance, public health and service planning based on the Secondary Uses System under development by the NPfIT Spine Project. The renal services community will call upon the services of the NAS as they become available.

For further information about this developing programme of work please refer to the NHS Information Authority website at http://nww.nhsia.nhs.uk/def/home.asp

Renal National Survey

2.4 The Department of Health has commissioned a national survey of renal treatment facilities in England for the year 2002. This survey will continue subject to approval by the Committee for Review of Central Information Requirements (ROCR) until the data can be provided automatically through the implementation of the actions in this Information Strategy.

The last renal national survey covered data from 1998. The analysis of this new renal national survey data will be completed in early 2004 and will be fed back to Renal Collaborative Commissioning Groups. This is step one of the early actions to be taken by 2006 mentioned in the Renal Services National Service Framework.

It is essential that basic information about the number of people entering the chronic renal failure programme and the prevalence of dialysed and transplanted people is known in total as well as within high risk groups. This is to ensure that the renal replacement programme can be planned and commissioned appropriately.

Data must be timely, accurate, accessible and intelligible if it is to help with planning and commissioning in a meaningful way. Commissioners and units can then use these data to support planning and to identify in local development the local priorities for improvement. See Local Action 3.4.

Performance Indicators

2.5 CHAI will work with the Department of Health and other key stakeholders to develop suitable performance indicators for national and local use.

As part of the NHS performance rating assessment one or more high-level performance indicators are being developed with the Commission for Healthcare Audit & Inspection (CHAI) along with key stakeholders. Such indicators should be capable of collection as a by-product of the direct care given to patients and should be available from the clinical information systems to be developed under the National Care Records Service.

CHAI will also include comparative information about renal services in its development programme of indicators for the NHS to use as appropriate locally. These will be based on the NSF standards and markers of good practice, professional standards, on NICE guidelines and appraisals, and will also cover other aspects of service quality such as equality of access, patient choice and resource utilisation.

Information for Audit

2.6 CHAI will work with the Department of Health, the Renal Association, the UK Renal Registry, UK Transplant and the renal services community to develop national comparative clinical audit plans within a framework of standards for national audit as a matter of priority.

This action is designed to enable data items identified to be collected and analysed to review clinical outcomes for audit and benchmarking purposes both nationally and locally.

Because of the importance of local and national audit it is essential that all Trusts with Renal Services are adequately served by electronic renal data management systems capable of transferring data to the UK Renal Registry and UK Transplant at the earliest opportunity. This need has been foreseen in National Action 1.1 regarding implementation of the Renal NSF Core Service by Local Service Providers under the National Care Records Service.

There is a need to monitor management of the quality of care through estimates of dialysis adequacy and technique failure, and the complications of renal failure such as anaemia, metabolic bone disease, ischaemic heart disease and hypertension must be assessed so that quality of life is as good as possible within the limitations of the condition.

For transplant recipients the outcome of the transplant must be monitored, including not only graft and patient survival but also as a minimum graft function, the number and type of rejection episodes and the development of major complications such as chronic allograft nephropathy, recurrent renal disease, post-transplant lymphoproliferative disease and cancer. Donor audit includes retrieval rate, condition of donated organs and cold ischaemic time.

3 Access to Knowledge

National Website of Information Links

3.1 The Department of Health Renal NSF website will act as a central link to supporting programmes of work including links to the NeLH, NHS Direct Online, the UK Renal Registry, UK Transplant, professional organisations such as the Renal Association and the British Transplantation Society as well as charitable organisations such as the National Kidney Federation and the National Kidney Research Fund.

National electronic Library for Health (NeLH) – Central Repository

3.2 Whilst designed primarily for the use of health professionals, the NeLH will act as the central repository for information from accredited organisations and sources about end-stage renal failure and its treatment and management, whether for patients and their carers, the public or health professionals. Their information resource will be used by NHS Direct and NHS Direct Online to develop information suitable for the needs of patients, their carers and the public.

The National electronic Library for Health at http://www.nelh.nhs.uk/ was established to provide a single source of health information primarily for health professionals but also accessible by patients and the general public. It provides links to national agencies, access to a wide range of expert knowledge and a wealth of information in its specialist libraries. NHS Direct and NHS Direct Online draw from the NeLH when they develop their services that, however, are designed specifically for the use of patients and the general public. Maintaining this information centrally aids in document management and ensures that all material used is in as current a format as possible.

National electronic Library for Health (NeLH) – Renal Specialist Library

3.3 The NeLH, along with key stakeholders, will develop a Renal Specialist Library designed for the use of health professionals. It will provide access to the evidence base where this exists, and identify areas where research is required to strengthen the evidence where it is lacking.

The Renal Specialist Library to be developed by the NeLH will be one of many such repositories of specialist information designed for health professionals. The NeLH will bring together knowledge from a variety of different sources. It will form a National

Knowledge Service for renal disease because it will be able to incorporate the knowledge into the electronic patient record itself. In the short term the NeLH will develop an electronic library, namely an integrated collection of best current knowledge. It will also be providing links to NHS Direct Online so that the patient who wants to know more than is in NHS Direct Online will be able to automatically go through to the appropriate section of NeLH.

National electronic Library for Health (NeLH) – Information from National Agencies

3.4 The NeLH will incorporate knowledge about end-stage renal failure and its treatment from all the national agencies such as NICE, UK Transplant and the Modernisation Agency and present this as a single interoperable source for healthcare professionals and interested members of the public.

Information from national agencies will be linked so that, for example, guidance from NICE will be automatically linked to the appropriate part of the British National Formulary.

NHS Direct Online – General Information for Patients, Carers and the Public

3.5 Drawing on information from the National electronic Library for Health (NeLH), NHS Direct Online will provide a web-based service giving access to recognised sources of high quality information about established renal failure and its treatment and management, designed primarily for use by patients and their carers and members of the public, as well as access to information about organ donation for the public and potential live donors.

The main source of knowledge for the general public will be NHS Direct Online which is expected to offer a full range of information about ERF and its treatment and kidney donation in formats suitable for all ages, educational backgrounds, physical disabilities, cultural backgrounds and mother tongues. This will be achieved through a partnership with UK Transplant and other recognised sources including professional organisations such as the Renal Association, British Association for Paediatric Nephrology and the British Transplantation Society and charities such as the National Kidney Federation (NKF), the umbrella organisation of patients' associations.

Individual sources of information can be quality checked using instruments such as DISCERN and Plain English guidance. The Information Partners Programme, run by NHS Direct Online provides an accreditation mechanism whereby the organisation's processes for creating information can be accredited and their information then released onto a range of resources including the NHS Direct Online website as a direct link from the Encyclopaedia and Self Help Guide. This accreditation process will also ensure links into the new NHS Digital TV channel as well as NHS Direct Kiosk information resources and can, if the organisation wishes, allow use of an NHS endorsement mark as an Information Partner.

The NHS Direct HealthSpace portal, due to be launched later in 2003, aims ultimately to link with the National Care Records Service to allow patients enhanced facilities, potentially, for example, for those waiting for a transplant to be able to check their registration status.

NHS Direct Online will be able to provide members of the public with access to the Organ Donor Register as well as enrolment facilities for new potential donors. This will be available via the Health Space portal section of its website that will access the Organ Donor Register details through the Spine Record of the National Care Records Service.

Potential live donors need independent advice from a well-informed source, not linked to family or to their unit, where they can receive unbiased advice without any pressure. Families of cadaveric donors also need information and reassurance that they are doing the right thing if they are called upon to make a decision about organ donation. NHS Direct Online will aim to be able to link to UK Transplant forall issues related to transplantation and organ donation in order to avoid duplication or giving conflicting information and to increase consistency and reliability of information.

Information for Third Parties

3.6 Drawing on information from the National electronic Library for Health (NeLH), NHS Direct Online will make available information about renal failure and its treatment written for use by third parties such as educational establishments, employers and insurance companies.

Renal failure and its treatment disrupt the lives of patients and their families and lack of knowledge about the needs of patients on dialysis or with a functioning transplant can cause problems in various ways. In order to further a better understanding of the needs of these patients, educational establishments, employers and insurance companies will be able to find information on NHS Direct Online that will enable them to better assess the needs of such individuals with whom they come in contact.

Local Action 3.2 encourages Trusts with Renal Services to ensure that patients know where to get this information from so that, when necessary, they can pass it on to third parties or tell them where to look for it.

Information for Children and Young People

3.7 Drawing on information from the National electronic Library for Health (NeLH), NHS Direct Online will make available information and advice for children and young people with renal failure about the problems of adjusting to their disease and how they might have a greater say in managing their disease as they grow up.

The needs of children and young people with renal failure, particularly as they start to get older, more independent and free-spirited, pose particular problems related to their increasing awareness and understanding of this life-limiting condition. They may or may not be reliant for the maintenance of their well-being on parents or carers and may or may not be easily disposed to the strict regimen required of them when receiving dialysis.

Information and advice that is seen by children and young people to be independent of parents, carers and the Renal Unit might be less threatening and intrusive, but it needs to be presented sympathetically and in a way which recognises the special needs of children and young people at different stages of their lives when looking at and trying to absorb and act upon information. It must also be sensitive to the needs and concerns of parents and carers.

Local Action 3.3 encourages Trusts with Renal Services to ensure that children and young people, as well as their parents and carers, are aware of how to find this information and advice on NHS Direct Online.

NHS Direct – Provision of Information and Advice for the Public

3.8 Working with all the appropriate stakeholders and sources of medical knowledge NHS Direct will undertake the necessary actions to enable it to become a safe source of information and advice for people with renal failure and members of the public enquiring over the telephone about issues relating to established renal failure and about the possibility of becoming kidney donors.

NHS Direct will have access to a full range of information about ERF in order to be able to handle callers appropriately and in confidence. In emergency situations callers will be advised to contact their local Renal Unit for advice and treatment. NHS Direct will carry out a review of existing algorithms to ensure that they are safe for people known to have renal failure.

Callers who show an interest in becoming kidney donors and wish to go on the Organ Donor Register will be given details in confidence of how to contact the Organ Donor Line which provides information about organ donation and a link to the UK Transplant website. Those who need further advice on live donation will be referred in confidence to their local live donor co-ordinator through UK Transplant, who could also arrange for independent advice from another renal unit if required.

Information about renal failure services and organ donation will be included in the information sources used in NHS Direct call centres including the NHS Clinical Assessment System and DORIS (Directory of Resources and Information Services) and will be compatible with that given by NHS Direct Online.

NHS Direct will link to UK Transplant for all organ donor issues in order to avoid duplication or giving conflicting information and to increase consistency and reliability of information.

4 Training and Development

Renal Informatics Special Interest Group

4.1 The NHSIA in partnership with the renal community, UK Renal Registry and UK Transplant will develop a renal informatics special interest group through the Informatics Learning Network available from the National Health Informatics Development (NHID) programme of the NHSIA. The first step will be to establish a web site and moderator.

For further information about this developing programme of work please refer to the NHS Information Authority website at http://nww.nhsia.nhs.uk/nhid/pages/default.asp

Educational Packages for Use of Systems

4.2 NHID, in partnership with the renal community, the UK Renal Registry and UK Transplant, will develop an educational package for units embarking on electronic data collection and for units who have systems not yet fully utilised, to provide a practical guide on how to embed an electronic clinical information system in the delivery of direct care.

For further information about this developing programme of work please refer to the NHS Information Authority website at http://nww.nhsia.nhs.uk/nhid/pages/default.asp

Educational Packages for Career Development

4.3 NHID, in partnership with the renal community, the UK Renal Registry and UK Transplant, will develop an educational package to support Trusts with Renal Services in providing career development and succession planning.

For further information about this developing programme of work please refer to the NHS Information

Authority website at http://nww.nhsia.nhs.uk/nhid/pages/default.asp

Supporting Information For The Local Actions

1 Information for the Direct Care of the Patient

Use of Electronic Clinical Information Systems

1.1 Local Service Providers (LSP) will work with Trusts with Renal Services through the National Care Records Service (NCRS) programme Cluster Management Boards to ensure that the electronic clinical information systems (ECIS) are embedded in the management and care of patients with established renal failure.

The National Programme for Information Technology (NPfIT) has responsibility for delivering the National Care Records Service through partnerships with national and local suppliers, known respectively as 'National Application Service Providers' (NASP) and Local Service Providers' (LSP).

The LSP will work within specified geographical areas known as 'clusters'. Cluster Management Boards will ensure that the implementation within the cluster runs to time and to budget and that all required resources are made available. They will instruct the LSP to proceed with the implementation of the services that have been specified in the documents known as Core Services.

The LSP will need to work with Trusts with Renal Services to ensure that information systems are specified, designed, developed and implemented to meet the needs of patients and staff as specified within the Renal NSF Core Service requirement under National Actions 1.1.

At its most fundamental the NCRS will deliver the mechanisms to enable professionals to have access to the views they need to support integrated care at the time and place required and to inform accurate diagnosis and optimum treatment. It will also support the goal of enabling people with renal failure to have access to and to be able to update their own records so as to assist them in becoming fully involved with their care through joint decision-making in a multi-skilled team environment.

As the National Programme moves forward with the National Care Records Service, Trusts with Renal Services will need to come together to work in partnership with the designated LSP to ensure that the systems developed for use within their cluster meet both their generic requirements for running the service and also those specific requirements that are essential to support patients with renal failure and the health professionals caring for them.

Great care should be taken by those Trusts providing renal services in working with the LSP to ensure that the functions of existing successful renal systems are not lost in this process, that new systems should be flexible and capable of evolving over time and that provision is made for them to be supported by well trained staff familiar with the special requirements of a renal unit. This applies to those who input data as well as those who will operate the system. It is essential that every Renal Unit should have its own system which integrates with other Trust systems. Historically this has not usually been the case since many renal information systems preceded wider hospital systems and have largely remained separate.

Approximately 20% of satellite dialysis centres in England are run by commercial organisations. Trusts with Renal Services contracting with these external organisations will need to include controls and specifications within contracts which will support an IT infrastructure for data returns to the parent renal unit. This will be essential for the continued provision of data for the direct care of the patient as well as to the UK Renal Registry from these patients in support of monitoring clinical governance and will help to ensure that this data does not lose visibility within the renal community. The ownership of any patient information held by these commercial organisations must remain with the renal unit commissioning these services.

Finally, the National Actions in section 4 Training and Development and the corresponding Local Actions are designed to ensure that staff with the responsibility for data receive adequate and ongoing training and support. See in particular National Actions 4.2 and 4.3 and Local Action 4.1

Access to Information for Primary Care Teams

1.2 PCTs should work with their Cluster Management Boards and LSP to ensure that primary care teams can access the records of patients with ERF, including a facility to view the patient's registration and status on the national transplant list.

The NCRS development must include the facility to share information about patients with ERF with primary care health professionals. PCTs will have a responsibility to ensure this is possible.

Introduction of Care Plans in Trusts with Renal Services

1.3 Trusts with Renal Services will be able to draw upon the national care plan model developed by the Department of Health to meet the needs of

their patients and to encourage its use by both patients and health professionals.

Care plans have long been used for the management of patients on wards, being largely the domain of the nursing staff. However, with conditions such as diabetes and renal failure, where self-management plays a crucial role in maintaining the patient's health and where professionals from not only within health but also frequently from other agencies such as social care and education services may have regular input to a patient's management and treatment, the use of care plans beyond wards in the form of a personalised plan drawn up and agreed in partnership with the patient is now seen as a vital element of the management and care of patients. The concept of the care plan may encompass the provision of a facility whereby the patient can enter details of events and results along the lines of a daily log book and review their results.

While there are undoubtedly examples of good practice in the use of care plans in this way there is no single recognised model available that can help to kick-start the process locally. The Department of Health has begun work on developing one such model in response to the Diabetes NSF and intends to use this work to inform care plans for people with renal failure.

The Department of Health is initiating this work through a national workshops with patients to discover their preferences – what care plans mean to patients and how they would like them to be recorded and reviewed. The outcome of this will help determine the care plan and how it links to primary care, other specialist services and social care.

The care plan will be the interim solution to NCRS and will probably be electronic, but some patients may prefer paper. The Modernisation Agency may pilot care plans and the pilots will look at the cost of implementation.

Support for Care Plans by PCTs

1.4 PCTs are encouraged to work with local renal units to access their care plan model, in order that primary care teams can promote its use by both health professionals and patients in the community.

Information Sharing

1.5 Trusts with Renal Services are encouraged to lead a formal examination of the issues relating to information sharing for all relevant stakeholders including those in primary care and to use the results to ensure that the interests of patients, donors and care professionals are recognised and properly safeguarded.

'Information sharing' is about communicating promptly, accurately and effectively with the patient and others involved in the patient's care within the legal framework of the Data Protection Act for the patient's benefit. Patients need to know what personal information about them is or may be shared by the professional caring for them with another care professional or indeed with another third party, knowing why that information is shared and giving or withholding consent for it to happen. For patients who may wish to view their own records there should be no surprises. For care professionals it is about ensuring that patients are prepared for and supported in viewing their own records and knowing what personal information about a patient or patients they can or cannot share with others and with whom they can or cannot share it. Special consideration must be given to the proper protection of third parties such as organ donors.

It is the intention to ensure that, by understanding these issues in a practical way and in ways that reflect local practice and by developing procedures that are clear to follow the interests of patients, third parties and care professionals are recognised and properly safeguarded.

In the case of renal patients special consideration should be given to the confidentiality of donors while maintaining the ability to access information relevant to the care of the recipient.

The local Caldicott Guardian should be involved to ensure that information is shared within the permitted limits of security and confidentiality. Reference can also be made to ongoing work within the National Programme for Information Technology (NPfIT) on the subject of Security and Confidentiality.

Because of the complex nature of renal disease, patients often come under the care of a number of different care professionals who will not always be on one site. They may belong to other agencies such as education and social care. Procedures, therefore, will need to address the geographical and the multi-agency issues and, whilst such issues may be best solved by sharing information electronically, the fundamental decisions about giving patients and care professionals the understanding about what may or may not be shared must be addressed whatever the method of sharing, be it on paper or electronically. Strategic Health Authorities might wish to take the lead in this respect with Primary Care Trusts working with the other agencies to bring together those Trusts with Renal Services where clear procedures for sharing information would be of benefit to all concerned.

Sharing information with patients will need to be recognised as a challenging process and great care will need to be taken over the delivery mechanisms taking into account language differences and differences of cultural background. Personal communication with face-to-face delivery is advised to be the primary method for sharing information with patients, backed up by written information.

Providing people with access to their own results and records, including sending them copy letters, helps to empower them and support them in becoming expert in managing their own care. However it is essential that the patient has been adequately prepared for any bad or unexpected information that may be included. The primary stakeholder is the patient and it is only logical that patients should be able to view their own records. This enables them to ensure completeness and accuracy of the content. Patient care is a partnership and sharing records is part of that process.

Special consideration should be given to information sharing when patients move from one unit to another, from dialysis to transplant units or for young people transferring from children's to adult units.

Access to information about donors also requires special consideration because of the need for information at short notice and the need for confidentiality. For example, at the time of death leading to organ donation the donor records must be accessed to consider the suitability of a potential donor or following the development of post transplant problems in the recipient there may be a need to review the donor details.

This action, therefore, seeks to encourage Trusts, PCTs and SHAs to help patients and care professionals to understand what information may or may not be shared and thereby to lead on to further benefits for patients of making results and records available to them and of enabling them to participate actively in their own care.

The NHS Information Authority, as part of its work to support the implementation of the Mental Health Information Strategy, has collated examples of information sharing protocols that have been developed around the country and links to those examples as well as to available guidance on the development of information sharing protocols can be found at *NHSIA : Mental Health Information Strategy*.

Decision Support

1.6 Trusts with Renal Services are encouraged to provide care professionals treating patients with ERF with access to decision support at the point of care in advance of this functionality being provided in the Renal NSF Core Service.

Decision support can take a number of different forms and, by its nature, is intended to support clinicians in their routine clinical work but not to replace the knowledge and experience that clinicians have of individual decision making as a result of the face-to-face interaction with patients.

At the simplest level decision support may take the form of prompts that highlight unusual or dangerous results or situations that require decisions to be made. More sophisticated systems may be based on a series of algorithms within a computer's clinical information system that gives simple prompts or complex responses when different measurable criteria are present. Clinicians see the prompts and responses and decide on their validity in the particular circumstances, choosing either to act or not to act, knowing that they have given due consideration in all cases.

On the other hand decision support could take the form of evidence-based guidelines accessible from a repository of knowledge such as the National electronic Library for Health (NeLH). Typically these would be based on existing publications such as NICE guidelines or other evidence-based material. Access to the guidelines might or might not be built into the clinical information system for use by the clinician at the point of care.

Decision support may take the form of locally produced practical guidelines or checklists indicating the local arrangements for procedures such as transplantation. In situations where no evidence-based guidelines exist best practice guidelines have been developed based on expert opinion. Such opinion-based documents do not have the rigorous basis of evidence-based guidelines. Relevant guidelines could be selected or adapted locally and made available either in paper format or via a local intranet.

The information contained within the developing Renal Specialist Library of the NeLH will provide valuable assistance for developing local protocols and guidelines for decision support at the point of care. Through its ready availability on the Internet it will reduce the difficulty for health professionals of accessing and processing quality information, and thus contribute to improvement in the care of patients.

Much of the training of doctors has focussed on gathering information about the individual patient and his or her condition and making individual decisions at every point in the patient journey. Now that so many patients have been treated for ERF by dialysis and transplantation it is logical to ensure that similar problems are managed in similar ways firstly to ensure that the best evidence-based practice informs each decision and secondly to ensure equity of access to treatment (e.g. organ allocation, management of haemoglobin). Although some information will be available nationally through the NeLH, the implementation of best practice when considering local circumstances such as geography and historical development require local interpretation of national guidelines.

The NCRS is expected to support functionality to enable decision support at the point of care. However, until such time as this becomes available every unit should be considering the introduction of a range of local protocols to enable consistent implementation of common procedures and treatments. Clinical staff could work with Chief Information Officers in identifying how local developments can enable decision support.

2 Information for Secondary Purposes

Clinical Information Systems

2.1 In order to submit the required data for secondary purposes, Trusts with Renal Services may use the agreed procedure to extract the data used by UK Transplant and the UK Renal Registry electronically.

The Renal NSF Core Service requirement referred to in National Action 1.1 will specify that the LSP will write an extract programme to enable Trusts with Renal Services to send data to UK Transplant and the UK Renal Registry based on the National Dataset for transplantation and dialysis services to be commissioned by the Department of Health and CHAI under National Action 2.2.

It will be the responsibility of Trusts with Renal Services to ensure that data are submitted to UK Transplant and the UK Renal Registry as required for audit and other secondary purposes. It would be good practice to use the electronic processes developed by the LSP.

Datasets

2.2 Trusts with Renal Services should collaborate with the LSPto implement the National Dataset upgrade to their electronic clinical information systems when available.

Once the National Dataset is complete and has received NHS Information Standards Board approval the Local Service Providers will be responsible for ensuring that system suppliers provide Trusts and Renal Units with the necessary upgrade to their systems. Trusts with Renal Services should collaborate in this process when the upgrade is offered to them.

Analytical Capacity

2.3 Access to the analytical and epidemiological skills required to handle and interpret the data required for audit and other purposes is essential if data are to be handled and interpreted correctly. It is good practice to use such services for data interpretation locally and nationally.

Outcome data once collected should be collated and adjusted for a variety of confounding factors, for example age, diabetes and ethnic mix, if data are to be meaningful and interpreted correctly. Inappropriate data management can lead to serious problems for planners and providers. Similarly, when interpreting audit data, the appropriate methods mustshould be used to ensure a meaningful outcome.

Trusts with Renal Services will have a relatively small number of patients, and so the effect of demographic and physiological variables on outcome generally needs to be analysed on a national basis. This means that Trusts will need access to the statistical and epidemiological skills required to handle and interpret the data required for audit and other purposes so that local data are interpreted appropriately in the national context and are available to inform management, planning and quality improvement.

It is acknowledged, however, that not only may such skills be in short supply but also there may not be enough patients in any one area to justify an individual Trust appointing such resources. It may, therefore, be prudent and more practical to use the resources of organisations such as the UK Renal Registry, UK Transplant or the National Analytical Service (NAS) who may be able to provide them with the feedback that they need. Alternatively, Strategic Health Authorities may consider a central pool of such resources to act on behalf of Trusts within their area.

In order to address this issue in a comprehensive way Strategic Health Authorities might wish to establish a review of the required and available analytical capacity in their area and work with Renal Collaborative Commissioning Groups to decide how such resources may be put to best use for the benefit of individual Renal Units.

Information about Services

2.4 Renal collaborative commissioning groups are advised to use information including local population demographic data and information about staffing, facilities and current capacity in renal services provided by Trusts with Renal Services to identify gaps and inequalities and plan future services to meet demand. National Survey data (see National Action 3.4) will be available as a baseline for comparison and improvement.

The incidence of ERF is rising and services have not kept pace with demand, leading to a shortage of facilities for patients and heavy workloads for staff. The prevalence is projected to continue to rise at least until 2020. It would be good practice to plan for an annual expansion of services to meet this need.

Unless providers, planners and commissioners are aware of the local resources in terms of beds, outpatient sessions, haemodialysis stations and staff, they will not be able to plan a safe and effective service to meet the projected changes in demand. Overcapacity is inefficient and wasteful while undercapacity will lead to difficulty in providing a service.

Local providers, planners and commissioners will receive information about their local services from

UK Transplant, UK Renal Registry and the National Survey. It will be up to them to adapt this information according to local circumstances.

Information for Audit

2.5 It is good practice for Trusts with Renal Services to participate in national comparative audit of the structure, process and outcome of their work. This could include, for example, patients' opinions, suggestions, transport arrangements, as well as audit of activity, outcomes, waiting lists and admissions to non-renal wards with feedback used to inform change.

This approach will provide a more patient focussed service more able to meet the needs of individuals. The information would also be valuable for commissioners in performance management. Further, CHAI expects participation in national audit using electronic transmission of renal unit data to the UK Renal Registry and UK Transplant to demonstrate their level of success to both CHAI and commissioners.

An efficient unit should have processes and systems in place to ensure that patient care is continuously improved. For example, the availability of patient information and organisation of patient education could form part of a structured process. A named person could be responsible for acquiring relevant information, organising and updating it and ensuring systematic delivery to each patient in an appropriate format. There should be a clear mechanism for patients and others to make constructive suggestions or voice complaints, backed up by a system for responding.

In the absence of such systems, problems that occur may not be addressed or not even recognised. Use of processes available for audit improves the efficiency of a unit and enables it to respond to problems and improve the service to patients systematically.

3 Access to Knowledge

Information for Patients, Carers and the Public

3.1 Trusts with Renal Services could, by using the services described in National Actions 3.1 to 3.7, make available a full range of information for patients, carers and the public about renal failure, its treatment and management and services available locally.

Personal, face-to-face communication is advised to be regarded as the principal method of communication with patients and their carers. Written and other media should be available to back up and reinforce points made during discussion.

Some patients, their carers and members of the public may wish to go into more detail than others. The information available must cover the needs of these individuals without compromising the needs of those who want only limited information.

By accessing the website of information links under National Action 3.1, and particularly by reference to the information to be provided by NHS Direct Online under National Action 3.5 to 3.7, Trusts with Renal Services should be in a position to develop a full range of information for patients, carers and the public about renal failure.

Trusts with Renal Services should ensure that there is a named individual responsible for the development and availability of information for patients. Renal units linked through networks should move towards consistency of information across the network. Renal collaborative commissioning groups may take a view on this.

The information provided locally would include information about ERF, its treatment and management, about what to do in an emergency, holiday dialysis and information about the transplant list and how it works. Trusts with Renal Services should add information about their own local services.

The information should be suitable for all patients, carers and members of the public, including different age groups, ethnic minorities, those with literacy problems or learning difficulties and those with sensory deficits. Depending on local circumstances Trusts with Renal Services may wish to concentrate their efforts, and their budgets, on one or more target groups and prepare the material in a way that meets the needs of the particular group or groups. For example, the delivery of information in a particular language may be more urgent in one area or material prepared for young people in a way that captures their attention might be more important in another.

Many patients who do not speak English are not able to read leaflets in their own language. For those patients it may be more useful and cost effective to have an interpreter present at a consultation using a good quality English leaflet as the basis for the discussion. This approach may be preferable to having large quantities of translated material that may only rarely be used and may quickly become obsolete. Questions can be asked and answered through the interpreter who can make notes that he/she can understand.

Not all patients have or wish to have access to the Internet. Those who do not may or may not wish to find out information for themselves. If they do they should be supported in doing so by having access to a computer terminal at the renal unit and offered help in using the equipment to find the information they require. Alternatively, patients who prefer written information could be offered material that meets their needs either prepared locally or downloaded from a reliable web-based source such as NHS Direct Online.

Initially patients' needs often centre on information about illnesses and their treatments and about the services that are available to them both locally and nationally. However, patients also need information about the things that will have a positive impact on their lives and not just about the things that they should not be doing. With the proposed approach local Trusts with Renal Services should be in a position to provide access to information that gives positive information about lifestyle decisions including diet, exercise, travel, holidays and work.

As a quality check, Trusts with Renal Services may wish to use the Centre for Health Information Quality (CHIQ – see www.hfht.org/chiq/) and DISCERN (see www.discern.org.uk/ for a brief online questionnaire which provides users with a valid and reliable way of assessing the quality of written information on treatment choices for a health problem) to assess the information products that they make available in this way to their local patients, carers and public.

Information for Third Parties

3.2 Trusts with Renal Services should ensure that patients are aware of how to obtain information, such as through the services described in National Action 3.6, about renal failure and its treatment that has been written for use by third parties, for example educational establishments, employers and insurance companies.

Under National Action 3.6 NHS Direct Online will make available on its website information about renal failure and its treatment that will be written for use by third parties such as educational establishments, employers and insurance companies.

In order to ensure that third parties get to see this information when it is needed patients must themselves know how to obtain it so as to be able to pass it on to third parties or to know where to direct third parties so that they can look at it on the NHS Direct Online website.

Information for Children and Young People

3.3 Trusts with Renal Services should ensure that children and young people, as well as their parents and carers, are aware of how to find the information and advice, such as through the services described in National Action 3.7, about the problems of adjusting to their disease and how they might have a greater say in managing their disease as they grow up.

Under National Action 3.7 NHS Direct Online will make available information and advice for children and young people with renal failure about the problems of adjusting to their disease and how they might have a greater say in how they manage their disease as they grow up.

In order to ensure that not only children and young people, but also parents and carers, get to see this information and advice they must know how and where to find it on the NHS Direct Online website.

Trusts with Renal Services can add their own local information for children and young people to that provided by the NHS Direct Online website. This might, for example, include information about transferring to an adult unit, including detailed information about their new unit, its staff and organisation prior to transfer in order to reduce the risk of non-adherence, anxiety, misunderstandings and treatment failure associated with transfer at this vulnerable time. Consideration will need to be given to the format of the local information bearing in mind the special needs of children at different ages.

Information for Transferring to Other Units

3.4 Trusts with Renal Services should give patients transferring to other units either within or outside their local renal network information about the receiving unit before they are transferred in order to ensure smooth transition.

Transferring to another renal unit in England for a transplant, for dialysis or for any reason can be inconvenient to patients at the least and traumatic at the worst. It will always be helpful for patients to receive information about their new unit before they transfer.

Access to the IT Infrastructure

3.5 Trusts with Renal Services need to consider how to ensure that professional staff and patients have ready access to the knowledge base through implementation of the necessary IT infrastructure.

Information for patients, carers and care professionals must be easily accessible otherwise there is a real danger that it will not be used and will fall into disrepute. Most information today, if it is to be up-to-date, consistent and readily available needs to be held in electronic format. For patients, carers and care professionals to be able to see that information they must have access to it via a reliable IT infrastructure with hardware and software that is easy to use.

It would be good practice for the Chief Information Officer of Trusts with Renal Services to examine the extent of the coverage of their IT networks for patients and staff and to consider extending it, where necessary and appropriate, in the light of the information needs proposed in these Local Actions.

4 Training and Development

Training and Support for Staff

4.1 Trusts with Renal Services are encouraged to give staff with responsibilities for data and the preparation of information the appropriate training and support in developing their skills and knowledge.

The information needs of health professionals in Trusts with Renal Services will be satisfied only if they have staff trained in the use of information systems, in data entry and data interpretation and whose skills and knowledge are kept up-to-date.

In addition, staff dealing with large amounts of data on patients who are receiving treatment for renal failure need special expertise about the conditions and treatments that can only be gained from within the renal unit.

Chief Information Officers of Trusts with Renal Services, therefore, may wish to review this element of their activities with a view to deciding how best to train as well as to support their staff and develop their careers and thereby to make the most of their investment in clinical information systems hardware and software. Support is also available through the services of UK Transplant and the UK Renal Registry. See also the support available from the National Health Informatics Development (NHID) programme of the NHSIA under National Actions 4.1, 4.2 and 4.3.

Support for Patients at Trust Premises

4.2 Trusts with Renal Services are encouraged to ensure that, wherever access to information is given to patients via, for example, a workstation located on their premises, help and support as well as sufficient material are readily available so that patients can use the IT system appropriately and understand the information they receive.

In the same way that the information needs of health professionals in Trusts and renal networks across the local community in both primary and secondary care will be satisfied only if they have properly trained staff , so too the information needs of patients and their carers will not be met if they do not have the knowledge of how to use the facilities that may be offered to them, such as a workstation located within their Renal Unit. Help should be available either in written form or ideally from an informed member of staff who can be on hand to support patients when they are looking for information.

Support for Patients at GP Surgeries

4.3 PCTs are encouraged to ensure that GP surgeries provide online access for patients to information about renal disease, renal failure, its management, local services and organ donation possibly by accessing the services described in National Actions 3.1 to 3.7, with appropriate support from staff.

Glossary of Terms

Term	Description
Care Professional	Any professional, whether for example, from health, social care or education, providing care to a patient.
Commission for Healthcare Audit & Inspection (CHAI)	CHAI is due to come into operation in April 2004 when it be responsible for monitoring standards of healthcare in the NHS and private healthcare organisations across England and Wales. It will take over from the CHI, the National Care Standards Commission for inspecting private healthcare providers, the Mental Health Act Commission, and the Audit Commission's value for money studies in health.
Clinical Information System (CIS)	A comprehensive computerised system operating within a healthcare environment recording data from healthcare professionals about patients' interaction with the service from appointment to discharge.
Local Service Provider (LSP)	Suppliers of local systems and/or services appointed by the National Programme to support the National Care Records Service.
National Application Service Provider (NASP)	Suppliers of national systems and/or services appointed by the National Programme to support the National Care Records Service.
National Care Records Service (NCRS)	One of the four key programmes for delivery by the National Programme, the NCRS concentrates on delivery of electronic patient records and integrated systems for the NHS.
National electronic Library for Health (NeLH)	The National electronic Library for Health provides a single source of health information primarily for health professionals but also accessible by patients and the general public. It provides links to national agencies, access to a wide range of expert knowledge and a wealth of information in its specialist libraries.
National Institute for Clinical Excellence (NICE)	NICE was set up as a Special Health Authority for England and Wales on 1 April 1999. It is part of the NHS, and its role is to provide patients, health professionals and the public with authoritative, robust and reliable guidance on current "best practice". The guidance covers both individual health technologies (including medicines, medical devices, diagnostic techniques, and procedures) and the clinical management of specific conditions. NICE offers the NHS and its patients a new service, which it is intended, shall earn, and retain, the confidence and respect of the community as a whole.
National Programme for Information Technology (NPfIT)	The National Programme for IT in the NHS focuses on the key developments that will make a significant difference to improving the patient experience and the delivery of care and services. There are four key deliverables: electronic appointment booking, an electronic care records service, electronic prescribing and an underpinning IT infrastructure with sufficient connectivity and broadband capacity to support the critical national applications and local systems. To ensure delivery of the National IT Programme there are also several supporting workstreams around streamlining procurement, managing implementation in the NHS and improving the partnership and capacity with IT suppliers.
NHS Direct	NHS Direct operates a 24-hour nurse advice and health information service, providing confidential information on what to do if people are feeling ill, particular health conditions, local healthcare services, such as doctors, dentists or late night opening pharmacies and self help and support organisations.
NHS Direct Online	NHS Direct Online is a website providing high quality health information and advice for the people of England. It is unique in being supported by a 24 hour nurse advice and information helpline. If users of NHS Direct Online are in any doubt about information they read or about what action to take, they can call NHS Direct on 0845 4647

NHS Information Authority	Special Health Authority established in April 1999 to replace the previous NHS Information Management Group (IMG) and the FHS Computer Unit.
NHS Information Standards Board (ISB)	The ISB is the governing board responsible for approving data standards and other changes for adoption by the NHS.
NHS Modernisation Agency	The NHS Modernisation Agency exists to help NHS staff and their partner organisations to improve services for patients. The Agency works in close partnership with Strategic Health Authorities to align its work to local priorities and commits funding, resources and expertise to local modernisation objectives. Operating across all sectors of the NHS - acute trusts, primary care, ambulance and Mental Health Trusts- the system redesign work of the Agency is underpinned by the major principles of quality of patient safety, leadership and workforce development.
Renal Collaborative Commissioning Groups	Groups established by PCTs to commission services identified in the Specialised Services National Definition Set. They are overseen by Strategic Health Authorities. Their decisions are binding on all PCT members.
Renal Unit	A unit, either run by the NHS or privately, that is dedicated to dialysis of patients with established renal failure.
Transplant List	A list, maintained by UK Transplant, of people waiting to receive an organ transplant.
Trusts with Renal Services	In the context of the Renal Services Information Strategy National and Local Actions any organisation within the NHS that delivers care to patients with impaired renal function. This could be, for example, a hospital or group of hospitals forming a trust which provides dialysis or transplantation either directly or through outreach clinics.
UK Renal Registry (UKRR)	The UK Renal Registry is a non-profit making organisation and, as part of the Renal Association, is registered as a charitable activity by the Charity Commission. The Registry was established by the Renal Association in 1997 with support from the Department of Health, the British Association of Paediatric Nephrologists, and the British Transplant Society as a resource for the development of patient care in renal disease. It provides a focus for the collection and analysis of standardised data relating to the incidence, clinical management and outcome of renal disease. It thus acts as a source of comparative data, for audit/benchmarking, planning, clinical governance and research. The UK Renal Registry monitors indicators of the quality as well as quantity of care, with the aim of improving the standard of care. There is currently a concentration on data concerning renal replacement therapy, including transplantation. At a later date there will be an extension to other forms of treatment of renal disease. For further information: http://www.renalreg.com/
UK Transplant (UKT)	UK Transplant is a special health authority. It has a statutory responsibility to acquire, record, update, keep and make available information about donors and recipients and organs that are or may be available for transplantation. It fulfils this responsibility by maintaining the national transplant database as a central, complete, accurate and up-to-date record of transplantation from donation to the death of the recipient. Thereafter UKT undertakes an ongoing programme of clinical audit and statistical analyses to both demonstrate and improve the quality of service delivered to patients. For further information: http://www.uktransplant.org.uk/default.htm)