

Appendix F: National Programme for IT Output Based Specification 167 – Renal services

Introduction

The text of the Output Based Specification (OBS) contract for renal services, is provided below. This is section 167 within the contract signed by the regionally based Local Service Providers (LSPs) as a component of the National Programme for IT (NPfIT).

This has been included in the Registry Report so that renal unit managers may reference this document in their negotiations within the Trust and with the LSPs.

OBS 167 – Renal Services

NSFs are not just about collecting data, and this part of the specification will not substitute for each LSP making particular reference to the specific documents available to help in satisfying the policy and service requirements for the prevention of renal disease and management of people with renal failure.

It is recognised that every area of specialist activity will have variations in the data it uses and the way it operates the basic primary clinical (and other) activity. This part of the specification identifies that which, in terms of overall activity and monitoring, is specific to people with renal disease, particularly those with renal failure.

In February 2001, the Secretary of State announced his intention to establish a new set of national standards to improve services for 30,000 kidney patients.

The incidence and prevalence of kidney failure is increasing steadily, and as such there is a real need to address issues of prevention and capacity to reduce incidence and increase choice and treatment options. This will be addressed through a number of processes:

- the development of improved preventative strategies based around well established risk factors and interventions.

- reduction in the variation in treatment rates and quality of service, including referral to
- nephrologists and the development of care plans.
- provision of sufficient capacity to ensure that patients consistently receive optimal care (i.e. choice of treatment and frequency of dialysis)
- optimization of access to and outcome of renal transplantation.

The new Renal Services NSF will be developed with the help of health and social care professionals and managers, patients, carers, partner, agencies and other advocates. It will be the blueprint for national standards and services that will improve treatment and care for the 30,000 patients in the UK on dialysis or living with a kidney transplant.

As with other published NSF's the Renal Services NSF standards will be supported by an information strategy, which will build on work already underway for existing national service frameworks to ensure that the specific renal issues can be addressed in an appropriate manner.

This will include (through close collaboration with the Renal Registry and UKT) the development of a nationally approved dataset. The dataset is expected to incorporate the two existing data sets and be developed to include those elements required that are not within the scope of the two current collections.

Renal Services NSF is expected to be published later this year. Further information can be found at the URL, <<http://www.doh.gov.uk/nsf/renal.htm>> .

Scope

The Renal NSF has been developed in 4 modules to consider the whole patient journey. This starts with those at risk because of congenital, acquired or inherited renal disease or risk factors, through the process of diagnosis, progression to renal failure, dialysis and transplantation and supported care and decisions at the end of life.

Module 1 This is concerned with haemodialysis and peritoneal dialysis and includes the year prior to the start of renal replacement therapy and issues surrounding appropriate and timely access surgery.

Module 2 This is concerned with maximising the benefits of transplantation, and includes key issues relating to live and cadaveric donors. Some donor issues are dealt with in the Transplant Framework, published by the DoH.

Module 3 This module is concerned with:

- identification of people at risk of renal failure because of previously identified renal disease or congenital, inherited or acquired conditions predisposing to renal disease and renal disease.
- detection of early progressive renal disease and early signs of renal failure by detection of proteinuria, hypertension or reduced or falling GFR.
- prevention of renal failure by evidence based management of those identified.
- Lifestyle choices that reduce risk and increase longevity.

This module also addresses acute renal failure which is an important source of morbidity and mortality and also provides a source of patients who do not recover and therefore have unplanned acute onset chronic renal failure.

Module 4 End of life care is an important choice for people with ERF, a difficult condition from which there can be no recovery. Planned and supported care at the end of life is important component of the services provided.

It should be noted that, at the time of publication of the OBS, Modules 1 and 2 are further advanced than Modules 3 and 4. As a consequence, the renal services requirements of ICRS address the needs within primary and secondary care settings. Further requirements relating to primary and palliative care settings are yet to be articulated.

Governance and audit

The ICRS spine and LSP must provide a facility for the direct care of the patient with renal disease, in primary, secondary and tertiary care and provide the functionality to deliver data for secondary purposes:

For the direct care of patients with renal failure the ICRS will ensure that the system will:

- provide a continuous lifelong record of the patient's history, care, discussions and wellbeing;
- Ability to support serial online biochemical and other tests, X-rays and biopsies;
- provide facilities for data transformation for assessing progress and adequacy of care (e.g., estimated GFR using the Cockcroft and Galt formula or KT/V for dialysis adequacy);
- enable the patient and health professionals to participate in the development and use of a personal care plan which enables the patient to have access to their own records and participate in their own management and joint decisions;
- share information appropriately between health sectors, members of the multidisciplinary team and other specialists in an accurate and timely way with due regard to confidentiality and with the patient's consent;
- provide the facility for prescribing information for patients with various levels of impaired renal function and with renal transplants;
- enable patients waiting for a transplant to access their status on the transplant list;
- provide decision support based on evidence;
- provide access to the knowledge base for patients and health professionals;
- functionality for decision support to clinicians at the point of care informed by evidence-based information such as that developed by the NeLH;
- information to monitor the standards of the Renal Association, the British Transplantation Society and other relevant professional bodies; and ICRS Output Based Specification
- information to monitor the standards outlined in the Renal National Service Framework for renal disease and other NSF's such as Diabetes, CHD and Children's & Maternity Services when published.

For the management of donors there should be facilities to support:

(For live donors)

- the needs of live donors as patients and organ donors;
- the ability of live donors to see the results of their tests and participate in shared decision making;
- the ability to provide statutory information about live donation to UK Transplant;
- the ability to provide follow up of the donor;

(for cadaveric donors)

- the needs of cadaveric donors, both heart beating and non-heart beating, including records that continue to function and are accessible after the death of the donor;
- functionality to support links for health professionals to the organ donor register in order to establish the status and wishes of a potential donor;
- functionality to enable health professionals to view the medical records of potential donors, both 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 cadaveric kidney donors or 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);
- enable information to be transferred from donor to recipients and from one recipient to others from a common donor, when required, with appropriate levels of confidentiality;
- provide information required for organ allocation through UK Transplant; and

(For healthy people)

- enable those who wish, to register on the organ donor register.
- Data for secondary purposes.

In addition the data required for secondary purposes (epidemiology, incidence, prevalence, activity, outcome, treatment modalities, audit, benchmarking, management, clinical governance, planning commissioning and research) must be derived from the Patient Record. This must include:

Information about patients with renal failure:

- information about patients with renal failure in primary secondary and tertiary care;
- data required for the renal registry and other key stakeholders. *(The details of the information required will be informed by a review of information to be undertaken by the NHSIA and commissioned by the DoH);*
- information on the waiting times and outcome of transplantation;

Information about donated organs:

- information required by UK transplant for statutory duties;
- information required to monitor the outcome of renal transplantation in relation to the type of organ, its condition and transfer;
- information about the organ allocation and transplantation process;

Information about donors:

- information on live donors, including follow up; and
- information about cadaveric donors.