

## Lay Introduction to Service Specification

### Introduction

Since April 2013, NHS England has taken on direct responsibility for many of the services delivered by the former Primary Care Trusts (PCTs). Amongst these are the '**commissioning**' of services for kidney patients, which were previously delivered regionally, in particular dialysis and **renal (kidney)<sup>1</sup> transplantation in adults**.

'Commissioning' is the term given to the planning and purchasing of NHS services to meet the health needs of a defined population. Some of these services are known as 'specialised services' and each has its own 'service specification', which is a legal contract between NHS England and the organisations that provide these services. This document explains what patients can expect from the renal transplantation service specification.

### What is Renal Transplantation (Adult) Service Specification?

The Renal Transplantation Service Specification is a legal document between NHS England and the 19 adult transplant centres plus 52 specialist renal centres in England (some of which are located in the same hospital).

The Specification clearly describes the services, care and outcomes that patients can expect from these centres, whether they need or have received a kidney transplant, either from a deceased (dead) or living organ donor.

The Specification also clearly describes the services, care and outcomes that living donors can expect from these centres.

### How was the Service Specification developed?

The Clinical Reference Group (CRG) for Renal Transplantation developed the Specification during 2012. It underwent public consultation, in particular with kidney patients, and was published by NHS England in summer 2013. The Service Specification for 2013-14 was adopted on 1 October 2013 and covers the period to 31 March 2014.

### What is a Renal Transplantation Service?

The Service is a comprehensive care package for adults who either need or who have received a kidney transplant. These patients will be recognised as having progressive chronic kidney disease (CKD) stage 4 and 5, and will include those who have already had a transplant.

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<sup>1</sup> The word 'renal' means 'kidney' and the two words are used throughout this document.

The Service has to be 'high quality', ie it must be effective, deliver a positive patient experience and be safe<sup>2</sup>. This applies equally to transplant recipients and living donors.

For **transplant recipients**, the Service starts when a patient is considered suitable for a kidney transplant. After an initial assessment, those patients who are considered medically suitable for a transplant, and who have agreed to the surgery, then progress to a 'work up'<sup>3</sup> in one of the specialist renal centres and/or renal transplant centres.

The transplant surgery takes place in one of the 19 transplant centres. After an agreed period of time following the operation, patients are transferred from the transplant centre to the specialist renal centre for long-term follow up. Service providers continue to support patients who have received a transplant until the patient dies or the transplant (known as a 'graft') fails.

For **living donors**, the Service starts when the person offering one of his or her kidneys has made an informed choice about donating a kidney. After the initial assessment, living donor 'work up' takes place at the most convenient centre for the donor, which may be different from the actual planned transplant centre.

Service providers must continue to provide support for living donors throughout their lives, through regular follow-up care.

Additionally, for living donors who are ineligible or prohibited from donation, it will be important for them to seek support to manage this disappointing and sometimes upsetting experience.

This Service is for patients ordinarily resident in England, excluding those who are registered with a GP in Wales and Scotland. However, it includes patients resident in Wales and Scotland who are registered with a GP in England.

#### What is in the Renal Transplant Service Specification?

The Specification describes in detail what each specialist renal centre and/or transplant centre must provide to every transplant patient and living donor.

A clear, unambiguous, evidence-based care pathway must be followed to ensure equity of access and high quality care throughout.

The Specification makes it clear that patients must be kept fully informed at every stage in the transplant process and care pathway, from being 'listed' as a potential transplant recipient, throughout all the assessments and tests, pre and post-surgery, and during follow up care.

Living donors must also be kept fully informed at every stage in the process and care pathway. Arrangements for reimbursement of expenses incurred by the living donor

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<sup>2</sup> This definition of quality is written down in the Health and Social Care Act 2012, and is expected of all NHS providers of healthcare.

<sup>3</sup> 'Work up' is a term widely used in medicine to cover all the evaluations, examinations, tests and other procedures involved in any proposed treatment or surgery

must be clearly described. It will be important for donors who are unsuccessful to seek psychological support if they choose to.

Patients – and relatives/carers – must also be given culturally appropriate information, allowed time for discussion with care providers, and offered psychological support and access to social care services. The risks and benefits associated with kidney transplantation must be clearly explained.

In addition, the Specification details other services that will or may be required to carry out a kidney transplant, such as special types of blood or genetic tests.

Finally, the Specification lists the national and international standards or guidelines that the transplant and renal centres must follow to deliver care to both transplant recipients and living donors.

#### Who evaluates the Service Specification?

A number of measures are included in the Specification to help the NHS decide how well or poorly the Service is being delivered by the 19 transplant centres and 52 renal centres.

These measures include ‘hard’ numbers, such as how many living and deceased transplants are performed, how long patients wait for a transplant, how long the kidney grafts and the patients survive.

Patient experience measures are also included which will help evaluate aspects of the Service, such as feedback on communications and individual quality of care.

**Links with other organisation:** To gain more information about what is available to you, about the advantages and disadvantages of transplantation and dialysis, or about research into kidney disease and dialysis there are numerous organisations willing to help you. These include:

National Kidney Federation [www.kidney.org.uk](http://www.kidney.org.uk)

Polycystic Kidney Disease Charity [www.pkdcharity.org.uk](http://www.pkdcharity.org.uk)

NHS Blood and Transplant <http://www.organdonation.nhs.uk/>

British Kidney Patient Association [www.britishkidney-pa.co.uk](http://www.britishkidney-pa.co.uk)

Kidney Research UK [www.kidneyresearchuk.org/home.php](http://www.kidneyresearchuk.org/home.php)

Donor Family Network <http://donorfamilynetwork.co.uk/>