

Multi-professional Criteria for Monitoring Implementation of the National Service Framework for Renal Services

Part One: Dialysis and Transplantation

Published on behalf of

Association of Renal Industries • Association of Renal Managers • Association of
Renal Technologists • British Association for Paediatric Nephrology •
British Association of Social Work • British Dietetic Association • British
Psychological Society • British Renal Society • British Transplantation Society •
EDTNA/ERCA • National Kidney Federation • RCN Nephrology Nurses Forum •
Renal Association • Renal Pharmacy Group • Royal College of Physicians •
Society for DGH Nephrologists

Contents

Section		Page
	Foreword	4
	Preface from the National Kidney Federation	6
	Members of the editorial panel	8
	Members of the British Renal Society Peer Review Committee	9
	Contributors	9
	Acknowledgements	9
1	Why do we need “Criteria for Success”?	10
2	Characteristics of “Criteria for Success”	13
3	<ul style="list-style-type: none"> ▪ How to use “Criteria for Success” 	15
4	<p>The Criteria</p> <ul style="list-style-type: none"> ▪ Standard 1: All children, young people and adults with chronic kidney disease are to have access to information that enables them with their carers to make informed decisions and encourages partnership in decision-making, with an agreed care plan that supports them in managing their condition to achieve the best possible quality of life. ▪ Standard 2: All children, young people and adults approaching established renal failure are to receive timely preparation for renal replacement therapy so the complications and progression of their disease are minimised, and their choice of clinically appropriate treatment options is maximised. ▪ Standard 3: All children, young people and adults with established renal failure are to have timely and appropriate surgery for permanent vascular or peritoneal dialysis access, which is monitored and maintained to achieve its maximum longevity. ▪ Standard 4: Renal services are to ensure the delivery of high quality clinically appropriate forms of dialysis which are designed around individual needs and preferences and are available to patients of all ages throughout their 	17

	<p>lives.</p> <ul style="list-style-type: none"> Standard 5: All children, young people and adults likely to benefit from a kidney transplant are to receive a high quality service which supports them in managing their transplant and enables them to achieve the best possible quality of life. 	
5	Patient surveys	46
6	References	47

Foreword

Part One of the National Service Framework for Renal Services¹ (Renal NSF) was published in January 2004. This contained modules which addressed issues in dialysis and transplantation. Part 2, the publication date of which is expected to be in 2005, is concerned with the prevention of kidney failure, the interface between acute, primary and secondary care and end-of-life issues.

In keeping with the government's strategy document "Shifting the Balance of Power", which outlines the move towards a more decentralised service with devolvement of responsibility for planning and procurement of services to a local level, the Renal NSF did not include measurable targets, nor did it promise additional "earmarked" resources. The thirty "Markers of Good Practice" which are associated with five "Standards" in the NSF are, for the most part, subjective and thus open to differences in interpretation. While this makes the service vulnerable to postcode variations, as it has been for many years, the renal community has previously proved itself adept at developing mechanisms to counterbalance this threat.

This document has been produced on behalf of the entire renal community and has been endorsed by the Kidney Alliance. It contains "Criteria for Success" which can be used to evaluate success in meeting the standards of care implied, but not defined, by the Renal NSF. It will also have a role in informing the commissioning of renal services and identifying good practice for dissemination to the wider renal community.

The editorial panel would like to acknowledge the earlier work done by the British Renal Society Peer Review Committee which has worked on multiprofessional service standards for some years. Their work has been included in this document. We also recognise the work of the Kidney Alliance which introduced the concept of Service Standards in its 2001 document, "End Stage Renal Failure – A Framework for Planning and Service Delivery"².

Many criteria were suggested by the individual members of societies. Others were adopted from existing sources including the Renal Association³ and British Transplantation Society⁴ standards documents and the Cardiology⁵, Diabetes⁶ and Children's⁷ National Service Frameworks. Other key resources include the National Renal Workforce Plan⁸ and the Transplant Framework for England – Saving Lives, Valuing Donors⁹.

Commissioners and managers are advised to read “The NSF for Renal Services: An Implementation Toolkit for Commissioners based upon best practice” which is available on the Department of Health web site (www.dh.gov.uk). This document provides further information and advice about renal commissioning and gives a context for use of these Criteria.

We were keen to involve patients in the production of these criteria and the National Kidney Federation was involved from the start. Many hundreds of potential criteria were collated, assessed and refined by the editorial panel to produce this document. This final version was subject to extensive public consultation prior to publication.

This document deals with part 1 of the Renal NSF. It is anticipated that further criteria will be developed by the same process to accompany part 2 of the Renal NSF when it is published next year.

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Preface From the National Kidney Federation

We are delighted to see the publication of Criteria for Success, a document which is designed to give providers of renal services the tools they need to judge their performance against the “markers of good practice” outlined in the Renal NSF. The National Kidney Federation (NKF) campaigned hard, through the Kidney Alliance, for a national service framework for renal services. We were pleased to be intimately involved in its preparation and warmly welcomed its publication in January 2004. At the same time we expressed our concern that, in keeping with the evolution of government policy from centrally set targets to local decision-making, the Renal NSF lacked the “measurables” necessary to benchmark the service. For years the NKF, which represents over 60 local kidney patients associations (KPAs), has been aware of worrying postcode variations in standards of treatment and access to the full range of services which people with chronic kidney disease require to live with dignity while carrying the burden of their illnesses. We are acutely aware that the price of local decision-making and the lack of targets could potentially be the continuation or even worsening of these postcode variations.

While the Renal NSF has undoubtedly raised the profile of the service and the document is being tabled at commissioning meetings up and down the country, the NKF has become aware that it is an incomplete tool in itself. What is missing is an interpretation of its vision and broad recommendations by patients and professionals into locally applicable measures and targets. The British Renal Society (BRS) was quick off the mark to set about this task. The Society, which represents the whole multidisciplinary provider team, was well placed to gather together affiliated society leads and patients to contribute to this exercise on behalf of their associations. Through the Kidney Alliance, the umbrella body representing patients, the professions, charities and industries involved in renal services, the BRS has been able to engage the whole renal community in this initiative and secure its support.

As patients and carers we value this coordinated, joined-up working through our Alliance and see it as a major strength in our quest for a fair and just service. We congratulate the BRS on this outstanding work and we commend this document to you.

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Acknowledgments

We are grateful to Patti and John Monkhouse and Dee Silver of the BRS secretariat who provided the administrative support for this project.

1 Why do we need “Criteria for Success”?

1.1 The Renal NSF may be used by commissioners, health professionals and patients in four related but discrete areas

- **Commissioning renal services** – commissioners will need clear measurable criteria with which to frame contracts and monitor service delivery.
- **Assessment/accreditation of renal units** – this will be the responsibility of strategic health authorities and the Healthcare Commission. Their assessments will need to be based upon measurable parameters.
- **Audit and continuous quality improvement** – it is essential that clinicians can measure their performance to identify areas that require attention and to determine trends.
- **Education** – it will be important to identify good practice so that this can be disseminated through educational visits, publications and presentations at meetings.

1.2 The Renal NSF contains 5 standards linked to 30 markers of good practice. These markers indicate broadly the components required to deliver effective renal care but do not define precisely what facilities are required or what outcomes are expected. For instance, the fifth marker for standard 4 reads: “Efficient patient transport available”. Until we define the elements that constitute efficient patient transport we cannot assess whether a service is satisfactory or compare one service with another.

1.3 Many organisations representing patients, renal professionals, commissioners and the government have an interest in the provision of renal services (Table 1). Each of these organisations will wish to use the Renal NSF for different but easily defined purposes encompassing one or more of the areas listed above.

Table 1

Government Organisations with an interest in the NSF for Renal Services
Department of Health
Healthcare Commission
NHS Information Authority
Strategic Health Authorities
Primary Care Trusts

Patient Organisations with an interest in the NSF for Renal Services
British Kidney Patient Association
National Kidney Federation
National Kidney Research Fund

Professional Associations with an interest in the NSF for Renal Services
Association of Renal Managers
Association of Renal Technologists
British Association for Paediatric Nephrology
British Association of Social Workers / Renal Special Interest Group
British Dietetic Association / Renal Nutrition Group
British Renal Society
British Transplant Society
EDTNA / European Renal Care Association
RCN Nephrology Nursing Forum
Renal Association
Renal Pharmacy Group
Royal College of Physicians
Society for DGH Nephrologists
UK Transplant Co-ordinators Association

Others with an interest in the NSF for Renal Services
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Association of Renal Industries

Kidney Alliance

The Renal Association UK Renal Registry

- 1.4 Accreditation of service providers and commissioning requires the development of “minimum” standards for service which define the lowest acceptable level of care. These standards can be used to identify and eliminate very poor practice but may lead to reduction of average performance towards the lowest common denominator. Continuous quality improvement, audit and education require aspirational or “gold” standards, which define a vision for the service and enhance best practice.
- 1.5 There is a danger that each of these organisations will develop their own targets to measure performance against the Renal NSF and there will be poor distinction between minimum and gold standards. This will lead to duplication of effort, confusion and geographical variations in services.
- 1.6 The criteria contained in this document have been developed and approved by all the professional bodies and patient organisations involved in renal service provision in England. They provide a consensus view from the whole renal community of what facilities and outcomes are needed if renal units are to meet standards contained in the Renal NSF.

2 Characteristics of Criteria for Success

- 2.1 The Renal NSF was intended primarily to improve standards of care for renal patients. Thus the criteria contained in this document are “gold” standards, which define the type of service we should try to achieve. Care has been taken to make the criteria realistic and achievable by most units in the medium term. We anticipate that as the quality of renal services improve these criteria will eventually come to be seen as minimum standards and will be replaced by new, even more challenging aspirational targets.
- 2.2 Criteria should have SMART characteristics. They should be (S)pecific, (M)easurable, (A)chievable, (R)elevant and (T)ime limited. These characteristics have been used widely in industry to define processes with considerable benefit.
- 2.3 There are many standards and targets already available in renal medicine. The Kidney Alliance set a framework for planning and service delivery in end stage renal failure in its 2001 document². The Renal Association Standards³ and British Transplantation Society Standards⁴ have been widely adopted as templates for good practice in the UK. Several other individual professional organisations in the UK and overseas have produced their own standards. These are not always consistent: the Renal Association standards for haemoglobin and the use of EPO differ from those used in Europe and in the United States. The consensus view at the start of this project was that existing national guidance produced by UK organisations should be incorporated without modification. Revisions of the standards contained in future editions of UK national guidance will automatically replace the relevant criteria in this document.
- 2.4 Other documents which relate directly to the criteria include the BRS National Renal Workforce Plan⁸ and Saving Lives, Valuing Donors – a Transplant

Framework for England⁹. Care has been taken to ensure that the criteria are consistent with the recommendation contained in these documents.

- 2.5 The editorial panel was conscious of the burden of data collection on service providers and where possible the criteria were written to take advantage of existing data sources such as the Renal Association UK Renal Registry. Nevertheless there will be a requirement for some additional data collection which will need to be undertaken locally in the first instance. In future it may be possible for the Renal Registry to collect additional information to support implementation of the Renal NSF.
- 2.6 The patient experience is central to the Renal NSF and feedback from patients is essential for monitoring its implementation. This document contains patient satisfaction questionnaires which can be used to obtain this feedback.
- 2.7 Advances in medical knowledge and technology mean that patient and staff expectations will change over time. While the Renal NSF sets out a vision for renal services over the next 10 years, these criteria will have a much shorter shelf life. It is expected that they will need to be updated every two to three years to keep pace with the changing healthcare environment.

3 How to use Criteria for Success

- 3.1 The criteria are intended primarily for use by renal units to examine their facilities, service and outcomes in relation to the vision provided by part 1 of the renal NSF. How this is done will vary from unit to unit depending on local experience, resources (particularly IT) and preferences. We anticipate that units will audit performance against each of these criteria at least once a year. This may be done piecemeal or all at once. Identified areas of underperformance may need more frequent assessment.
- 3.2 Feedback from patients will be an important part of the evaluation. The editorial panel has commissioned a series of patient questionnaires (see section 5), which can be used to collect this feedback from specific patient groups including pre dialysis, haemodialysis, peritoneal dialysis and transplant patients. The questions relate only to part 1 of the NSF. These core questions should not be modified, in order to allow comparison of performance between units. Further questions can be added to collect other information for local use.
- 3.3 While local audit can identify areas of underachievement it does not of itself lead to an improvement in performance. Units will need to develop action plans for changes in practice.
- 3.4 Local audit may also identify areas of excellent performance resulting from innovative practice which should be shared with the wider renal community. Mechanisms for sharing good practice are currently inefficient and need to be improved if we are to realise the full benefit of using the criteria. Consideration needs to be given to developing comparative audit, peer review and educational meetings and to publication of audit results in journals and on the World Wide Web. Developing collaboratives is one of the most effective tools in spreading improvement.

3.5 Some criteria highlight the need for new resources such as patient educational materials and care planning documentation. There is scope for these to be developed centrally, rather than piecemeal by individual renal units. We have indicated in the comments column where we feel that a centralised approach is appropriate or we are aware that such work is under way. The British Renal Society will track these developments and publish progress reports on the web site (www.britishrenal.org) to prevent duplication of effort.

4 The Criteria

<p>STANDARD ONE: All children, young people and adults with chronic kidney disease are to have access to information that enables them with their carers to make informed decisions and encourages partnership in decision-making, with an agreed care plan that supports them in managing their condition to achieve the best possible quality of life.</p>			
<p>Marker of good practice</p> <ul style="list-style-type: none"> • Provision of high quality, culturally appropriate and comprehensive information and education programmes. 			
<p>Criteria for success</p>		<p>Aspiration</p>	<p>Evidence</p>
<p>Patient information - variety of presentation styles</p>	<p>Patients can access information which is appropriate to their needs. This may include written, audio tape, internet or video.</p>	<p>Suitable materials available</p>	<p>There is scope to commission development and distribution of such materials at a national level.</p>
<p>Patient information – language</p>	<p>Access to independent interpreters as required.</p>	<p>Patient Survey Patient Survey Unit Checklist</p>	
<p>Patient information - range of topics covered for all groups of patients</p>	<p>A wide range of information is encouraged but should include as a minimum the following core topics:</p> <p>Introduction to the unit including operational information and contact information</p> <p>Understanding renal illness including implications for physical, social and psychological well being and treatment options (including conservative/palliative management)</p> <p>Promoting good health including recognising and responding to symptoms, effective use of medicines, treatments, diet and fluid regimens, smoking cessation and exercise.</p> <p>Understanding the psychological and social impact of renal disease on the patient and their wider networks, the treatments and</p>	<p>Materials available</p>	

	developing strategies to adapt. This will include details of local and national support groups, and access to support and information on social, vocational/educational and financial issues related to renal illness, as well as access to psychological support. Patient satisfaction with presentation format, range, language and cultural content			
Patient information – quality		Patient Survey	Units may wish to refer to The Plain English Society for endorsement of any materials	
Patient information - patient involvement		Evidence of patient input, including patient representation on the education programme Materials available		
Where appropriate separate information is available for children and young people Education programmes – core involvement		Programme timetable		
Education programmes – range of topics covered	The multi-professional staff should be included and represented in the education programme, a minimum should include Doctor, nurse, Renal Dietician, Renal Pharmacist, Renal Social Worker and an existing patient (as above) A wide range of educational programmes are encouraged but should include as a minimum the core topics. listed under patient information – see above	Programme timetable Patient Survey		
Education programmes – patient groups covered	Programmes should be available for pre-dialysis, haemodialysis, peritoneal dialysis and transplant patient groups All patients should have access to the internet and appropriate assistance, which includes user instructions and links to useful web sites	Programme timetable		
Internet access		Available	The Renal Information Exchange Group is currently developing a system called Patient View which allows patients to access their own blood results and other personal clinical information over the internet.	

Criteria for Success

<p>STANDARD ONE: All children, young people and adults with chronic kidney disease are to have access to information that enables them with their carers to make informed decisions and encourages partnership in decision-making, with an agreed care plan that supports them in managing their condition to achieve the best possible quality of life.</p>			
<p>Marker of good practice</p> <ul style="list-style-type: none"> Education programmes tailored to the needs of the individual. 			
<p>Criteria for success</p> <p>Patient experience of personalised education programmes</p>		<p>Aspiration</p> <p>All patients/carers/parents confirm they were encouraged to identify their information needs.</p>	<p>Evidence</p> <p>Patient survey</p>
<p>Personalised information</p>		<p>All patients confirm their understanding of the information / education was checked and the information adjusted as appropriate until they understood it.</p>	
<p>Flexibility of programmes</p>		<p>Individualised information is held by all patients (if they wish) in relation to the core topics listed above</p> <p>Variation in programme delivery to suit different patient groups</p>	<p>Materials available</p> <p>Patient Survey</p>

Criteria for Success

STANDARD ONE: All children, young people and adults with chronic kidney disease are to have access to information that enables them with their carers to make informed decisions and encourages partnership in decision-making, with an agreed care plan that supports them in managing their condition to achieve the best possible quality of life.

Marker of good practice

- Individual care plans, regularly audited, evaluated and reviewed.

Criteria for success		
Aspiration	Evidence	Comment
<p>Care plans - availability</p> <p>All patients have a written (paper or electronic) individualised care plan which identifies their health, including physical, psychological & social care needs, how they will be met and who will be responsible for meeting them</p> <p>Patients should have copies of letters sent to GP following a clinic appointment, if desired</p> <p>All patients with other long term conditions requiring care plans will have complementary/integrative care plans agreed with the other service(s)</p> <p>Care plans are available for patients to take with them when transferring units or when going on holiday</p> <p>All patients will confirm their care plan is regularly discussed with them within a partnership model</p> <p>All care plans will have a review date not longer than a year</p>	<p>Audit of Care plans</p> <p>Patient survey</p>	<p>Standardised documentation for care plans could be developed at a national level.</p>
<p>Audit and review</p> <p>Care plans should be reviewed within 1 week of a significant change of circumstances, such as a change of dialysis modality or change of social circumstances</p> <p>Every patient will be given a named contact for their renal care needs</p>	<p>Audit of care plans</p> <p>Patient Survey</p>	
<p>Transitional care for adolescents</p> <p>All paediatric and adult units should have a written policy dealing with the transitional care of children to adult care</p> <p>The policy should include⁷</p> <ul style="list-style-type: none"> • Evidence of a coordinated transfer process with identification of named co-ordinator, primary health care and social care involvement • Age guidelines for timing of transfer • Preparation period and education programme with written information. • Process for supported transition with choice for young person • Measures to monitor process and outcomes for young person 	<p>Policy available</p>	

STANDARD ONE: All children, young people and adults with chronic kidney disease are to have access to information that enables them with their carers to make informed decisions and encourages partnership in decision-making, with an agreed care plan that supports them in managing their condition to achieve the best possible quality of life.

Marker of good practice

- Access to a multi-skilled renal team whose members have the appropriate training, experience and skills.

Criteria for success	Aspiration	Evidence	Comment
Training, experience and skills	<p>Annual appraisal for all members of the multi-professional team</p> <p>All of the multi-professional team have a Personal Development Plan</p> <p>The renal team utilises the Skills for Health renal skills and competencies framework within the staff appraisal system</p>	Documentation available	We recommend that units undertake an annual skills and competencies audit linked to workforce planning, individual appraisals and PDPs
Patient experience	<p>All patients report satisfaction with access to appropriately skilled staff in all disciplines</p>	Patient survey	
Professional paediatric skills available for children	<p>For paediatric units, additional specialist skills should cover child development; parents as partners, resuscitation, use of medicines, child protection, news breaking, pain management and care of parents after the death of their child⁷</p> <p>For paediatric units, all children should have access to skills of:</p> <ul style="list-style-type: none"> • Paediatric renal trained nurses • Paediatric nephrologist, paediatric surgeon, transplant surgeon • Paediatric dietitian • Paediatric clinical psychologist • Play specialist • Paediatric social worker • Paediatric pharmacist • Teacher 	<p>Availability of courses</p> <p>Evidence of training</p> <p>Audit against recommendations of BAPN review of services 2003¹⁰</p>	

<p>STANDARD ONE: All children, young people and adults with chronic kidney disease are to have access to information that enables them with their carers to make informed decisions and encourages partnership in decision-making, with an agreed care plan that supports them in managing their condition to achieve the best possible quality of life.</p> <p>Marker of good practice</p> <ul style="list-style-type: none"> For children and young people, meeting the standards of <i>Getting the right start: National Service Framework for Children, Young People and Maternity Services</i>. 			
<p>Criteria for success</p> <p>Patients and carers given appropriate information'</p>	<p>Aspiration</p> <p>Guidelines exist to enable information to be provided in terms of whether it is valid, relevant, up to date, timely, understandable, developmentally, ethically and culturally appropriate.</p> <p>A range of communication methods is used about specific conditions, medicines, procedures, services and support groups in a variety of formats, media and languages.</p> <p>All copies of letters sent to carers and/ or young person if requested/desired</p> <p>Option of audio recording of consultation offered</p>	<p>Evidence</p> <p>Examples of material available</p> <p>Local audit</p> <p>Audit of copy letters</p>	<p>Comment</p>
<p>Staff receiving appropriate training</p>	<p>Staff should have the training on communication skills covering:</p> <ul style="list-style-type: none"> How to communicate with parents and children in an age and developmentally appropriate manner Providing factual, non directive information on renal conditions, management and outcome to allow informed choice 	<p>Audit of training</p>	
<p>Documented admission plans</p>	<p>Planned admissions will be preceded by developmentally appropriate preparation and information including the option of a ward visit'</p>	<p>Patient Survey</p>	

Criteria for Success

STANDARD TWO: All children, young people and adults approaching established renal failure are to receive timely preparation for renal replacement therapy so the complications and progression of their disease are minimised, and their choice of clinically appropriate treatment options is maximised.

Marker of good practice

- Referral to a multi-skilled renal team, where possible at least one year before the anticipated start of dialysis treatment, for appropriate clinical and psychological preparation. This principle should also be followed for people with a failing transplant.

Criteria for success	Aspiration	Evidence	Comment
Range and numbers of members of the predialysis team	Appropriate numbers of trained nurses, dieticians, pharmacists, nephrologists, social workers, transplant co-ordinators, educators, psychologists and counsellors	Compare to the BRS Workforce document ⁸ /BAPN review 2003 ¹⁰	This may vary between units depending upon the model used to deliver the service. It is not possible to give precise figures for staffing levels
Timely referral to the pre dialysis team	All patients known to the unit, begin predialysis education at least 12 months before starting dialysis treatment.	Audit date first seen by nephrologist, predialysis team and start of RRT.	
Infrastructure	Availability of : <ul style="list-style-type: none"> • Locally agreed protocols regarding the pathway for pre-dialysis patients • Regular multi-professional meetings where pre-dialysis patients are discussed • Patient information (reference Standard 1) • Designated team member(s) responsible for pre dialysis care 	Protocols available Minutes available Materials available	

STANDARD TWO: All children, young people and adults approaching established renal failure are to receive timely preparation for renal replacement therapy so the complications and progression of their disease are minimised, and their choice of clinically appropriate treatment options is maximised.

Marker of good practice

- Accelerated process with intensive input from the renal team for those who present late to renal units or as acute uraemic emergencies.

Criteria for success	Aspiration	Evidence	Comment
Accelerated process with intensive input available	<p>Patients who present to the unit less than one year from starting treatment should start pre dialysis education within one month of first attendance</p> <p>Patients who require immediate dialysis at presentation should still receive appropriate information about treatment options, as well as the psychological and social issues as soon as they are well enough to receive it</p>	<p>Audit date first seen by nephrologist, predialysis team and start of RRT.</p> <p>Audit of care plan</p>	

STANDARD TWO: All children, young people and adults approaching established renal failure are to receive timely preparation for renal replacement therapy so the complications and progression of their disease are minimised, and their choice of clinically appropriate treatment options is maximised.

Marker of good practice

- People with ERF given information about all forms of treatment so that an informed choice can be made.

Criteria for success	Aspiration	Evidence	Comment
Infrastructure	<p>Pre-dialysis education and information programme available to all patients. This should include the involvement of patients receiving renal replacement therapy</p> <p>Educational materials available – see Standard 1</p> <p>Record in the care plan the patient education delivered, preferred choice of dialysis modality and modality ultimately started</p> <p>Patients feel that they receive adequate information and, where appropriate, a free choice of treatment options.</p>	<p>Patient Survey</p> <p>Audit of care plans</p>	<p>In the absence of evidence that any form of dialysis is best in the majority of patients, a free choice of dialysis modality should be allowed unless there are clear medical indications</p>
Patient experience		Patient Survey	

STANDARD TWO: All children, young people and adults approaching established renal failure are to receive timely preparation for renal replacement therapy so the complications and progression of their disease are minimised, and their choice of clinically appropriate treatment options is maximised.

Marker of good practice

- Patients put on the national transplant list within six months of their anticipated dialysis start date if clinically appropriate.

Criteria for success	Aspiration	Evidence	Comment
Patients listed within six months of anticipated start date	All patients should be assessed and if suitable, are put on the transplant list within six months of their dialysis start date	Audit date first seen by the unit, date first registered with UKT and date of first RRT	

Criteria for Success

STANDARD TWO: All children, young people and adults approaching established renal failure are to receive timely preparation for renal replacement therapy so the complications and progression of their disease are minimised, and their choice of clinically appropriate treatment options is maximised.

Marker of good practice

- Anaemia treated to maintain an adequate haemoglobin level.

Criteria for success	Aspiration	Evidence	Comment
Adequate haemoglobin levels	All adult patients approaching established renal failure should achieve a haemoglobin of more than 10 g/dl within 6 months of being seen by a nephrologist ³	Local Audit	This is based upon current Renal Association targets (see paragraph 2.3). European Best Practice Guidelines suggest a target of 11 g/dl, and many nephrologists in the UK would support this. The RA targets may be updated in 2005-6 in which case the new targets should be adopted.
Infrastructure	Locally agreed protocols for the management of anaemia Availability of erythropoiesis stimulating agents and intravenous iron to all patients who require it	Protocols available	NICE guidance should be available in 2005
Children-adequate haemoglobin levels	All children and young adults approaching established renal failure should achieve the recommended target haemoglobin within 6 months of being seen by a paediatric nephrologist ³	Local Audit	

Criteria for Success

STANDARD TWO: All children, young people and adults approaching established renal failure are to receive timely preparation for renal replacement therapy so the complications and progression of their disease are minimised, and their choice of clinically appropriate treatment options is maximised.

Marker of good practice

- Management of cardiovascular risk factors and diabetes according to the National Service Frameworks for Coronary Heart Disease and for Diabetes.

Criteria for success	Aspiration	Evidence	Comment
Adequate blood pressure control	<p>Patients approaching established renal failure should have a blood pressure less than 140/90</p> <p>In children systolic BP should be maintained at < 90th centile for age gender and height</p>	Audit blood pressure	Adapted from the Renal Association recommendations for patients on dialysis ³ 130/80 is more consistent with guidance from British Hypertension Society, NICE diabetes guidance, NICE essential hypertension & SIGN
Adequate control of diabetes	As described in the diabetes NSF ⁶	HbA1c	
Smoking cessation programme	<p>Access to a smoking cessation programme for all patients who wish to stop smoking</p> <p>Smoking cessation advice should be recorded in the notes</p>	Care plan audit	
Serum Cholesterol	As described in the cardiology NSF ⁵		
Serum phosphate	<p>Patients approaching established renal failure should have a serum phosphate between 0.8 and 1.6 mmol/l</p> <p>All patients should have dietetic education which should include risk factors for coronary heart disease</p>	Audit phosphate	Modified from (K)DOQI guidelines as no UK guidelines exist
Diet		Care plan audit	

Criteria for Success

<p>STANDARD THREE: All children, young people and adults with established renal failure are to have timely and appropriate surgery for permanent vascular or peritoneal dialysis access, which is monitored and maintained to achieve its maximum longevity.</p>			
<p>Marker of good practice</p> <ul style="list-style-type: none"> • Early referral for assessment and investigation for the best means of access, and timely surgery (current best practice being six months before haemodialysis, four weeks before peritoneal dialysis) which enables patients to begin dialysis with their vascular or peritoneal dialysis access established and functioning. 			
<p>Criteria for success</p>			
<p>Timeliness of referral and surgery</p>	<p>All adult patients known to the service have first vascular access surgery at least 6 months before starting haemodialysis</p> <p>All adult patients known to the service have a peritoneal dialysis catheter placed at least 4 weeks before starting peritoneal dialysis therapy.</p> <p>In children peritoneal dialysis catheters should be allowed to “rest” for up to four weeks prior to usage.</p> <p>67% of new adult patients presenting within 3 months of the start of dialysis should start with functioning permanent access (AV fistula, graft or PD catheter)³</p> <p>80% of existing adult haemodialysis patients have functioning permanent access (AV fistula or graft)</p>	<p>Aspiration</p>	<p>Evidence</p> <p>Audit date first seen by nephrologist, date of access surgery, date started RRT, first dialysis modality and type of access at start.</p> <p>Record type of access used for each dialysis</p>
			<p>Comment</p> <p>In children, long-term dialysis by a cuffed double lumen catheter may be appropriate</p> <p>DOPPS shows that these levels are achievable in France, Germany, Italy and Spain</p>

STANDARD THREE: All children, young people and adults with established renal failure are to have timely and appropriate surgery for permanent vascular or peritoneal dialysis access, which is monitored and maintained to achieve its maximum longevity.

Marker of good practice

- Monitoring and early intervention to minimise complications of the access.

Criteria for success	Aspiration	Evidence	Comment
Monitoring	Presence of a surveillance programme monitoring dialysis access performance.	Programme in place	Many different methods have been advocated and there is currently no consensus as to which is best
Infrastructure	24 hour emergency surgical cover for failed vascular access. Urgent radiology and surgery (within 1 week) for problem access identified through the monitoring programme Emergency surgical cover (within 24 hours) for removal of infected peritoneal dialysis catheters	Audit access failures; surgical and radiological interventions and their success rates	

STANDARD THREE: All children, young people and adults with established renal failure are to have timely and appropriate surgery for permanent vascular or peritoneal dialysis access, which is monitored and maintained to achieve its maximum longevity.			
Marker of good practice			
<ul style="list-style-type: none"> Recording and regular auditing of the type of access in use at the start of dialysis, time from referral to surgery, and complication rates for each procedure. Temporary access replaced by permanent access as early as possible. 			
Criteria for success	Aspiration	Evidence	Comment
Recording/audit in place	Recording and audit of: <ul style="list-style-type: none"> Type of access used for every dialysis session Waiting time from referral to surgery Primary surgical patency rates for AV fistulae Primary surgical patency rates for PD catheters Surgical complications Cancelled operations with reason for cancellation Rate of line related sepsis (including MRSA) calculated in episodes per month per 100 haemodialysis patients(adults) 	Audit results and annual action plans	
Timeliness	No patient on dialysis should wait more than 4 weeks for access surgery	Audit results	DOPPS shows this is achievable in France, Germany, Italy and Spain
Children	Children have a dialysis access line infection rate of less than 1 in every 12 patient months averaged over 3 years ³ All paediatric units should audit catheter malfunction rates exit site and tunnel infections ³	Audit results	

Criteria for Success

STANDARD THREE: All children, young people and adults with established renal failure are to have timely and appropriate surgery for permanent vascular or peritoneal dialysis access, which is monitored and maintained to achieve its maximum longevity.

Marker of good practice

- Proper training for patients, carers and members of the renal team in the care of the access.

Criteria for success	Aspiration	Evidence	Comment
Information	All patients receive individualised information on care of their dialysis access (see standard 1)	Patient Survey	
Protocols	Protocols exist for care of temporary and cuffed dialysis lines, arteriovenous fistulae and peritoneal dialysis catheters	Protocols exist	
Patient experience	Protocols exist for the management of access infections Patients are satisfied that they have received adequate education about care of their access	Patient survey	

STANDARD THREE: All children, young people and adults with established renal failure are to have timely and appropriate surgery for permanent vascular or peritoneal dialysis access, which is monitored and maintained to achieve its maximum longevity.

Marker of good practice

• For children and young people: Dialysis access surgery to follow the principles set out in *Getting the right start: the National Service Framework for Children, Young People and Maternity Services – Standard for Hospital Services*.

Criteria for success	Aspiration	Evidence	Comment
Patient /parent experience	Children should be given the option of all dialysis modalities	Patient survey	
All appropriate staff involved in preparation	Children should be appropriately prepared for procedures according to their age and developmental needs	Patient survey/audit	
Paediatric experience in all	Surgeons and anaesthetists must have specific paediatric training	Audit	
Comply with recommendations of children's NSF recommendations on pain ⁷	Children should have <ul style="list-style-type: none"> • Appropriate prevention, assessment and treatment of pain especially after procedures <p>There should be</p> <ul style="list-style-type: none"> • Protocols for safe use of pain controlling medicines • Appropriate training of staff in management of pain • Regular audit of pain management 	Protocol for pain management	
Procedure related anxiety	Procedure related anxiety assessment and interventions available from the clinical psychologist and play specialist as needed	Audit results	
Achieve standards	Annual audit against Renal Association standards for dialysis access should be recorded at least once per year.	Patient survey	
		Audit results	

Criteria for Success

<p>STANDARD FOUR: Renal services are to ensure the delivery of high quality clinically appropriate forms of dialysis which are designed around individual needs and preferences and are available to patients of all ages throughout their lives.</p>				
<p>Marker of good practice</p> <ul style="list-style-type: none"> All dialysis methods available interchangeably for patients, including home haemodialysis and automated peritoneal dialysis. 				
<p>Criteria for success</p> <p>Availability of modalities</p>		<p>Aspiration</p> <p>Hospital, satellite and home haemodialysis, CAPD and APD are all available to patients when medically appropriate.</p> <p>All patients receive their first choice of dialysis modality as agreed in Care Plan.</p>	<p>Evidence</p> <p>Care plan audit</p>	<p>Comment</p>

Criteria for Success

<p>STANDARD FOUR: Renal services are to ensure the delivery of high quality clinically appropriate forms of dialysis which are designed around individual needs and preferences and are available to patients of all ages throughout their lives.</p> <p>Marker of good practice</p> <ul style="list-style-type: none"> • Patients receive an adequate and effective dialysis dose. 			
Criteria for success	Aspiration	Evidence	Comment
<p>Adequate dialysis achieved</p>	<p>Every patient receiving thrice weekly haemodialysis should show: either urea reduction ratio >65% or equilibrated KT/V of >1.2³</p> <p>Peritoneal dialysis patients should receive a weekly creatinine clearance of > 50 l/week/1.73 m² or a weekly KT/V urea of > 1.7³</p> <p>Renal Association standards³ should be achieved for serum: Bicarbonate Calcium Phosphate Parathyroid hormone Albumin Potassium Aluminium</p> <p>95% of haemodialysis should receive thrice weekly treatment³</p> <p>All units should comply with Renal Association guidelines³ for the production of pure water for haemodialysis and with standards for dialysis equipment and disposables</p> <p>Haemodialysis concentrate should contain bicarbonate buffer³</p>	<p>Renal Registry plus local audit results</p>	<p>Achieving Renal Association standards for biochemical parameters requires more than just adequate dialysis. Dietary interventions, appropriate use of drugs and patient compliance are also important.</p> <p>Children with residual renal function may be dialysed with a URR <65%³</p>

Criteria for Success

<p>STANDARD FOUR: Renal services are to ensure the delivery of high quality clinically appropriate forms of dialysis which are designed around individual needs and preferences and are available to patients of all ages throughout their lives.</p> <p>Marker of good practice</p> <ul style="list-style-type: none"> Peritonitis rates to be less than one per 18 patient months for adults undergoing peritoneal dialysis, one per 14 patient months for children. 			
<p>Criteria for success</p> <p>Peritonitis rates</p>	<p>Aspiration</p> <p>All patients use a disconnect system³</p> <p>Peritonitis rates should be less than 1 episode per 18 patient months for adults and less than 1 episode per 14 patient months for children³</p> <p>The negative peritoneal fluid culture rate in patients with clinical peritonitis should be less than 15%³</p> <p>The initial cure rate of peritonitis should be greater than 80% (without necessitating catheter removal)³</p>	<p>Evidence</p> <p>Record and audit episodes of peritonitis, culture results and cure rates</p>	<p>Comment</p>

Criteria for Success

STANDARD FOUR: Renal services are to ensure the delivery of high quality clinically appropriate forms of dialysis which are designed around individual needs and preferences and are available to patients of all ages throughout their lives.			
Marker of good practice			
• Patients have their nutritional status monitored and appropriate nutritional support in place.			
Criteria for success	Aspiration	Evidence	Comment
Nutritional status monitoring	<p>All adult patients new to dialysis are seen by a renal dietician within one month of starting dialysis</p> <p>All adult dialysis patients have an annual nutritional assessment including weight, mid upper arm circumference and triceps skin fold thickness. The nutritional status of dialysis patients should be recorded and audited against <i>Renal Association Standards</i></p> <p>All paediatric patients new to dialysis are seen by a renal dietician within one week of starting dialysis</p> <p>All children should have a full nutritional assessment every 3 months including weight, height, mid upper arm circumference and triceps skin fold thickness. Puberty Status should be recorded regularly</p> <p>Numbers of dieticians comply with BRS Workforce Planning guidelines⁸</p> <p>MDT meetings include discussion of nutritional support</p> <p>Food should be available for all patients away from home more than 6 hours.</p> <p>Written patient information is available – see Standard 1</p> <p>Protocols exist for dietetic referral and for follow up of nutritionally at risk patients.</p>	Local audit	
Infrastructure		Staff survey	
		MDT minutes	
		Local audit	
		Information available	
Protocols		Protocols available	

Criteria for Success

STANDARD FOUR: Renal services are to ensure the delivery of high quality clinically appropriate forms of dialysis which are designed around individual needs and preferences and are available to patients of all ages throughout their lives.			
Marker of good practice			
• Efficient patient transport services available.			
Criteria for success	Aspiration	Evidence	Comment
Efficient transport	All patients travelling by hospital transport should arrive within 30 minutes of their starting time for dialysis and should be picked up within 30 minutes of finishing dialysis Patients should not travel for more than 30 minutes unless by choice Patients travelling independently should receive free car parking close to the dialysis unit Patients should be satisfied with the transport services available to them	Local audit Patient survey Patient survey Patient survey Care plan audit Guidelines exist	This may be impractical in some rural areas and for paediatric services.
Patient experience	A documented transport plan should be agreed with each patient Local guidelines should be available to determine which patients are eligible for hospital transport.		
Eligibility for hospital transport			There is scope to develop a National consensus on eligibility for transport to prevent inequity of access.

Criteria for Success

<p>STANDARD FOUR: Renal services are to ensure the delivery of high quality clinically appropriate forms of dialysis which are designed around individual needs and preferences and are available to patients of all ages throughout their lives.</p> <p>Marker of good practice</p> <ul style="list-style-type: none"> Specialist renal staff, equipment and care available throughout admission, whatever the setting, for patients with established renal failure admitted to hospital. 			
Criteria for success	Aspiration	Evidence	Comment
Specialist staff available	<p>Appropriate numbers of nephrologists, nurses, access surgeons, dieticians, renal social workers, clinical psychologists, renal counsellors, clinical technologists and teachers</p> <p>Discharge planning should include assessment of patients social care needs and a carers assessment if appropriate</p> <p>Children with ERF should be transferred to a Paediatric Renal Unit</p> <p>Lines of communication with members of the renal team are published and available to all hospital staff</p> <p>Emergency haemodialysis available 24 hours in hospitals with a renal service</p> <p>24 hour emergency contact with a nephrologist by telephone</p> <p>Emergency transfer of inpatients to a specialist renal centre within 24 hours when necessary</p>	<p>Audit against BRS Workforce Planning document⁸/BAPN review 2003¹⁰</p> <p>Local audit</p> <p>Local audit</p>	
Equipment and staff available			
Facilities for patients admitted to hospitals without a renal service			

<p>STANDARD FIVE: All children, young people and adults likely to benefit from a kidney transplant are to receive a high quality service which supports them in managing their transplant and enables them to achieve the best possible quality of life.</p> <p>Marker of good practice</p> <ul style="list-style-type: none"> • Early provision of culturally appropriate information; discussion with and counseling of patients, relatives and carers about the risks and benefits of transplantation with a clear explanation of tests, procedures and results. 			
Criteria for success	Aspiration	Evidence	Comment
<p>Appropriate information</p>	<p>Patients should be placed on, or removed from the transplant waiting list only after discussion with transplant surgeons, nephrologists and the patient themselves. The decision should be recorded in the care plan⁴</p> <p>Patients on the transplant waiting list should have their fitness for transplantation reassessed every 12 months</p> <p>Patients/carers should receive culturally and age appropriate information on the risks and benefits of transplantation including the risks of infection and malignant disease</p> <p>All non-English-speaking patients being counselled about risks and benefits of transplantation should have availability of translator services</p> <p>Visually impaired patients to have information available in large print and audio tape</p> <p>All patients should receive specific and written information regarding the use of marginal donors, and indicate their willingness to receive a kidney from a marginal donor⁴ (Not applicable for children)</p> <p>Units undertaking a non heart beating donor programme should have a written protocol that identifies local practice based on national guidance⁴.</p>	<p>Review of Care plan</p> <p>Audit suspensions and activations</p> <p>Patient survey</p> <p>Information available</p>	

Criteria for Success

STANDARD FIVE: All children, young people and adults likely to benefit from a kidney transplant are to receive a high quality service which supports them in managing their transplant and enables them to achieve the best possible quality of life.

Marker of good practice

- Application of a national matching scheme using criteria agreed through UK Transplant to optimise blood group and tissue matching for kidneys from deceased donors.

Criteria for success	Aspiration	Evidence	Comment
Optimal matching	<p>All transplant units participate in national or local alliance matching schemes⁴</p> <p>Screening for pre- and post transplant antibodies must be in accordance with BTS Standards guidelines⁴</p> <p>A consultant led and accredited histocompatibility service is an essential part of a successful kidney transplant programme⁴</p> <p>Each renal transplant team should achieve annually 13.6 cadaveric and 6.2 living donors pmp⁴</p> <p>In children, centres should aim for 60% of kidneys to be favourably matched³</p> <p>Children with low matchability points (1-5) should only receive a favourably matched kidney unless there are exceptional circumstances</p> <p>Kidneys from donors < 5 years and > 55 years should not be used in children³</p>	Local audit and UKT data	

STANDARD FIVE: All children, young people and adults likely to benefit from a kidney transplant are to receive a high quality service which supports them in managing their transplant and enables them to achieve the best possible quality of life.

Marker of good practice

- Effective preventive therapy to control infections.

Criteria for success	Aspiration	Evidence	Comment
CMV prevention	All transplant units to have an agreed and written policy for the prevention of post-transplant CMV infection ⁴	Presence of policy	
Prevention of infections	Children should have received childhood vaccinations as stipulated by the Department of Health. Units should have a protocol for vaccination of children pre transplantation	Local audit	

STANDARD FIVE: All children, young people and adults likely to benefit from a kidney transplant are to receive a high quality service which supports them in managing their transplant and enables them to achieve the best possible quality of life.

Marker of good practice

- Timely operating theatre availability to ensure optimal cold ischaemia times.

Criteria for success	Aspiration	Evidence	Comment
Ischaemia times	The cold ischaemia time should be below 24 hours in 90% of cases ⁴ The time between receipt of a negative cross match and the time of transplant commencement, should be less than 4 hours ⁴	Local audit	Where possible cold ischaemic times should be below 21 hours – recent BTS data

<p>STANDARD FIVE: All children, young people and adults likely to benefit from a kidney transplant are to receive a high quality service which supports them in managing their transplant and enables them to achieve the best possible quality of life.</p> <p>Marker of good practice</p> <ul style="list-style-type: none"> • Appropriate immunosuppression and anti-rejection treatment in accordance with forthcoming NICE guidance and effective monitoring and treatment to minimise the risks of adverse effects of immunosuppressive treatment. 			
Criteria for success	Aspiration	Evidence	Comment
Appropriate immunosuppression treatment	<p>Each transplant unit should have a written, agreed immunosuppressive policy⁴</p> <p>All adult patients undergoing renal transplantation should receive initial treatment with an Interleukin-2 receptor blocker¹¹</p> <p>Adult patients should only receive mycophenolate mofetil or rapamycin where indicated in line with NICE guidance¹¹</p> <p>Steroid avoidance or minimization protocols should be adopted wherever possible</p> <p>In children – centres should be encouraged to enter children into prospective randomised clinical trials to assess the efficacy of immunosuppressive agents³</p>	<p>Presence of policy</p> <p>Local audit</p>	NICE guidance only applies to adults at present

STANDARD FIVE: All children, young people and adults likely to benefit from a kidney transplant are to receive a high quality service which supports them in managing their transplant and enables them to achieve the best possible quality of life.

Marker of good practice

- Clear explanation for patients of tests, procedures and results, and especially information and education about anti-rejection therapy.

Criteria for success	Aspiration	Evidence	Comment
<p>Patient experience</p>	<p>All patients/carers report that they have tests and investigations clearly explained to them</p> <p>All patients/carers should be given verbal and written information about their anti-rejection medications in a format that they understand</p>	<p>Patient survey</p> <p>Materials available</p>	

STANDARD FIVE: All children, young people and adults likely to benefit from a kidney transplant are to receive a high quality service which supports them in managing their transplant and enables them to achieve the best possible quality of life.

Marker of good practice

- Specialist advice from the transplant team available for patients with a renal transplant admitted to hospital, whatever the setting.

Criteria for success	Aspiration	Evidence	Comment
<p>Range of specialist advice available to transplant patients</p> <p>Availability of specialist medical staff</p>	<p>Nephrologist, transplant surgeon, specialist nurse, pharmacist, dietician, social worker, psychologist, counsellor, play specialist (children) available for inpatients and outpatients in the base hospital</p> <p>On the transplant ward – within 12 hours</p> <p>On other wards in the hospital – within 24 hours.</p> <p>In other hospitals – advice by telephone within 12 hours</p> <p>For emergencies</p> <p>24 hour immediate availability in transplant centres and 24 hour telephone advice in other hospitals</p>	<p>Staff available</p> <p>Local audit</p>	

STANDARD FIVE: All children, young people and adults likely to benefit from a kidney transplant are to receive a high quality service which supports them in managing their transplant and enables them to achieve the best possible quality of life.			
Marker of good practice			
• Organ procurement and transplantation to follow the principles set out in <i>Saving Lives, Valuing Donors: A Transplant Framework for England</i> .			
Criteria for success	Aspiration	Evidence	Comment
Effective organ procurement	<p>All transplant Centres participate in UK Transplant Potential Donor Audit</p> <p>Centres should review and audit organ retrieval procedures to ensure that the donor and their relatives are treated with respect and that organ and tissue removal is performed in a dignified manner</p> <p>Each acute hospital trust should identify an individual with responsibility for organ and tissue donation to work with Critical care Networks and Regional Co-ordinator Teams</p> <ul style="list-style-type: none"> • All units should: • Undertake annual local patient surveys to ensure that staff are sensitive to the psychological and emotional needs of donors, their relatives and family, and that they have access to appropriately trained support • Ensure that donors and their families know where to go for more information • Use transplant coordinators as a link between donor family and the recipient where appropriate 	<p>Data returns</p> <p>Local audit and patient survey</p> <p>Protocols exist</p> <p>Individuals identified</p> <p>Patient survey</p>	<p>All covered in <i>Saving Lives, Valuing Donors</i>⁹</p>
Patient centred care	<ul style="list-style-type: none"> • All units should: • Undertake annual local patient surveys to ensure that staff are sensitive to the psychological and emotional needs of donors, their relatives and family, and that they have access to appropriately trained support • Ensure that donors and their families know where to go for more information • Use transplant coordinators as a link between donor family and the recipient where appropriate 	<p>Patient survey</p>	<p>All covered in <i>Saving Lives, Valuing Donors</i>⁹</p>
Success rates	<p>All transplant units should audit their outcomes against BTS agreed standards⁴</p> <p>Major complications should occur in less than 1% of live donors⁴</p>	<p>UKT data</p> <p>Local audit</p>	
Graft Failure	<p>In the event of graft failure every effort should be taken to refer the patient, at an appropriate time, to the pre dialysis information and education programme to ensure they receive support and information regarding treatment options, social and psychological implications</p>	<p>Audit of referral to pre dialysis team</p>	

Criteria for Success

5 Patient Satisfaction Surveys

These are currently under construction and should be available by the end of 2005.

6 References

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- 4) British Transplantation Society. Standards for solid organ transplantation in the United Kingdom. London, 2003
- 5) Department of Health. The National Service Framework for Coronary Heart Disease. London 2000
- 6) Department of Health. National Service Framework for Diabetes. London, 2001
- 7) Department of Health. National Service Framework for children, young people and maternity services. London, 2004
- 8) National Renal Workforce Planning Group. The Renal Team: A Multi-professional Renal Workforce Plan for Adults and Children with Renal Disease. British Renal Society, 2002
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- 11) The National Institute of Clinical Excellence. Renal transplantation - immuno-suppressive regimens (adults) (No. 85) London: The National Institute of Clinical Excellence, 2004