

European Renal Best Practice (ERBP)

A Paper for Patients

1. General Introduction.

The prime function of ERBP is to provide evidenced based information for: nephrologists, physicians and other health care professionals to enhance the care of patients with kidney disease. The ERBP advisory board gathers the evidence from published clinical trials and, using the expertise of specialists in the relevant subject areas, produces recommendations on what to do in certain clinical situations and makes judgements on grading the quality of evidence that these recommendations are based on.

This process inevitably influences those physicians who follow ERBP guidance appropriately and as a consequence, impacts on the treatment of the patients they care for. On this basis alone, there is an obvious relevance to patients and for this reason ERBP has decided to edit their published work and present it in a form accessible to patients.

2. The history of kidney disease guidelines development

“In 1997, the National Kidney Foundation (NKF) in the USA established the Dialysis Outcome Quality initiative (**DOQI**) which produced clinical practice guidelines in four areas: haemodialysis adequacy, peritoneal dialysis adequacy, vascular access and the management of anemia. Subsequently, guideline development was extended to the management of non-dialysis-dependent kidney disease, and the name of the program was changed to the Kidney Disease Outcomes Quality Initiative (**KDOQI**).

In 1999, the European Renal Association and European Dialysis and Transplant Association (**ERA-EDTA**) initiated the European Best Practice Guidelines (**EBPG**) and most National Nephrology Associations also produced guidelines for best practice <http://www.era-edta.org/page-8-38-0-38-erbpeuropeanrenalbestpractice.html>

KDIGO (Kidney Disease Improving Global Outcomes) was founded in 2003 to establish global nephrology guidelines on a worldwide basis and coordinate the development of the clinical practice guidelines of different international organizations in the field of kidney disease. However the number of topics and necessary updates were too large to be dealt with by KDIGO alone. In 2006 KDIGO decided to concentrate on selected topics only. http://www.kdigo.org/pdf/Eckardt_NatRev_2009.pdf This presented an opportunity for European and other bodies to take a more active role in the formulation of nephrology recommendations.

3.Can patients use ERBP guidelines to improve their understanding of their treatment?

The format of advice promulgated by the ERBP advisory board is intended for use in circumstances that require professional training and judgement. But this should not be used as an excuse for restricting the information on which such advice is based to the professionals alone. To judge whether an individual patient should be treated in a particular way will depend

on many factors and a myriad of variations. A treatment plan is ultimately agreed by the interaction of the physician and patient in the context of a consultation, taking into account not only the scientific/medical reasoning but also quality of life issues. Although the arguments that underpin guidance may be complex, its conclusions should be clear and accessible to patients in language that members of the general public will find easy to understand so that they can evaluate the impact of certain decisions on their life in a holistic way. This paper is ERBP's attempt to fulfil that requirement. Fully informed patients are more likely to become willing partners in the management of their illnesses.

4. Patients will expect their nephrologist or physician to take heed of guidelines and guidance published by internationally recognised bodies such as KDIGO and ERBP.

Patients believe that their doctors, nurses and health care professionals will have the knowledge, skills, attitudes and ethical standards expected of those professions. This guarantee is provided, primarily by the registration of professional qualifications and the issuing of licences to practice by the relevant statutory authorities in each country or state. Patients will also want to know if the statutory authorities expect their professional members to be cognisant of the most up to date guidance relevant to their stated specialty. But to demand that physicians slavishly follow guidance misunderstands the nature of clinical practice. Guidance is to inform and not to direct. Clinical practice involves judgements that enable the choices and decisions that doctors take, in conjunction with patients, to be based on verifiable evidence and modified according to individual circumstances.

5. The Pitfalls of Guideline development

The aim of guideline development is to improve patient care and outcomes by:

- i) Reviewing the results of clinical research in order to derive recommendations for diagnosis and therapy
- ii) Identifying gaps in knowledge in order to prioritize which research questions will generate new knowledge.

However patients should be aware of the pitfalls that can occur in producing guidelines.

i) Professional medical societies have frequently considered guideline development as one of their tasks, but they have not always established robust methodologies, transparent rules and policies, nor provided sufficient resources for their development.

ii) Industry has promoted guideline development in areas related to their products, which can result in 'guideline publication bias', by producing many clinical practice guidelines in commercially attractive areas but few in other areas that, although equally or even more important from a clinical perspective, are less commercially attractive.

iii) The objectivity of any guidelines may be questioned if there is any association by members of guideline work groups with industry

iv) **Inappropriate performance measures** can be developed if insurance or health authorities derive these measures from clinical guidelines that have themselves been based on weak or limited evidence.

6. How are topics selected?

The selection of topics for guideline development is a critical component of the process. KDIGO has held conferences to this end on a wide range of subjects since 2004. ERBP has decided to focus on literature reviews and the development of position statements rather than clinical practice guidelines, in order to complement the work of KDIGO.

The ERBP Board's priority is to update existing 'guidelines' rather than create new recommendations. Maintaining outdated 'ghost guidelines' is not desirable. KDIGO's role is more concerned with the coordination and generation of traditional guidelines and less with issuing position statements.

7. ERBP's current statements and guidance

A. General Statements

ERBP has issued 2 general statements about the nature of its work:

- i) It is the intention for European Guidelines to be issued only when evidence has been searched for by a structured, in depth and transparent process, otherwise they will be termed 'recommendations' or 'position statements' and published in a different format from Guidelines. As high levels of evidence are often lacking in nephrology, it was decided to change the name of the responsible body from: (EBPG) **European Best Practice Guidelines** to (ERBP) **European Renal Best Practice**.
<http://ndt.oxfordjournals.org/content/23/7/2162.full>
- ii) The second general statement answered the question 'Is there still a place for an institution generating European Nephrology Guidance?'
<http://ndtplus.oxfordjournals.org/content/2/3/213.full>

**Appendix A: How do I know if a recommendation is really well-established?
I don't want to agree to something and then find it is not the best treatment.**

B. Specific Statements

ERBP has addressed a number of 'specific clinical' topics by issuing 'position statements' and 'clinical advice'. The appendices listed in this section contain the edited versions of the original ERBP papers and links to the original full statements. To facilitate a patient's search for information relevant to a particular clinical problem, each appendix has a title in the form of a question that may be commonly asked:

Appendix i) What should my Hemoglobin be?
<http://ndt.oxfordjournals.org/cgi/content/full/24/2/348>

Appendix ii) What does Hepatitis C mean to me as a CKD patient?

<http://ndt.oxfordjournals.org/cgi/content/short/gfn608v1>

Appendix iii) Are High Flux dialysers better for me than Low Flux ones?

<http://ndt.oxfordjournals.org/cgi/content/full/gfp626v1>

Appendix iv) Are venous catheters safe in terms of Blood Stream Infection? What should I know?

<http://ndtplus.oxfordjournals.org/cgi/content/full/3/3/234> and
<http://ndt.oxfordjournals.org/cgi/content/full/gfq205v2>

Appendix v) Why is it important to regularly test the function of my Peritoneal Membrane if I am on PD?

<http://ndt.oxfordjournals.org/cgi/content/full/gfq100v1>

Appendix vi) What sort of dialysis should I choose?

<http://ndtplus.oxfordjournals.org/cgi/content/full/3/3/225>

8. Other matters of concern to patients affecting outcomes of care:

The aim of Best Practice for health care professionals (HCPs) must be to improve patient outcomes in clinical practice. However there are aspects of service provision that may not be wholly dependent on the clinical actions of doctors and HCPs. European Renal Best Practice could legitimately seek evidence to express opinions on such non-clinical matters.

8 i) Access to Care

The importance of early diagnosis of renal impairment is well documented. Good public health information will raise awareness in the general population. Most professional bodies and National Health Service providers have published evidence on this topic, <http://www.cks.nhs.uk/patient-information/leaflet/kidney-disease-chronic>. Screening programmes can identify affected individuals although there is a debate regarding the cost-effectiveness of so doing. <http://www.evidence.nhs.uk/search.aspx?t=kidney+disease&am=%5B%7B%22ain%22%3A%5B%22+public+health+%22%5D%7D%5D>

Access to high quality primary care services will facilitate early detection. Access to specialist services for diagnosis and management is dependent on the number and distribution of these secondary care services in the health care systems of each EU member state. Such access will be impeded by a scarcity of specialists and long distances between the specialist unit and the patient's home. This is directly related to the financing of the services whether by the state, health insurance companies, or individual patients.

8 ii) Range and Choice of Services

Specialist nephrology services, in addition to providing a diagnostic facility will monitor patients and offer interventions where appropriate. Choice is of prime importance if patients are to receive optimal care. The choice may be between: the modality of dialysis (haemodialysis and PD); the location for dialysis (Hospital; satellite and home dialysis); the scheduling of dialysis (to

fit in with work, educational, social and holiday requirements); or between dialysis and Active Supportive Care (formerly referred to as conservative or palliative care). For many the treatment of choice is Transplantation but this is dependent upon the supply of donor kidneys as well as the suitability of the recipient. A choice can be made to remain on a waiting list for a deceased donor kidney or to seek a live donation from a relative or friend, or even to participate in a paired or pooled donation scheme. There may be a choice between accepting a less than optimum functioning kidney and staying on the waiting list for a better kidney.

To help patients make such choices, sound evidence on the pros, cons and outcomes of each option must be provided.

8 iii) Information on the quality of services

Information about the process and outcome of renal services is important to patients. For example, the renal National Service Framework (UK) 2004, sets out (in figure 5, Chapter 2 Page 17), 5 standards and 30 markers of good practice for the providers of renal services to aim for and against which commissioners (the funders of NHS services) can measure performance.

The UK Renal Registry publishes detailed information about each renal unit in the UK <http://www.renalreg.com/index.html> This is of interest to patients and enables them to know how their own renal unit is performing <http://www.kidney.org.uk/Medical-Info/your-renal-unit.html>

9. Conclusion

The information promulgated by European Renal Best Practice is as important to patients and their carers as it is to the HCPs who advise them. However professional guidance is often couched in terms that require professional training and knowledge for it to be understood and applied. To ensure that the information itself is more widely known, the conclusions and advice of European Renal Best Practice Advisory Board, as summarised in this paper, are presented in language that the general reader will find acceptable.