



UK Renal Registry

Information Protocol: British Kidney Patient Association/UK Renal Registry Patient Information Leaflets

Document Ref:	M006/
Review Date:	September 2019

Protocol

This Protocol should be read in conjunction with *UK Renal Registry Information Production System (IPS)* which contains the scope and commitment by the UK Renal Registry to the Information Standard. In addition each product will be commissioned using the Renal Association commissioning contract. During each stage of production the Editorial Board (EB) will ensure compliance with the IPS and Information Standards. The information process map & check list is available as appendix A.

Product Aims and Purpose

The British Kidney Patient Association (BKPA) is a well-established charity working to improve the quality of life for adults and children with kidney disease.

They provide:

- Information and advice for those with kidney disease
- Grants to help patients and families with kidney disease, cover the costs of domestic bills, hospital travel, education and holidays
- Financial support to kidney units throughout the UK to help improve kidney services and patient care

The BKPA are working with the UK Renal Registry to provide a series of leaflets aimed at patients and family members on a variety of kidney-related topics. The work is overseen by the Renal Association's Patient Information Subcommittee which aims to develop and maintain a high quality patient information resource for use by kidney doctors, patients, families and carers in the UK.

Target Audience

The specific target audience for the leaflets varies depending on the topic but in general they are aimed at patients, family members and carers of those with kidney problems, as well as the general public who are interested in kidney health.

Choice of Media Type

The choice of media is determined by the information to be conveyed and the target audience of that product. The patient information leaflets will be made available on the BKPA and UKRR's websites, with paper copies available upon request. The variety of media type ensures that the information is made accessible to different demographics of patients and carers.

Sources of Information, Research & Referencing

Each product is researched and referenced according to the guidelines set out in Section 10 of the Information Production System. Information is largely provided by clinicians involved in the Renal Association Patient Information Programme, following extensive literature searches to identify existing information sources on the selected topics.

The programme itself is designed to fill the current knowledge gap in regards to a selection of topics relating to kidney health. The clinical experts involved in producing patient-focused information are writing with authority using their own experience and hypotheses. They will also check any new primary research such as recent clinical developments.

Peer Review

All of the patient information leaflets are peer-reviewed by Dr Rebecca Suckling, Chair of the Renal Association Patient Information Subcommittee. They are also reviewed by the BKPA's Editorial Board, which include patient representatives.

Governance

The governance structure consists of Dr Rebecca Suckling, Chair of the Renal Association Patient Information Subcommittee, Paul Bristow, BKPA Director of Marketing and Communication and Ron Cullen, Chief Executive of the UKRR. Information products are produced in association with external communication and branding consultants.

Date of Publication

The first meeting of the Renal Association's Patient Information Subcommittee was held in June 2016. The first leaflets will be produced by November 2016. A Product Gap Analysis will be undertaken every three years unless there is a major re-write in the meantime.

Training

The training of EB members will be logged within HR department of UK Renal Registry. The training and training requirement of Authors (see below) will be logged within the HR department of the UK Renal Registry

Editorial Board

The Editorial Board (EB) has responsibility for the product structure, design and content and the ultimate responsibility for product compliance with Information Standards is the Chair of the Editorial Board. It will operate according to the procedures laid down in the Information Standard. The EB will actively seek high value external sources of information and obtain agreement to link to or display such information for the readership. The EB is responsible for auditing the product, responding to feedback from users and dealing with complaints.

The EB will ensure that all authors complete the Commissioning Contract before any work can be produced.

The Renal Association's Patient Information Programme's Editorial Board consists of Rebecca Suckling at Committee Chair, Paul Bristow as BKPA Director of Marketing and Communication and Melanie Dillon as Project Manager, as well as patient representatives from the BKPA's Editorial Board.

Direction to Further Information

Within the product there will be clear references regarding other sources of information. These references will include helplines, patient support groups and other publications and websites.

Finances

The Renal Association's Patient Information Programme has sufficient funding and resources in place to ensure continued adherence to the Information Standard.

Potential Conflicts of Interest

The policy for handling potential conflicts of interest is set out in the RA IPS.

Third Parties

Virtual Pudding act as the web designers for the UKRR's website. While they may be asked to upload a patient information leaflet, they are not responsible for the content or a part of the editing process.

Auditing patient information

The Editorial Board is responsible for auditing material produced for patients and carers. The Board undertakes to select items for auditing, and will cover approximately 10% of all the information.

A member of the Renal Registry Senior Management Team (or their nominated person) with the support of the Editorial Board will conduct quarterly self-audit of the product (ensuring that all pages of large products or websites are audited at least every 3 years). Corrective action must be completed within 28 days of the audit report. The audit report will be made available to the UKRR Director and Karen Thomas (programme manager) in Workshare. On completion of the work it will require re-validation which will be verified by Karen Thomas. In the event of a non-conformity the remedial action will be authorised by Karen Thomas (product authority) and signed off in the Change Request Log.

Documentation

All documentation will be stored in line with the IPS.

Approved By:

	Authority	Signature	Date
Approved by:			
Review Date			

Process Map for Information Products

