UK Renal Registry
Information Production System

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Appendices

1. Introduction

The UK Renal Registry (UKRR) is part of the Renal Association, a not for profit organisation registered with the Charity Commission and is recognised as having one of the very few high quality clinical databases open to requests from researchers. The UKRR collects analyses and reports on data from 71 adult and 13 paediatric renal centres.

The data is published annually in the UK Renal Registry Annual Report. The report is used by a variety of stakeholders but its principle purpose is to act as a source of data for audit and benchmarking against the quality of care standards created by the Renal Association and other organisations.

The UKRR predominately produces information for professionals and researchers in renal care but has recently expanded to include information for the general renal communities to include, but not exclusive to, membership of patient groups such as British Kidney Patients Association and National Kidney Federation. This means that Information produced by the UKRR will now have different readerships. The specific aims of the products will be described within the Product Protocol but the intent is that all products, where appropriate for the product, will include recommendations on best practice in the planning, initiating and withdrawal of treatments as well as information on available treatment options and where possible, will link to the objectives relating to renal replacement therapy described within the National Service Framework for Renal Services which was published by the Department of Health.

This document is to be used by staff and volunteers who are involved with the production of patient information.

2. Policy Statement

The UKRR aims to provide good quality information for those seeking further information on renal care and other kidney related diseases. Information is produced for the benefit of patients, families, carers, medical professionals, researchers and other interested parties. This policy is specifically aimed at, information produced for patients, families and carers.

As part of the NHS Five Year Forward View we are expected to empower patients to become more involved in making decisions about their care. Information produced by the UKRR will help to enable informed decision making when discussing their care and treatment with medical professionals and is seen as an essential part of the overall quality of the patient experience.

The UKRR is fully committed to adopting the Information Standard, and to ensure the criteria set by the Information Standard scheme are met and will adhere to strict guidelines by adopting rigorous methods and systems to make sure that information is:

- Clear
- Relevant
- Evidence-based
- Authoritative
- Complete
- Secure
- Accurate
- Well-designed
- Readable
- Accessible
- Up-to-date

The UKRR commits to:

1. producing high quality information using the greatest expertise of its members and associates,
2. ensuring that within the scope of this policy information produced will meet the requirements of the Information Standard
3. reviewing all information products for continued suitability and renewing them as appropriate
4. ensuring that all those involved with the production of information are aware of and comply with the policy and the requirements of the Standard
5. maintain records to demonstrate compliance with the policy.

This policy statement is fully accessible and available for all those involved in the production of information and is available via Workshare, a secure on-line document depository used by the UKRR.

3. Resourcing Information Standards

The UKRR takes the development of patient information seriously and it forms a key element of the UKRR 5 year plan. These plans are translated into annual business plans which are funded from a capitation fee paid for by units undertaking dialysis. The need to submit data to the UKRR is part of all Kidney Units service specification resulting in a reliable funding stream. It is the intention of the UKRR to produce more patient facing material and they are currently in funding discussions with NHS England to develop a whole series of Kidney Patient Focussed Outcome Measures.

The Patients Council will help to steer its strategic development and priorities and responsibility for patient focussed measures with responsibility allocated to a single post which will help the UKRR in general to sustain the Information Standard.

4. Scope

The UKRR provides various pieces of Information for professionals, patients, families and carers these are made up in various media types according to need. The following types are those generally recognised as in scope with the Information Standard, but individual information products within each type may be excluded. Please refer to List of IS Products held in Workshare for further details.

- Public Websites
- Information Leaflets
- Reports
- Posters
- Webcasts
- Newsletters

This scope does not apply to external linked information referred to in our publications or websites.

5. Implementation Plan

The UKRR has been producing information for several years and is in the process of reviewing existing processes to ensure they conform to the Information Standard recommendations. Existing products will be migrated to the new system over the next three years, but all new products will follow these guidelines from the start. A roll-out plan with timescales for this work is attached as Appendix 1.

6. Responsibilities & Authorities

The UKRR will be responsible for the implementation and roll out of the Information Production System (IPS). A chart showing the management structure for the IPS is found in Appendix 2

Authorities for the IPS will lie with the Director of the UKRR, all changes to the IPS will need approval from the Director of the UKRR.

6.1 Identified Staff and Volunteers

Each Information Product will have a named person who will take responsibility for ensuring the end product complies with the recommendations set by the UKRR in the IPS, this person will be identified alongside other staff and volunteers in the Product Protocol.

6.2 Documentation

All documents and records will be managed by the UKRR in its offices in Bristol. Shared documents will be stored in Workshare, a secure on-line document depository available to staff and volunteers from the other partner groups at any time. All documents relating to the IPS and product protocol will be subject to document version control. Only the most current version will be made available with old versions archived within Workshare. Full details for version control within the UKRR can be found in Workshare in the Registry Policies and Procedures folder.

6.3 Staff Awareness and Training

The UKRR is committed to ensure that staff and volunteers involved in the information process are aware of the Policy Statement within the IPS, and the criteria set by the Information Standard.

Methods to inform staff will include but not be exclusive to:

- During induction of new staff members
- Team meetings
- National events – i.e. Informatics Meeting and Annual Audit
- Staff briefings
- In-house training
- Product Specific Events
- Webinars

A record of all training, meetings and minutes will be filed in Workshare.

7. Product Criteria

All information products must comply with the following criteria and the evidence recorded in the relevant documents.

- The information is consistent with up-to-date clinical evidence, medical research and social research.
- The product is presented in the most appropriate format for the specified audience
- Any related conflict of interest is disclosed.
- Each product has a consistent layout
- There is a clear distinction between personal opinion and evidence-based information.
- Sources of evidence are accessible or signposted by providing contact details, hyperlinks direct to the evidence source or listed as part of the product information.

- If necessary the product contains specific navigation aids such as contents lists, indexing and search facilities.
- Any advertising or sponsorship is clearly identified.
- Details where to get further information e.g. help-lines, support groups or websites
- A review date of the information product (maximum 3 years from the publication date or previous review)
- Date of the publication of the information product

In addition each product containing specific disease information shall include:

- The nature of the condition
- Treatment options
- Benefits of the treatment
- Risks of the treatment
- Alternatives to the treatment including the option not to treat

8. Record Keeping

All documentation will be managed using the UK Renal Registry Document and Version Control Procedure which is located in Workshare/Registry Policies and Procedures folder.

In addition all documents will be filed electronically in Workshare. Archived documents and source information, where possible, will be stored electronically and backed up regularly to prevent loss. Archived documents and source data are to be archived for a minimum of 5 years.

Authors will be permitted to keep their own systematic review documents and referencing information but it must be documented within the commissioning contract held in Workshare.

9. Product Protocol

Each product will have its own product protocol which will include the following:

- Commitment to follow the IPS policy
- Aim and purpose of the product
- Details of the target audience and how it was selected
- Choice of media type and the reason for that choice
- Main source of information and/or research evidence and referencing method used
- Detailed information of the process from start to end – flow charts can be used
- Process and/or Editorial Board logs to ensure the product is verified, validated, monitored and reviewed
- Information on the roles and responsibilities of the production team & editorial board and who they report to
- A list of all the products within a suite of products i.e. website
- Frequency and method of Self Audits
- Process review date
- Commitment to comply with the product criteria listed in this document
- Use of third parties

10. Author and Editorial Responsibilities

All authors are required to complete a commissioning contract (CC) when writing for new products and updating on reviews. This is to ensure that the information provided is consistent with up-to-date clinical evidence and the author has used medical research and social research using a systematic review. Guidelines to conduct a systematic review are available in Workshare/Registry Policies and Procedures.
Evidence can also be based on patients/service users and professional opinion but must be referenced within the product that it is personal opinion within the product.

Where possible, evidence that is used must remain balanced and impartial and acknowledges any uncertainty. It is the responsibility of the Chair for each programme to ensure that, when any changes to the products are made, the overall balance of the content is maintained and any uncertainties with evidence remain acknowledged.

The Commissioning Contract will also include information about:

- the Target Audience (if not already identified within the product protocol)
- Conflicts of Interest
- Information about their literature search
- Peer Reviews

Information obtained from external sources including research will need to be obtained from reliable sources such as the Cochrane Library, NHS Evidence, PubMed, Medline or other peer-reviewed medical journals. Any information used from these sources must be referenced in the information product using Harvard principles or other similar referencing methodology, where information is a direct quote from the publication it must be referenced with name of the book, article, or other resource; the name of its author; information (if applicable) about the journal it came from; the date it was published and when it was accessed if it was read online.

Each product must have an editorial board and a defined editorial process. This process must include evaluation or review by either the UKRR Patient Council or another agreed specialist group such as British Kidney Patients Association or other similar patient groups who represents the target audience for the product. This process must be clearly defined in the PP.

On completion of the product and before publication all products must have a Product Gap Analysis (PGA) undertaken and Final Product Checklist completed before being made available to the public. The Analysis and Checklist must be filed in Workshare.

All existing products created prior to November 2014 will also be required to have the PGA completed before November 2017.

11. Peer Review

Each product will be the subject of peer review of the author. Evaluation and improvement recommendations made by the author's peers will be submitted to the Editorial Board and must be reviewed before any changes are agreed and implemented

12. Third Party Information

All information provided by a third party will need to be evaluated for suitability and relevance to the Information Product.

Third parties will be selected according to need of the product, and the expertise of the group or organisation providing the information and will be recognised either nationally or medically as a 'good' source for information.

If the third party is both suitable and relevant, additional checks will need to be undertaken to ensure that they are either happy to comply with or have an existing IPS which is in line with the UKRR guidelines for Information Production.

13. Product Reviews

Every product must undertake a full review at least every 3 years to ensure that the product is still relevant and up to date and evidence that this has occurred must be recorded in the Review Log located in Workshare.

To ensure that a full review is undertaken each product will need to be re-commissioned and a commissioning contract will be issued to the product authors. Once the review has been completed by the author it is then submitting to the Product Authorities who will approve:

- the continuation of the product as it currently exists,
- approve any recommended changes
- if not approved authorise its removal from publication.

Upon completion of the changes the product must:

- be submitted to the UKRR patient council or other authorised patient group for final review
- A product gap analysis is completed and submitted to UKRR authorised assessor
- A Final Product Checklist is completed and submitted to UKRR authorised assessor

14. Audit

The UKRR will undertake self-audits in the form of a Product Gap Analysis (PGA).

The PGA will be undertaken on every new product as part of the sign off process and again when the product has had a review.

A master log of all products, their review dates and dates where audit has been undertaken will be maintained by UKRR to ensure these audits have been completed.

Gap Analysis will be completed by one of the following:

- the product owner – if not directly involved as an author or editor
- a nominated person as identified by the product owner

and Assessed by:

- a member of the Registry Business Support Team
- a nominated person as identified by the UKRR Senior Management Team (SMT)

Any non-conformities and corrective work that has been identified in any gap analysis must be actioned within an agreed timescale but no longer than 28 days of date of the report.

Non-conformities and corrective work must be reported to the product authority to agree actions and to sign off when the work has been completed.

In addition non-conformities are also to be reported to the UKRR SMT. On completion of the corrective work the UKRR SMT will need to see evidence that the work has been done satisfactorily and give final sign off to close the work order.

In addition to the PGA the UKRR process will be evaluated and updated at least every 3 years to ensure it remains up to date and relevant.

15. New Products

All new products which provide information for patients, carers and other lay groups, and are to be produced by the UKRR will need to be reviewed by the UKRR SMT and the UKRR Patient Council with final approvals for publication being made by the UKRR SMT.

Applications for new products can be made by any member of the UKRR or the extended renal community via the UKRR Business Support Team or the UKRR patient council, using the form 'New Information Product Proposal'. If the proposal is accepted for production a timescale will be agreed.

All unplanned products will still need to go through the above process but depending on the urgency i.e. press releases it can be fast tracked via email and or phone calls to the UKRR SMT and the chair of the patient council.

16. Product Updates and Corrective Work

All updates and corrective work should conform to the following guidelines.

Where a product requires an update or has been identified as needing corrective work:

- A work request needs to be submitted to the editor or other nominated person for the product and will be managed as defined in the product protocol.
- Any corrective actions will need re-validation to ensure the correction has been completed satisfactorily.
- Timescales for this work will be agreed between the product editor, the author and/or person requesting the update, but should be no longer than 4 weeks.

Any non-conformance issues must be raised using the Information Product Change Request form and must be submitted to the Product Authorities and the UKRR Management Team. Remedial actions should be immediately implemented.

The person responsible for completing the work will be given 28 days, from the day it was identified, to rectify the non-conformance. Upon completion of the work the product will need sign off by the Product Authorities and the UKRR Senior Management Team as well as re-validation by the person who identified the non-conformance.

A support work log will be maintained listing work requests, type of request, urgency, actions required and progress.

17. Feedback and Complaints

All products will clearly display the relevant contact information for feedback and complaints within the product, this should include the point of contact should the reader wish to obtain information about the evidence used within the product, or, in the case of a website a hyperlink to the reference source.

On receipt of any feedback or comment the nominated person for receipt of this information will complete the Feedback and Complaints Log stored in Workshare.

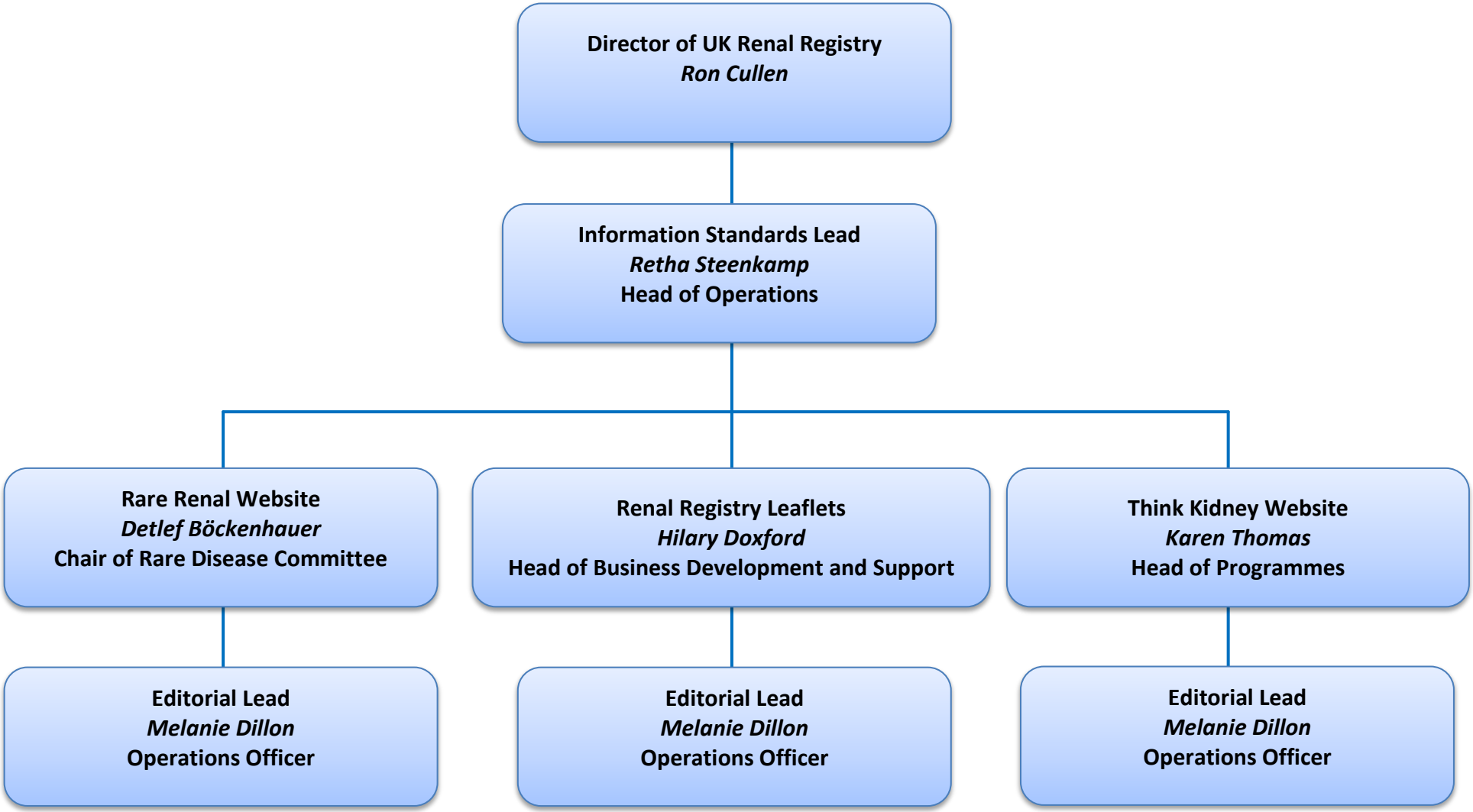
18. Approvals

Prepared by:	**Sue Shaw,** Lead for IS Project; **Melanie Dillon,** RaDaR Operations Officer		
Approved By:	**Ron Cullen,** Director UKRR		February 2017
Next Review Date:	February 2020		

Appendix 1: Roll Out Plan

Phase	Product	Complete By
Year 1	RareRenal Website	Summer 2013
Year 2	UKRR Website	Summer 2014
	UKRR Information Leaflets	
	Information Posters	
Year 3	Think Kidney Website	Summer 2015

Appendix 2: Information Production Systems and Process: Management & Accountability Structure



Appendix 3: Glossary

	Description
Commissioning Contract	Contract of work requirements from the authors
Information Product	Any piece of media information - i.e. leaflets, reports, podcast, press releases etc. Note: Websites are made up of several products (each page is a single product)
Information Production System	UK Renal Registry Process for production of information products
Product Protocol	Individualised process for a single information product or for the process of managing multiple products within a single domain such as a website.
Non-Conformance	a) the product does not comply to the original product specification b) the product process does not comply with the process set by the UKRR c) the product process does not comply with Information Standards
Product Authorities	The named person/persons who are authorised to 'sign off' as senior product manager as defined within the Product Protocol

Appendix 4: Document Control Record

Document Title: Information Production Systems		
Document Description & History: Description of the production system in place within the Renal Association, this includes our compliance with Information Standards Criteria for certification		
Project or Workgroup:	**Date of 1st Issue:** 27/09/2013	**Document Ref No:** M005
Owner/Authorised Signatory: Ron Cullen	**Author:** Sue Shaw Melanie Dillon	**Document Location:** Workshare/ Information Standards

Version Number	Revision Date	Summary of Changes
1.0	27/09/2013	First edition
1.2	27/10/2013	**Add** Resourcing Information Standard Peer Review Product Reviews Commissioning Contracts Template for Protocol Template for Commissioning Contract Systematic Review Process Glossary of terms used **Change** IPs to Product Protocol **Update/Clarify further** New Products to include further information on unplanned products Non-Conformance
2.0	02/11/14	**Change** Renal Association to UK Renal Registry Change introduction to be relevant to UK Renal Registry **Update** Timescales to be relevant to UK Renal Registry only **Add** New product think Kidneys
2.1	12/12/14	**Add** Page 7, section 9 add to include website hyperlink **Update** Reference to appendix 1 changed to view in Workshare Update appendix 2 to 5 references **Delete** Appendix 1
2.2	12/7/15	Reviewed following a review of the process and changes to V2 of the Information Standards a full document review/re-write has been undertaken

Version Number	Revision Date	Summary of Changes
3	24/02/2017	Reviewed following annual Information Standard Assessment. **Add** Page7, section 10 clarifying responsibility of programme Chair to ensure that content balance is maintained following any product revisions **Update** Formatting changes Reetha Steenkamp as Lead for Overseeing IS process rather than Sharece Charles in Appendix 2 **Delete** Mention of Annual Reports as falling under IS scope in Appendix 2