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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.

In addition to the annual report the RR also produces additional information for other professionals, patients and their carers.

Information products will have different readerships and the specific aims will be described in the Information 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. This information, 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.

Information is produced by different work groups under the direction of the Renal Association. Each work group is managed by a committee made up of, but not exclusive to, members of the Renal Association and with the exception of the UKRR are run by volunteers with a special interest in the work group. Not all work groups will be covered by the Information Standard, details of the groups and what is in scope will be described later in this document.

This document is to be used by staff and volunteers who are involved with the Information Production Process, and will give details of the requirements for the production of information within the UKRR and Rare Disease Initiative to be referred collectively as the UKRR for the purpose of this document and its aim to meet the required standards for Information Standards.

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 aimed at, information produced for patients, families and carers. The provision of this information will 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.

The UKRR will adhere to strict guidelines, and by adopting rigorous methods and systems, that information is:

- Clear
- Relevant
- Evidence-based
- Authoritative
- Complete
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 all the information production processes meet the requirement 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.

The UKRR has communicated and will carry on communicating its commitment to the Information Standard scheme to staff and volunteers involved in the process at meetings and other related events. A record of all communications with those involved in producing information will be kept and maintained by the UKRR in the Bristol offices.

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.

3. Resourcing Information Standards:

The UKRR takes the development of patient information seriously and it forms a key element of the 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 for accreditation 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
The 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 adhere to the following 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 RR.

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 (PP).

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 so they are available to staff and volunteers from the other partner groups at any time. All documents relating to the IPS and PP will be subject to document version control. Only the most current version will be made available with old versions archived at the RR. 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
Webinars

A record of all training, meetings and minutes will be maintained by the RR and held in the Bristol offices.
7 Product Specific Documentation:

Each product will have its own protocol, commissioning contracts and logs which will contain 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 and 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

Each author will be issued with a commissioning contract when the product has been approved for production. The commissioning contract will provide detailed information on the target audience, the method chosen to identify the target audience, conflicts of Interest, peer review, evidence searches and any third party involvement.

Templates for the Protocol and Commissioning Contract are available in Workshare and must be completed prior to commencement of production.

8 Product Criteria:

All information products must comply with the following criteria and the evidence recorded in the Protocol and commissioning contracts:

- 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 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
- A Product Quality Check form
• 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

9 Sources of Evidence:

As part of the commissioning contract all products are required to record precise information regarding the evidence source.

All authors are required to check that the information provided is consistent with up-to-date clinical evidence using medical research and social research using a systematic review. A summary of the Systematic Review Process is available in appendix 3. A full detail of the process is available in Workshare/Registry Policies and Procedures.

Evidence can also be based on patients/service users and professional opinion but must be referenced that it is personal opinion within the product.

Where possible evidence that is used must remain balanced and impartial and acknowledges any uncertainty.

Each product will contain details of a point of contact should the reader wish to obtain this evidence or in the case of a website provide a hyperlink to the reference source.

10 Validation and Checks:

All Information obtained from external sources including research will need to be obtained from reliable sources such as the Cochrane Library, NHS Evidence or other peer-reviewed medical journals. Any information used from these sources must be referenced in the information product using Harvard principles, 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.

Information specific to non-medical professionals will need to have an ‘editorial’ process in place; this process will need participation from a patient, a patient representative or a non-medical professional to ensure that the content is both relevant and readable for lay people. The editorial process for each product must be clearly defined in the protocol.

On completion of the product and before publication all products must be checked as fit for purpose using form ‘Product Quality Check’ these must be completed and filed in Workshare. All existing products which were created prior to November 2014 will also be required to have this form completed within the next 12 months.

11 Peer Review:

Each product will be the subject of peer review. The commissioning contract will list all people involved in the peer review process. Evaluation and any continual improvement recommendations will be submitted to the Editorial Board and logged in Workshare.
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, addition checks will need to be undertaken to ensure that they are either happy to comply with or have an existing IPS which conforms to the RA guidelines for Information Production.

13 Record Keeping:

All documentation used in the production of and record keeping for information products 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 current documents will be filed electronically in Workshare.
A record will be maintained at the UKRR offices of all source information, documents with document reference number and review dates.
Any 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.

14 Product Reviews:

Every product must undertake a full review 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 the product will need to be re-commissioned and a renewal of commissioning contract is to be issued to the product authors. In addition the Patient Council will also be required to review the product for relevance and suitability for the given target audience. Once reviewed by the Patient Council the commissioning contract is to be sent to the Product Authorities who will approve the continuation of the product as it currently exists, approve any recommended changes or if not approved authorise its removal from publication.

15 Self-Audit:

The UKRR undertakes to conduct self-audits/reviews at least once a year to ensure that the IPS is implemented and effective and that staff involved in the IPS process are adhering to its guidelines.

Any non-conformities and corrective work that has been identified in the report must be actioned within an agreed timescale but no longer than 28 days of date of the report. On completion of the corrective work the UKRR Senior Management Team (SMT) will need to see evidence that the work has been done and all documents supporting this will be filed in Workshare.
In addition to the annual audits each product team will be required to review their product on a regular basis but no more than 3 years apart to ensure that the product remains relevant, up to date and is still being managed according to the requirements of the IPS. These checks need recording in the UKRR Product Self-Audit log located in Workshare. The methodology used and frequency of the audit will be recorded in the Product Protocol documentation.

The Self-Audit tool, ‘Self-Review Gap Analysis and Assessor RAG Report’ will be stored and managed via Workshare. Any updates to these forms are to be re-loaded back to Workshare where the previous version will automatically be saved for reference.

The UKRR will maintain a register of all Audits and Reviews conducted and by whom.

The following information should be checked during the audit and review:

- Information is consistent and up to date
- Sources are clearly identified
- Date information issued with review dates documented
- Treatment options and outcomes are clearly presented
- The product is relevant to the target audience, aims of the product and the purpose of the product
- Consistent layout throughout
- Conflict of Interest is declared
- Clear distinction between personal opinion and evidence-based information
- Appropriate navigation aids, content lists, indexing and search facilities.
- Any advertising is clearly identified

16 New Products:

All new products which provides information for patients, carers and other non-medical groups, and are to be produced by the UKRR will need to be reviewed by the Patient Council and the UKRR SMT 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 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.

17 Product Updates and Corrective Work:

All updates and corrective work needs to be dealt with using the following guidelines.

Product Updates:
If the product requires an update a new request marked update needs to be submitted to the editor or nominated person for the product and will be managed as defined in the Information Protocol, and will be referenced with the new version number. Timescales for this work will be agreed between the product editor and the author or person requesting the update, but should be no longer than 4 weeks.
Corrective Work:
If errors are identified in the product they should be submitted to the editor or nominated person for the product using the attached form Appendix 4 (Information Product Change Request) and filed using Workshare. Upon completion of the work it must be re-validated to ensure the work has been done satisfactorily and recorded in the Change Request Log.

Non-Conformance:
On identification of any non-conformance it is essential that a Information Product Change Request form is completed immediately. The form then needs submission to the UKRR Management Team and the Product Authorities so that remedial actions can be authorised without any delay. 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 it needs to be submitted for re-validation and will require final sign off by the Product Authorities and the UKRR Senior Management Team.

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

18 Feedback and Complaints:
All products will clearly display the relevant contact information for feedback and complaints within the product.
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.

19 Approvals:

<table>
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<tr>
<th>Prepared by:</th>
<th>Sue Shaw, Lead for IS Project</th>
</tr>
</thead>
<tbody>
<tr>
<td>Approved By:</td>
<td>Authority: Ron Cullen</td>
</tr>
<tr>
<td></td>
<td>Signature: R A Cullen</td>
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Appendix 1.

ROLL OUT PLAN

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NOTE: This structure identifies the Information Product Leads and their line of accountability, each product will have its own accountability structure which is available within the Information Protocol.
Appendix 3

Summary of process for Systematic Review

1. Define the Information required for inclusion in the product
2. Develop a search strategy
3. Define which databases will be used
4. Define specific key phrases or keywords to be used in the search
5. Identify the time period covered by the systematic review
6. Review references cited in reviewed documents but not identified in the original search
7. Action the search based on the above definitions
8. Identify other relevant systematic reviews and use to inform the current systematic review
9. Appraise publications identified as suitable for product content.
10. Review of publications by a 2nd reviewer to establish relevance to the information product
11. Review of publications by a 3rd reviewer (only necessary where disagreements occur between 1st and 2nd reviewers)
12. Document process using Prisma guidelines
13. Record in commissioning contract

Full details are available in Workshare
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Date Completed: 

* Please note this form is on an excel sheet and has drop down list to record answers
## Glossary

### Description

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<td>Commissioning Contract</td>
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<tr>
<td>Information Product</td>
<td>Any piece of media information - i.e. leaflets, reports, podcast, press releases etc. &lt;br&gt;Note: Websites are made up of several products (each page is a single product)</td>
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<tr>
<td>Information Production System</td>
<td>UK Renal Registry Process for production of information products</td>
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<td>Information Protocol</td>
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<tr>
<td>Product Authorities</td>
<td>The named persons within the Information Protocol who are authorised to 'sign off' at senior management level</td>
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## UK Renal Registry

### 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

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<td>Sue Shaw</td>
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- **Change**
  - PSIPP to Protocol

- **Update/Clarify further**
  - New Products to include further information on unplanned products
  - Non-Conformance

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- **Update**
  - Timescales to be relevant to UK Renal Registry only

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### Changes Made

- 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
  - PSIPP to Protocol

- Update/Clarify further
  - New Products to include further information on unplanned products
  - Non-Conformance

- 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
  - 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