UK KIDNEY RESEARCH CONSORTIUM (UKKRC) TERMS OF REFERENCE

The UK Kidney Research Consortium (UKKRC) was established in 2007 by Kidney Research UK and the Renal Association to promote clinical research in adults and children affected by kidney disease. Now jointly hosted and supported by the Renal Association, Kidney Research UK and the British Renal Society, it serves as an advisory group to support the development of a stronger and sustainable research portfolio, aiming to facilitate the best collaborative clinical research for health in kidney disease.

STRUCTURE

**Membership**

**Renal Association**
- President, President Elect, Academic Vice President, Chair-Research Committee, Chief Executive, Chair- Rare Diseases Committee, Medical Director-UK Renal Registry, Representative-Renal SpR Club, President-British Association for Paediatric Nephrology

**Kidney Research UK**
- Chair, Chief Executive, Chair-Research Strategy Committee, Director of Development (Research), Director-Research Operations

**British Renal Society**
- President Elect/Past President, Vice President (Research)

**Others**
- Chairs of the Clinical Study Groups (CSGs) and Networks
- National Lead of NIHR Clinical Research Network Renal Disorders Specialty Group
- Local Leads of the NIHR Clinical Research Network Renal Disorders Specialty Groups
- Representative, Clinical Research Collaboration Cymru
- Representative, Northern Ireland Research Network
- Representative, Scottish Clinical Research Network
- Representatives, Patient Involvement Network
- Representative, National Kidney Federation
- Representative, Kidney Care UK

Rev 1.4 Approved and adopted by the Steering Group 15.11.2018
Steering Group

The operation of the UKKRC is governed by a Steering Group comprising one representative (President or Chair) from each of the three collaborating organisations as well as the Chief Executive of Kidney Research UK. The Steering Group will meet at least annually in November. The current Chair and, when applicable, the nominated next Chair, will be invited to attend the annual meeting in November.

The function of the Steering Group is to:
1. Review the activity and progress of the UKKRC
2. Make strategic decisions regarding the UK Renal Research Strategy
3. Approve nominations for Chair of the UKKRC
4. Agree and review the role description of the Chair.
5. Provide direction to the Chair regarding aims and expectations
6. Review and update the Terms of Reference of the CSGs and Networks
7. Make decisions to add, remove or change CSGs or Networks
8. Make decisions regarding any changes to the Terms of Reference or governance arrangements of the UKKRC

Meetings

Meetings of the UKKRC will be held twice a year in conjunction with the meeting of the NIHR Clinical Research Network Renal Disorders Specialty Group.

Chair

The Chair of UKKRC will rotate biennially at the end of the December meeting of that year between Kidney Research UK, the Renal Association the British Renal Society*. The respective organisation will nominate the Chair at least six months before the handover is due for approval by the steering group.

Structural support and resources

Kidney Research UK provides resources to support the UKKRC structure and the delivery of its objectives including:

- Financial support for UKKRC and CSG/Network meetings
- Support from the Development team including meeting facilitation, as well as advice and guidance to identify strategic objectives and help develop and implement plans for CSGs and Networks
- Provide the secretariat for UKKRC meetings including meeting facilitation, minute taking and circulation.

Clinical study groups (CSGs) and Networks

The CSGs and Networks are the core subgroups of UKKRC and operate to an agreed Terms of Reference (see Appendix A) which will be reviewed biennially by the Steering Group. Their aims are:

CSGs - to identify research priorities and generate a portfolio of high quality clinical studies that can and should be undertaken in the UK for the benefit of kidney patients.
Networks - to support the CSGs and assist investigators in developing research studies.

Approval and Review

These Terms of Reference shall be approved by the Steering Group, considered annually and reviewed every two years at the November meeting.

*June 2019 – Kidney Research UK; June 2021 – British Renal Society; June 2023 – Renal Association (cycle continuing in order)
APPENDIX A: TERMS OF REFERENCE FOR CLINICAL STUDY GROUPS AND NETWORKS

Aims
The aims of the CSGs and Networks are to:

- Generate a portfolio of clinical studies that can and should be undertaken in the UK.
- Co-ordinate and encourage collaborative research activities using multi-disciplinary approaches to contribute to the evidence base necessary to justify the promotion and recommendation of renal research outcomes.
- Encourage, advance and support multi-disciplinary, multi-centre, grant application activity.
- Support translational research, clinical utility and implementation of renal research in the UK.
- Be the first point of reference for evaluation of renal research study protocols, advising on research methodologies and contributing to research boards in the UK.
- Work across all CSGs and Networks to ensure that clinical studies recruit to target and are delivered successfully in the NHS for the benefit of patients.
- Involve patients and carers in the design, delivery and dissemination of renal research by having at least one patient representative in each CSG and Network.
- Form partnerships with industry, potential funders and charity organisations to design quality renal research in the UK and leverage greater funding into the renal sector.
- Generate ideas for new research topics, identify gaps in knowledge and drive innovation in the renal sector.

Membership
Membership should include representation from the multi-professional team and wherever possible include trainees and patient/carer representatives. The maximum term for a CSG chair is three years, with the opportunity to renew for a further three years. The appointment of a new chair should be subject to a formal application and review process, where the position has been advertised within the renal research community. Where possible Co-chairs should be considered. Changes of membership should be reported to Kidney Research UK, and patient representation can be facilitated where needed.

Meetings
Bi-annual face-to-face meetings of each CSG and Network with interim teleconference updates as required. CSG and Network leads will report at each meeting of the UKKRC sharing reports and presentation slides with the UKKRC and secretariat.

Communications
CSGs and Networks will maintain a focus on profiling the excellent track record, future potential and impact of research by working with Kidney Research UK to keep their online presence updated.

Patient Engagement
Where possible CSGs and Networks will embed patients into the core group and work stream activity, maximising opportunities to promote new focus and potential, as well as achievements.