



UK Renal Health Data Research Network (UKRHDRN)

Vacancy for Co-chairs

There is now an exciting opportunity in the early-stage development of a UK Renal Health Data Research Network (UKRHDRN), for the position of two co-chairs, to lead the important work of this group and drive forward research in this area. This network will sit under the auspices of the [UK Kidney Research Consortium \(UKKRC\)](#).

This new network will foster collaboration between researchers working with large datasets to undertake research on kidney diseases, with the ultimate aim of reducing the burden of kidney disease and reducing health inequalities in kidney disease and its treatment.

By enabling better use of health datasets, we can improve renal healthcare now and enable future research discoveries.

The co-chairs will develop a clear roadmap with key milestones in line with agreed goals, driving forward identified workstreams and new projects to accelerate progress in the use of data to improve outcomes for kidney patients.

This network will:

- Draw on expertise from the wider data research community and other stakeholder organisations, including the UK Renal Registry, Health Data Research UK networks and the BHF Data Science Centre to identify gaps in knowledge and explore the potential of data to generate new studies that can and should be undertaken in the UK.
- Undertake research activities to contribute to the evidence base in line with the UK Renal Research Strategy and its recommendations for renal research outcomes.
- Undertake horizon-scanning to map out current datasets and their metadata plus current data linkage across the UK.
- Act as a point of reference and a source of expertise and experience in health data research (e.g. issues relating to access and governance) to support other groups and networks in the design and delivery of quality research, leading to successful funding applications and publication.
- Help to ensure any published health data research is seen through to broader and sustainable clinical utility and implementation to improve prevention, diagnosis and healthcare of kidney patients including where health inequalities exist.
- Encourage, advance and support multi-disciplinary, multi-centre, grant application activity in data research.

- Ensure patients and carers, are core members of the network and are integral to the design, delivery and dissemination of health data research.
- Support education, peer support and mentoring for trainees and early career researchers in data science to build future capacity for health data research.
- Collaborate with wider stakeholders to leverage funding and influence relevant funding bodies to strengthen opportunities for health data research activity.
- Work with the commercial sector where there is a clear clinical need and defined clinical outcomes to maximise the use of data for the benefit of patients.
- Aim to improve the efficiency and the potential to improve outcomes for kidney patients to facilitate data linkage and to influence relevant policy makers.
- Provide endorsement of a project's health data management plan under conditions as defined in the attached **Appendix A**. This will involve the appointment and running of a UK Renal Health Data Research Review and Endorsement sub committee.

Co-Chair Roles and Responsibilities

- Support the strategic planning, implementation and continued development of a sustainable UK Renal Health Data Research Network.
- Bring the right people together and lead the network to fulfil agreed aims and objectives and ensure effective working with other stakeholders, including the UK Renal Registry, HDR UK and expertise in data covering primary care, secondary care and laboratory domains.
- Ensure network membership includes representation from a wide range of stakeholder organisations with relevant knowledge to drive forward data research, including younger researchers and those with experience to research and address health inequalities.
- Report into the UK Kidney Research Consortium (UKKRC) and attend bi-annual meetings.
- Publicise the work of the UK Renal Health Data Research Network, working with [Kidney Research UK](#), the [UK Kidney Association](#) and others through promotion at events and maintaining an on-line presence.
- Lead collaborative funding applications to support infrastructure of the network and to support research delivery.
- Ensure patient members are involved from the start in the set-up of the network and that patients and public are always embedded into workstream activity.
- Organise network meetings at least twice a year with support from Kidney Research UK.

- Act as a point of contact for other CSGs and Networks across the UKKRC (e.g. the UK Renal MedTech Network) and the Special Interest Groups of the UK Kidney Association to facilitate discussion and collaboration.
- Ensure the establishment and convening of a UK Renal Health Data Research Review and Endorsement sub committee – see **Appendix A**.

As agreed in the [terms of reference](#) for the UKKRC, the term of office for network Co-chairs is four years. At the end of the third year, Co-chairs-elect will be recruited and appointed to allow a handover during the fourth year. The maximum term for a Co-Chair is four years.

In addition to the responsibilities outlined above, there are some additional criteria to fulfil the requirements of the role:-

Essential:

- Involvement in current data research activity in the UK.
- Understanding of data governance issues and complexities around access and data linkage working across a range of organisations.
- Proven leadership skills.
- A collaborative outlook.
- Good communication and networking skills.
- Strong and relevant individual research track record (publications, successful grant applications).
- A commitment to equality, diversity and inclusion.

Desirable:

- An active member of other collaborative networks.
- Experience of working with industry and involvement in commercial opportunities.

The co-chairs will be working in a voluntary capacity but remuneration for reasonable expenses (e.g. travel) will be covered. Kidney Research UK will be able to provide some co-ordination and development support for meetings of the Network.

It's envisaged that the average time commitment for the co-chairs will be c. 3 hours/week but much will depend on early-stage development activity levels, the scale of future projects and the support from any workstream leads within the network.

Application Process

To apply for this position, please submit a short CV, with relevant experience and a two-page expression of interest to the UK Kidney Research Consortium Steering Group via UKKRC@kidneyresearchuk.org. **The expression of interest should set out your vision for this network over the first three years of your term of office.** The closing date for applications is 5pm on Friday 26 November 2021.

Appendix A

UK Renal Health Data Research Network (UKRHDRN) - Review and endorsement of research data plans

A sub committee of the UKRHDRN will be established to provide a review and endorsement of renal health data research plans within submitted research protocols/applications.

The co-chairs of the UKRHDRN will be responsible for the setting-up and running of the review and endorsement sub committee.

UKRHDRN review and endorsement sub committee membership will include individuals with the following expertise and experience :

- Co-chairs of the UKRHDRN.
- A statistician.
- At least one health economist.
- A representative from the UK Renal Registry (UKRR).
- A member with expertise in patient reported data.
- Two patient expert members (with at least a professional scientific background).

Plus, to be co-opted from the following pool of expertise in line with the orientation of the renal health research data proposal under review:

- A member with expertise in routine data analysis (primary care).
- A member with expertise in routine data analysis (hospital records).
- A member with expertise in routine data analysis (laboratory data records).
- A member with expertise in routine data analysis (national data linkages).
- A member with expertise in pharmaco-epidemiology.
- At least one member with expertise in large data governance.

Submission and endorsement of research proposals

Investigators seeking endorsement from the UKRHDRN may submit their data research plans using the UKRHDRN proforma or, where a protocol has been developed or detailed grant application has been prepared, such documentation may be submitted for the UKRHDRN sub committee's consideration.

To allow sufficient time for review, proposals must be received by the UKRHDRN at least four weeks before the outcome of such a review is required. The UKRHDRN cannot provide letters of endorsement for proposals received less than four weeks from the date that such letters are required.

Conditions of review and endorsement:

- The UKRHDRN will provide endorsement for renal health data research plans.
- The UKRHDRN will be under no obligation to endorse proposals where issues raised by the review process have not been satisfactorily addressed.
- The UKRHDRN reserves the right to refuse endorsement of renal health data research proposals.

- Endorsement will only be provided after discussion at a UKRHDRN sub committee meeting, where the decision to endorse rests on majority vote.
- It is recognised that circumstances may arise that require endorsement to support renal health data research plan submissions where timelines do not allow discussion at a scheduled UKRHDRN sub committee meeting. In this setting, endorsement may be agreed after ad hoc discussion by UKRHDRN members that include, as a minimum, the co-chairs. Where decisions to provide endorsement are taken outside scheduled meetings of the UKRHDRN, such discussions will be minuted and minutes tabled at the next UKRHDRN meeting.

Feedback to applicants:

The UKRHDRN will provide written feedback to proposers within four weeks following the meeting at which proposals have been discussed. Feedback will be provided by the lead reviewer, normally the co-chairs, and may take the form of an email to the proposer.

Where endorsement is provided, this will be explicitly stated in an email.

If the UKRHDRN is unable to endorse a proposal, the reasons for non-endorsement will be provided in writing, including a description of the UKRHDRN's assessment of the research data plan and the conditions under which resubmission may be considered.