|  |
| --- |
| **RaDaR data analysis application form** |
| Thank you for your interest in data held in the UK Kidney Association’s (UKKA) National Registry of Rare Kidney Diseases (RaDaR). All statistical analyses are conducted by substantive employees of the UKKA who then share the information with successful applicants. The first step in applying for RaDaR data analysis is to complete an expression of interest (EoI) available [here](https://renal.org/audit-research/how-access-data/radar-data/apply-access-radar-data-analyses). If your EoI is approved, you will be invited to complete this full application form – **do not complete this form until asked to do so.**Your application will be assessed by a group of clinical and methodological experts who meet up to 6 times a year as the RaDaR Data Analysis Group – please ensure you email your application at least four weeks prior to the meeting in which you want your application to be reviewed – for meeting dates see [here](https://ukkidney.org/audit-research/how-access-data/radar-data/apply-access-radar-data-analyses). If approved, you will be invited to discuss your analyses with a RaDaR statistician who will conduct the analyses on your behalf and share them with you in the form of tables and figures. To help us process your application, please answer the questions below as fully as you can in **clear and plain** English and then email your form to radar@ukkidney.org.**Eo** |
| **UKKA use only** |
| Application number |  |
| Date received |  |
|  |
| **Applicant please complete all the following fields** |
|  |
| **Section one – overview**  |
| Project title |  |
| Main applicant |  |
| Application author, if different to main applicant |  |
| Email address |  |
| Telephone no.  |  |
| Institution/organisation |  |
| Co-applicants, including their email addresses |  |
| Name of [rare disease group](https://renal.org/rare-renal/rare-disease-groups) (RDG) |  |
| Name of RDG lead |  |
| Will you be collaborating with the commercial sector? If so, provide details |  |
| Is the project funded? If so, complete the next section |  |
|  |
| **Section two – finance** |
| Is the UKKA a co-applicant on your grant? |  |
| Who is funding your research? Please provide confirmation letter(s) |  |
| How much funding is available? |  |
| Have you purchased UKKA stats team time? |  |
| Who is the finance contact at your institution? |  |
| Is a collaboration agreement required? If so, how many institutions will be involved and who will co-ordinate this process? |  |
|  |
| **Section three – research or non-research** |
| Is your project research or non-research?  | Research |  |
| Non-research |  |
|  |
| **Section four – protocol and analysis plan**  |
| Project summary, addressing each of the bullet points (max 400 words in plain English – this will be shared with the UK Kidney Association Patient Council, so please write your responses below each of the bullet points |
| * What is already known about this topic and why is it important?
* How will you decide which patients are included in your study?
* How many patients do you anticipate including?
* For how long will you follow up these patients?
* What value will RaDaR data add to the project?
* What new information will your study generate?
* How will this benefit patients?
 |
| Project background – provide a summary of research previously published in this area (max 200 words) |
|  |
| Project objectives (max 100 words) |
|  |
| Key deliverables, including outputs (max 100 words) |
|  |
| Study type – descriptive, hypothesis generating or hypothesis testing |
|  |
| Study designPlease state if you will have direct contact with either patients or health professionals, e.g. to complete a questionnaire. We will need to see copies of the consent forms |
|  |
| Sample size/power calculation (provide justification of sample size) |
|  |
| Study population, including estimate of expected number of relevant patients in the RaDaR dataset |
|  |
| Please justify any exclusion of minority individuals/groups or specific populations (e.g. children) from the study population. |
|  |
| Selection of comparator group(s) and/or control(s)  |
|  |
| Exposures, outcomes and covariates – what RaDaR data are you interested in? A full list can be found in the RaDaR data dictionary, available [here](https://ukkidney.org/audit-research/data-permissions/data/radar-database)If you are interested in accessing data items held in the UKRR, Patients Know Best and/or in the shared NHSBT-UKRR dataset, please contact the research team directly, because different permissions and processes apply. |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |
| Clearly describe the exposures |
|  |
| Clearly describe the outcomes |
|  |
| Do you want us to link RaDaR data to other data? (If yes, please state the datasets) |
|  |
| Explain exactly what information you plan to put in each figure and table – please insert dummy tables and figures |
|  |
| Plan for addressing confounding |
|  |
| Plan for addressing missing data |
|  |
| Plan for addressing small numbers/risk of re-identification |
|  |
| Patient/user group involvement |
|  |
| Limitations of the study design, data sources and analytical methods |
|  |
| Plans for disseminating and communicating results |
|  |
| Has this protocol been reviewed by another committee? If so, which and what was the outcome? |
|  |
| List at least three references relating to your protocol |
|  |
|  |
| **Section five – timeline** |
| Explain when you would like the analyses to be completedPlease understand that the capacity of our statisticians is limited and therefore your analyses may not be able to be conducted immediately |
|  |
|  |
| **Section six – conditions, declaration and signature** |
| Conditions of using RaDaR aggregate data |
| * Data must be destroyed once the results of the study are published.
* Data are released for specific projects to specific people. RaDaR data cannot be used for other research projects by the same researchers or used by other researchers for any purpose, without prior RaDaR approval.
* Authorship:
	+ RaDaR or the relevant rare disease group(s) (RDG) must be included as an author on any outputs that incorporate results derived from RaDaR data (affiliation: The UK Kidney Association, Bristol, UK).
	+ Individuals connected with RaDaR or the UK Kidney Association who make a significant contribution to the analysis of RaDaR data must be offered authorship on any outputs that incorporate results derived from RaDaR data.
	+ All authors must be given adequate time to review and approve outputs prior to submission for publication.
	+ The RaDaR must be notified when outputs based on RaDaR data are published.
	+ The following acknowledgement must be used in all outputs:

*We thank all patients who participate in the National Registry of Rare Kidney Diseases (RaDaR).* |
| Declaration |
| In signing this declaration the applicant confirms that all the information they have provided on this form and in supporting documentation is, to the best of their knowledge, accurate and that they have the authority to submit this application on behalf of their organisation and co-applicants. The personal information you submit to the RaDaR on the analysis application form will be used to process your application and will only be viewed by employees of the UK Kidney Association. The UK Kidney Association relies on legitimate interest (GDPR article 5 (1)(f)) as its legal basis for processing data for the application process. Should you have any questions about how your data will be processed, or wish to exercise your data subject’s rights, please contact the UK Kidney Association’s data protection officer, Tom Gray: tom.gray@ukkidney.org |
| Signature |
| Name (print) |  |
| Role |  |
| Date |  |
| Signature |  |
|  |
| Please return your completed analysis application form toradar@ukkidney.org |