|  |
| --- |
| **UK Renal Registry data request – application form** |
|  |
| Thank you for your interest in using pseudonymised patient level data held by the UK Kidney Association’s (UKKA’s) UK Renal Registry (UKRR). Currently, we only release patient level data to academic and clinical organisations – we do not release patient level data to commercial organisations.The first step in applying to access UKRR data is to complete an expression of interest (EoI) available [here](https://renal.org/audit-research/how-access-data/ukrr-data/apply-access-ukrr-data). If your EoI is approved by the UKRR’s review panel, you will be invited to complete this application form and the accompanying data protection impact assessment (DPIA) – **do not complete these forms until asked to do so.** Your application form and DPIA will be assessed by a group of clinical and methodological experts who meet up to 6 times a year as the UKKA Data Release Group – please ensure you email your application and DPIA to ukrr-research@ukkidney.org at least four weeks prior to the meeting in which you want your application to be reviewed – for meeting dates see [here](https://renal.org/audit-research/how-access-data/ukrr-data/apply-access-ukrr-data). The group comprises members with diverse skill-sets. It is very important, therefore, that all questions are answered in **clear and plain** English.If your application and DPIA are approved, you will be asked to complete a data sharing agreement (DSA) with the UK Kidney Association prior to data release. |
| **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 |  |
| 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? |  |
| 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 – involvement of UKKA statistics team**  |
| Have you purchased UKKA stats team time? |  |
| Do you want any UKKA stats team involvement? | None |  |
| Stats team to be acknowledged in outputs |  |
| Stats member to be a co-author (review the output) |  |
| Stats member to be a main author (perform the analyses) |  |
|  |
| **Section four – permissions** |
| Is your project research or non-research?  | Research |  |
| Non-research |  |
| If research, do you have research ethics committee (REC) permission or are you applying to use the UKRR’s REC permission? Does your institution require you to apply for institutional ethics permission? If you have REC and/or institutional permissions, please provide your reference number(s) and a copy of your letter(s) of approval |
|  |
| What are your legal bases to collect and process UKRR data? Please complete each category – for guidance, use the following resources: [The UK GDPR | ICO](https://ico.org.uk/for-organisations/data-protection-and-the-eu/data-protection-and-the-eu-in-detail/the-uk-gdpr/) and [Legal basis for processing data - Health Research Authority (hra.nhs.uk)](https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/data-protection-and-information-governance/gdpr-detailed-guidance/legal-basis-processing-data/) |
| GDPR (personal identifiable data) |  |
| GDPR (special category data) |  |
| Common law duty of confidentiality |  |
|  |
| **Section five – protocol**  |
| Project summary, addressing each of the bullet points (max 400 words in plain English – this will be shared with the Renal 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 carry out your study?
* 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 UKRR 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 UKRR 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 UKRR-held data would you like to obtain? Please check data completeness in the [Data portals | The UK Kidney Association](https://ukkidney.org/audit-research/data-portals)If you are interested in accessing data items held in RaDaR, Patients Know Best and/or in the shared NHSBT-UKRR dataset, please contact the research team directly, because different permissions and processes apply. Also, please note that the UKRR is unable to release any comorbidity data from HES – you must apply yourself |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |
| Clearly describe the exposures |
|  |
| Clearly describe the outcomes |
|  |
| Do you plan to link UKRR data to other data? (If yes, please state the dataset you intend to link to and what identifiers you would share with the UKRR to enable matching) |
|  |
| Data/statistical analysis plan |
|  |
| 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 six – data transfer and processing** |
| How frequently do you require the data items to be transferred?  | One-off |  |
| Daily |  |
| Monthly |  |
| Quarterly |  |
| Annually |  |
| Other |  |
| If other, please specify |  |
| Select the preferred method(s) of data transfer | Via SFTP link |  |
| Via NHS.net email accounts |  |
| Via encrypted files |  |
| Other |  |
| If other, please specify Note, the UKRR will only transfer data via methods that ensure end-to-end security |  |
| Who in your organisation will handle the data? |
| Name | Role/job title | Email address |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |
| Will the data be processed by any third parties as part of your project? | Yes |  |
| No |  |
| If yes, please list who and for what purposes |
| Name of third party | Purpose of processing |
|  |  |
|  |  |
|  |  |
|  |  |
|  |  |
|  |
| **Section seven – declaration and signature** |
| 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 UKRR on the data release application form and DPIA will be used to process your application and will only be viewed by members of the UKKA’s Data Release Group. The UKKA 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 UKKA’s data protection officer, Tom Gray: tom.gray@ukkidney.org |
| Signature |
| Name (print) |  |
| Role |  |
| Date |  |
| Signature |  |
|  |
| Please return your completed application form and DPIA to ukrr-research@ukkidney.org  |