|  |
| --- |
| **UK Renal Registry data request – expression of interest** |
|  |
| Thank you for your interest in using pseudonymised patient level data held by the UK Kidney Association’s (UKKA’s) UK Renal Registry (UKRR). To ensure as smooth an application process as possible, we need to understand the data you wish to obtain and how you intend using it. To help us with this, we ask that you complete this short expression of interest (EoI) and email it, along with any supporting documents, to ukrr-research@ukkidney.org.Currently, we only release patient level data to academic and clinical organisations – we do not release patient level data to commercial organisations.You can submit your EoI at any time. It will be assessed by a review panel comprising members with diverse skill sets. It is very important, therefore, that all questions are answered in **clear and plain** English. If your EoI is approved by the review panel, you will be invited to complete a full application form and data protection impact assessment (DPIA). Your full application and DPIA will be assessed by clinical and methodological experts who meet up to 6 times a year as the UKKA Data Release Group – please ensure you submit your application and DPIA at least 4 weeks prior to the meeting in which you want them to be reviewed – for meeting dates see [here](https://renal.org/audit-research/how-access-data/ukrr-data/apply-access-ukrr-data). If your application and DPIA are approved, you will be asked to complete a data sharing agreement (DSA) with the UKKA prior to data release. |
| **UKKA use only** |
| Application number |  |
| Date received |  |
|  |
| **Applicant, please complete all the following fields** |
| Project title |  |
| Main applicant |  |
| EoI 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, provide funder details |  |
| Is this EoI part of a grant application? | Yes |  |
| No |  |
| If yes, will the UKRR be a named collaborator on your grant application or provide a service only? | Named collaborator |  |
| Service only |  |
|  |
| 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 carry out your study?
* How will you decide which patients are included in your study?
* Please justify any exclusion of minority individuals/groups or specific populations (e.g. children) from the study population.
* 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?
* How will you involve the patients in the study?
* How will you keep patients informed and engaged?
* How will you assess any patient feedback both during and after the study?
 |
| Project objectives (max 100 words) |
|  |
| Key deliverables, including outputs (max 100 words) |
|  |

|  |  |  |
| --- | --- | --- |
| What is the age range of your cohort?  | Paediatric, i.e. <18 years |  |
| Adult, i.e. >18 years |  |
| Paediatric and adult |  |

|  |  |  |
| --- | --- | --- |
| Will you project address any potential inequalities in kidney care as part of your analysis? (e.g. concerning ethnicity, gender, deprivation etc.) | Yes |  |
| No |  |
| If yes, please describe which characteristics will be considered: |
|  |

|  |  |  |
| --- | --- | --- |
| Is your project research or non-research? For guidance, complete the four questions of the [Health Research Authority decision tool](http://www.hra-decisiontools.org.uk/research/) – leave the IRAS project ID field blank  | Research |  |
| Non-research |  |
|  |
| What permissions do you have in place to conduct your research? Will you need to apply for ethics permission from your institution? |  |
|  |
| Does your team have a statistician to conduct the required analyses? It might also be useful to have someone on your team with epidemiological expertise to help interpret the data | Yes, we have a statistician |  |
| Yes, we have a statistician and epidemiologist |  |
| No, we do not have a statistician |  |
| No, we would like to buy a UKRR statistician’s time |  |
|  |
| What UKRR-held data items 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 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 |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |
|  |
| Are you planning to link UKRR data to other data? (If yes, please state the dataset(s) you intend to link to) |  |
|  |
| Please return your completed expression of interest to ukrr-research@ukkidney.org |