SharE-RR
Sharing Expertise to support the set-up of Renal Registries

SharE-RR national and regional registry survey

1. The SharE-RR survey of national and regional registries, 2018

Thank you for completing this global survey of renal registries - part of the International Society of Nephrology project: *SHARing Expertise to support the set-up of Renal Registries* (SharE-RR). SharE-RR supports the development and sustainability of renal registries around the world. Further details can be found on the ISN website www.theisn.org/advocacy/share-rr

The answers you provide to this survey will be shared via an online resource. The survey will take around half an hour to complete, depending upon the size and complexity of your registry and will need to be completed by someone with good working knowledge of their registry. You should aim, if possible, to complete the survey in one sitting to avoid potential loss of data. If you have any problems with the survey or require further information, please contact katharine.evans@renalregistry.nhs.uk

Kind regards,

The SharE-RR Team

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You are answering questions about your national registry (covering only one country) or regional registry (covering part of only one country). If you manage an international registry (covering two or more countries), please complete the survey available here www.surveymonkey.co.uk/r/SharE-RR_International

If you manage both an international and a national/regional registry, please complete this survey first, then the international survey. The link to the international survey is available again at the end of this questionnaire and in the invitation letter.

* 1. What is the name of your renal replacement therapy (RRT) registry

* 2. Please provide your contact details

Name	
Address	
Address 2	
City/Town	
State/Province	
ZIP/Postal Code	
Country	
Email Address	
Phone Number	

* 3. Please indicate which categories of patients are included in your RRT registry (tick all that apply)

- [ ] Adult haemodialysis
- [ ] Paediatric haemodialysis
- [ ] Adult peritoneal dialysis
- [ ] Paediatric peritoneal dialysis
- [ ] Adult transplant
- [ ] Paediatric transplant
- [ ] Acute kidney injury
- [ ] Chronic kidney disease

* 4. What kind of registry do you manage? What areas of your country are covered by the different component parts of your registry?

It is a national registry: all parts of our registry have complete coverage of the country	It is a regional registry: all parts of our registry cover the same region of the country	It is a regional registry: different parts of our registry cover different regions of the country
○	○	○

Please provide further details if you have a regional registry - what area(s) does your registry cover?

If you have a document or website that has this information available, you could direct us to it from here.

* 5. In what year did your RRT registry first attempt to collect data?

* 6. Has your RRT registry run continuously or have there been breaks?

- ○ It has run continuously
- ○ There have been breaks
- ○ There was another RRT registry before ours was set up

If there have been breaks, please provide further information

* 7. From what year has your RRT registry successfully collected data without interruption?

* 8. Which of the following provide funding to your RRT registry? (tick all that apply)

	Provides funding
Government	☐
Charity	☐
Renal centres	☐
Professional body or society	☐
Industry links	☐
Academic institution	☐
Other	☐

If other funders are involved, please provide further information

* 9. Select the **main** funder of your RRT registry?

Please provide further information here - what percentage of your registry's budget is covered by this funder?

* 10. Does your RRT registry receive any **non-financial** support, for example office space or data-capture assistance?

- ○ No
- ○ Yes

If you answered yes, please provide further information here.

* 11. How many **paid** staff from each training background does your RRT registry employ?

	Number of paid staff	Number of full-time equivalent posts
Clinician – fully-qualified nephrologist		
Clinician – nephrologist in training		
Clinician – clinical epidemiologist/ public health		
Clinician – nurse		
Non-clinician – epidemiologist/ public health		
Statistician/ data analyst (analyses data)		
Programmer (builds and maintains software and hardware)		
Data manager (manages data returns and validation)		
Business/ admin/ management		
Other		

If other paid staff are employed, please provide further information

* 12. How many **voluntary staff** does your RRT registry employ?

	Number of voluntary staff	Number of full-time equivalent posts
Voluntary staff		

What roles do your voluntary staff members have?

SharE-RR
Sharing Expertise to support the set-up of Renal Registries

SharE-RR national and regional registry survey

2. Data sharing and permissions

* 13. Are you allowed to share data with clinicians or researchers in **your own country**?

- ◯ Yes, summary data only
- ◯ Yes, patient-level data
- ◯ Yes, both summary and patient-level data
- ◯ No sharing allowed

Please provide further information, including details of any special permissions that are needed to share data

* 14. Are you allowed to send data to collaborators in **other countries**?

- ◯ Yes, summary data only
- ◯ Yes, patient-level data
- ◯ Yes, both summary and patient-level data
- ◯ No sharing allowed

Please provide further information, including details of any special permissions that are needed to share data

15. What permissions must be in place to collect individual-patient data for use within your country to measure quality of care and outcomes, i.e. **for audit/quality improvement purposes**? (tick all that apply)

- [ ] Ethical approval (please specify)
- [ ] Legal approval (please specify)
- [ ] Individual patient consent (please specify)

Please provide further infomation, including other required permissions

16. What permissions must be in place to collect individual-patient data for use within your country **to conduct research**? (tick all that apply)

- [ ] Ethical approval (please specify)
- [ ] Legal approval (please specify)
- [ ] Individual patient consent (please specify)

Please provide further infomation, including other required permissions

* 17. If individual patient consent is required, is this to opt-in or opt-out of inclusion?

- ( ) Not applicable: patients do not individually consent to opt-in or opt-out of inclusion
- ( ) Patients are included in the registry unless they individually opt-out
- ( ) Patients must individually opt-in before they are included in the registry
- ( ) Other (please specify)

* 18. Please indicate from which patient groups **individual** patient consent is required for inclusion in your RRT registry (tick all that apply)

- [ ] Not applicable: individual patient consent is not required
- [ ] Haemodialysis recipients
- [ ] Peritoneal dialysis recipients
- [ ] Transplant recipients
- [ ] Paediatric patients, or their guardians

Please provide further detail, if necessary

* 19. Is your RRT registry predominantly profession-run or government-run?

- ( ) Predominantly government-run
- ( ) Predominantly profession-run
- ( ) Other (please specify)

* 20. Does your RRT registry produce or publish a report?

- ( ) Yes
- ( ) No

* 21. Are you willing to provide a contact to be publicly available on the ISN SharE-RR webpages so that you can be contacted by people wishing to set up an RRT registry?

- ( ) No, sorry
- ( ) Yes, I'd like to help other people who want to set up a registry

If you are happy to help, please provide a contact email address

* 22. Does your RRT registry have a website?

- ◯ Yes
- ◯ No

If yes, please provide the website URL

SharE-RR
Sharing Expertise to support the set-up of Renal Registries

SharE-RR national and regional registry survey

3. RRT registry report

* 23. How frequently do you publish or produce the report? (please select the option that best fits)

- ○ Continuously updated
- ○ Twice a year
- ○ Annually
- ○ Less than annually
- ○ Other (please specify)

* 24. In what year did your RRT registry first publish a report?

* 25. Where is the report or publication accessed? (please provide URL if it is available online)

* 26. What language(s) is the report available in? (tick all that apply)

- ☐ Arabic
- ☐ Bengali
- ☐ English
- ☐ French
- ☐ German
- ☐ Hausa
- ☐ Hindustani (Hindi/Urdu)
- ☐ Italian
- ☐ Japanese
- ☐ Javanese
- ☐ Korean
- ☐ Malay (incl. Indonesian and Malaysian)
- ☐ Mandarin Chinese (incl. Standard Chinese)
- ☐ Marathi
- ☐ Persian
- ☐ Portuguese
- ☐ Punjabi
- ☐ Russian
- ☐ Spanish
- ☐ Swahili
- ☐ Tamil
- ☐ Telugu
- ☐ Vietnamese
- ☐ Wu Chinese (incl. Shanghainese)
- ☐ Yue Chinese (incl. Cantonese)
- ☐ Other (please specify)

* 27. What was the first year's data included in this report?

* 28. Do you publish centre-level data? (a renal centre is defined as a main renal unit, which is responsible for RRT via in-centre, home and satellite facilities).

- Yes
- No

SharE-RR
Sharing Expertise to support the set-up of Renal Registries

SharE-RR national and regional registry survey

4. Centre-level data

* 29. Are the centre-level data publicly available?

- Yes
- No

* 30. Are centres anonymised in your report?

- Yes
- No

* 31. Are centres provided with individual centre reports?

- Yes
- No

SharE-RR
Sharing Expertise to support the set-up of Renal Registries

SharE-RR national and regional registry survey

5. Incentivisation

* 32. Is centre participation mandated or incentivised (e.g. by payment for data-provision or penalty for non-provision)?

- Yes
- No

If yes, please provide further information

* 33. Do you have access to information about human resources, such as the number of nephrologists working within the area covered by your RRT registry?

- Yes
- No

If you have answered yes, please provide further details

SharE-RR
Sharing Expertise to support the set-up of Renal Registries

SharE-RR national and regional registry survey

6. Geography and coverage of your registry

* 34. How do you collect data? (please select all that apply)

- [ ] Paper-based form completion
- [ ] Web-based form completion
- [ ] Extraction - data are uploaded directly from clinical systems
- [ ] Billing - data are uploaded directly from funding systems
- [ ] Email - data are shared via email
- [ ] Secure data transfer - data are shared via a secure data link
- [ ] Other (please specify)

* 35. How many **haemodialysis** centres are there in the area covered by your RRT registry? (a haemodialysis centre is a main renal unit, which is responsible for HD via in-centre, home and satellite facilities).

36. What proportion of these **haemodialysis** centres submit data to your RRT registry?

* 37. How many **peritoneal** dialysis centres are there in the area covered by your RRT registry? (a peritoneal dialysis centre is defined as a main renal unit which is responsible for care of patients who receive peritoneal dialysis).

38. What proportion of these **peritoneal** dialysis centres submit data to your RRT registry?

* 39. How many **transplant** centres are there in the area covered by your RRT registry? (a transplant centre is defined as a main renal unit where transplantation is performed).

40. What proportion of these **transplant** centres submit data to your RRT registry?

* 41. For **incident** patients, are individual level data collected from centres or are data aggregated at centre level?

	Individual level data	Aggregate level data	A mixture of individual and aggregate data are received
Adult haemodialysis	☐	☐	☐
Paediatric haemodialysis	☐	☐	☐
Adult peritoneal dialysis	☐	☐	☐
Paediatric peritoneal dialysis	☐	☐	☐
Adult transplant	☐	☐	☐
Paediatric transplant	☐	☐	☐

If a mixture are received, please indicate what proportion of centres provide **individual level** data:

* 42. For **prevalent** patients, are individual level data collected from centres or are data aggregated at centre level?

	Individual level data	Aggregate level data	A mixture of individual and aggregate data are received
Adult haemodialysis	☐	☐	☐
Paediatric haemodialysis	☐	☐	☐
Adult peritoneal dialysis	☐	☐	☐
Paediatric peritoneal dialysis	☐	☐	☐
Adult transplant	☐	☐	☐
Paediatric transplant	☐	☐	☐

If a mixture are received, please indicate what proportion of centres provide **individual level** data:

SharE-RR
Sharing Expertise to support the set-up of Renal Registries

SharE-RR national and regional registry survey

7. Data items collected (Part 1 of 2)

* 43. Please select **all items that are collected by your RRT registry** (tick all that apply, even if collected only once. Different coverage by component parts of your registry will be asked about in the next section)

- [ ] Date of RRT initiation
- [ ] Date of RRT stopping
- [ ] RRT modality in use
- [ ] Modality change (including date)
- [ ] Reason for modality change
- [ ] Location of treatment (home/in centre)
- [ ] Dialysis adequacy
- [ ] Date of death
- [ ] Cause of death
- [ ] Dialysis access used (e.g. fistula, line, graft)
- [ ] Dialysis access complications
- [ ] Blood stream infections
- [ ] Peritonitis episodes
- [ ] Comorbidity data
- [ ] Biometric data (height, weight etc.)
- [ ] Ethnicity
- [ ] Date of referral to nephrology
- [ ] Primary renal diagnosis
- [ ] Others (please specify)
- [ ] Smoking status
- [ ] Medications
- [ ] Treatment funder
- [ ] Treatment provider
- [ ] Haemoglobin
- [ ] Iron studies
- [ ] Full blood count
- [ ] Inflammatory markers (e.g. C reactive protein)
- [ ] Liver function tests
- [ ] Serum albumin
- [ ] Serum calcium
- [ ] Serum phosphate
- [ ] Serum parathyroid hormone
- [ ] Serum sodium
- [ ] Serum potassium
- [ ] Serum urea
- [ ] Serum creatinine
- [ ] Serum bicarbonate
- [ ] Blood pressure
- [ ] Patient-reported outcomes (e.g. quality of life, treatment satisfaction)
- [ ] Transplant waiting list status
- [ ] Date of transplant
- [ ] Transplant type (living donor, deceased cardiac death, deceased brain death)
- [ ] Transplant details match grade
- [ ] Live donor characteristics
- [ ] Deceased donor characteristics
- [ ] Hepatitis status
- [ ] HIV status
- [ ] CMV status
- [ ] BK status
- [ ] Date of transplant failure
- [ ] Cause of transplant failure
- [ ] Immunosuppression prescription
- [ ] Immunosuppression levels

SharE-RR
Sharing Expertise to support the set-up of Renal Registries

SharE-RR national and regional registry survey

8. Data items collected (Part 2 of 2)

44. Please select the option that best describes the completeness of data in your**haemodialysis** registry (leave blank if you do not have a haemodialysis registry):

	Collected once on entry to registry	Data available for every dialysis session/blood test	Data points once a week	Data points once a month	Data points twice a year	Data points once a year	Data points less than once a year	Data points at modality change
Blood tests	○	○	○	○	○	○	○	○
RRT modality in use	○	○	○	○	○	○	○	○
Dialysis adequacy	○	○	○	○	○	○	○	○
Dialysis access used (e.g. fistula, line, graft)	○	○	○	○	○	○	○	○
Dialysis access complications	○	○	○	○	○	○	○	○
Blood stream infections	○	○	○	○	○	○	○	○
Comorbidity data	○	○	○	○	○	○	○	○
Biometric data (height, weight etc.)	○	○	○	○	○	○	○	○
Smoking status	○	○	○	○	○	○	○	○
Medications	○	○	○	○	○	○	○	○
Blood pressure	○	○	○	○	○	○	○	○
Patient-reported outcomes (e.g. quality of life, treatment satisfaction)	○	○	○	○	○	○	○	○
Transplant waiting list status	○	○	○	○	○	○	○	○
Hepatitis status	○	○	○	○	○	○	○	○
HIV status	○	○	○	○	○	○	○	○
[Insert text from Other]	○	○	○	○	○	○	○	○

45. Please select the option that best describes the completeness of data in your **peritoneal dialysis** registry (leave blank if you do not have a peritoneal dialysis registry):

	Data collected once on entry to registry	Data available for every clinic visit attended/blood test	Data points once a week	Data points once a month	Data points twice a year	Data points once a year	Data points less than once a year	Data points at modality change
Blood tests	○	○	○	○	○	○	○	○
RRT modality in use	○	○	○	○	○	○	○	○
Dialysis adequacy	○	○	○	○	○	○	○	○
Dialysis access complications	○	○	○	○	○	○	○	○
Blood stream infections	○	○	○	○	○	○	○	○
Peritonitis episodes	○	○	○	○	○	○	○	○
Comorbidity data	○	○	○	○	○	○	○	○
Biometric data (height, weight etc.)	○	○	○	○	○	○	○	○
Smoking status	○	○	○	○	○	○	○	○
Medications	○	○	○	○	○	○	○	○
Blood pressure	○	○	○	○	○	○	○	○
Patient-reported outcomes (e.g. quality of life, treatment satisfaction)	○	○	○	○	○	○	○	○
Transplant waiting list status	○	○	○	○	○	○	○	○
Hepatitis status	○	○	○	○	○	○	○	○
HIV status	○	○	○	○	○	○	○	○
[Insert text from Other]	○	○	○	○	○	○	○	○

46. Please select the option that best describes the completeness of data in your **transplant** registry (leave blank if you do not have a transplant registry):

	Data collected once on entry to registry	Data available for every clinic visit attended/blood test	Data points once a week	Data points once a month	Data points twice a year	Data points once a year	Data points less than once a year	Data points at modality change
Blood tests	○	○	○	○	○	○	○	○
RRT modality in use	○	○	○	○	○	○	○	○
Comorbidity data	○	○	○	○	○	○	○	○
Biometric data (height, weight etc.)	○	○	○	○	○	○	○	○
Smoking status	○	○	○	○	○	○	○	○
Medications	○	○	○	○	○	○	○	○
Blood pressure	○	○	○	○	○	○	○	○
Patient-reported outcomes (e.g. quality of life, treatment satisfaction)	○	○	○	○	○	○	○	○
Hepatitis status	○	○	○	○	○	○	○	○
HIV status	○	○	○	○	○	○	○	○
CMV status	○	○	○	○	○	○	○	○
BK status	○	○	○	○	○	○	○	○
Immunosuppression prescription	○	○	○	○	○	○	○	○
Immunosuppression levels	○	○	○	○	○	○	○	○
[Insert text from Other]	○	○	○	○	○	○	○	○

SharE-RR
Sharing Expertise to support the set-up of Renal Registries

SharE-RR national and regional registry survey

9. Challenges and expertise

* 47. What are the greatest challenges that you have faced in setting up or maintaining a national/regional RRT registry?

48. What expertise could your RRT registry share with other people hoping to set up their own?

49. Please use this space to make any final **confidential** comments. What you write here will not be shown on the SharE-RR website. We may contact you to get further details about what you write.