

SharE-RR: steps in establishing a renal registry

Feasibility and appropriateness

1. What is the health service or public health goal you are trying to achieve?

2. Is a registry the best way to achieve this?
 - a. Does the data I need already exist?
 - b. If so, is it of sufficient quality for my intended purpose?
 - c. And, if so, are they accessible?

3. What are the potential sources of funding for a renal registry?

Establishing your team

4. What experts do you need on your team? Involve them now.

5. Who are individuals and organizations that will have an interest in your registry? Involve them now.

Detail

6. What is (are) the objective(s) of your registry?

7. What is the target population for your registry?

8. What data will your registry collect?

- a. Administrative, including personal identifiable information
- b. Characteristics
- c. Exposure
- d. Confounder
- e. Outcome

9. How are you going to collect these items? Using a paper case report form, an electronic document or spreadsheet, or webpage? How often will you collect these data? Are any of the data items already collected in your region country? Could you reduce data collection by linking to this existing data source?

10. How will each of these variables be defined for consistency?

- a. Create a data dictionary defining these variables, including variable names, formats, value domains/ code lists, units of measurement, ranges/ validation rules, qualifiers, frequency of collection, and whether each is mandatory/ conditional/ optional.
- b. Consider creating a model of your registry
- c. Consider creating a data map

11. What information system are you going to collect your data in?

- a. Develop your information system

Final steps

12. Pilot test your data collection processes and systems

13. Write the policies, protocols, and plans necessary for quality assurance and governance oversight

14. Secure all necessary permissions, legal, privacy, and ethical.