



## Tool: Registry Evaluation Checklist

Use this checklist to help you determine if you are ready to expand your contact registry into a research registry. A research registry includes more detailed medical information for each patient and therefore requires additional considerations. Before you take the leap toward developing a more advanced registry, review this checklist to determine examples of steps you may need to consider or complete before you begin:

- Have you created a registry plan that includes both short- and long-term goals, constraints, roadblocks and solutions, a timeline, and milestones?
- Have you defined the criteria for the patients you want to join your registry?
- Do you know patients who seem engaged and interested in sharing more details and information about themselves (e.g., through your contact registry)?
- Are there researchers studying or interested in studying your disease?
- Have you communicated with researchers about the type of patient data they need?
- Are you familiar with the Internal Review Board (IRB) process?
- Have you researched and documented the next steps, which should include your goals for your more comprehensive registry?
- Have you identified what data collection method you will use to collect the more detailed patient information (e.g., registry platform)?
- Have you created an informed consent to share with patients?
- Have you started to identify sources of financial support for the registry?
- Have you established a set of permissions for researchers requesting to use the registry data i.e., a data use agreement)?
- Have you instituted data quality control procedures and data security protocols?
- Have you developed a plan for promoting your registry and for managing data requests?