




Tool: Participant Criteria Checklist

This tool helps you determine who is eligible to join your registry. Ask yourself the questions below and consider patient language, location, diagnosis, and whether you need a certain number of patients in your registry to meet your goals (e.g., to attract researchers).

Location	Language	Diagnosis
		
<ul style="list-style-type: none"> ❖ Do you know any other people with the disease? ❖ Do you know how many people have the disease (e.g., incidence or prevalence)? ❖ Are you aware of any other countries that have reported any people with the disease? 	<ul style="list-style-type: none"> ❖ Do you plan to only recruit English-speaking patients/caregivers/parents or guardians? ❖ If you plan to recruit non-English speaking patients, do you have the staff to assist with translation? ❖ If you do not have the staff who speak other languages, does your budget allow for professional translational services? 	<ul style="list-style-type: none"> ❖ For what disease(s) are you recruiting? ❖ Is there a specific test to diagnosis patients with the disease? Or is the diagnosis based on a set of symptoms or clinical findings? ❖ Does the diagnosis have to be made by a doctor? Does the doctor have to be a particular specialist? ❖ Do you want to collect information about how the diagnosis was made?