

# Support: Who is Your Community?

To make sure you're meeting the needs of your community, you first need to know who they are. Don't assume! You know what assuming does. It makes an - never mind. You are just one person with one perspective. It's best to get data on the community's needs from a diverse group. This worksheet will help you identify your community in preparation for conducting a community needs assessment.

1. Figure out who your community is. This might sound like an easy first step, but it's more complicated than you think.

Each disease community is made up of different types of individuals with different relationships to the disease. Everyone's experience is different. The most obvious is people living with the disease, but they are just one part of a vast web of individuals impacted by this disease. Take a few moments to write down who all is impacted by this disease.

In case you're having difficulty, below are a few different types of individuals in disease communities. If the roles listed do not apply to your disease community, cross them out or delete them.

- People living with the disease
- Loved ones of people living with the disease such as friends, coworkers, etc.
- Caregivers
- Former caregivers
- Asymptomatic gene carriers
- Potential gene carriers
- Health care professionals treating and/or supporting individuals with the disease
- Advocates with no connection to the disease

Great job! Now that you have your list, share it with a few patients, caregivers and loved ones impacted by this disease. Can they think of others? If so, please list them here. Teamwork makes the dream work!



2. Time to gather the community! Pull out your Rolodex! (That's an old-fashioned version of a contact list, if you don't know what a Rolodex is.) Who do you know that fits into those categories? Write in 5–10 names per category.

Don't worry if people can fit into multiple categories. Life is complicated and so is your list. Just put them in the category that best fits them.

Here's an area for you to start making your lists! We prepopulated this space, but feel free to delete them and/or add more.

- People living with the disease
- Loved ones of people living with the disease
- Caregivers
- Former caregivers
- Asymptomatic gene carriers
- Potential gene carriers
- Health care professionals treating and/or supporting individuals with the disease
- Advocates with no connection to the disease
- Can't think of five people? Don't fret! Ask people within your network to help you out.

3. Quality assurance check! Are you really representing the community? Look over your list of individuals. Write out their ages, race, gender identity and geography.

Age	Number of people
18-25	
26-34	
35-34	
45-54	
55-65	
65+	

Geography	Number of people
Urban	
Suburban	
Rural	

Gender	Number of people
Man (cisgender)	
Woman(cisgender)	
Transgender and non-binary	

Race	Number of people
Asian	
Black/ African-American	
Hispanic or Latino	
Native American	
White	

Are certain populations over or underrepresented? Investigate this by searching for demographic information about those diagnosed with this disease. If that’s not available, use your national census as a guide. If a group is underrepresented, try to find individuals that help make your list represent the community impacted by the disease.

Way to go! You now have a list of people you can call upon to do a needs assessment. Collect their email addresses and you are on your way to forming a powerful collective!