

# Support: Resource Guide

Navigating a new diagnosis can be difficult, exhausting and overwhelming! One reason is that all of the information can be in 100 different places. You're about to fix that by having the best of the best resources in one place! This document will help you figure out what resources are available within your community and how to create a resource guide. It is a lot of work upfront, but building this resource for your community will be invaluable.

1. It's time to collect information from your community. Surveys and interviews are a GREAT way to collect info from those you aim to serve.

The great thing about surveys is that the information respondents provide will already be written down. It's less time intensive for you. The drawback is that the people filling out the survey may not be as candid and comprehensive as you need them to be.

The great thing about interviews is that people might be more likely to fully explain their thoughts and experiences as conversation tends to be more enjoyable than surveys. Talking to people and hearing their stories can be fun & inspiring too! And you can ask for follow-up in real time. The drawback is that interviews are rather time consuming.

There are lots more pros and cons to doing either of these information collection methods. Think through them. Use the space below to write them out.

Surveys

Pros	Cons

Interviews

Pros	Cons

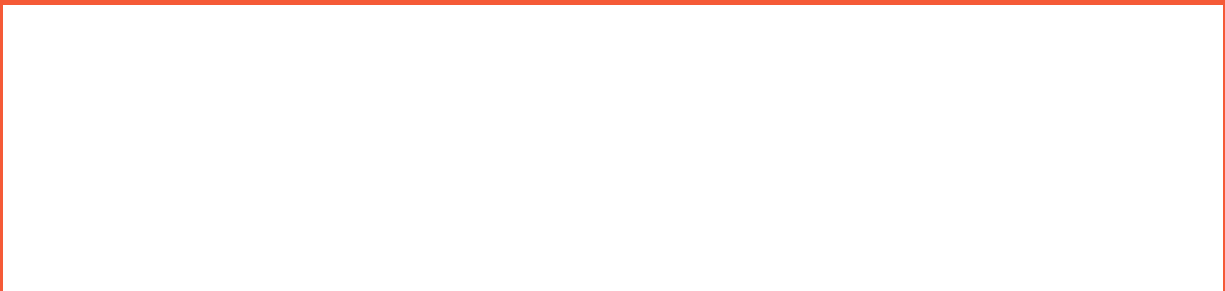
Now that you’ve listed the pros and cons. It’s decision time! Figure out what works for you. Or do both! If you decide to do both, you haven’t wasted your time with this exercise as you’ll have a deeper understanding of each information gathering technique.

2. You know who you're going to ask and how, but ... what are you asking?  
Good question!

Ask yourself: What about your community's needs, resources and support systems do you want to know about? Take a moment to write this out.



Based on what you want to know, create questions.



Here are some questions to help get the information you want to know:

- What would you say are the top three non-medical needs for people living with this disease? (Not including finding meaningful treatments and cures.)
- What advice would you offer others recently diagnosed with this disease?
- What questions and needs did you find yourself having when this disease entered your life?
- How did you look for information? What sources did you use? What website or agency did you turn to fulfill those questions and needs? (Be sure to go through each question and need stated.)
- What did each website and agency do well? What did you like about the resource?
- Where did they fall short? What did you find lacking?

Now that you have your questions done, it's crowdsourcing time! Get out there and ask people questions!

3. After you’re done, go through your data and fill in the chart below. In the first column, write the question or need. In the next three columns write the websites and agencies people engaged with in the appropriate column. For example, if your community said a need was housing and that ABC Nonprofit was an excellent resource for information on housing, write “housing” in the first column and “ABC Nonprofit” in the Excellent column in the same row. Write next to it what evidence was provided to support that rating.

If a website or agency provides resources or information in more than one area, list them in each area.

Need	Excellent	Adequate	Poor

After filling out this chart, you should have a pretty good understanding of your community’s available resources! You are on your way to creating a pretty rocking resource guide!

At the end of this document is a suggested format for your resource guide which you should use for this exercise. Once you’re finished, feel free to use any format you wish. But for now, let’s stick with this.

Note: These ratings are not meant to shame any organization. This is an internal document to help you figure out your next steps-- whether that be creating a resource guide or providing a new service!



4. Column one in the chart above is a list of community needs. You have to decide what order to list the needs in. Alphabetical might be the easiest as users can easily navigate the document. Or you might want to organize themes by your perceived importance. If you do this, don't make this decision alone. Ask others to review your ranked list and offer suggestions. For guidance on how to format your resource guide, refer to the last few pages of this worksheet.

Once the alphabetical or ranked list is complete, replace "First Need" in the below guide format with the need listed first on your list, then replace "Second Need" with the need listed second on your list and so on.

5. Refer to the chart above. All of the excellent and adequate resources listed are going into your Resource Guide. Under each Need, replace "Excellent or adequate resource" with the name of an agency or website that received an excellent or adequate rating within that need category.

In the below Resource Guide, there are four slots for sources.

If you have more than four resources, add more slots.

If you have less than four, delete slots. If there are no excellent and adequate agencies or websites for a need category, don't put the need in your document.

Don't put agencies into need categories that don't fit there. Don't list resources that the community told you were poor. You're building a reputable and helpful guide. You don't want to compromise your guide's integrity.

While having gaps is not good for your disease community, you've actually learned something. You have learned of a gap you can help fill. (That's for another day.)

Remember it is okay if a website or agency is under more than one need category.

6. Replace the "Contact information" under each resource with the website address, email, phone number, physical address and any other relevant contact information that helps the community access these resources.

7. Under each resource replace “Summary of services and resources” with a summary of the information you’ve collected from community members. You should keep in the positive and complimentary feedback they provided to highlight what the agency does really well so that people know what to expect. No need to use quotes, but make sure it’s clear that the community appreciates the resources.

Don’t summarize negative reviews and critiques. If a resource receives negative reviews on a service, then don’t list that service. Mention what they do well, not what they don’t. By doing this you are including the community’s knowledge without discrediting an organization that does provide at least one service well. Once you’ve gained your footing in the disease landscape, you can work with them on improving that service. And that’s incredible and meaningful work!

If all of their services are negatively reviewed, don’t list the resource.

8. Now that you’ve summarized the information you collected, it’s time to go directly to the source! Use the contact information you collected to review websites and call or email agencies to find out more about what is provided and how it’s accessed.

While it may sound odd that this step is later in the process, collecting information from the community first helps ensure that your process and guide are community centric.

To help you in this process, duplicate the chart below and use it to document your review of websites, emails and phone calls.

What resources do you provide the community?	
What is the best way to gain access to those resources?	
What information should people know or have before they contact you?	

9. Combine the information you collected in the Step 8 charts with the “Summary of services and resources” text created in Step 7. Exclude any services or information collected from the website or agency that your community members told you were poor.

Your resource guide is almost done!

10. Have the community members who helped you create this resource guide provide feedback. Ask them to review the content and edit the grammar and spelling.

Be open to editing! Nothing is good on the first draft. If they have a hard time understanding what you are trying to explain, other people will too.

Once you incorporate their edits, then you are done! Kind of. Sort of.

Resource Guides are living documents that need to be updated as you discover new resources, as agencies expand or reduce their services and as websites become updated or outdated.

So keep at it and check in on your resources at least every six months. You don’t want your Resource Guide to become outdated and useless.

Always remember to stay positive within your Resource Guide. Building bridges is one of the many ways to build a disease community.

## Suggested Resource Guide Format

### First Need

Excellent or adequate resource #1

- Contact information
- Summary of services and resources

Excellent or adequate resource #2

- Contact information
- Summary of services and resources

Excellent or adequate resource #3

- Contact information
- Summary of services and resources

Excellent or adequate resource

- Contact information
- Summary of services and resources

## Second Need

Excellent or adequate resource #1

- Contact information
- Summary of services and resources

Excellent or adequate resource #2

- Contact information
- Summary of services and resources

Excellent or adequate resource #3

- Contact information
- Summary of services and resources

Excellent or adequate resource #4

- Contact information
- Summary of services and resources

## Third Need

Excellent or adequate resource #1

- Contact information
- Summary of services and resources

Excellent or adequate resource #2

- Contact information
- Summary of services and resources

Excellent or adequate resource #3

- Contact information
- Summary of services and resources

Excellent or adequate resource #4

- Contact information
- Summary of services and resources

## Fourth Need

### Excellent or adequate resource #1

- Contact information
- Summary of services and resources

### Excellent or adequate resource #2

- Contact information
- Summary of services and resources

### Excellent or adequate resource #3

- Contact information
- Summary of services and resources

### Excellent or adequate resource #4

- Contact information
- Summary of services and resources

## Fifth Need

### Excellent or adequate resource #1

- Contact information
- Summary of services and resources

### Excellent or adequate resource #2

- Contact information
- Summary of services and resources

### Excellent or adequate resource #3

- Contact information
- Summary of services and resources

### Excellent or adequate resource #4

- Contact information
- Summary of services and resources

## Sixth Need

### Excellent or adequate resource #1

- Contact information
- Summary of services and resources

### Excellent or adequate resource #2

- Contact information
- Summary of services and resources

### Excellent or adequate resource #3

- Contact information
- Summary of services and resources

### Excellent or adequate resource #4

- Contact information
- Summary of services and resources

## Seventh Need

### Excellent or adequate resource #1

- Contact information
- Summary of services and resources

### Excellent or adequate resource #2

- Contact information
- Summary of services and resource

### Excellent or adequate resource #3

- Contact information
- Summary of services and resources

### Excellent or adequate resource #4

- Contact information
- Summary of services and resources