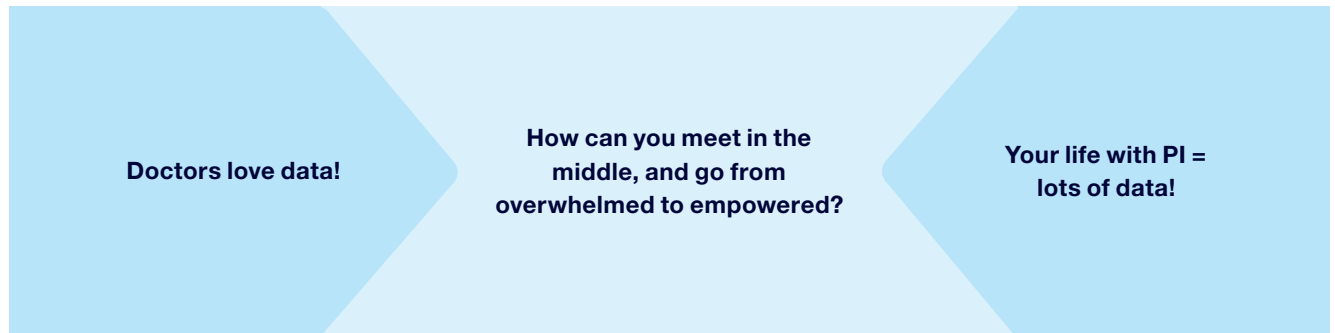


MyGuide to: Patient-Doctor Partnerships



Living with primary immunodeficiency (PI), you’ve probably been told you should “record your health.” But you may not know what that really means, why it matters, or how to do it.

Recording your health means giving your doctors data about your symptoms, infections, infusions, and more. This can help to better manage your health! So, how do you do it?



Facts are a great place to start.

Data can help your doctors make better care decisions. When telling them how you feel, try starting with facts and being as specific as possible.*

Instead of...	Try this...
I feel like I’m sick a lot.	I’ve had X infections and was on antibiotics for X days.
I’m really tired.	I’ve been too tired to do my daily activities 10 out of the last 15 days.
I feel like my infusions take too much time.	My infusions take 2 hours and 30 minutes every week. I would love if it would take less than an hour a week.

*Life with PI can be complicated. And feelings matter—your emotions can impact your physical health. Once you give specifics about your symptoms, it’s okay to be open about your emotional health, too.



The best patient-doctor relationships are partnerships.

Chances are, your care team has grown. It may feel overwhelming. It’s okay to ask questions, especially about what kinds of information your doctors would like to receive from you—and how best to communicate with them. This can help you play a more active role in your care decisions.



Communication is key.

It’s all about knowing (and going with) the flow of information. Consider asking about your doctor’s communication preferences right from the start.

- What’s the best way to get information to you? (Email, phone, text, etc.)
- If I get sick, should I call you or someone else?
- What if I get sick after hours or on a weekend?
- Do you want updates from my other specialists, or only if there is a specific need?
- How can I help you help me?

Preparing for your visits.

You make a list for the grocery store, right? The same thinking applies here. **When recording your health, try to keep track of all your medical details, questions, and concerns as they occur**, so you'll have the information ready to go for your appointment.



Note your health information since your last visit:

- # of infections
- # of days spent on antibiotics
- Antibiotics taken, dose, and duration
- Any new doctors you're seeing
- Any new diagnoses
- Any symptoms you're having, even if they're not new



Got a complicated question?

You may want to email your doctor *before* your visit to give him/her time to consider it. It's helpful to keep your note short, but specific.



Keep track of your infusions:

- Remind the doctor of your brand, route, and rate of infusion
- Any side effects you're experiencing
- How often you're infusing
- Any changes you're hoping to make
- How long infusions are taking you
- How many needlesticks you're using
- If you've been sticking to the recommended schedule

Check-in: Do you know your doctor's treatment goal for you? Knowing this will help you know what to communicate to your care team.

Keep partnering.

Knowing the follow-up plan from your visits will help you feel more prepared and empowered to work with your care team on decisions that impact your health and life. If you have questions after your appointment, try reaching out to your doctors. And try to make recording your health a priority. The data really makes a difference. And remember—managing life with PI gets less overwhelming!

MyGuide to Patient-Doctor Partnerships is part of an educational series from MylgSource. If you'd like more information, please visit [MylgSource.com](https://mylgsource.com) or contact a Patient Advocate at 855-250-5111.

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