



FREQUENTLY ASKED QUESTIONS

- **Why is PARTNERS PPRN needed?**

Our initiative enables the collection of very large amounts of information required for research, and research is essential for answering key questions about pediatric rheumatology. Unlike other data-gathering projects, ours is driven by a variety of individuals affected by pediatric rheumatic diseases, either living with the condition or as a parent or caretaker, clinician, researcher or advocate, and it is informed by their input and ideas. In addition, we are among the first examples of a 'large-scale approach' to research, an approach many believe is essential to tackle the complexities of disease effectively.

- **Why should I participate in PARTNERS PPRN?**

We will only succeed if thousands of people living with pediatric rheumatic diseases participate. We are centered on those living with the disease and depend on your participation. You will not be excluded based on what kind of pediatric rheumatic disease you have, your level of disability, or what other conditions you may have. In addition, we rely on patients and caregivers to not only contribute your health information, but also to provide your ideas for research topics and questions to move research in directions that are important to you. That means that as a participant, you will have the power to influence what types of research are conducted through the PARTNERS PPRN. The bridge between researchers and those with the disease is a key feature and benefit of participation.

- **What diseases does PARTNERS PPRN currently represent?**

The PARTNERS PPRN currently represents the three most common pediatric rheumatic diseases: juvenile idiopathic arthritis (JIA), childhood-onset systemic lupus erythematosus (cSLE), and juvenile dermatomyositis (JDM).

- **What kinds of questions might the PARTNERS PPRN help answer?**

There are many questions that may be answered through the use of health information from the PARTNERS PPRN. For example:

- What causes these conditions?
- What factors affect disease activity in pediatric rheumatic diseases?
- Which treatments work best in which people?
- How helpful are things like diet and exercise in reducing the effects of pediatric rheumatic disease?
- Can these conditions be prevented?
- Is it possible to predict someone's future experience with pediatric rheumatic diseases based on the experiences of others?



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- **How much data do you need from me, and how much is 'enough'?**

The more information you can contribute about your experience the better!

Also, our initiative will evolve as research advances. Our research questionnaires will vary in the future: some will be short because only a few answers are needed; others will be more comprehensive, as needed for research. Your continued commitment to providing information is essential. In turn, we commit to keeping you up to date on how PARTNERS PPRN is contributing to research.

- **How many people do you need?**

There are approximately 300,000 children currently living with pediatric rheumatic disease. We would like to collect information, analyze data, and return any research results to as many of these 300,000 patients and caregivers as possible. We cannot succeed without as many people participating as possible!

One person can ask an important research question, but information from thousands of individuals may be needed to answer that question. An example of that can be found in heart disease, where important healthcare advances have been made through the analysis of data from thousands of people.

Data Collection

- **What kinds of information will PARTNERS PPRN ask me to contribute?**

You will be asked to contribute information about your pediatric rheumatic disease history, symptoms, and treatments. In addition, you'll be asked about your general health and health history; your gender and other demographic information; family history; nutrition; lifestyle; and exposure to environmental factors.

- **How does PARTNERS PPRN protect my privacy and personal health information?**

The PARTNERS PPRN Project Team takes your privacy very seriously and has policies and processes in place to safeguard your identity and protect your health data. For instance, only authorized personnel will have access to your contact information, and this information will never be attached to the health information that we share with researchers. Before sharing your health information with researchers, all information that identifies you directly will be removed. In terms of data security, the PARTNERS PPRN Project Team will take industry-



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standard physical and electronic technical precautions to protect the information that you share with the PARTNERS PPRN. Will the PARTNERS PPRN share my health information?

Yes, the health information you contribute to the PARTNERS PPRN will be shared in a de-identified manner to enable research. Qualified researchers will be invited to request health information from PARTNERS PPRN for the purpose of conducting research studies. The PARTNERS PPRN Research committee will oversee the approval process for these requests. In other cases, qualified researchers will be asked to use PARTNERS PPRN health information to conduct research studies that arise from questions submitted by PARTNERS PPRN participants. This process will also be overseen by the PARTNERS PPRN Research Committee.

In addition, statistics and summary information based on all of the participants' health information pooled together will be shared with PARTNERS PPRN participants and others to show, for example, what types of people are participating and how the participant base is growing over time.

- **Why do I need to agree to an informed consent statement to submit my data?**

We want to make sure that you clearly understand how and why the study is being conducted, as well as the ways you will be asked to participate and any risks or benefits there are in doing so.

This [informed consent statement](#), along with other PARTNERS PPRN materials, has been reviewed and approved by an Institutional Review Board.

- **What makes PARTNERS PPRN different from other pediatric rheumatic data-collection initiatives?**

PARTNERS PPRN is different in several ways from other data-collection efforts. First, it is a governed by people living with and impacted by pediatric rheumatic disease, and includes the patient voice every step of the way. Second, it is centered on research driven by people living with pediatric rheumatic disease on topics of interest to them. We are also part of PCORnet, a national network of research networks. This gives us the power to easily contribute our data to many research efforts and gives researchers access to data from millions of people across the country. While other efforts share some of these qualities, PARTNERS PPRN is the only pediatric rheumatic research initiative that is nonprofit, patient-centered and governed, and part of a nationwide research network.



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Can I participate in PARTNERS PPRN if I already participate in other pediatric rheumatology studies?

Absolutely! PARTNERS PPRN is a separate effort and there's no restriction to participating.

- **How often should I visit the PARTNERS PPRN website?**

From time to time, there will be new surveys for you to complete on the site; you'll be notified when these are ready. In the near future, you'll be asked to provide health status updates to the PARTNERS PPRN whenever certain events happen, such as a relapse or a change in treatment.

In addition to returning to update your health information, please visit as often as you'd like. You will be able to read updates about the initiative, see summaries about the pooled data from all participants in PARTNERS PPRN, and learn about the research that is underway. We always welcome your feedback and ideas.

- **Will PARTNERS PPRN share my data with pharmaceutical companies?**

Researchers from pharmaceutical companies and other academic, commercial, and government entities are invited to request de-identified data from PARTNERS PPRN. These requests, like requests submitted by researchers in any sector, are carefully reviewed by the PARTNERS PPRN Research Committee. Decisions will always be made with the best interests of people with pediatric rheumatic diseases in mind.

Connection to Research

- **How does PARTNERS PPRN connect me to the research community?**

Your ideas about research topics that interest you will be shared with the Research Committee. As these ideas are developed into specific research queries, they can be shared with the wider research community.

Please note that this website will not allow researchers to contact you directly without your prior permission.

- **What kinds of research questions can I submit to PARTNERS PPRN?**

You should feel free to submit questions and ideas on any topic related to pediatric rheumatic disease.



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- **Will I know how my data is being used by researchers?**

Your information will be pooled with information from hundreds or even thousands of other people with pediatric rheumatic disease. The pooled information is used by researchers to see patterns that would not otherwise be visible, and to gain insights into the causes and mechanisms of the disease.

PARTNERS PPRN will provide updates about the research studies and their results as they advance.

- **Are researchers ever going to contact me directly?**

Researchers will never contact you directly without your prior permission.

Your Involvement

- **How are patients involved with PARTNERS PPRN?**

People living with and impacted by pediatric rheumatic diseases are involved with every aspect of PARTNERS PPRN, from the governance of the initiative, to ideas for research, to design and content of the website, to communications, and so on. These people are the heart and soul of PARTNERS PPRN.

- **If I join PARTNERS PPRN, what am I committing to?**

We ask that you continue to share your information by completing surveys on the site. You are free to skip surveys or to withdraw at any time.

- **Can my family and friends join PARTNERS PPRN?**

Yes, they can. While our primary goal is the collection of information from people living with these conditions, we welcome information from your family and friends.

- **How often will I receive updates from PARTNERS PPRN?**

You will receive updates from us periodically, for example, when there is a new survey, important news, and/or research findings.



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Funding and Other Support

- **Who is funding the PARTNERS PPRN initiative?**

The initial 18-month funding for PARTNERS PPRN is provided by the [Patient-Centered Outcomes Research Institute \(PCORI\)](#), an independent, nonprofit organization authorized by Congress in 2010.

PARTNERS-PPRN

- **What is the PARTNERS Patient-Powered Research Network and how does it relate to PARTNERS PPRN?**

PARTNERS formally links childhood arthritis and lupus patients, family members, the CARRA network, the Lupus Foundation of America, the Arthritis Foundation and a quality improvement network called PR-COIN. Our vision is to improve the lives of children with rheumatic diseases through research that matters to YOU. PARTNERS is a patient-powered research network funded by PCORI.

- **What is PCORnet and how does it relate to PARTNERS PPRN?**

[PCORnet](#) (the National Patient-Centered Clinical Research Network) is a large, highly representative, national network for conducting clinical outcomes research to improve healthcare. The network's Coordinating Center will integrate data from 29 PCORI-funded health data network projects, including the PARTNERS-PPRN.