



Sickle Cell FAQ

About PicnicHealth

What does PicnicHealth do?

- PicnicHealth works directly with patients like you to help collect and manage your medical records. That means going out and collecting all of your medical records from your different doctors and keeping them up-to-date over time. PicnicHealth will then transform your records into a timeline that makes it easier to find what you're looking for. When you see your doctor again, PicnicHealth will update your timeline with new records. You can access your PicnicHealth timeline from anywhere and even share it with your doctors with a few clicks. You'll receive PicnicHealth's service free of charge for as long as you're a participant in the study.

Why we're called PicnicHealth

- When we started PicnicHealth, we heard from everyone we spoke with about how hard it is to manage medical records. Slow response times. Complicated forms. Waiting on faxes. People from across the country with all kinds of health challenges kept using the same few words to describe their experience—it's no picnic. We wanted to change that. We clean up the chaotic mess of disconnected healthcare systems to give everyone complete, organized medical records. We know from experience that better medical information leads to better health. When it came time to name ourselves, we wanted to show what we're doing for patients right from the start. We know managing healthcare will never be a picnic, but we won't stop trying.

Study & Research Basics

Who can join this study?

- You can join this study if you have been diagnosed with sickle cell disease, live in the U.S., and have received medical care in the U.S. in the past 7 years.

Will I see the study results?

- Yes! We believe it's important for you to see the results of research produced using your data, and we'll make every effort to share published results back with you.

Can medical records really help with research?

- Medical records record what's actually happening when doctors see patients, so they can be really helpful for understanding how care is delivered in the real world. They also

contain a lot of information about how you experience sickle cell disease -- your symptoms, your health status, and your treatments. Putting all of this information together for a diverse group of patients will allow the scientific community to see patterns that no one doctor can see on his or her own.

Is this a clinical trial?

- This is not a clinical trial. A traditional clinical trial involves testing a specific treatment, like a drug or medical device. In this study, we are only looking at data from medical records produced during your normal visits to the doctor. The goal is to better understand how patients with sickle cell disease are being treated and how to advance care for patients everywhere.

Who will conduct the research?

- PicnicHealth partners with select third party organizations specializing in conducting scientific research or analysis on this type of medical data. These third parties might include government, academic, or commercial organizations. Data access for these institutions will be controlled through an application process managed by PicnicHealth, where partners will be evaluated based on their commitment to advance science for the public good. While PicnicHealth may be compensated for providing access to this data, we will always grant free access for non-commercial research - meaning, research that is not intended to make money but rather to contribute to science and the public good.

What type of research will be conducted with my data?

- Your de-identified health information and data will be analyzed in order to advance sickle cell disease research. The study data may be recorded, analyzed, and published. No names or personally identifying information will be disclosed to any researchers or research organizations. No patient will be identified in any report or publication from this study. It's hard for us to know every research question that your data may help answer. Since science is continually evolving, new questions may arise that we can't predict yet. Some research objectives that your data may help answer could include but are not limited to:
 - Understanding effectiveness of treatments on different patients
 - Understanding unmet needs in the patient populations
 - Understanding patient and physician behavior
- Additionally, we may link the data collected here to other existing healthcare data sets (e.g., patient registries) to help answer key research questions. Any data you contribute will be de-identified before using it in any study regardless of whether it is linked to other healthcare data sets. You may at any point contact PicnicHealth to get more information about how your de-identified data is being used.

What to expect

Can I see what my records will look like in my PicnicHealth account?

- Yes. You can view this [sample timeline](#).

What if I can't remember the names of all my doctors?

- You can just enter as many doctors as you remember. The hospital or clinic name is usually enough and the PicnicHealth team will follow up with you if there's any confusion. If PicnicHealth finds doctors mentioned in your records who you did not include on your doctor list, you will get an email asking for your permission to request records from that new doctor.

How will my doctor know it's okay to share my records?

- When you sign up, you'll read and sign a form that authorizes PicnicHealth to request your medical records on your behalf. You can e-sign this form online -- no printing or mailing involved. Your doctor will then know that it's okay to share your medical records with PicnicHealth.

What if my doctor doesn't have electronic records?

- No problem. PicnicHealth can work with data in any format, whether your doctor takes notes with a pen or on an iPad.

How can I use my PicnicHealth timeline?

- Your PicnicHealth timeline provides a single source of information for you and your doctors. It is a tool to help you coordinate care and understand your own health. You can share your timeline with any of your doctors with a few clicks. The doctor will receive a secure link and get access to your medical history.

Will PicnicHealth cost me anything?

- You'll receive PicnicHealth's service free of charge for as long as you're a participant in the study.

How will I get my \$200?

- PicnicHealth will send you a \$200 Visa gift card via email that can be used anywhere, similar to a debit or credit card. Note that first we will confirm your sickle cell disease diagnosis from your medical records, so it will likely take several weeks before you receive the \$200. If you have your records in your Timeline, but have not received your Visa gift card, please email help@picnichealth.com.

How long will it take to get my medical records?

- It takes about 3 to 6 weeks to retrieve most of your historical medical records. After that, it can take another couple of months for us to track down the oldest and trickiest records

to access. The timing depends on how quickly your doctors respond to PicnicHealth's requests for your records.

How far back will you collect historical records?

- For this research study, we will collect records going back as far as possible. In most states, doctors are required to keep records for at least 7 years, but many will keep them for much longer. So how far back we can go really depends on the record keeping practices of your doctors.

When I first see my PicnicHealth timeline, will it be complete?

- When you first see your timeline, it's possible that some of your medical records are not yet available. That's because PicnicHealth is still working hard to collect them for you. You should be able to see your medical records within a month of signing up. After the first month, your timeline will be updated regularly with information from your new doctor visits.

What should I do if I notice there are medical records missing from my PicnicHealth timeline?

- In the first months, some records might be missing because PicnicHealth is still collecting them for you. After the first month, if you suspect that records are still missing, you can let us know about those records by clicking "Request Records" at the top of your timeline.

What kinds of medical records will you collect?

- PicnicHealth will collect medical records from all the doctors, hospitals, and clinics that you tell us about. PicnicHealth does not collect dental or optometry records.

Will I get records from my scans and imaging?

- Yes! You will be able to view your imaging files right in your PicnicHealth timeline.

Will PicnicHealth update my medical records every time I see the doctor?

- PicnicHealth will update your medical records regularly. To keep your records most up-to-date, you can always tell PicnicHealth when you have seen the doctor. Just click the "Request Records" button at the top of your timeline, and PicnicHealth will retrieve your new records for you.

What should I do if I see a new doctor?

- At the top of your timeline, click on "Doctors" to add new doctors or medical facilities. PicnicHealth will then collect your records from your new doctors.

Can I stop participating in the study?

- Yes. Your participation in this study is completely voluntary and you can withdraw at any time. If you choose to stop participating, your medical records will remain available for you through your PicnicHealth account. At that time we will stop collecting any new

medical records. You can download copies of your records at any time. You can always tell PicnicHealth to delete your medical records, although the information that has already been shared with third party partners can't be deleted.

Data and Privacy

How does PicnicHealth make sure my data is secure and personal information private?

- PicnicHealth is committed to transparency in our research practices, security for users, and advancing research for the public good. PicnicHealth uses 256-bit military grade encryption to keep medical records safe and is HIPAA compliant. They remove any and all personally identifiable information before sharing with researchers, and data is never shared without a patient's explicit permission. Your data is yours to share—or delete if you no longer wish to use PicnicHealth. An independent ethics board known as an Institutional Review Board (IRB) also reviews PicnicHealth's studies to ensure participants are well informed.

Who will be able to see my medical records?

- By signing up for this study, you're agreeing to share your medical records with researchers and organizations working in the sickle cell disease space. They will only receive records stripped of any information that could be used to identify you personally. Outside of that, no one will be able to see your medical records unless you choose to share them by clicking "Send Records" at the top of your PicnicHealth timeline.

Can I delete my medical records from PicnicHealth?

- You may choose to delete your medical records and data from the PicnicHealth service at any time and for any reason. Just email PicnicHealth at SCD@picnichealth.com. Once records have been collected for the study, you can't remove them from the study.

Will my medical records be secure?

- PicnicHealth takes privacy very seriously. Your personal data is never shared without your explicit permission. Your medical records are kept safe using the highest encryption standard available: 256-bit SSL. This is the same technology that banks use to keep account information safe.

Help and more information

How can I learn more?

- Check out [this blog post](#) about how PicnicHealth is using real-world data for a new kind of research in sickle cell.

Who can I reach out to if I need help signing up or have questions?

- Please reach out to help@picnichealth.com.