

Sharing Your Personal Data

Information and advice for patients



Patient registries, databases, studies and clinical trials are a critical part of the search for new treatments for rare neuromuscular diseases. Your participation is valuable, because without you we won't learn important information about the diseases or advance the search for new therapies.

That said, protecting your personal data and being a smart registry or study participant is a big responsibility, and can often feel confusing.

These tips will help you to make sure that your data is only shared with people you want to share it with. These tips also apply for other personal information you might provide to organisations, for example case studies or photographs.

✓ **READ** the patient information provided.

This can be a lot of reading, so don't be afraid to ask questions or request a copy to take away and read in your own time.

✓ **RESEARCH** the organisation.

Who is asking for your data? Make sure this is for a legitimate project which has been set up with all the necessary ethical approvals and data protection in place. If this information is not freely available on their website, ask for it.

✓ **CHECK** the small print.

Who will have access to your data? What will they use it for? Who are they allowed to share it with? Sometimes this part is an opt-out, so unless you spot it you might be agreeing to things without realising.

✓ **THINK** about the future.

How long will your data be kept for, and what will be done with it afterwards? Remember that your data will always belong to you and you should be able to withdraw from the project or ask for your data to be deleted at any time.

✓ **BE SURE** that you feel comfortable.

You should never feel obligated to share your data or agree to anything before you are fully informed and confident that it's the right decision for you.

✓ **ASK** for help if you aren't sure.

If you have any questions, you can talk to your specialist, your GP, or an independent patient advocacy organisation for advice.