



Duchenne
UK



DMD Hub Central Recruitment Database Participant Information for Children aged 6 – 10

Information for Participants

We are asking if you would like to join in a project called the Duchenne Muscular Dystrophy (DMD) Hub Central Recruitment Database. This information sheet tells you what will happen if you agree to take part.

The decision part is up to you.

Please ask any questions that you have about the project.

Why have I been asked to take part?

You have Duchenne Muscular Dystrophy and your doctor and parents/guardians will have explained what that means.

What will happen to me if I take part in the project?

If you are happy to be part of this project, then we will collect information about you from your parent(s)/guardian(s).

You will not be asked to have any extra medical tests (no blood tests) done.
You will not need any time off school.

You will be looked after in the same way even if you decide not to take part in the project.



Do I have to take part?

You do not have to take part in the project and if at any time you do not want to do the research any more, just tell your parent(s)/guardian(s), doctor or nurse. They will not be cross with you and you will be looked after in the same way.

Will joining help me?

We cannot promise that the project will help you but the information we get might help other children with DMD in the future.

Will anyone else know I am doing this?

We will keep information about you private. This means we will only tell those who need to know you are taking part in the project.

Only people allowed by Professor Guglieri will be able to see the information about you.

Did anyone check this project is OK to do?

Before this project is allowed to happen, it has to be checked by a group of experts called an Ethics Committee. They make sure that the project is fair and done properly.

Who do I contact if I have any questions or need further information?

Please ask us or your parent(s)/guardian(s) if you do not understand the project or do not understand the words used.



**Thank you for reading this – please ask any
questions if you need to.**