

## 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 study called the Becker Muscular Dystrophy (BMD) Hub Central 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 study.

#### *Why have I been asked to take part?*

You have Becker 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 BMD Hub Central Recruitment Database?*

If you are happy to be part of the BMD Hub Central Recruitment Database, 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 study.

#### *Do I have to take part?*



You do not have to take part in the BMD Hub Central Recruitment Database and if at any time you do not want to be part of it anymore, 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 study will help you but the information we get might help other children with BMD 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 BMD Hub Central Recruitment Database.

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

***Did anyone check this study 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.**



*This study was approved by the Faculty of Medical Sciences Research Ethics Committee, part of Newcastle University's Research Ethics Committee. This committee contains members who are internal to the Faculty. This study was reviewed by members of the committee, who must provide impartial advice and avoid significant conflicts of interests.*