

Parent Information Sheet



The 'Well mi' study

Wellbeing, health and fitness of children with mobility impairments (Well mi)

Project title: The 'Well mi' study:

Wellbeing, health and fitness of children with mobility impairments

Research officer: Dr Llinos Haf Spencer

Thank you for reading this information sheet about the Well mi study

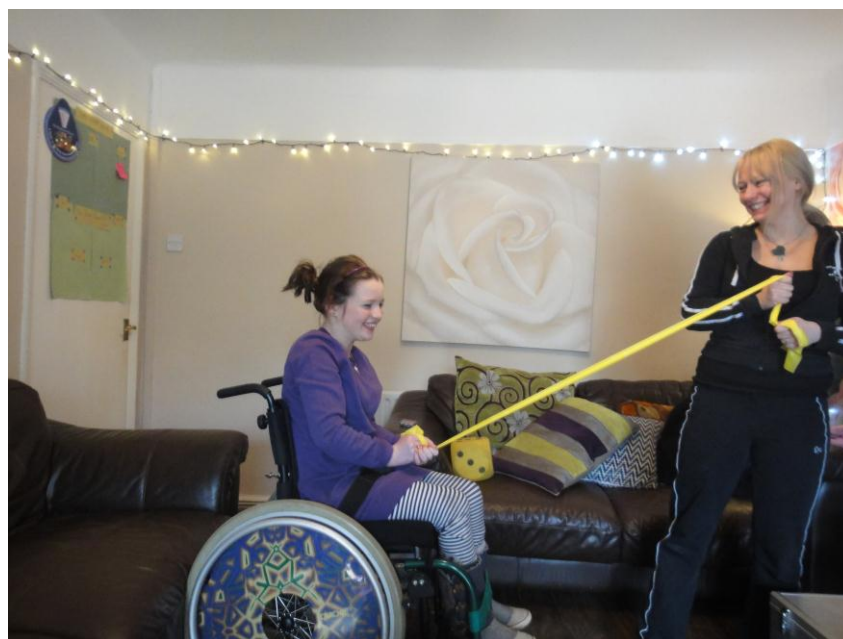
You and your child are being invited to take part in a research study called the Well mi study. Before you decide whether they you take part, it is important for you to understand why the study is being done and what it would involve.

What is the Well mi study about?

Researchers from Bangor University have been commissioned to carry out a research study to develop assessment methods and explore preferences for exercise for children with mobility impairments and their families. It is hoped that by the end of the study individually tailored keep fit interventions will be designed. We hope to test out the new keep fit interventions in another study in the future.

Why has my child been chosen?

Your child has been chosen because he/she uses a wheelchair.



Does my child have to take part?

Participation in this study is completely voluntary. It is up to you and your child to decide whether or not to take part. If your child does decide to take part you would be asked to sign a consent form and be given a copy of the form and this sheet to keep. If your child decides to take part they are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a

decision not to take part, would not affect the care your child receives.

Children age 16 and over can in law decide themselves if they want to take part. Children under 16 years may also decide for themselves, but we will ask parents and legal guardians to sign an additional consent form.

What will happen if my child takes part?

Focus group or face to face interview

The study involves your child participating in a 'focus group' or face to face interview in the first instance. The conversation would be recorded with a digital voice recorder and if it is okay, with a video recorder.



Images of voice and video digital recorders

In a focus group your child will meet similar age children and young people to talk about the exercise and activities that they currently do or would like to do in the future. We will ask him/her questions regarding exercise and their feelings about taking part in exercise. In a few weeks, we would like to ask your child to complete wellbeing questionnaires and we would also like to measure your child's health and fitness.

Questions for parents – We would like to ask you as parents questions about where you live, and about your health. In a few weeks, we would like to measure your health as well as your child's as we wish to examine the relationship between the health status of parents and their children.

Where will my child have to go to take part?

Your child can choose one of the following options:



1. The researcher to come and talk to your child and you in your home.



2. The researcher to talk to your child and other people (who will be around your child's age) in a group at a place near where you live (such as a Sports Centre). Travel expenses will be reimbursed by Bangor University.

Does my child get anything for taking part?

If your child takes part in an interview or focus group, he/she will get a £15 'thank you' token each time. Your child will be able to choose from High Street Vouchers **or** iTunes vouchers.



**Love2shop
High Street Vouchers**



**iTunes®
gift vouchers**

What will happen to the information my child provides?

The person who undertakes the focus group/interview will listen to the tape and transcribe it word for word into a typed document. The main issues that the children and young people raise will

be drawn out. We will use the information to design individually tailored keep fit exercises and activities for children and young people who use wheelchairs.



What are the possible disadvantages and risks of taking part?

We do not foresee any disadvantages or risks to your child taking part in the study.

What are the possible benefits of taking part?

The exercise opportunities available to you and your child is unlikely to change in the short term. What your child tells us would be used to develop individually tailored exercise interventions for children and young people who use wheelchairs.

What if something goes wrong?

If you have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal Bangor University complaints mechanisms should be available to you.

Will my taking part in this study be kept confidential?

- All information will only be accessible by members of the research team.
- No individual names or details that would identify specific individuals will be included in the themes or outputs from the study.
- Quotations from interviews may be used in reports, presentations and papers but these will not be traceable to specific individuals.
- All published and unpublished reports will disguise the identity of individuals.
- Information will only be disclosed for the purpose of protecting the individual child or family member. If there are serious concerns about the safety of a child or family member, standard procedures will be followed.

What will happen to the results of the study?

- The final study report will be produced in 2014.
- This will be followed by a wide-ranging exercise to make known the findings, including publications in
 - professional and academic journals
 - seminar and conference presentations.

Who is organising and funding the research?

NISCHR CRC Research Funding Scheme has funded the study and a team from Bangor University are carrying out the study. There is no organisational or individual payment for participation in the study – apart from a £15 token given as a ‘thank you’ to each child participating in a focus group/interview.

Who has reviewed the study?

The study has been reviewed and approved by the **NHS Research Ethics Committee North West Wales.**

Do you want to take part?

If you and your child want to take part in the research, please fill in the paper contact form or the contact form on the Well mi study website, or ring or e-mail Llinos today for more information.

Any questions?

If you want to know more about the study before you decide about taking part, you can phone, e-mail, or write to Llinos.



Ring or e-mail Llinos
if you want
to take part

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What should I do if I have any concerns about the study that cannot be resolved by the research team?

If you have any concerns about the study, please contact:

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