

Parent Information Sheet (Stage 2)



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

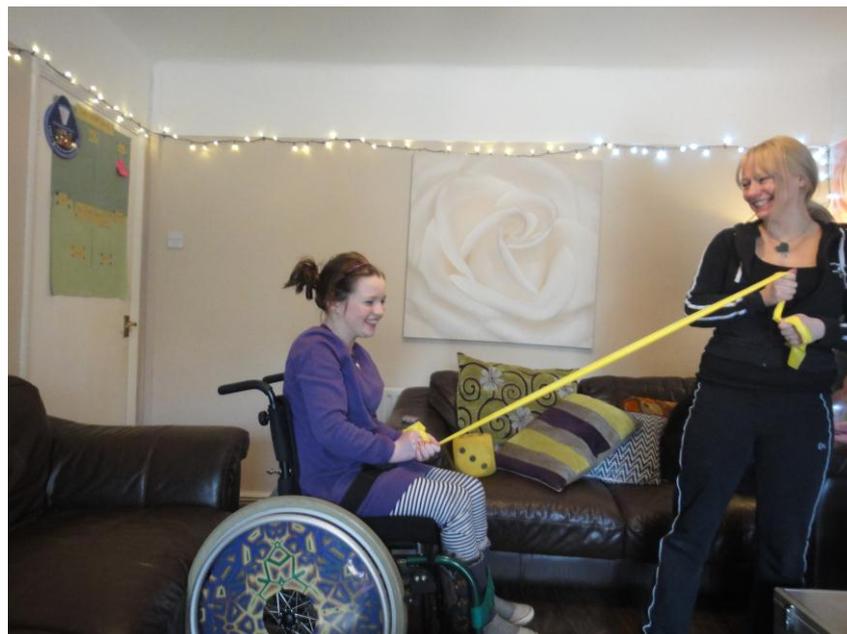
You and your child are being invited to take part in a research study called the Well mi study. Before you decide whether they you take part, it is important for you to understand why the study is being done and what it would involve.

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 has been issued with 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?

In Stage 2 of the Well mi study, your child's health and fitness will be measured. We will measure the following things:

Heart rate: We will monitor your child's heart rate to assess their aerobic fitness. We will do this by asking your child to wear a heart rate monitoring belt for a day, and by asking your child about their activities that day on an activity log sheet.



Body composition: Your child's body fat percentage will be estimated through multi-frequency bioelectrical impedance. This means that two self-adhesive electrodes will be placed on your child's foot and hand with him/her sitting down. This is a painless procedure.



Breathing: A portable metabolic cart (Cortex) will be used to measure the amount of oxygen your child breathes in and carbon dioxide they breathe out. Your child will be asked to lie down and to breathe normally into a small face mask covering his/her mouth and nose for up to 30 minutes. Your child will wear headphones and listen to calm music. We will also ask your child to perform a few maximum effort breaths in and out.

Strength:

We will measure your child's strength by asking them to lift a weighted medicine ball and using a hand-grip tool. We'd also like to assess your child's mobility, where appropriate, when they self-propelling their wheelchair and if they can walk without it.



We will notify your child's GP of any unusual test result.

Quality of life and wellbeing: Your child will be asked to provide their opinion on different wellbeing questionnaires.



Your child's diet: We will ask you questions about what your child typically eats in a day. We will gather your opinions on typical diet sheets.

A 'ROUND FOOD INTAKE FORM' is shown. It has a header with the title 'ROUND FOOD INTAKE FORM' and a date field. Below the header is a table with columns for 'Food Item', 'Amount', 'Times', 'Times', 'Times', 'Times', and 'Calories'. The table has several rows for recording food intake. At the bottom, there are fields for 'Total Food Intake (g)' and 'Total Food Intake (kcal)'. The form is decorated with cartoon characters.

Questions for parents – As there is a health economics component to this study, **we would like to ask you as parents questions about where you live and your income, as well as questions about your health.** You do not have to answer every question if you do not wish to do so. We would also like to measure **your** fitness 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?



The Research Officer and Research Technician will come and see you in your home.

Does my child get anything for taking part?

If your child takes part in any stage of the Well mi study, he/she will be given a £15 'thank you' token. Your child will be able to choose from High Street Vouchers **or** iTunes© vouchers each time.



**Love2shop
High Street Vouchers**



**iTunes©
gift vouchers**

What will happen to the information my child provides?

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 this stage of the research or in another stage of 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.



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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