



The Sydney
children's
Hospitals Network

Young Person Information Sheet

Study Title	A digital health education program promoting physical activity for childhood cancer survivors: A hybrid effectiveness-implementation trial of 'Making Moves'
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1. Introduction

You are invited to participate in a research study titled, *A digital health education program promoting physical activity for childhood cancer survivors: A hybrid effectiveness-implementation trial of 'Making Moves'*. This information sheet tells you about the study. It will help you choose if you want to join or not. You can ask your parents, carer, friend or doctor if you need. You do not have to join this study if you do not want to.

Before you think of joining this study, you should know why and how the research is being done. Please read this information sheet carefully.

2. What is the purpose of this study?

The purpose of this study is to see if our online physical activity program called 'Making Moves', can help improve childhood cancer survivors' physical activity self-efficacy. Physical activity self-efficacy means a person's confidence in their ability to be physically active. The higher your physical activity self-efficacy, the more confident you are to be physically active.

Many young people who had cancer do not do enough exercise and may have low physical activity self-efficacy. It is important for all cancer survivors to do regular exercise because it can improve physical fitness levels and reduce the risk of developing other diseases such as obesity and heart disease.

‘Making Moves’ aims to teach you about living a physically active lifestyle. The program will provide you with a free activity tracker, fun facts, health education, guided exercise videos, and tailored online sessions with an Exercise Physiologist.

This research study is funded by a grant from The Kids’ Cancer Project.

3. Why have I been invited to this study?

You are invited to take part in this study because you:

- Had cancer as a child or adolescent (before the age of 18 years old)
- Are currently 8-21 years old
- Have finished active cancer treatment 6 or more months ago OR you are currently on maintenance therapy.

4. Do I have to be in this study?

You do not have to participate in this study if you don’t want to. The doctors and nurses will take the best care of you as they have in the past, regardless of whether you are in the study or not. If you choose to participate, you can stop being in it at any time. All you need to do is tell one of the researchers or your parents/carers that you don’t want to take part anymore.

5. What will happen to me in this study?



If you choose to join the study, you will learn about living a healthy lifestyle using our online program called ‘**Making Moves**’. You can use Making Moves on a phone, tablet/iPad, or computer. You will also be gifted a **Fitbit activity tracker** so that you can monitor your physical activity levels throughout the study period (and after the study finishes). You may keep your Fitbit, even after the study finishes.



Making Moves has **8 modules** for you to complete. Each module includes physical activity information, fun facts, tips to get active, and exercise videos to follow along to at home. We recommend you do 1 module each week (total 8 weeks). Each module will take around 10-20 minutes to complete. The Making Moves module topics are:






Module number	Topic
1	Welcome
2	Living a physically active lifestyle
3	Sedentary behaviour: don’t just sit and sit and sit!
4	How much exercise do I need to do?



5	Staying fit and motivated
6	Let's get stronger!
7	Flexibility, balance, and coordination
8	Healthy eating

There will be a variety of guided exercise videos for you to choose from in each module. You can follow along to these videos at home or you can use them as inspiration. You can watch as many videos as you like and exercises can be done with friends or family.

Examples of exercise videos are:

Exercise type	Video examples
 Strength	Learning correct technique of performing bodyweight exercises (e.g., squat or push up)
 Cardio	Short circuit training to get your heart pumping
 Balance	Yoga flows
 Skills and coordination	Sports skills (e.g., soccer or basketball drills)
 Flexibility	Stretching, warm up and cool down sessions



You will also have the opportunity to **talk with an Exercise Physiologist up to 5 times**. During these sessions, you will:

- Talk about your physical activity levels.
- Set goals.
- Ask any questions you may have.
- Do a short walking test (you only have to do this 3 times)
- Do a short strength test (you only have to do this 3 times)

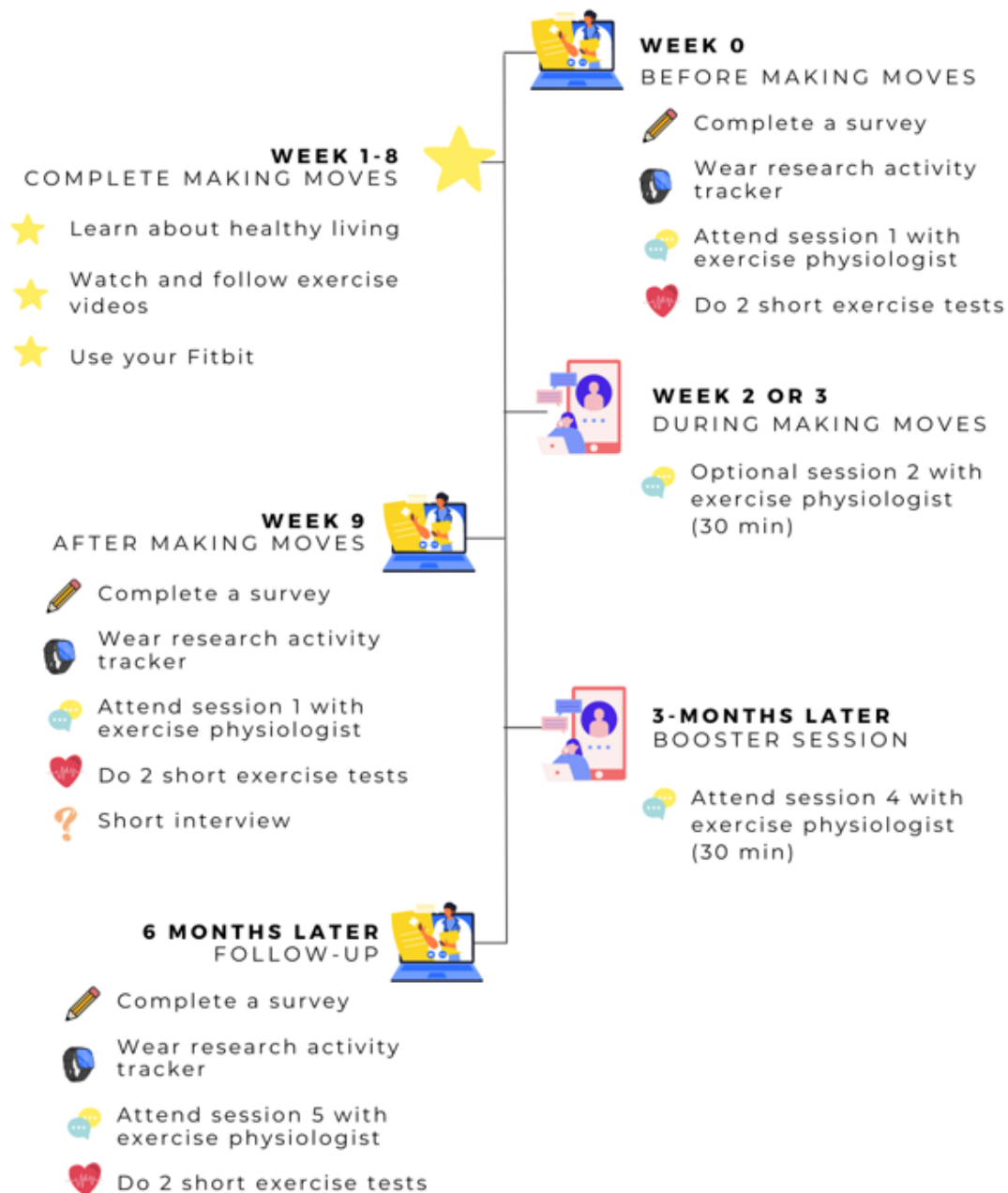
These sessions should take around 45-60 minutes. The 3 sessions where you complete the walking and strength test (before you start Making Moves, after you finish Making Moves, and 6-months later), will be a little longer. During the session after you complete the Making Moves program (week 9), your Exercise Physiologist will also interview you and your parent/carer and ask for your feedback about the program.



We will ask you to **complete a survey** and **wear a research activity tracker** (different to the Fitbit) 3 times throughout the study period (before and after Making Moves, and 6 months later).



This research activity tracker records your physical activity levels throughout the day. We will ask you to wear this activity tracker for 5 days in a row (including the weekend). After you have finished wearing it for 5 days, you will need to mail it back to the researchers (you cannot keep it). Researchers will assess whether your physical activity levels changed after using Making Moves. All information will be private. No one will know it was your physical activity levels.



6. How do I use the Fitbit activity tracker? Will I be monitored? What information is collected?

You can use the Fitbit device independently and monitor your physical activity levels by viewing the screen on the device. You do not need download the Fitbit app for this study, but you can if you wish to. If you decide to download the app, you will need a smart phone (iPhone or Android phone) or tablet. The Fitbit activity tracker is for you to keep so that you can continue to monitor your physical activity levels after the study.

Researchers will not monitor or collect information from your Fitbit.

When you use the Fitbit, the Fitbit company will collect your personal information if you set up the activity tracker (name, email address, password, date of birth, gender, height, weight in some cases,

and phone number). It will also collect additional information if you enable certain features such as food logs and sleep. The Fitbit company will not share your personal information except when you agree, for customer support, for legal reasons to prevent harm, or if you choose to connect your account with Google.

7. What platform is Making Moves on? What information is collected?

The Making Moves program is powered by Wix, a professional website software company.

Information collected includes:

- Information researchers provide to Wix: nothing.
- Information Wix will collect when you use the program: your browsing, your activity when using the website, your internet browser, screen resolution, language and keyboard settings, internet provider, and the date/time. Wix also collect the number of times you access each page, how long you were on each page and the type of device you used.
- Information Wix collect from other sources: security providers, fraud detection and prevention.

We will create an anonymous user account for you so that Wix will not collect any personal information about you. After the study finishes, we will delete all user accounts.

8. Can anything bad happen?

Nothing bad should happen when you do this research study. Doing this research study might inspire you to do more exercise. There are very small risks of exercising, but the risks are like playing sport. To make sure it is safe for you to exercise, your doctor will be asked if they think you can join this study.

If anything you talk about during the research does make you upset, you can stop the research. Your parents/carers will be told and you will be given the names of people you can talk to about what is making you upset, if that is what you want to do. The researchers can help you do that.

You can also call the Kids Helpline (telephone number: 1800 551 800) or Lifeline (telephone number: 13 11 14) at any time.”

9. Will there be any benefits for me in this study?

We cannot promise that you will receive any benefits from this research; however, possible benefits may include improved physical activity self-efficacy, improved physical activity levels, improved fitness levels, improved muscle strength, improved flexibility, improved quality of life, improved body composition and a reduced risk of developing chronic diseases.

10. How will my privacy be protected?

Your privacy and confidentiality will be protected at all times in this study. Unless you allow us, we will not tell anybody else you are or have been a part of this study. We will not release any information to anybody else that could be used to identify you, unless we are required to do so by law. For example, researchers are required to report if a participant is believed to be at risk of harm.

In order to protect your privacy, the study team will remove any information that may be used to identify you from any study documents, and instead of your name appearing on them, you will be

identified by a specific study code number that applies only to you. Only this code number will be used on any research-related information collected about you for this study, so that your identity as part of the study will be kept completely private. Only the study team at the University of New South Wales, Sydney will have the ability to link this code number with your personal information, and the linking information will be kept in the UNSW secure network in a password-protected folder.

Your data will be stored for a minimum of 15 years after the study finishes or until the youngest participant turns 25.

If you decide to leave the study, we will not collect any more information about you. We would like to keep the information we have already collected about you to help us ensure that the results of the research project can be measured properly. Please let us know if you do not want us to do this.

11. What will happen to the study results?

We would like to share the study results by publishing them in relevant journal articles and presenting them at different conferences. We will make sure that information is published/presented in such a way that you are not identifiable, unless you have given us permission to do so. You can also tell us on the consent form if you want to receive a simple summary of the study findings for information.

12. Who should I contact if I have any questions?

If you have any questions or want more information about this study before or during participation, you can talk to Dr Lauren Ha on (02) 9065 0406 or email lauren.ha@unsw.edu.au.

You can also ask your parents/carers to talk to us.

13. Who do I contact if I have concerns about the study?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). This study has been approved by the Sydney Children's Hospitals Network HREC (**approval number: 2023/ETH01614**).

Please talk to your parents/carers if you are worried about being in this study, or you have a complaint. They can talk to Dr Lauren Ha on (02) 9065 0406 or email lauren.ha@unsw.edu.au or they can contact the Human Research Ethics Committee on (02) 9845 1253 or SCHN-Ethics@health.nsw.gov.au.