



Chief Investigator: Dr Shelley Gorman
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Promoting Safe Sun Behaviours in Teenagers Project School Student Information Form

Dear Student,

My name is Shelley Gorman and I am from the Telethon Kids Institute. I invite you to take part in a research project that I am leading. This project aims to help teenagers make balanced and healthy decisions around how they spend time outdoors, in the sun. Our research team has developed a smartphone app, designed with the input of young teenaged co-researchers. We need you to take part in the project to help us to test the capacity of the app to improve the knowledge and behaviours that young teenagers have around their sun health. I will only be asking students from your school to be involved.

Northern Entrance,
Perth Children's Hospital
15 Hospital Avenue
Nedlands WA 6009

PO Box 855,
West Perth WA 6872

Aim of the study. Too much sun exposure in childhood and as a teenager is harmful, increasing the risk for skin cancers in later life. Even with education about the risks, teenagers in Western Australia are sun-seeking, with tanned skin desirable. Sunburn remains common, and increases the risk of developing melanoma - the most common cancer of young adults. However, regular exposure to non-burning levels of sunlight is necessary for vitamin D and healthy bones. New ways are needed to support young people make healthy and balanced decisions around sun protection and sun exposure. In this project we have developed an app which promotes safe sun exposure practices in teenagers. This app aims to improve the knowledge and behaviours that young teenagers have around sun protection and exposure, and how to best balance their needs to both limit the damage of excessive sun exposure and receive enough for vitamin D. The app is still under-development, and some aspects will be changed, based on findings from this study.

Possible benefits. Your participation in this study may benefit other young people in Western Australia by contributing towards the development of an app that will support them make balanced and healthy decisions around how they spend their time in the sun. You may increase your understanding of healthy sun behaviours, and how health promotion apps are produced. Both your consent and your parent's consent are needed for your participation in this study. You will require access to an ipad or iphone and internet access at home to participate.

What would I be asked to do? You will be asked to participate in a **10-week study**.

Week 1: (a) Complete a multiple-choice test (20 min); and, (b) receive UV badges, to be worn on your wrist (like a watch) during the day for the next 7 days to measure your sun exposure for 1 week.

Week 2: (a) Complete a sun health questionnaire (~30 min) that gathers information on your skin type, sensitivity to sun exposure and normal sun exposure patterns; and (b) download the control (unrelated/placebo) or developed (test) app. A placebo app is used in this study to control for the 'digital placebo effect', which may occur through expecting a beneficial effect, as personal devices such as iPhones/iPads are considered an 'extension of self'.

Weeks 3-8: Use the downloaded app for 6 weeks. Researchers will encourage you to use the app when first downloaded. Other elements of the app will encourage use throughout the 6 weeks (e.g. notifications).

Week 9: (a) Re-do the multiple-choice test (20 min); and, (b) receive UV badges, to be worn during the day for the next 7 days to measure your sun exposure for 1 week.

Week 10: (a) Complete a shortened version of the sun health questionnaire (~15 min) that gathers information on your sun exposure patterns over the past 6 weeks; and (b) complete a survey that asks questions about how easy the app is to use, and how much the user enjoyed using it (~30 min). You will also be given an opportunity to verbally provide any further feedback to the research team as part of this final session.

In weeks 1, 2, 9 and 10, in-class sessions will be conducted to collect data, supervised by researchers.

- Those not participating in the study will continue to participate in normal curriculum activities supervised by a participating teacher (in your normal classroom).
- Participants will be given a study identification number at the beginning of the study during online recruitment so that all future collection of data in-class will be de-identified.

Discover. Prevent. Cure.





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- During online recruitment, we will collect a limited amount of personal data (name, age, gender, postcode) to potentially evaluate the influence of gender or postcode (proxy for socioeconomic status) on outcomes.
- We will only analyse data if there are sufficient numbers (per group), to protect privacy of participants.
- An Apple ID account will be needed to download the app onto an iOS (Apple) device (provided by the participant) as both apps are hosted on the Apple app store.
- During the online recruitment and consent process we advise you to check through the privacy policies of data providers for the apps with your parent, prior to use. You will have the option to freely withdraw from the study if desired.
- *Privacy and data security:* Neither app collects data on app use through app analytics. The app may require the user's location and IP address to provide location-specific information; however, this data is not stored by the app or provider of the information.
- You will be given the correct answers to the multiple-choice test at a general information session at the end of the study. We will also reveal which app was the test app and provide an opportunity for participants to give any further feedback to the research team.

Do I have to take part? You are free to say yes or no. We will respect your decision whichever choice you make, and we will not question it. Participating in this research will not affect your grades, your relationship with your teacher(s), or with your school.

What if I change my mind? If you say no, but then change your mind and want to take part, contact me and I will let you know if you can still join in. If you say yes, but then want to stop participating, that's OK. Just let your teacher or me know and you can withdraw any time. Your data can be withdrawn at any stage of the research process, except once research findings have been published.

Possible risks and risk management. We do not foresee any major risks associated with participating in this research project. However, we ask participants to inform parents of any sunburn events and seek medical attention if treatment is required during the trial. We do not recommend that participants unlock any aspects of the test or placebo app as these do not add any noticeable functionality but this can be done for a small fee via the iOS Apple Store (through an Apple ID account).

What will happen to the information I give - is it private and confidential? Yes, all information provided will be private and confidential. Recruitment will be done online using the *Qualtrics* program managed by the University of Western Australia. Encrypted recruitment data will be hosted online until the trial is completed, when it will be downloaded immediately and securely stored at Telethon Kids. Data stored on *Qualtrics* is encrypted and backed-up at a secure server located in Canada (via encryption). Information that identifies you will be removed from the data collected. The data is then stored securely. All paper-based data will be stored in locked filing cabinets, in a secure location at the Telethon Kids Institute. Electronic data stored on computers will be on password-protected computers or server, accessible only to the investigators in a secure location. All data will only be accessed by Telethon Kids Institute staff who have signed confidentiality agreements. The means to re-identify data will be kept in a separate location to the original data files. All records will be maintained for 13 years after the date of publication or project completion (whichever is the latter) as required by law.

After we have collected all the information for the project and analysed it, we will write about what we have found and publish it in a journal, which is like a magazine, so that other people can read about it. We will also present the findings in an open forum, and through conference presentations. When we do this, we won't write or tell anyone your name, or the names of any other students or your school. A summary of the project will be made available to your school when it is completed. You can also ask for a copy by contacting me directly. The summary should be available in December 2020. The information you provide for this project will be used only for this project, and we will not use the data in any future research without first getting permission from you and your parents/carers.

Will you tell anyone what I say while I am contributing to the project? In most situations, we will treat what you tell us as being private and confidential (we won't tell anyone unless you agree that we should). If you tell us something





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that we need to tell someone else because the law requires us to do so, then we will have to. We may also have to reveal something you say to us if we think that you are being mistreated by someone. If this happens we will make sure that someone will come and talk with you about it.

Is this research approved? The research has been approved by the University of Western Australia Human Ethic Research Committee and has met the policy requirements of the Department of Education as indicated in the attached letter.

Who do I contact if I wish to talk about the project further? Please first talk to your parents about this project. Then, if you would like to talk with me more, please contact me on 6319 1747 (work) or 0409 114452 (mobile) or shelley.gorman@telethonkids.org.au (email). If, at any time, you wish to speak with a person who is not involved in the project about how something was handled, please contact the Human Ethics office at the University of Western Australia by telephone (08 6488 4703) or email (humanethics@uwa.edu.au).

OK – so how do I become involved? If you have already discussed the project with at least one of your parents and you do want to be a part of the project, please complete the **Online Consent Form** with your parent or guardian.

Yours sincerely,

Shelley Gorman
Group Leader, Telethon Kids Institute
Perth Children's Hospital (Level 7, 15 Hospital Ave, Nedlands)
08 6319 1747 or 0409114452 or shelley.gorman@telethonkids.org.au

Approval to conduct this research has been provided by the University of Western Australia with reference number RA/4/20/4424, in accordance with its ethics review and approval procedures. Any person considering participation in this research project, or agreeing to participate, may raise any questions or issues with the researchers at any time. In addition, any person not satisfied with the response of researchers may raise ethics issues or concerns, and may make any complaints about this research project by contacting the Human Ethics office at UWA on (08) 6488 4703 or by emailing to humanethics@uwa.edu.au. All research participants are entitled to retain a copy of any Participant Information Form relating to this research project.





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Promoting Safe Sun Behaviours in Teenagers Project **School Parent Information Form**

Dear Parent/Carer,

Project: Developing an online tool to promote safe sun behaviours in teenagers

My name is Shelley Gorman and I am writing to you on behalf of the Telethon Kids Institute. I am conducting a research project that aims to help teenagers make balanced and healthy decisions around their behaviours when spending time outside, in the sun. Our research team has developed a smartphone app, designed with the input of young teenaged co-researchers, and contains information relevant to teenagers around safe sun behaviours. The project is funded by Healthway (Government of Western Australia) and is being conducted by the following researchers:

- **Chief Investigators** - Dr Shelley Gorman (Telethon Kids Institute), Mr Mark Strickland (Cancer Council WA), Professor Robyn Lucas (Australian National University)
- **Associate Investigators** - Ms Rebecca Nguyen (Telethon Kids Institute), Mr Mohinder Jaimangal (Curve Tomorrow), Dr Gail Alvares (Telethon Kids Institute), Professor Prue Hart (Telethon Kids Institute), Dr Lucinda Black (Curtin University)
- **School Staff Providing Support** - Mr Mark Muir, Ms Michelle Edwards
- **University Students** - Ms Nisali Gamage, Ms Isabelle Clare, Mr Enrico Orsini (University of Western Australia; undertaking research projects using de-identified data only)

I invite your child to take part in the project. We need your child to participate in a pilot study to test the capacity of the app to improve the knowledge and behaviours that young teenagers have around their sun health. Your child's school is the only school we have approached in Western Australia for their participation. The principal has consented to your child's school being involved in this study. Your child has also been provided with a letter from us that we encourage you to discuss with him/her. Both your consent and your child's consent are needed for their participation in this study. Your child will require access to an ipad or iphone and internet access at home to participate.

Aim of the study. Too much sun exposure in childhood and as a teenager is harmful, increasing the risk for skin cancers in later life. Even with education about the risks, teenagers in Western Australia are sun-seeking, with tanned skin desirable. Sunburn frequently occurs and increases the risk of developing melanoma - the most common cancer of young adults. However, regular exposure to non-burning levels of sunlight is needed for vitamin D and healthy bones. New strategies are required to better support young people make healthy and balanced decisions around sun protection and sun exposure. In this project we have developed an app which promotes safe sun exposure practises in teenagers. This app aims to improve the knowledge and behaviours that young teenagers have around sun protection and exposure, and how to best balance their needs to both limit the damage of excessive sun exposure and to receive enough for vitamin D. The app is still under-development, and some aspects will be further developed in the future to be more self-contained and not require access to external platforms, based on findings from this study.

Possible benefits. Your child's participation in this study may benefit other young people by contributing towards the development of an app that will support them make balanced and healthy decisions around how they spend their time in the sun. Their participation may benefit you and your family by increasing your understanding of healthy sun behaviours, and the research process that underlies how these online health promotion tools are produced.

What would my child be asked to do? Your child will be asked to participate in a **10-week study**.

Week 1: (a) Complete a multiple-choice test (20 min); and, (b) receive UV badges, to be worn on their wrist (like a watch) during the day for the next 7 days to measure their sun exposure for 1 week.

Week 2: (a) Complete a sun health questionnaire (~30 min) that gathers information on their skin type, sensitivity to sun exposure and normal sun exposure patterns; and (b) download the control (unrelated/placebo) or developed (test)





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app. A placebo app is used in this study to control for the 'digital placebo effect', which may occur through expecting a beneficial effect, as personal devices such as iPhones/iPads are considered an 'extension of self'.

Weeks 3-8: Use the downloaded app for 6 weeks. Researchers will encourage participants to use the app when first downloaded. Other elements of the app will encourage use throughout the 6 weeks (e.g. push notifications).

Week 9: (a) Re-do the multiple-choice test (20 min); and, (b) receive UV badges, to be worn during the day for the next 7 days to measure their sun exposure again for 1 week.

Week 10: (a) Complete a shortened version of the sun health questionnaire (~15 min) that gathers information on their sun exposure patterns over the past 6 weeks; and (b) complete a survey that asks questions about how easy the app was to use, and how much the user enjoyed using it (~30 min). Your child will also be given an opportunity to verbally provide any further feedback to the research team as part of this final session.

In weeks 1, 2, 9 and 10, in-class sessions will be conducted to collect data, supervised by researchers.

- Young people not participating in the study will continue to participate in normal curriculum activities supervised by participating teacher (in their normal classroom).
- Participants will be given a study identification number at the beginning of the study during online recruitment so that all future collection of data in-class will be de-identified.
- During online recruitment, we will collect a limited amount of personal data (name, age, gender, postcode) to potentially evaluate the influence of gender or postcode (proxy for socioeconomic status) on outcomes.
- We will only analyse data if there are sufficient numbers (per group), to protect the privacy of participants.
- An Apple ID account will be needed to download the app onto an iOS (Apple) device provided by the participant as both apps are hosted on the Apple app store.
- During the online recruitment and consent process we advise parents to check through the privacy policies of data providers for the apps, prior to use by their child. You will have the option to freely withdraw your child from the study if desired.
- *Privacy and data security:* Neither app collects data on app use through app analytics. The app may require the user's location and IP address to provide location-specific information; however, this data is not stored by the app or provider of the information.
- Your child will be given the correct answers to the multiple-choice test at a general information session at the end of the study. We will also reveal which app was the test app and provide an opportunity for participants to give any further feedback to the research team.

Voluntary participation and withdrawal from the study. Participation is voluntary and your decision will be respected. Your decision will not affect your family's relationship with your child's teacher or the school. If a decision is made to participate, it will need to be made by 9th March 2020 for your child to be included in the project. Once a decision is made to participate, either you or your child can change your mind at any time. Your data can be withdrawn at any stage of the research process, except once research findings have been published.

Possible risks and risk management. We do not foresee any major risks associated with participating in this research project. However, we ask participants to inform parents of any sunburn events and seek medical attention if treatment is required. We do not recommend that participants unlock any aspects of the test or placebo app as these do not add any noticeable functionality but this can be done for a small fee via the iOS Apple Store (through an Apple ID account).

What will happen to the information my child gives - is it private and confidential? The privacy and confidentiality of participants is assured. Recruitment will be done online using the *Qualtrics* program managed by the University of Western Australia. Encrypted recruitment data will be hosted online until the trial is completed, when it will be downloaded immediately and securely stored at Telethon Kids. Data stored on *Qualtrics* is encrypted and backed-up at a secure server located in Canada (via encryption). All paper-based data will be stored in locked filing cabinets, in a security-tagged location within the Telethon Kids Institute. Information that identifies your child will be removed from the collected data. Electronic data stored on computers will be on password-protected computers or server and accessed only by the investigators in a security-tagged location. All data will only be accessed by Telethon Kids Institute staff or students who have signed confidentiality agreements. The means to re-identify data will be kept in a separate location to the original data files. We will have identifying data to provide feedback to participants on test results, and to be able to remove data from individuals that withdraw from the study, if requested. All records will be maintained





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for 13 years after the date of publication or project completion (whichever is the latter) as required by law. Paper-based data will be archived at an approved offsite storage provider within the Perth region. After the time of archival elapses, all data will be destroyed through confidential shredding.

Participant privacy and the confidentiality of information disclosed by participants is assured except in circumstances that require reporting under the Department of Education *Child Protection* policy, or where the research team is legally required to disclose that information. The data will be used only for this project and will not be used in any extended or future research without first obtaining explicit written consent from both you and your child. It is intended that the findings of this study will be published in a journal and available through 'open access' so that anyone can access it through the internet. We will also disseminate the findings of this study in an open forum, and through conference presentations. A summary of the research findings may be requested on completion of the project. This summary should be available in December 2020. You will also be able to access the report in the future by contacting me directly.

Is this research approved? The research has been approved by the University of Western Australia Human Ethics Research Committee (RA/4/20/4424) and has met the policy requirements of the Department of Education.

All members of research team who will be having contact with children have their Working with Children Check. All persons undertaking research activities on Department sites must complete a Confidential Declaration. Under the *Working with Children (Criminal Record Checking) Act 2004*, people undertaking research that involves contact with children must undergo a Working with Children Check. Evidence that these checks are current for each member of the research team who will have contact with children has been provided to the principal of your child's school.

Who do I contact if I wish to discuss the project further? If you would like to participate or discuss any aspect of this study please feel free to contact myself (Shelley Gorman) on 08 6319 1747 (work) or 0409 114 452 (mobile) or shelley.gorman@telethonkids.org.au (email). If you wish to speak with an independent person about the conduct of the project, please contact the Human Ethics office at the University of Western Australia by telephone (08 6488 4703) or email (humanethics@uwa.edu.au).

How do I indicate my willingness for my child to be involved? If you and your child are both willing for them to be involved, please complete the **Online Consent Form** with your child.

Yours sincerely,

Shelley Gorman
Group Leader, Telethon Kids Institute
Perth Children's Hospital (Level 7, 15 Hospital Ave, Nedlands)
08 6319 1747 or 0409114452 or shelley.gorman@telethonkids.org.au

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