

# Parent/Guardian Information Statement

Title	Designing a paediatric competency framework for Dietitians in Australia
HREA Protocol Number	96941
Project Sponsor	Monash University
Coordinating Principal Investigator	Ms Nicole Murray Accredited Practising Dietitian, PhD Candidate Monash University
Other Principal Investigators	Professor Claire Palermo (Monash University) Dr Kristie Bell (Children's Health Queensland) Dr Louise Van Herwerden (Bond University)

Thank you for taking the time to read this Parent/Guardian Information Statement and Consent Form. We would like to ask you and your child to participate in a research project that is explained below.

## It is ok to say no

#### What is an Information Statement?

These pages tell you about the research project. It explains to you clearly and openly all the steps and procedures of the project. The information is to help you decide whether or not you and your child would like to take part in the research. Please read this Information Statement carefully.

Before you decide if you and/or your child would like to take part or not, you can ask us any questions you have about the project. You may want to talk about the project with your family, friends, or a health care worker.

# Important things to know

- It is your choice whether you and your child take part in the research. You do not have to agree if you do not want to.
- If you decide you do not want your child to take part, it will not affect the treatment and care your child receives through Children's Health Queensland

If you decide you want to take part in the research project, you will be asked to sign an online consent form. By signing it you are telling us that you:

- Understand what you have read
- Consent for you and/or your child to take part in the research project
- Consent to the use of your and/or your child's personal and health information as described below.

You will be given a copy of this Participant Information Statement to keep.

## 1. What is the research project about?

This study aims to determine the knowledge, skills and attributes required by dietitians to provide safe, efficient and person-centred care to children and families.

We recognise that delivering care to children, parents and caregivers requires specialist skills. We don't currently have a framework that describes the skills required of a dietitian who works with children ("paediatric dietitians") in the Australian setting. This study aims to address this gap. We intend to determine how the framework could be used to inform teaching and training, and to understand the current and future roles of paediatric dietitians in Australia.

We recognise children, and their parents or caregivers play an essential role in the development of this framework. They can help by describing the skills required of a dietitian delivering their care. As a parent of a child who has received care from a dietitian, we are asking you to participate in this study. We will also involve paediatric dietitians and other paediatric healthcare professionals in this study.

# 2. What does participation in this research involve?

Prior to participating in this study, you will be asked to provide your consent through an online form. It is important that you understand what is required of you in this study before providing consent. Once you have provided consent, you will be asked to respond to a few key questions about your background, and your child's health care condition. We will ask you about this information in an online survey.

To be eligible for this study, your child needs to have received care from a paediatric dietitian. At the time of receiving care, they need to be aged less than 18 years. If your child is over 12 years of age, we will give you the option of inviting them to participate in the interview with you. We will obtain consent from both you and your child (if they can do so) to participate.

This study will involve participation in an interview which is estimated to take 60-90 minutes. The interview will take place online via Zoom. We will plan a time that is convenient to you to conduct the interview and provide you with a link to join the interview. We can also assist you with setting up access to this online platform if required. We will video and audio-record the session so we can capture your perspectives accurately when we analyse the data.

During the interview, we will ask for your opinion regarding the important skills of a paediatric dietitian delivering your care. We will also ask you about your thoughts on the education and training of paediatric dietitians and their current and future roles in delivering care to infants, children and young people.

We expect this study will take 12-18 months from the time the study commences through to the distribution of findings to our study participants.

## 3. Who is funding the research project?

This is a student research project and will form the PhD thesis of Ms Murray (Coordinating Principal Investigator), who is supported by a part-time Research Training Program Scholarship administered by Monash University. There is no funding attached to this study.

## 4. Compensation

In recognition of your time and valuable contribution to this study, we will offer you a Woolworths Gift Card to the value of \$50.

## 5. What if I wish to withdraw from the research project?

Your decision whether to participate will not prejudice your future relations with Children's Health Queensland or Monash University, or the care your child receives. If you decide to participate, you are free to withdraw consent and to discontinue participation. For your data to be withdrawn, you will need to withdraw from the study prior to the transcription of your interview. Once your interview has been transcribed, we will not be able to identify which one was yours. If you decide to withdraw, your interview and personal information provided during consent will be deleted and removed from all secure storage platforms.

The decision to withdraw from the study will not affect your child's routine medical treatment or your relationship with the people treating them.

## 6. What are the possible benefits for my child and other people in the future?

This project seeks to improve the practice of paediatric dietitians through establishing a framework that outlines the expectations of their practice. This framework will also be used to inform education and training. It may also be used as a way to identify dietitians who have the appropriate skills to deliver care to children, parents and caregivers. Ultimately, the framework seeks to enable safe, effective, culturally sensitive, and personcentred care.

## 7. What are the possible risks, side-effects, discomforts and/or inconveniences?

It is not anticipated that this project will cause any harm or discomfort, other than the inconvenience related to the imposition on your time. If participation does cause you, or your child, any unintended emotional stress through discussing your health care experiences, we encourage you to contact Lifeline Australia on 13 11 14. Lifeline Australia is a free and confidential service.

#### 8. What will be done to make sure my information is confidential?

The confidentiality of your information is of the highest importance to our research team, and we will protect your identity at all stages of the research process. Your information will not be shared with your treating health care team, or anyone else outside of our research team.

The background information you provide as part of a survey at the time of consent will be stored separately to your interview responses, as these details include identifying information. The video-recording of your interview will be transcribed by an automated transcription service that is familiar with handling research data. All your personally identifying features will be removed in this process. This will ensure your information and perspectives remain anonymous in the data analysis process. Findings from the study will be reported in such a way that protects your anonymity, privacy and confidentiality.

Data will be stored electronically on secure Monash drives in accordance with Monash University regulations. This data will only be accessible by the members of the research team. Data will be kept for a period of 5 years after completion of the project. If your child participates in the interview, the data will be kept for 15 years after your child turns 18 years of age. After this time has passed, all files will be deleted. If we acquire any of your information in a paper-based form (e.g. consent forms), they will be scanned, saved and destroyed securely to maintain your confidentiality.

## 9. What will happen when the research project ends?

The information from this study will be used to inform the next phase of our research. After the interview is complete, we will ask if you consent to be being contacted to participate in the next phase of the study. The next phase of this study aims to define the knowledge, skills and attributes required of paediatric dietitians in more detail. You are under no obligation to consent to further contact from our research team. If you do consent to contact, you will be able to consent for participation in that study later nce the details of what participation will require are provided to you.

We expect this stage of the study will take approximately 12-18 months to complete. You will be provided a summary of the findings once the study is complete via your nominated contact details.

#### 10. Who should I contact for more information?

If you would like more information about the project or if you need to speak to a member of the research team in an emergency please contact:

Name: Ms Nicole Murray

**Position:** Accredited Practising Dietitian, PhD Candidate

Contact telephone: 0410 481 559

Email: nicole.murray@monash.edu

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). **Reviewing HREC approving this research and HREC Executive Officer details.** 

#### 11. HREC Information:

The Children's Health Queensland Hospital and Health Service Human Research Ethics Committee (HREC) has approved this study. If you have any concerns and/or complaints about the project, the way it is being conducted or your child's rights as a research participant, and would like to speak to someone independent of the project, please contact the HREC Office.

Name: HREC Coordinator

Contact telephone: (07) 3069 7002

Email: CHQETHICS@health.gld.gov.au

#### 12. Local Governance Contact Information:

Name: Research Governance Officer

Contact telephone: 07 3069 7008

Email: CHQ\_RGO@health.qld.gov.au

