

# Childhood Obesity LANDSCAPE Study: Survey Participant Information

You are being invited to take part in an online research study to be carried out by the Obesity Research and Care Group at RCSI, in collaboration with the HSE. Before you decide whether or not you wish to take part, you should read the information provided below carefully. Please feel free to ask questions about the study before deciding, by contacting the researcher, Louise Tully (louisetully@rcsi.com) or the principal investigator.

You should clearly understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. This process is known as 'Informed Consent'. You don't have to take part in this study. You do not have to take part in this survey, it is entirely voluntary. You can change your mind about taking part in the survey even if you have started it.

# Why is this study being done?

Childhood obesity is a challenging public health and health services concern. This survey is aimed at health professionals in Ireland, who provide healthcare for children and adolescents with obesity in their daily practice, either for weight management specifically or for treatment of other conditions. The aim of the survey is to map the currently available services and practice in Ireland in relation to caring for children with obesity and their complications, to help us understand how these may differ across the country and in various settings. It may also help us to gain insight to the potential barriers for provision of weight management services.

# Who is organising and funding this study?

This study has been funded by the Health Research Board of Ireland's Applied Partnership Award and the HSE. It is being undertaken by the Obesity Research and Care Group at the Royal College of Surgeons in Ireland (RCSI University of Medicine and Health Sciences), led by Dr Grace O'Malley (Principal Investigator) in collaboration with the HSE Health and Wellbeing Division.

# Why am I being asked to take part?

You have been invited to take part because you are a healthcare professional who works with children and adolescents, so your insight will help us to answer our research questions.

# How will the study be carried out?

This study will require around 15-25 minutes of your time to complete an online questionnaire.

# What will happen to me if I agree to take part?

If you agree to take part, you will be taken to our online questionnaire, which you will be asked to fill out and complete. This will involve giving some information about yourself (anonymously, such as geographical region and discipline), and your current practice in relation to caring for children who may have a suspected or confirmed diagnosis of obesity. We will ask you to think about different aspects of care that you might offer or conduct as part of your routine practice or which aspects you do not carry out. You will also have the opportunity to add any information that you feel is important. At the end of the survey, you will have the chance to give your contact details (on a separate form, unrelated to your questionnaire responses so they will not be linked), in order to be invited to a later study which will entail taking part in an online focus group about the same topic. There is no obligation to give your contact details, or to take part/accept the invitation if you do give your details.



Dr Grace O'Malley (Principal Investigator) Research Lecturer School of Physiotherapy Division of Population Health Sciences RCSI University of Medicine and Health Sciences Beaux Lane House Mercer St, Dublin 2

By taking part in this study you will provide invaluable insight into current services, practices and areas for improvement within healthcare for children and adolescents in Ireland. This will inform our research, but there will be no direct benefit to you for participating.

#### What are the risks?

There are no perceived risks to participating in this study, however it will require contributing some of your valuable time. It may be burdensome to answer detailed questions and think about which answers best fit your role.

### Is the study confidential?

This survey will be carried out anonymously. That is, none of your personal details will be attached to your responses to the questions asked. We will collect information however about your clinical role and this data will be processed by the study team. We will use the Anonymous Responses feature on SurveyMonkey to ensure your IP address is not collected and your results cannot be linked to you. See their privacy statement here: https://www.surveymonkey.com/mp/legal/privacy/

#### **Data protection**

- 1. We will not be processing any directly indefinable data belonging to you as part of our survey. However we will be processing the details you give us about your role and clinical practice to help map the current landscape for childhood obesity services. This may be indirectly identifiable. We will anonymise the survey results by removing all potentially indirectly identifiable data once our analysis is complete. If you provide your contact details and consent after the study, we will use these for later inviting you to a focus group.
- 2. We will use your data for health research purposes in line with Article 6(j) of the General Data Protection Regulations.
- 3. Members of the research team only will have access to your anonymous data and if provided, your contact details. Your survey responses may be made available to other researchers through a certified and trusted online repository once all potentially indirectly identifiable is removed (i.e. the data has been completely anonymised).
- 4. We will store your anonymous data until the study is completed. We will store your personal data only until you have been invited to the second part of the study.
- 5. If there were to be a breach of data within the data controller's systems, it is possible that your contact details (if you provided them) may be seen by people outside of the research team. Your survey responses, linked to potentially indirectly identifiable data may also be compromised in such circumstances.
- 6. It will not be possible to withdraw consent for use of anonymous data once you have completed the survey, because the data is no longer linked to you or identifiable in any way.
- 7. You have a right to lodge a complaint with the Data Protection Commissioner should you have any concerns regarding the use of your data.
- 8. You have a right to request access to your data and obtain a copy of it at any time during this research.
- 9. You have a right to let us know if you object to any aspects of our plans for processing your data, and add restrictions to our use of your data.
- 10. You have a right to have any inaccurate information about you corrected or deleted while we are processing your data.
- 11. You have a right to have your personal data deleted while we are processing it.
- 12. You have a right to move your data from RCSI to somewhere else in a readable format.
- 13. Our research will not include any automated decision making.
- 14. You have a right to object to automated processing where applicable.
- 15. Beyond the use of your survey responses for analysis in this study and de-identification, we have no further planned processing of your data. If provided, your contact details will be used to invite you to a focus group, unless withdrawn prior to this. They will not be used for anything further without your explicit consent.

#### 16. Your data will be stored in the EU.

LANDSCAPE study

Planning designated services for child and adolescent obesity, with professionals and families as expert stakeholders



### **Consent to future uses**

Before taking part in this survey, you will be asked to consent to future use of your data. Below you will find some information on what that would mean.

Once our research study has been completed, your <u>fully anonymous</u> data (your survey responses) may be uploaded to a trusted and certified research repository, which would allow its use for further studies on this topic. We cannot currently say what that research would be for, but it would likely be in relation to provision of child/adolescent obesity services. For example, perhaps researchers may wish to carry out a similar survey in the future and compare the difference in services now and then. This might be undertaken by our research team or a separate external research team.

The data would not be linked to you in any way, but you are <u>not</u> obliged to consent to this. However, once you consent and the anonymised data is collected, you cannot withdraw as it will not be possible to trace your data in order to remove it.

### Where can I get further information?

If you have any further questions about the study or if you want to opt out of the study, you can rest assured it won't affect you in anyway.

If you need any further information now or at any time in the future, please contact:

Louise Tully, Researcher louisetully@rcsi.com

Niamh Arthurs, Researcher niamharthurs@rcsi.com

Grace O'Malley, Principal Investigator & Data Controller graceomalley@rcsi.com

Donall King, Data Protection Officer dataprotection@rcsi.com

#### Consent

The consent questions you will be asked to agree to if you decide to complete the online survey are listed below.

- I have read and understood the participant information sheet about this research project. The information has been fully explained to me and I have been able to ask questions by contacting the research team if needed.
- I understand that I don't have to take part in this study and that I can opt out at any time. I understand that I don't have to give a reason for opting out.
- I am aware of the potential risks of this research study.
- I have been given the opportunity to download a copy of the participant information sheet and this completed consent form for my records.
- I consent to take part in this research study having been fully informed of the risks.
- I give informed explicit consent to have my anonymous data processed as part of this research study.
- I consent to be contacted by researchers for the next part of this research study, should I provide my details at the end.



### STORAGE AND FUTURE USE OF INFORMATION RETENTION OF RESEARCH MATERIAL IN THE FUTURE [choose one or more as appropriate]

OPTION 1: I give permission for data to be stored for possible future research related to the current study only if consent is obtained at the time of the future research but only if the research is approved by a Research Ethics Committee.

Yes 🗆 No 🗆

OPTION 2: I give permission for data to be stored for possible future research related to the current study without further consent being required but only if the research is approved by a Research Ethics Committee. Yes 🗆 No 🗆

OPTION 3: I give permission for data to be stored for possible future research unrelated to the current study only if consent is obtained at the time of the future research but only if the research is approved by a Research Ethics Committee.

Yes 🗆 No 🗆

OPTION 4: I give permission for data to be stored for possible future research unrelated to the current study without further consent being required but only if the research is approved by a Research Ethics Committee. Yes 🗆 No 🗆

OPTION 5: I agree that some future research projects may be carried out by researchers working for commercial/pharmaceutical companies. No 🗆

Yes 🗆

OPTION 6: I understand I will not be entitled to a share of any profits that may arise from the future use of my data or products derived from it. Yes 🗆 No 🗆

Proceed to anonymous survey