

# **PARTICIPANT INFORMATION SHEET**

## **for patients, survivors, parents and partners**

### **G-FORce: Global Framework for Oncofertility Care**

#### **Invitation**

You are invited to participate in a research study into fertility preservation models of care.

The study is being led by **Dr Antoinette Anazodo**, Paediatric and Adolescent Oncologist, Kids Cancer Centre, Sydney Children's Hospital, with an international group of cancer and fertility clinicians crossing a number of disciplines in America, Australia, Canada, New Zealand and the United Kingdom.

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

#### **1. What is the purpose of this study?**

The purpose is to investigate fertility preservation models of care and to develop a competency framework for health care professionals working in oncofertility.

#### **2. Why have I been invited to participate in this study?**

You are eligible to participate in this study because you are or have been a person with cancer facing a fertility-threatening treatment regimen, or a parent or partner of a patient.

Health care professionals who have knowledge and/or experience with discussing or delivering fertility preservation care to cancer patients will also be invited to participate in the study.

#### **3. What does participation in this study involve?**

If you agree to participate in this Delphi study you will then be asked to take part in an online questionnaire about fertility preservation models of care. The questionnaire will seek input into developing an oncofertility competency framework with the aim being to reach agreement about how we deliver reproductive care to cancer patients and provide support to them and their parents or partners.

The content of the questionnaire will focus on your views about oncofertility care delivery rather than specific or personal experiences you have had. The questionnaire will take approximately 30 minutes to complete (although does not have to be completed in one sitting) and will involve indicating your level of agreement with each statement about delivery of fertility preservation care on a scale. You will also be asked to provide comments.

A second round of the study will occur to confirm the agreed model of care and this questionnaire will take approximately 20-30 minutes. In this round, you will be able to see how your ratings compare with the rest of the group as a whole but it will not identify any members. It is expected that two rounds of the Delphi process will be sufficient.

Consensus will be considered to be achieved if 90% of participants agree with the statement. If consensus on the necessary components of a competency framework is not reached, a third round questionnaire or face-to-face focus group may be conducted.

If you agree to participate, simply go to the study's website and click on the link to take part in Round 1: <http://www.futurefertility.com.au/research-tab/oncofertility-competency-framework/>

You will be invited to participate in later rounds by email as they become available.

- 4. What if I don't want to take part in this study, or if I want to withdraw later?**  
Participation in this study is voluntary. It is completely up to you whether or not you participate.

If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason and you will not have to do any further questionnaires.

- 5. How is this study being paid for?**  
The study is being paid for by a grant provided by the Kids Cancer Alliance.

- 6. Are there risks to me in taking part in this study?**  
The only foreseeable risk in taking part in this study is inconvenience. It will take approximately 30 minutes of your time on two occasions. The content of the questionnaires should not pose a risk as the statements will be generic in nature and not controversial.

If, however, you become upset as a result of your participation in the research project, the research team will be able to arrange for counselling or other appropriate support. This will be provided free of charge.

**7. Will I benefit from the study?**

This study aims to further knowledge and may improve future delivery of fertility preservation for cancer patients. You will not benefit directly but we are hopeful that future patients will benefit from this study.

**8. Will taking part in this study cost me anything, and will I be paid?**

Participation in this study will not cost you anything, nor will you be paid. If a face-to-face meeting goes ahead, your out-of-pocket travel costs would be paid for you.

**9. How will my confidentiality be protected?**

This study does not need to collect identifiable information, apart from basic contact details in order to contact you for the second/third rounds of the study. Any identifiable information that is collected in connection with this study will remain confidential and will not be disclosed except as required by law. Only the researchers will have access to your details and results that will be held securely at Sydney Children's Hospital.

**10. What happens with the results?**

We plan on publishing the results in peer-reviewed journals and at relevant conferences.

In any publication, information will be presented in such a way that you or other participants cannot be identified.

**11. What should I do if I want to discuss this study further before I decide?**

When you have read this information, you may contact the research team with any queries you have. If you would like to know more at any stage, please do not hesitate to phone Dr Anazodo on 02 9382 1690 or email [g-force@futurefertility.com.au](mailto:g-force@futurefertility.com.au)

**12. Who should I contact if I have concerns about the conduct of this study?**

This study has been approved by the South Eastern Sydney Local Health District Human Research Ethics Committee. Any person with concerns or complaints about the conduct of this study should contact the Research Support Office which is nominated to receive complaints from research participants. You should contact them on 02 9382 3587, or email [SESLHD-RSO@health.nsw.gov.au](mailto:SESLHD-RSO@health.nsw.gov.au) and quote **17/217**.

**Thank you for taking the time to consider this study.**