**PARTICIPANT INFORMATION LEAFLET - 13-17 years**

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| **Study Title:** | “Molecular and Genomic Interrogation of Childhood Cancer – Ireland” (MAGIC-I)  |
| **Participant Name:** |  |

Hello! Thank you for agreeing to learn more about our research project.

In this information leaflet, we would like to explain this project, and what is involved if you agree to take part.

Please ask your parents and/or your doctor if there are any words that you do not understand.

**Part 1: What is this study about?**

We want to learn more about why cancer happens in children and young people. We plan to do this by taking a small sample of your blood, skin, bone marrow, or your tumour, at the same time as you are having these tests as part of looking after you.

Your body is made up of lots and lots of tiny cells. These cells contain genes which tell cells how to work. The genes give instructions to tiny workers, called proteins, telling them what to do to keep your cells working healthily. In order to do this, the proteins need to make building blocks called metabolites, and they also need to produce energy to keep your cells working well. Sometimes, genes can get damaged and can give faulty instructions to the proteins in your cells. If this happens, the proteins may not work correctly which can then make the cells grow too much. The result is a cancer, which can be a lump of tissue that shouldn’t be growing in your body, or might be too many cells that are misbehaving in your blood. When this happens, you can feel sick, and you will need treatment that stops the cells with the faulty genes growing.

In this project, we will do some special tests in the laboratory to study the changes in the genes, proteins and metabolites that enable your cells to grow and cause cancer. Because this information is complicated, we will use computers to help us understand it better. We hope that finding these changes will give us lots of helpful information about cancer in children and young people. It may even help us to discover newer and better treatments.

We want you to know that you do not have to take part in this study if you don’t want to, and if you decide not to, it will not change how you are treated in any way.

**Part 2: Some more information**

**What do I have to do if I decide to take part in this study?**

* As part of your regular tests and treatments, your doctor will take some extra samples of blood/skin/bone marrow/tumour for us to study. You will not have to have any extra needles or procedures if you decide to take part in this study and you will not need to spend any extra time in hospital because of the study.
* With your permission, we will collect some information from your medical notes about you and your cancer and we will follow your progress during your treatment.

**What happens to my samples?**

* Your samples will be sent to laboratories in Ireland where we will study the genes, proteins, and metabolites in your cells.

**What else should I know about this study?**

* An important part of a research study like ours is that we share the results with other

doctors and scientists around the world, so that we can learn from each other and help more children like you. To share our results we use research papers, conferences, and social media. When we do this, we do not share your name or where you are from, so that your information will always remain private and safe.

* We may also ask if we can share the data about your genes, proteins, and metabolites with other doctors and scientists so that they can use the data in their own studies. We use a European Union database called the European Genome – phenome Archive (EGA), where we can store your anonymised data for a long time and share them with other doctors and scientists. They can only access and use your data with our permission and they will never know your name, address or where you are from. You can still participate in the study, even if you do not want us to store and share your data in the EGA. We are also creating a website which will be regularly updated to give you information about all of the research projects that will access this data. That website can be found here: www.ucd.ie/sbi/magic-i

As this study is a research study, there is no payment for families who take part, and similarly, there is no payment for the doctors or researchers who perform the study. Everybody takes part because they want to learn more about why cancer happens.

**What are the possible good and bad things?**

* You do not have to take part in the study if you don’t want to. You will receive the best available treatment for your cancer even if you don’t wish to take part, and your doctors will not mind whether you take part or not.
* You will not have to undergo any additional procedures if you decide you would like to take part.
* This study will help us understand better what exactly causes cancer in children and young people and what we can do about it in the future, so it is possible that taking part in this study will help you and others who are undergoing cancer treatments, now and in the future.

**What if I change my mind later?**

* You can change your mind at any time. If you decide that you don’t want to be in the study at any time, you will just need to tell your parents and your doctor.

**Why is the study being done?**

* We know from research that cancer is caused by important changes in genes, proteins and metabolites in cells. We have not yet discovered which genes, proteins, and metabolites are involved in many cancers, and what exactly goes wrong within the cells. This study will try to answer some of these questions.

**Where is the study taking place?**

* The samples will be taken here in the hospital at the same time as your other tests. We will then send the samples to scientists in the University College Dublin (UCD), which have special research equipment and computers necessary to look at the genes, proteins and metabolites.

**When will the study finish?**

* We will finish the study after 5 years, when we expect to have enough data to draw good conclusions. The analysis of the data may continue for another 2 years after that.

**Who is in charge of the study?**

The study team includes your doctors, who are in charge of the study. They work closely with scientists in a research team.

**Who will tell me about the results?**

* If your tests show us that you have a change in any important genes that could help us to understand and treat your cancer in a better way, your doctor will tell your parents.

**What happens next?**

If you would like to take part and as you are currently under 18 years of age, you will have the opportunity to sign an assent form that tells us that you agree to be part of this study and your parents will be asked to sign a consent form that gives us permission to enrol you in this study. Once you have been enrolled in the study, the research team and your doctors will collect your medical information and will arrange for your samples to be taken and sent to our research team.

If you turn 18 during the study, we will recontact you through your parent/legal guardian to ask if you still want to be part of this research study, and if you agree, you will then be allowed to sign your own consent form to remain in the study.

Ask your parents or your doctors if you would like any more information about this study.

We would like to thank you for taking the time to read this information leaflet and for taking the time to consider whether you would like to take part in this study.

**Thank you for your help!**