



**A study of transition from child to adult health services for young people with cerebral palsy in Ireland**

**Questionnaire Information Leaflet for young people and parent(s) or carer(s)**

We would like to invite you to take part in a research study. Whether or not you wish to take part is entirely up to you. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Feel free to talk to others about the study, such as your family, friends or GP, if you wish. Take time to ask questions. Don't feel rushed and don't feel under pressure to make a quick decision.

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 can change your mind about taking part in the study at any time you like. Even if the study has started, you can still opt-out. You don't have to give us a reason. The researcher in this study is not linked to the service you attend. The information you give is completely confidential, meaning that no one else except the researcher will see this information and answering the questions will not in any way affect your medical care.

If you have any questions about this research, you can contact:

Dr Jennifer Fortune by emailing  
[ignitionstudy@rcsi.ie](mailto:ignitionstudy@rcsi.ie) or calling 087 719 6661

You can find out more about the study and the research team by  
visiting our website [www.ignitionstudy.com](http://www.ignitionstudy.com)

**Part 1** of this leaflet tells you the purpose of this research and what will happen if you take part.

**Part 2** gives you more detailed information about the conduct of the research.

## Part 1: Overview of the Study

### **Why is this study being done?**

Transition is the process of planning for the needs of young people as they move from child to adult health services. International research identifies key practices can improve this transition. Some examples of key practices include meeting with the people who will manage your care in adulthood or having a key worker who helps coordinate your move to adult health services. However, there is no research examining how transition is managed for young people with cerebral palsy in Ireland.

In this project, we want to examine how transition is managed for young people with cerebral palsy in Ireland and explore the views of young people, their families and health professionals on how to improve this process. We will use the findings from this research to identify resources that might make it easier for young people with cerebral palsy to move from child to adult health services.

### **Who is organising and funding this study?**

This research is being conducted by researchers in the Royal College of Surgeons in Ireland (RCSI), in collaboration with health professionals from the Central Remedial Clinic (CRC). This research is funded by the Health Research Board (HRB).

### **Why am I being asked to take part?**

We are looking for young people aged between 16 years and 22 years with cerebral palsy, who live in Ireland, to take part in this study.

### **How will the study be carried out?**

We will gather information about the transition from young people using a questionnaire. This questionnaire may be completed online or during an interview with a researcher in person or over the phone. We can also post you a copy of the questionnaire.

We encourage you to complete this questionnaire with a parent, family member or carer. However, you can complete the questionnaire alone. Please let us know if you have difficulty reading or understanding or filling out the questionnaire and we will support you. Please let us know if you require translation to complete the questionnaire and we will facilitate this.

When you complete the questionnaire we will ask you if you want to take part in an interview. This is completely voluntary. If you would like to take part in an interview, we will ask you to complete the enclosed reply form or follow the link at the end of the online questionnaire to provide your contact details and we may contact you with more information about the interview. We will only ask a small number of people to take part in interviews, so we may not contact you.

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

If you want to take part in this study:

You can complete the questionnaire online by following this link <https://bit.ly/30mFWWhQ>. This online questionnaire is anonymous in that we do not ask for your name or any identifying information. If you are under 18 years you and your parent or guardian will also be asked to state if they consent to you taking part.

**OR**

You can contact the research team by emailing [ignitionstudy@rcsi.ie](mailto:ignitionstudy@rcsi.ie) or calling 087 719 6661. Jennifer will ask if you would like her to visit your home or somewhere convenient to complete the questionnaire, to call you to complete the questionnaire over the phone or to post you a copy of the questionnaire. If you want her to post you a copy, she will also

send you a stamped addressed envelope to return the questionnaire. If you would like to complete the questionnaire in person with the researcher you are welcome to bring a friend, relative or advocate to support you. You will be asked to sign a consent form or give verbal consent on the phone before you complete the questionnaire. If you are under 18 years, your parent or guardian will also be asked to sign a consent form or give verbal consent over the phone.

To say thank you for taking part in the questionnaire you will receive a €20 gift voucher. You can opt in to receive the gift voucher by completing the enclosed reply form or following the link at the end of the online questionnaire and providing your contact details. The contact details you give cannot be linked to your online questionnaire responses and hence your questionnaire responses will always be anonymous.

### **What are the benefits?**

There are no direct benefits to you taking part in this research. However, we hope that this research will improve the process of moving from child to adult health services for young people with cerebral palsy in Ireland.

### **What are the risks?**

The study will take up some of your time, which might be an inconvenience. We will try to minimise this as much as possible by letting you decide how you want to complete the questionnaire.

### **Will it cost me anything to take part?**

It will not cost you anything to take part in this research. If you want to complete the questionnaire with a researcher, she will travel to meet you. If you want to complete the questionnaire on the phone, the researcher will call you. If you want to complete a paper questionnaire in your own time, we will give you a stamped addressed envelope to post it back to us.

## Part 2: Further information on the conduct of the

### Is the study confidential?

All information collected during the research will be kept strictly confidential. We will store all information securely. We will not contact your GP or any other healthcare provider. We will publish the findings of this research in medical journals and will present the findings at conferences. However, we will not share any information that people may use to identify you. We will share the findings of this research on our website [www.ignitionstudy.com](http://www.ignitionstudy.com)

### Data protection

We will be using your personal information in our research to help us examine how transition is managed for young people with cerebral palsy in Ireland. The legal basis under which we are processing your data is consent. That is, you will give consent to us to process your data for the purpose of examining how transition is managed for young people with cerebral palsy in Ireland.

Only members of the research team will have access to your data. Your information will be securely stored for five years after the study has ended and then it will be destroyed. We will store any identifiable information (e.g. your name) separately to your responses to the questionnaire to ensure if somebody unauthorized accesses your data, they will not be able to identify you from your questionnaire responses.

You can change your mind about taking part in the study at any time, even if the study has started. You can tell us if you would like to withdraw your consent by contacting Dr Jennifer Fortune (Tel: 0877196661; email [ignitionstudy@rcsi.ie](mailto:ignitionstudy@rcsi.ie)). You also have the following rights:

- You have a right to lodge a complaint with the Data Protection Commissioner.

- You have a right to request access to your data and a copy of it. You can request a copy of your data.
- You have a right to restrict or object to processing of your data.
- You have a right to have any inaccurate information about you corrected or deleted.
- You have a right to have your personal data deleted, unless your request would make it impossible or very difficult to conduct the research. For example, if you requested to have your responses to the questionnaire removed at the end of the study, just before the research was due to be published in a medical journal.
- You have a right to data portability, meaning you have a right to move your data from one controller to another in a readable format.

You can make any of these requests by contacting Dr Jennifer Fortune (Tel: 0877196661; email [ignitionstudy@rcsi.ie](mailto:ignitionstudy@rcsi.ie)).

Your data will not be used for automated decision making, including profiling. Profiling is automatically collecting data about a person and using that data to send targeted adverts to that person. We will contact you if we intend to further process your data and will provide you with information on that purpose. We may transfer your data to a country outside of the EU or an international organisation. If we do, your data will be completely anonymised and we will not transfer any identifiable information. We will transfer any data securely through a data repository.

### **Consent to future uses**

We are asking you to give permission to use your information for this research study only. However, we wish to make the information we collect as usable as possible in order to maximise the possible benefits of this research for people with cerebral palsy. We will therefore ask you for permission to use your information in future research or to share your information with other researchers for future research. Your data will only be used for future research relating to young people with cerebral palsy. Your data will be anonymised before it is shared with any other researchers. You can change your mind at any time about letting us use or share your data for future research. If you would like to withdraw your

consent you can contact Dr Jennifer Ryan at [Jenniferryan@rcsi.com](mailto:Jenniferryan@rcsi.com) or 01 402 2413.

### **The research team**

Dr Jennifer Ryan (RCSI) and Mr Michael Walsh (HSE) are leading this research. You can contact Jennifer Ryan by emailing [jenniferryan@rcsi.com](mailto:jenniferryan@rcsi.com) or phoning **01 402 2413**. Dr Jennifer Ryan is also the data controller as she decides why and how your information is processed.

The research team includes Dr Owen Hensey (CRC), Ms Mary Owens (CRC), Dr. Aisling Walsh (RCSI), Dr Grace Lavelle (King's College London), Dr Meriel Norris (Brunel University London), Dr Claire Kerr (Queen's University Belfast) and Dr Michael Byrne (HSE).

### **Data protection officer**

Mr Dónall King is the data protection officer at RCSI. He can be contacted by emailing [donallking@rcsi.ie](mailto:donallking@rcsi.ie) or calling 01 402 8554.

**Thank you for taking the time to read this and considering taking part in this study**