



BMJ Open Transition from child to adult health services for young people with cerebral palsy in Ireland: a mixed-methods study protocol

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ABSTRACT

Introduction The transition from child to adult health services is a challenging and complex process for young people with cerebral palsy (CP). Poorly managed transition is associated with deterioration in health, increased hospitalisations and reduced quality of life. While international research identifies key practices that can improve the experience and outcomes of transition, there is a paucity of data in the Irish context. This research study aims to gain an insight into the experience of transition for young people with CP in Ireland.

Methods and analysis A convergent parallel mixed-methods design will be used to collect, analyse and interpret quantitative and qualitative data. Participants will be young people aged 16–22 years with CP, their parent(s)/carer(s) and service providers. Quantitative and qualitative data will be collected through questionnaires and interviews, respectively. Quantitative data will be reported using descriptive statistics. Where sufficient data are collected, we will examine associations between the experience of transition practices and sociodemographic and CP-related factors, respectively, using appropriate regression models. Associations between service provider characteristics and provision of key transition practices may also be explored using appropriate regression models. Qualitative data will be analysed using the Framework Method. A coding matrix based on key transitional practices identified from the literature will be used to identify convergence and divergence across study components at the integration stage.

Ethics and dissemination The study has been approved by the RCSI University of Medicine and Health Sciences Research Ethics Committee (REC201911010). Results will be presented to non-academic stakeholders through a variety of knowledge translation activities. Results will be published in open access, peer-reviewed journals and presented at national and international scientific conferences.

INTRODUCTION

Cerebral palsy (CP) is one of the most prevalent disabling conditions among children worldwide.¹ CP is an umbrella term used to describe a group of lifelong conditions that

Strengths and limitations of this study

- This study will provide a comprehensive understanding of the experiences of transition among young people with cerebral palsy in Ireland.
- This study uses a mixed-methods design to integrate quantitative and qualitative data from multiple stakeholders.
- This study involves young people with cerebral palsy, their parent(s)/carer(s) and service providers throughout the study to ensure relevance, responsiveness to needs and translation of findings to practice.
- Transferability to other health and social care systems will be limited as all data will be generated in Ireland.
- Findings from quantitative data are at risk of selection bias as convenience sampling will be used and participation is voluntary.

affect movement and posture causing activity limitations, which result from disturbances to the developing fetal or infant brain.¹ Many people with CP also experience associated impairments such as sensory, communication and cognitive impairments.¹ The type and severity of impairment vary considerably among people with CP. The majority of children with CP will survive into adulthood, with many having a life expectancy similar to that of the general population.² Continual improvements in longevity have resulted in a transitional care period between child and adult health services for young people with CP. Transition is defined as ‘the purposeful planned process that addresses the medical, psychosocial, educational and vocational needs of adolescents and young adults with chronic medical and physical conditions as they move from child-centred to adult-orientated healthcare systems’.³ Despite the



importance of transition for supporting the long-term health and well-being of people with chronic conditions, international research indicates that this process is poorly managed for young people with CP.⁴⁻⁷ Poor management of transition is associated with deterioration in health, increased hospitalisations and reduced quality of life among young people with long-term conditions.⁸⁻¹¹ For young people with cerebral palsy, transition from child to adult health services coincides with a decrease in visits to specialist and coordinated services, difficulties accessing clinical care¹² and an increase in unmet health needs.⁵ This is concerning given a growing body of evidence shows that adults with CP experience an increasing number of physical and mental health conditions with age, such as cardiovascular disease, arthritis, depression and anxiety.^{13 14} These conditions often co-occur with worsening physical functioning, pain, fatigue and joint deformities¹⁵ due to musculoskeletal progression, or the comorbidities associated with CP.¹⁶ Poor management of transition from child to adult health services may therefore contribute to the development of chronic conditions among adults with CP.

A recent review of the quality of care provided to young people with CP in the UK highlighted that young people have difficulty in navigating adult services, a lack of multi-disciplinary teams and leads for adult neurodisability care, and that young people increasingly rely on general practitioners (GPs), after discharge from child services.¹⁷ Further challenges to implementing successful transition for young people in the UK include differences between the funding and organisational structure of child and adult services, lack of service level coordination, lack of involvement of GPs in transition planning¹⁸ and inadequate training of adult health professionals in paediatric conditions.^{19 20} However, a recent programme of research also identifies key practices associated with improved outcomes including a level of parental involvement that is deemed appropriate by both the young person and parent, promotion of health self-efficacy, meeting the adult team before transfer and incorporation of developmentally appropriate healthcare throughout the transition process.¹⁸

Transition in an Irish context

The National Policy and Strategy for the Provision of Neuro-Rehabilitation Services in Ireland and the Integrated Care Programme for Children emphasise the need for appropriate planning and clear protocols to support transition to adult services for young people in Ireland.^{21 22} However, there is no research examining transition for young people with CP in Ireland. Two studies have examined the experience of transition in an Irish context by surveying parents of young people with cystic fibrosis²³ and consultant psychiatrists working in mental health services,²⁴ respectively. Both studies identified a lack of standardised national practice, lack of written transition plans, lack of interaction between child and adult services and lack of information on self-management and

signposting to alternative supports. While this research suggests that transition is poorly managed within the Irish healthcare system, examination of whether these findings are applicable to young people with CP warrants investigation. Moreover, existing evidence regarding transition in the Irish context focuses on the views of parents and service providers. The voice of young people with disabilities or long-term conditions has not been engaged with to date.

In order to facilitate implementation of successful transition for young people with CP in Ireland, we need to first assess the gaps in the current management of transition, and second explore the experiences of transition from the multiple perspectives of young people with CP, their families and health professionals on how to implement successful transition in an Irish context.

Aim

The aim of this study is to examine how transition care is provided to and experienced by young people with CP in Ireland.

The specific objectives are as follows:

1. To assess the experience of key transition practices among young people with CP and their parent(s)/carer(s) in the Irish healthcare system.
2. To assess the provision of key transition practices to young people with CP, from the perspectives of disability service providers in the Irish healthcare system.
3. To explore the perspectives of young people with CP and their parent(s)/carers(s) on how to implement transition in the Irish healthcare system.
4. To explore the perspectives of service providers on transition for young people with CP.

METHODS AND ANALYSIS

We will use a convergent parallel mixed-methods design to address the overall aim of this study. Quantitative and qualitative data will be collected and integrated at the interpretation stage. This study will be conducted between January 2020 and December 2021. **Figure 1** illustrates the planned timeline. Recruitment is ongoing.

Framework of key transition practices

The following framework of key transition practices was informed by a recent research programme conducted in the UK,^{18 25} the United Kingdom's National Institute for Health and Care Excellence guideline on transition,²⁶ and relevant Irish policy documents^{21 22 27 28} as practices that improve the experience and outcomes of transition from child to adult services (online supplemental appendix 1). The framework was also informed by discussions with members of the Project Management and Study Steering Groups, which includes health professionals, young people with CP and parents. This framework will be used to assess gaps in the current management of transition and to explore enablers, barriers and supports required to implement successful transition in the Irish healthcare system, for young people with CP.

Phase	Deliverable	Month																							
		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24
Study preparation	Develop and pilot study documentation																								
	Obtain ethical approval																								
Data collection and analysis	Quantitative data																								
	Qualitative data																								
	Data integration																								
Dissemination	Prepare and submit manuscript																								
	Produce dissemination materials																								

Figure 1 Gantt chart outlining study timeline.

1. A named worker, known to the young person, who oversees, coordinates or delivers transition support, acts as the link between the young person and the various practitioners involved in their care including their GP. This person may not be formally allocated and may not be a health provider but should be in close contact with health services.
2. Involvement of parent(s)/carer(s) in the young person's care at a level that is deemed appropriate by both the young person and parent(s)/carer(s).
3. Child and adult services provide young people and families with information that describes the transition process and the support available before and after transfer. The information should specifically mention health services, which encompasses services that have a direct impact on people's physical health, mental health and social well-being. This information should be provided early enough to allow young people time to reflect and discuss with parent(s)/carer(s) or health professionals and be in an accessible format. Where there is no adult service for a young person to transfer to, information about known and trusted voluntary organisations who could provide support should be provided to the young person.
4. Promotion of health self-efficacy (ie, actively helping young people to feel confident in managing their condition), where health encompasses complete physical, mental and social well-being, including provision of information to the young person about their condition and encouragement to take responsibility for their health.
5. Promotion of opportunities for self-management, where the individual is directly involved in planning and decision-making around their needs and takes responsibility for maintaining optimal physical, mental and social well-being.
6. A health professional from the relevant adult services or primary care meets the young person before they transfer from child services
7. A senior manager with responsibility for implementing transition strategies and policies, including facilitating good working relationships between child and adult services, ensuring appropriate materials are available, and monitoring that the person has a suitable appointment in adult services. This person may not be known to the young person
8. Where there is no adult service for a young person to transfer to, a detailed discharge letter is sent to the young person's GP.
9. Formal training, relevant to health condition, in wider life skills—education, gaining employment, finances, housing, social relationships, sexual health, mental health. The health service may not provide such training but during consultations, staff should inquire about such matters and make referrals to other agencies as needed.

Patient and public involvement statement

A Study Steering Group of young people with CP, parent(s)/carer(s) and service providers will work closely with the Project Management Group and advise on all steps in the research processes. This will include developing study documentation such as information sheets, developing and piloting questionnaires, developing and piloting topic guides and interpreting findings. The Study Steering Group has informed the development of the framework of key transition practices. The group will also contribute to the development of materials to share findings with young people, families and service providers, such as an information leaflet and infographic. Further, based on the findings, the group will support the Project Management Group to identify and develop resources to facilitate successful transition for young people with CP in Ireland.

Participants

Participants will be young people with CP aged 16–22 years, their parent(s) or carer(s), and individuals who provide health services to young people with CP who are residing or working in Ireland. We will include people with CP of all severities of physical impairment.

Recruitment

Participants will be recruited from across Ireland via disability service providers, special education needs schools, universities, general practices, professional organisations and organisations for people with disabilities and through media, social media and word of mouth. Advertisements and participant information leaflets will include the URL to access an online version of the questionnaire and contact details for the research team, so that participants may request further information or the questionnaire in alternative formats.

Young people, their parents or carers and service providers who complete the questionnaire will be asked to contact a member of the research team if they would like to participate in an interview. We will develop a sampling frame and purposively sample young people, parents or carers and service providers for interview based on characteristics that may affect the experience or provision of transition. For young people, these may include age, gross motor function, intellectual disability and geographical location. For service providers, these may include the professional role of the individual, sector and geographical location.

Quantitative data collection

We will aim to collect quantitative data from up to 100 service users (ie, young people, parent(s), carer(s)) and service providers via a questionnaire. Participants may complete the questionnaire online, in person, by post or by telephone or video-conference. Young people may obtain support from a parent, family-member or carer to complete the questionnaire. To maximise inclusivity, we will make the questionnaire accessible to people with varying impairments including mild-to-moderate intellectual disability, for example by providing the survey in alternative formats and using various enhancements such as visual aids, simple words, clear questions and story technique. Where it is not possible to provide sufficient adaptations to obtain the young person's perspectives, a parent or carer may complete the questionnaire on their behalf. The questionnaire was developed in collaboration with, and piloted on young people, parents and service providers prior to use.

The following data will be collected from young people with CP:

1. Sociodemographic and condition-specific data.
2. Current and previous service use.
3. Experience of key transition practices.
4. Unmet health needs using an unmet needs questionnaire.⁵

The following data will be collected from service providers:

1. Service-related data.
2. Predominant transition model.
3. Provision of key transition practices.

Qualitative data collection

Face-to-face, telephone or videoconference in-depth interviews will be conducted with service users and service providers. Approximately 25 service users and 20 service providers will participate in interviews. Service user interviews may be conducted individually with the young person or jointly with young people and their parent(s) or carer(s). If the young person is under 18 years, they must be interviewed with a parent or guardian present. Adaptations will be made within the interview to allow for inclusion of people with mild-to-moderate intellectual disability, communication impairment, visual impairment, hearing difficulty or other impairments. These may include providing them with the topic guide in lay

language in advance, using alternative systems of communication and providing pictorial memory aids. Individual interviews with parent(s)/carer(s) will be facilitated where it is not possible to provide sufficient adaptations to obtain the young person's perspectives. Interviews will be conducted at the participant's home, workplace or other suitable and convenient venue.

We will use the framework of key transition practices to develop the topic guide for interviews. However, we will also explore participants' perspectives of transition more broadly. Separate topic guides for service users and service providers will be developed in collaboration with and piloted on young people, parents and service providers.

Examples of topics to be explored during interviews with service users will include (1) experience of key transition practices; (2) if they believe these practices improved the experience of transition or in the case where practices were not experienced if these practices may have improved their experience; (3) how these practices should be implemented, for example, through structured programmes, written information, verbal information and (4) other supports that improved or would improve their experience of transition. Examples of topics to be explored during interviews with service providers will include (1) perceptions of successful and unsuccessful transition; (2) barriers and enablers to implementing key transition practices including organisational structures, processes and relationships; (3) readiness for implementation and (4) supports required to implement successful transition including the content and format of resources to facilitate implementation.

Analysis

Descriptive statistics will be used to report quantitative data such as sociodemographic data and experience of key transition practices. Where sufficient data are collected, we will examine associations between the experience of transition practices and sociodemographic and CP-related factors (eg, Gross Motor Function Classification System (GMFCS) level), respectively, using appropriate regression models. Associations between service provider characteristics and provision of key transition practices may also be explored using appropriate regression models where sufficient data are available.

Interviews will be analysed using the Framework Method, which allows for both deductive and inductive analysis of data. The Framework Method is appropriate for this study as we have predefined topics that we wish to explore but are also open to the emergence of additional themes. The Framework Method involves five iterative stages: familiarisation, thematic framework identification, labelling, charting and mapping and interpretation.²⁹ A sample of transcripts will be read by two members of the research team until familiarity with the data is established. They will independently develop provisional codes before agreeing on an initial framework through discussion. The initial framework

developed will be applied to all transcripts and will be iteratively refined through our analytic process if new codes are identified. Analysis will be undertaken by one researcher. A proportion of coded transcripts will be checked by a second researcher. We will explore if demographic and CP-related factors (eg, GMFCS level) influence participants' perspectives of transition. Data will be arranged into charts that summarise themes, issues and individual responses. Finally, members of the Project Management Group will discuss emerging categories and themes collaboratively. Preliminary results and interpretations will also be shared with the study steering group who will have the opportunity to reflect and input on the findings. Strategies to enhance the trustworthiness of the findings, such as negative case analysis, peer-debriefing and reflexivity, will be used.

Integration

Integration of quantitative and qualitative data will be carried out at the interpretation stage of the research.³⁰ We will use the key transition practices as a framework for developing themes and meta-themes. We will search for data related to each theme in questionnaires and interviews. We will also identify any additional emerging themes from questionnaires and interviews. We will use a convergence coding matrix to integrate themes and to develop meta-themes.³¹ This will involve grouping themes according to similar concepts and interpreting them to generate meta-themes. We will search for agreement and disagreement between studies according to meta-themes. Agreement and disagreement will be defined as convergence (ie, findings agree directly), complementarity (ie, findings offer complimentary information), dissonance (ie, findings seemingly contradict each other) or silence (ie, themes arise in quantitative data or qualitative data but not both). Integration will be supported by discussions with the Project Management Group and Study Steering Group.

Data management

A data management plan will be created prior to the start of data collection. All data will be stored securely. All participants will be assigned an ID number, which will be recorded on study documentation. Anonymous data entered electronically via Online Surveys will be downloaded securely into a study database. Data collected on paper forms will be entered into the study database and paper forms will be stored securely in a locked cabinet. Data entry and validation will be a continuous process. Audio files will be downloaded to an encrypted laptop on completion of interviews before being transferred to secure servers. Audiofiles will be transcribed verbatim by a professional transcription service and imported into qualitative data management software (Nvivo V.12: QSR International). Pseudonyms will be used to report participant quotes with consent. Identifying details will be removed to preserve participant anonymity.

Project management

The Project Management Group, consisting of the Chief Investigator (JR), co-applicants for the grant and post-doctoral researcher will be responsible for delivering all objectives.

ETHICS AND DISSEMINATION

This study has been approved by the RCSI University of Medicine and Health Sciences Research Ethics Committee (REC201911010). All participants will provide informed consent prior to data collection. For young people aged 16–18 years, a parent/guardian will also provide consent for the young person to participate. Examples of the participant information sheet (online supplemental material 1) and consent form (online supplemental material 2) are available in the online supplementary material. Information for potential participants is also shared on the study website <https://www.ignitionstudy.com>. We will use findings from this research, and discussion with the Study Steering Group, to identify resources that will facilitate successful transition from child to adult services for young people with CP in Ireland. A detailed dissemination plan will be developed in the early phases of the study. We will use a variety of knowledge translation activities to ensure that the outputs generated from this research are accessible to non-academic stakeholders including young people with CP, families and service providers. We will work closely with the Study Steering Group to identify and develop materials to share findings, such as an information leaflet and infographic summarising the findings and a seminar for young people, families and service providers. Results will be published in open access peer-reviewed journals and presented at national and international scientific conferences.

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Contributors All authors listed meet the International Committee of Medical Journal Editors criteria for authorship. JR and MW conceived the study, MN, OH, MO, TK, CK, AW, GL and MB designed the study. JR will lead the running of the study. JF will lead the collection, management and analysis of the data. MN and AW will lead the qualitative analysis. JR will lead the statistical analysis. All authors have read and approved the final manuscript.

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	Framework point	Facilitating transition of young people with long-term health conditions from children's to adults' healthcare services – implications of a 5-year research programme	NICE 2016 ²⁶	National Policy and Strategy for the Provision of Neuro-Rehabilitation Services in Ireland	A National Model of Care for Paediatric Healthcare Services in Ireland
1	A named worker	'key worker' ²⁵	Section: 1.2.5 – 1.2.10	'Case management/key worker' (pg79) ²¹ 'A case manager ' (pg52) ²⁸	-
2	Appropriate parental involvement	'appropriate parent involvement' ^{18 25}	Section:1.2.19 -1.2.22	'Involvement of family and friends' (Fig 17; 8, pg55 ²⁸)	parents or guardians who will likely support and guide them through the process (pg7) ²²
3	Information provision which describes the transition process	'a written transition plan' ²⁵	Section:1.2.4, 1.2.14, 1.3.4, 1.3.8	'effective communication and the provision of information, particular attention is needed during transition phases' (pg79) ²¹ 'a written rehabilitation plan' (pg92) ²¹ 'Information and education' (Fig 17; 8, pg55) ²¹	Effective information transfer (pg 6) ²² Appropriate planning to ensure seamless transition to adult services (pg 13,16) ²⁷
4	Promotion of health self-efficacy	'promotion of health self-efficacy' ^{18 25}	Section 1.1.4, 1.2.17, 1.2.21	'Supporting self-care'(pg 39) ²¹ 'increase service users' skills and confidence in managing their health problems' (pg 61) ²⁸	-
5	Promote opportunities for self-management	-	Section: 1.1.4, 1.2.17, 1.3.5-1.3.7	Promotes opportunities for 'self-management', where the individual is directly involved in planning and decision-making around their needs and takes responsibility for maintaining optimal health, functioning and participation (pg20) ²¹ Empowering and enabling people to have an active role in the management of their condition (pg 60) ²⁸	'coaching patients and family members in disease self-management' (pg7) ²² 'more responsibility for their own health care' (pg 6) ²² 'encourage independence and reassess their understanding of their condition' (pg 7) ²²

6	A health professional from the relevant adult services or primary care meets the young person before they transfer from child services.	'meet the adult team before transfer of care' ^{18 25}	Section: 1.3.1	-	-
7	A senior manager with with responsibility for championing, implementing, monitoring and reviewing effectiveness of transition strategies and policies.	'Transition manager for clinical team.' ²⁵	Section 1.5.1-1.5.3	'Rehabilitation Coordinator' (pg 52) ²⁸	-
8	Where there is no adult service for a young person to transfer to, a detailed discharge letter is sent to the young person's GP.	-	Section 1.1.8; 1.1.9; 1.3.9	'Role of GP, as the first point of contact for medical services and in linking to care pathways' (pg84) ²¹	'GPs may be consulted by young people during transition and asked to take on a wider role'. (Pg 6) ²²
9	Formal life skills training relevant to health condition, in wider life skills - education, relationships, health maintenance etc.	'holistic life-skills training'	Section: 1.2.8; 1.2.13, 1.2.15, 1.3.3	'Access to supports' (pg 47) ²⁸ 'Social prescribing' (pg 61) ²⁸ 'Vocational support' (pg 90) ²⁸	'help with self-care and in developing their communication and decision making skills, to manage social, educational and employment opportunities and challenges as part of independent living' (pg 6) ²²



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 or calling 0877196661

You can find out more about the study and the research team by visiting our website 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) and CRC.

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, over the phone or by videoconference. 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 also take part in an interview at a later date. This is completely voluntary. If you would like to take part in an interview, we will ask for 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:

- 1) 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

- 2) You can contact the research team by emailing ignitionstudy@rcsi.ie or calling 0877196661. 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 by videoconference 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 can choose to be entered into a prize draw to win one of three €50 gift vouchers. You can opt in



to the prize draw by contacting the research team at the end of the questionnaire.

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 study

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

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).

You also have the following rights:

1. You have a right to lodge a complaint with the Data Protection Commissioner.
2. You have a right to request access to your data and a copy of it. You can request a copy of your data.
3. You have a right to restrict or object to processing of your data.
4. You have a right to have any inaccurate information about you corrected or deleted.
5. 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.
6. 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).

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 or 01 402 2413.

The research team

Dr Jennifer Ryan (RCSI) and Mr Michael Walsh (HSE) are leading this research. 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 Controller

Dr Jennifer Ryan from RCSI is the data controller for this study. She decides why and how your information is processed.

You can contact Jennifer Ryan by emailing jenniferryan@rcsi.com or phoning **01 402 2413**.

Data protection officer

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

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



Consent Form Young Person Questionnaire

Yes No

- I have read and understood the **Information Leaflet** about this research project. The information has been fully explained to me and have been able to ask questions, all of which have been answered to my satisfaction. Yes No
- 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 and I understand that opting out won't affect my future medical care. Yes No
- I am aware of the potential risks, benefits and alternatives of this research study. Yes No
- I have been given a copy of the Information Leaflet and this completed consent form for my records. Yes No
- I consent to take part in this research study having been fully informed of the risks, benefits and alternatives. Yes No
- I give informed explicit consent to have my data processed as part of this research study. Yes No
- I consent to be contacted by researchers as part of this research study. Yes No
- I consent to be re-contacted by researchers about possible future research related to the current study for which I may be eligible. Yes No



Storage and future use of information

Yes No

Please choose one or more of the following options

- Option 1:** I give permission for material/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.
- Option 2:** I give permission for material/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.
- Option 3:** I give permission for material/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.
- Option 4:** I give permission for material/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.
- Option 5:** I agree that some future research projects may be carried out by researchers working for commercial/pharmaceutical companies.
- Option 6:** I understand I will not be entitled to a share of any profits that may arise from the future use of my material/data or products derived from it.

Name of participant

Date

Signature

To be completed by the Principal Investigator or nominee.

I, the undersigned, have taken the time to fully explain to the above person the nature and purpose of this study in a way that they could understand. I have explained the risks involved as well as the possible benefits. I have invited them to ask questions on any aspect of the study that concerned them.

Name

Qualifications

Signature

Date