



<b>Name</b>	<b>Research Privacy Notice</b>
<b>Date</b>	<b>March 2022</b>
<b>Version</b>	<b>1</b>
<b>Approved by</b>	<b>CRC Research Ethics Committee</b>

## CENTRAL REMEDIAL CLINIC

# PARTICIPANT PRIVACY NOTICE

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This privacy notice provides information on how the Principal Investigator of this research project collects and uses your personal information when you take part in this study. The Central Remedial Clinic (CRC) is the joint Data Controller with RCSI University of Medicine and Health Sciences of any personal data that you supply for this research. This means that we are responsible for looking after your information and using it properly.

We respect your right to privacy, and we comply with our obligations under the relevant data protection legislation. Please refer to the participant information leaflet for further details about the study.

### **Who we are:**

The CRC is a representative organisation and service provider for people with disabilities. We are a registered charity under number 4998 and a Section 38 Agency under the Health Act 2004. We operate a number of centres in Ireland; in Waterford, Limerick and in areas around Dublin as well as outreach clinics throughout the country.

### **Why we need your information:**

1. To describe current participation in physical activity by adolescents with physical disability in Ireland
2. To understand and achieve consensus on the priorities for future PA participation in physical activity from the perspective of adolescents with physical disability, considering the individual, contextual and environmental factors that can enable or constrain this participation.

### **What personal data we will collect:**

We collect the following types of personal data from you:

- **Data Subject Identify (name, surname)** - *This will be collected for the purposes of consent only*
- **Contact details** - *This will be collected for the purpose of distributing the next round(s) of the questionnaire only.*
- **Health data** - *This will entail information with regards to diagnosis (name of condition causing disability), level of mobility (Functional Mobility Scale) and hand function (Manual Ability Classification System). These data will be stored anonymously, not linked to identifying details.*



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**The legal basis for collecting your data is:**

- You are consenting to providing it to us; and/or
- Processing is necessary for the performance of a task in the public interest such as research.

The legal basis for the processing of your special category data (sensitive data such as health data) are:

- You have given CRC explicit consent to do so; and/or
- Processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes.

**Where your data will be stored:**

Your data will be stored securely within electronic and paper records, that can only be accessed by Dr. Ailish Malone (Principal Investigator) and Karen Brady (Clinical Researcher) Electronic data will be processed securely and stored on the RCSI secure One Drive with protective passwords using encrypted devices. Hosting and storage of your data takes place in CRC Clontarf, Dublin.

**Will your personal data be shared with third parties?**

Yes, this project is a collaboration between the CRC and RSCI. Your personal data will only be accessible to the Clinical Researcher (KB).

**Will your personal data be transferred outside the EU or EEA?**

No. This research is being completed in Ireland and personal data will remain in Ireland.

**Will there be any automated decision making using your data?**

No.

**How long your data will be held for:**

Research findings will be anonymised. Your personal data (name, contact details) will be kept until the completion of the study and dissemination of results and then securely destroyed as per CRC policy. These details will not be used in any other instance.

**Are there any consequences of not providing the requested information?**

No. There are no consequences of not providing data for this research. It is purely voluntary.

**Your rights under GDPR:**

- You have the right to know what data we hold about you and how it is used
- The right to request access to your data
- To correct your data if it is wrong or ask for your data to be deleted
- To object to processing as well as the right to data portability
- You have rights in relation to using your data in automated decision making and profiling
- Where our processing of your personal data is based on your consent to that processing, you have the right to withdraw that consent at any time but any



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processing that we have carried out before you withdrew your consent remains lawful

**Who you can contact if you have concerns:**

If you have any questions about your participation or concerns about the way in which this research study has been conducted, please contact the Principal Investigator in the first instance: Dr.Ailish Malone, [ailishmalone@rsci.ie](mailto:ailishmalone@rsci.ie)

In the event you wish to complain about how we have handled your personal data, please contact CRC's Data Protection Officer (DPO) [dpo@crc.ie](mailto:dpo@crc.ie) who will investigate your complaint and work with you to resolve the matter. Address: Data Protection Officer, Central Remedial Clinic, Penny Ansley Building, Vernon Avenue, Clontarf, Dublin 3, D03 R973.

You also have the right to lodge a complaint with the Data Protection Commission (DPC) via their website at [www.dataprotection.ie](http://www.dataprotection.ie).