### Withdrawal form

[affix\_barcode]

Version: 5, 23 October 2024

Local Lead Investigator: [local\_lead\_investigator\_name]

Chief Investigator: Prof JK Baillie, University of Edinburgh

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| **This document gives you details of how to withdraw from the GenOMICC study.**   * Please read it carefully. To withdraw from the study, please fill in the form that follows. * You can also use this form to withdraw your child from the study. You do not have to be taking part yourself to withdraw your child. You can only withdraw one child using this form. Please use a separate form for each child you want to withdraw. * You do not have to give a reason for your decision. Please ask your clinical team if you have any questions about withdrawing from the study. * Withdrawing from this study will not affect your participation in any other research study you are part of. * We will begin acting on your wishes as soon as we have received and processed this form.   **There are two options if you want to withdraw.** |
| Option 1 – Partial withdrawal |
| This option is for situations where you would be content for your data to continue to be used for research, but want no further contact:  We **will**   * update our records to ensure you are not contacted * continue to update and store information from your health and other records for use in approved research |
| Option 2 – Full withdrawal |

This option is for situations where you no longer wish for you or your child’s data to be used for research and want no further contact:

We **will**

* + delete the personal information we hold about you or your child
  + destroy your DNA sample
  + delete your genetic information (if it has not already been included in an analysis)

We **will not**:

* + contact you directly
  + continue to update and store information from your health and other records
  + allow new research access to information that is held about you
  + use your information for purposes other auditing

Even if you choose option 2, we **cannot:**

* + remove data from research that is underway or has already been done but the information we hold at this stage is de-identified, meaning no-one would know anything was related to you
  + remove original records held by the NHS and an audit trail confirming your participation in GenOMICC will remain with the NHS

### Withdrawal form

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **I have read and understood the withdrawal information.** | | | | |
|  |  | | |  |
|  | **Initial** here to show you agree. |  |  | |

|  |  |  |  |
| --- | --- | --- | --- |
| **For adult participants** | | | |
| **I want to withdraw from the GenOMICC study**. | | | |
|  | | | |
| **Initial** your choice. | | | |
|  |  |  | |
|  | 1. Option 1 – Partial withdrawal |  |  |
|  |  |  | |
|  | 1. Option 2 – Full withdrawal |  |  |
|  | | | |
| You: | | | |
|  | | | |
|  | **Your full name (BLOCK CAPITALS):** |  | |
|  | |  | |
|  | **Signature:** |  | |
|  | |  | |
|  | **Date:** | (DD/MM/YY) | |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Parent on behalf of your child:** | | | |  |
| **I want to withdraw my child from the study.** | | | | |
|  | | | | |
| **Initial** your choice. | | | | |
|  | | | | |
|  | 1. Option 1 – Partial withdrawal |  |  | |
|  | |  |  | |
|  | 1. Option 2 – Full withdrawal |  |  | |
|  |  |  |  | |
|  |  |  |  | |
| You: | | | | |
|  |  |  | | |
|  | **Your child’s full name (BLOCK CAPITALS):** |  | | |
|  |  |  | | |
|  | **Your relationship to the child:** |  | | |
|  |  |  | | |
|  | **Your name:** |  | | |
|  |  |  | | |
|  | **Your signature:** |  | | |
|  |  |  | | |
|  | **Date:** | (DD/MM/YY) | | |
|  |  |  | | |

When you have filled in this form:

* 1 (the original) will be kept in your GenOMICC study records.
* You will keep a copy.
* The GenOMICC study team will keep a copy.

**For completion by GenOMICC research staff only**

|  |  |
| --- | --- |
| **Person receiving this form:** |  |
|  |  |
| **Signature**: |  |
|  |  |
| **Date:** | (DD/MM/YY) |
|  |  |
| **Name of interpreter if used (BLOCK CAPITALS):** |  |
|  |  |
| **Signature:** |  |
|  |  |
| **Date:** | (DD/MM/YY) |
|  |  |
| **GCC Number:** |  |
|  |  |

|  |  |
| --- | --- |
| **Insert local contact details here**  **Phone number:**  **Email address:**  **Hospital address:** |  |