Note: All parties signing the consent form must date their own signature.

**Section 1 : Genomic Testing Details**

It is my choice for my child/person under my care to have genomic testing.

I [Parent/Guardian Name] , understand that my child's/ the person under my care's DNA will be tested by :

[Panel] [Exome] [Genome]

to look for changes in genes that may be associated with :

[Condition or Clinical Indication]

**About the Test**

[] Genomic test results are based on current knowledge, which may change in the future

[] If I change my mind, I can choose not to be told about the result

**Potential Outcomes**

[] This test might find a cause for the condition(s)

[] This test might not find a cause for the condition(s)

[] This result might be of 'unknown significance', which means it cannot be understood today

[] There is a chance that genomic testing could find other medical conditions (incidental findings)

[] Genomic testing may show unexpected family relationships

[] Further tests or information sharing may be needed to finalize the result

**Results**

[] I will be told the results by a health professional

[] Results may have implications for the health/genetic risks for ;y child/the person under my care and family members

[] Results can be used to inform counselling and testing of family members, though my child's/ the person under my care's identity will not be revealed to them

[] Results from these tests may affect my child's /the person under my care's ability to obtain some types of insurance

[] The results will be available to health professionals involved in the care of my children/the person under my care

[] Results are confidential and may not be release without my consent unless allowed by law

[] The following individual can be given my child's / the person under my care's results if I am unable to be contacted

**Contact Information :**

Contact Name :

Contact Number :

Relationship to Patient :

**Section 2 : Consent for Data Sharing**

I provide consent to share my child’s/ person under my care’s sample, genomic data, and related health information for

(CASE) Data is available for future general research use

(CASE) Future is limited for health/medical/biomedical research

(CASE) Future use is limited to research involving the following disease area(s)

**Specified diseases :**

(CASE) Future commercial use is prohibited

(CASE) Future use by for-profit entities is prohibited

(CASE) Future use for methods research (analytic/software/technology development) outside the bounds of the other specified restrictions is prohibited

(CASE) Future use of aggregate-level data for general research purposes is prohibited

(CASE) Future use as a control set for diseases other than those specified is prohibited

(CASE) Future use is limited to research involving a particular gender

(......)

(CASE) Future use is limited to pediatric research

(CASE) Future use is limited to research involving a specific population

(CASE) Future use is limited to data generated from samples collected after the following consent form date

**Section 3 : Consent Summary**

I have had enough time to consider the information in this consent form and have :

(CASE) Had the opportunity to discuss genomic testing and its implication with a health professional

(CASE) Been given access to information about genomic testing

(CASE) Been able to ask questions until I am satisfied with the answers

(CASE) Been offered a copy of this consent form

I provide consent to have genomic testing as summarized in these forms

**Child’s name :**

**Date of Birth :**

**Parent/ Guardian’s ID :**

**Print Parent/ Guardian’s Name :**

**Email/ Address :**

**Health Professional AHPRA ID :**

**Health Professional Name :**

Note: All parties signing the consent form must date their own signature.

**Section 4: Confirmation for Research Study**

I confirm that :

| 1. I have read the information statement about the study and I understand its contents. | ð |
| --- | --- |
| 2. I understand what my child and I have to do in this study. | ð |
| 3. I understand the risks my child could face because of their involvement in this study | ð |
| 4. I voluntarily consent for myself and/or my child to take part in this research study. | ð |
| 5. I have had an opportunity to ask questions about the study and I am satisfied with the answers I have received. | ð |
| 6. I understand that this study has been approved by a suitable Human Research Ethics Committee. I understand that the study is required to be carried out in line with the *National Statement on Ethical Conduct in Human Research (2023).* | ð |
| 7. I understand I will receive a copy of this Information Statement and Consent Form | ð |

### **Section 5: Genomic Testing Consent**

| | Please choose from the following options | I consent | I **do not** consent | | --- | --- | --- | | **b. Consent for use of my child’s NBS card and diagnostic specimen**  Consent for researchers to access my child’s NBS card and diagnostic specimen to see if it is possible to detect the gene change/changes in my child from the original heel prick sample taken when they were born |  |  | | **c. Consent for future contact**  Consent for me to be contacted again after this study for potential follow-up studies |  |  |          | Child’s Full name |  | Child’s co-signature (optional) |  | Date | | --- | --- | --- | --- | --- |        | Parent 1/Guardian 1 Name |  | Parent 1/Guardian 1 Signature |  | Date | | --- | --- | --- | --- | --- |      | Parent 2/Guardian 2 Name |  | Parent 2/Guardian 2 Signature |  | Date | | --- | --- | --- | --- | --- |     Note: All parties signing the consent form must date their own signature. |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |

| Please choose from the following options | | Yes | No |
| --- | --- | --- | --- |
| **I would like to receive a summary of the study findings** | |  |  |
| **If yes, please provide your contact details** | | | |
| **Email** |  | | |
| **Phone number** |  | | |
|  |  |  |  |

**Section 06 : Declaration by Researcher**

I have explained the study to the parent(s)/guardian(s) who has signed above. I believe that they understand the purpose, extent, and possible risks of their child’s involvement in this study.

| Research Team Member Name |  | Research Team Member Signature |  | Date |
| --- | --- | --- | --- | --- |

Note: All parties signing the consent form must date their own signature.