### GenOMICC Acute - Parent/guardian consent 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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| * I have read the information sheet (v5 – 23 October 2024) for this study (or it has been read to me). I understand it and have had the opportunity to ask questions.
* I agree for my child to provide a blood sample that will be used to obtain DNA and other molecules from their cells. These will be analysed to look for genetic factors and to understand other biological processes important in critical illness.
* I can withdraw my child from the study at any time without giving any reason.
* There is no direct benefit to taking part in the study, but we hope to be able help other people who become critically ill in future. There is a very small possibility that findings which are relevant to my child will arise through this research. There is a process through which I or my child can be informed of this.
* My child’s DNA, and data derived from their DNA, including the whole sequence of their genome and information about biological processes, may be stored and used for future research. Researchers may include national or international scientists, companies and NHS staff. To access the data, researchers must all be approved by an independent committee of experts, including clinicians, scientists and patients. There will be no access to the data by personal insurers or marketing companies.
* Different aspects of my child’s health data will be collected by the GenOMICC investigators, the study sponsor (NHS Lothian and the University of Edinburgh), and partner organisations.
* I agree that the investigators of this study may contact my child in the future to participate in future research studies, including clinical trials and studies unrelated to critical illness.
* I agree to life course follow up including the collection and analysis of my child’s health data for research that will continue across their entire lifetime and beyond. My child will be re-contacted when they turn 16 to confirm they agree to this.
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| I confirm that I am the parent/guardian for \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  |

**Please sign here to indicate that you agree with the statements above:**

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| ***If the Parent/Guardian cannot write or read the form:*** I have no involvement in this research study and I attest that the information concerning this research was accurately explained to the participant in language they can understand, and that informed consent was given freely by the parent/guardian. | \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_Print name of witness\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_Signature of witnessDate: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |

Original to be retained in site file. One copy to be given to parent/guardian.