NHS SCOTLAND

NICCS
NETWORK FOR INHERITED CARDIAC CONDITIONS SCOTLAND

Predictive genetic testing for children (<16 years old) at risk of Inherited Arrhythmias and Inherited Cardiomyopathies

NOTE
This guideline is not intended to be construed or to serve as a standard of care. Standards of care are determined based on all clinical data available for an individual case and are subject to change as scientific knowledge and technology advance and patterns of care evolve. Adherence to guideline recommendations will not ensure a successful outcome in every case, nor should they be construed as including all proper methods of care or excluding other acceptable methods of care aimed at the same results. The ultimate judgement must be made by the appropriate healthcare professional(s) responsible for clinical decisions regarding a particular clinical procedure or treatment plan. This judgement should only be arrived at following discussion of the options with the patient, covering the diagnostic and treatment choices available. It is advised, however, that significant departures from the national guideline or any local guidelines derived from it should be fully documented in the patient's case notes at the time the relevant decision is taken.

This guideline has been prepared by NHS National Services Scotland (NSS) on behalf of the Network for Inherited Cardiac Conditions Scotland (NICCS). Accountable to Scottish Government, NSS works at the heart of the health service providing national strategic services to the rest of NHS Scotland and other public sector organisations to help them deliver their services more efficiently and effectively. NICCS is a collaboration of stakeholders involved in care of inherited cardiac conditions who are supported by an NSS Programme Team to drive improvement across the care pathway.

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Introduction

Predictive genetic testing in children for inherited cardiac conditions is highly contentious within the cardiac genetics community with many groups unable to establish a broad consensus position. The Genetic Screening in Children Short Life Working Group was tasked by the NICCS Steering Group to review available evidence and existing practice to give consensus for practice in Scotland.

The aim of this guidance is to support healthcare professionals in NHS Scotland to deliver a consistent approach to predictive genetic testing for children (up to 16 years old) who are at risk of Inherited Arrhythmias and Inherited Cardiomyopathies.

Diagnostic genetic testing in children is not covered in this guideline.

Predictive genetic testing in children

When a pathogenic or likely pathogenic variant in a gene known to cause an inherited arrhythmia (IA) or inherited cardiomyopathy (IC) has been detected in an affected individual then it may be appropriate for that individual's children to have predictive genetic testing.

The familial phenotype and genotype should be confirmed before considering predictive genetic testing in a child. Predictive genetic testing for IA/ IC should be offered if it is in the best interest of the child. The classification of gene variants can change over time due to improved knowledge and updates in guidelines for variant classification. Therefore, discussion in the local ICC or clinical genetics MDT may be required when considering predictive genetic testing in children.

Informed consent should be obtained from parents/ legal guardians following the process established by the clinical genetics service. When appropriate, the child should be involved in the decision making and may be competent to provide their own consent.

Specific issues to consider when counselling children include a child's competency to decide on genetic testing, ensuring information given is appropriate to child's understanding, and impact on their lifestyle including participation in school activities, sports and future employment.

Predictive genetic testing in related children for Inherited Arrhythmias

Long QT Syndrome	• Recommended from any age (birth onwards) • Maternal cord blood sample appropriate*
CPVT	• Recommended from any age (birth onwards) • Maternal cord blood sample appropriate*
Brugada syndrome and sodium channelopathies	• May be considered from any age (birth onwards) following discussion with local ICC group/ clinical genetics
Progressive cardiac conduction disease	• May be considered from any age (birth onwards) following discussion with local ICC group/ clinical genetics
Short QT syndrome	• May be considered from any age (birth onwards) following discussion with local ICC group/ clinical genetics

Predictive genetic testing in related children for Inherited Cardiomyopathies

Hypertrophic Cardiomyopathy	• May be considered from any age (birth onwards) • Ensure appropriate genetic counselling • Maternal cord blood sample appropriate*
Dilated Cardiomyopathy	• May be considered from any age (birth onwards) following discussion with local ICC group/ clinical genetics
Arrhythmogenic cardiomyopathy	• May be considered from any age (birth onwards) following discussion with local ICC group/ clinical genetics

***Where maternal cord blood is sampled this should be recorded in the laboratory referral.**

References

European Heart Rhythm Association (EHRA)/Heart Rhythm Society (HRS)/Asia Pacific Heart Rhythm Society (APHRS)/Latin American Heart Rhythm Society (LAHRS) Expert Consensus Statement on the state of genetic testing for cardiac diseases
https://doi.org/10.1093/europace/euac030

2023 ESC Guidelines for the management of cardiomyopathies: Developed by the task force on the management of cardiomyopathies of the European Society of Cardiology (ESC)
https://doi.org/10.1093/eurheartj/ehad194

Royal College of Physicians, Royal College of Pathologists and British Society for Genetic Medicine: *Genetic testing in childhood. Guidance for clinical practice (November 2022)*
Genetic-testing-in-childhood.pdf

Appendix 1

This document was developed by the Genetic Screening in Children Short Life Working Group. The NICCS Steering Group endorsed this guidance on 18 June 2025. Full membership of both groups is noted below.

The Scottish Strategic Network for Genomic Medicine provided feedback on this document.

Genetic Screening in Children Short Life Working Group		
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