



NICCS

NETWORK FOR INHERITED CARDIAC CONDITIONS SCOTLAND

Guidance for Post Mortem investigation into Sudden Unexpected Death (SUD), Sudden Arrhythmic Death (SAD), Sudden Cardiac Death (SCD), and Aortopathy

NOTE

This guidance 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 guidance 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 guidance 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 guidance 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

The Network for Inherited Cardiac Conditions Scotland (NICCS) support improvements in the diagnosis, treatment, and outcomes of people with inherited cardiac conditions (ICCs).

This guidance, developed by NICCS and endorsed by the Crown Procurator Fiscal, outlines three pathways which should be followed in the event of a sudden cardiac death:

- Pathology Pathway: Initial Steps
- Pathology Pathway: Next Steps (where SUD/SAD/SCD/Aortopathy suspected)
- Relatives' Pathway: First degree relatives of deceased person with SUD/SAD/SCD

The guidance highlights the importance of exploring if there is a genetic basis to the sudden cardiac death, the risk posed to relatives of deceased individuals, and referral of the next of kin to their local ICC service. Suggested text to include in post mortem reports, and in communication with relatives, is included. Links to further supporting information available on the NICCS website is also highlighted.

Sudden Unexpected Death

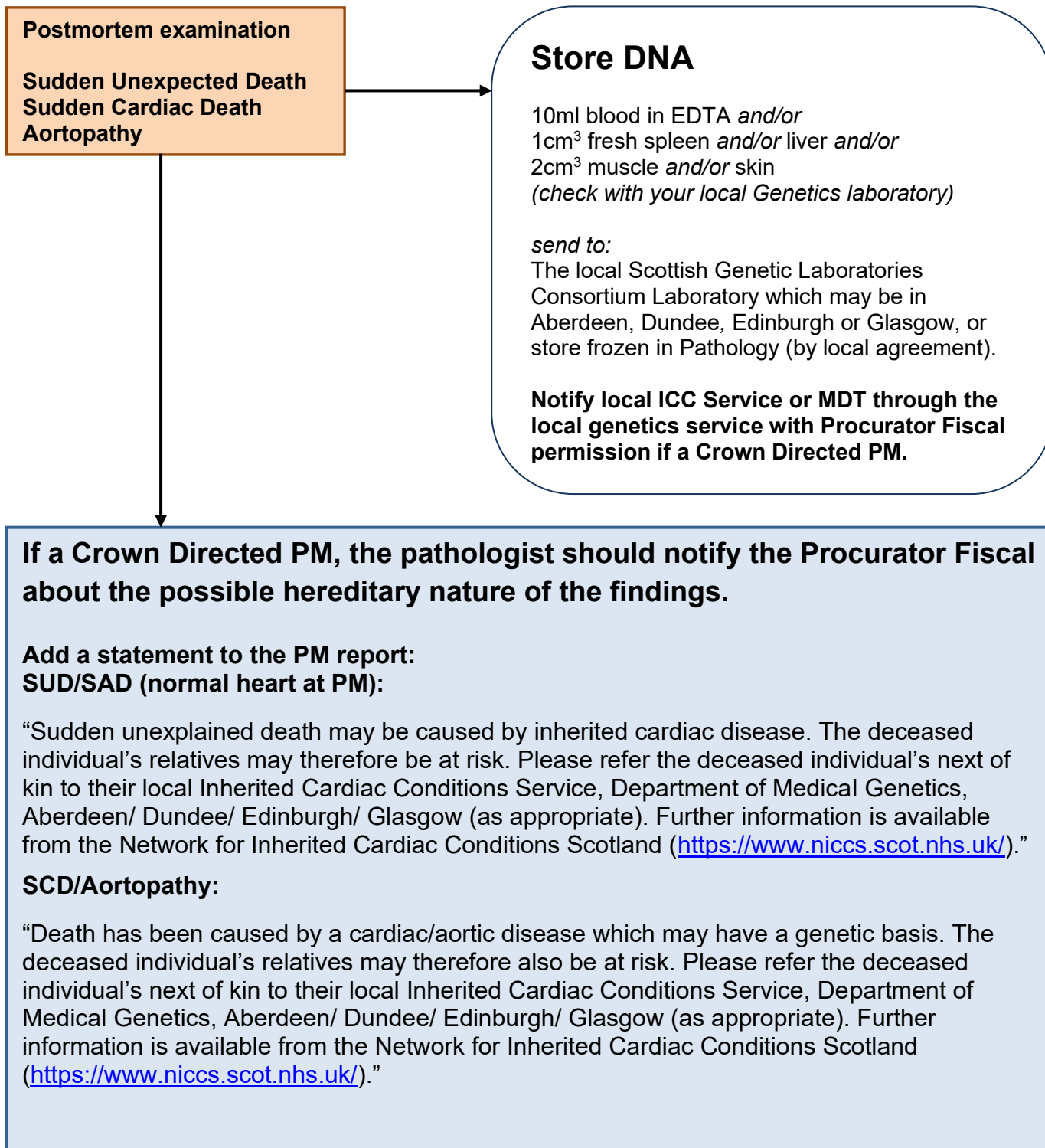
Sudden Unexpected Death (SUD) in a young person (generally <40 years of age) raises the possibility of an inherited cardiac arrhythmia syndrome ('sudden arrhythmic death' or SAD), although inherited cardiac arrhythmia syndromes can present at any age. A Post Mortem examination (PM) may be requested by the Procurator Fiscal service (a Crown directed PM), or it may be carried out in a hospital setting.

SUD may also be attributable at autopsy to a specific cardiac diagnosis that is likely to have a genetic basis ('sudden cardiac death'). Examples include hypertrophic cardiomyopathy, and arrhythmogenic cardiomyopathy. Dissection of the thoracic aorta in a person aged < 60 years, or anywhere in the aorta in association with pregnancy (even in the absence of Marfan syndrome-like features) raises the possibility of aortopathy due to an inherited connective tissue disorder.

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Pathology Pathway: Initial Steps



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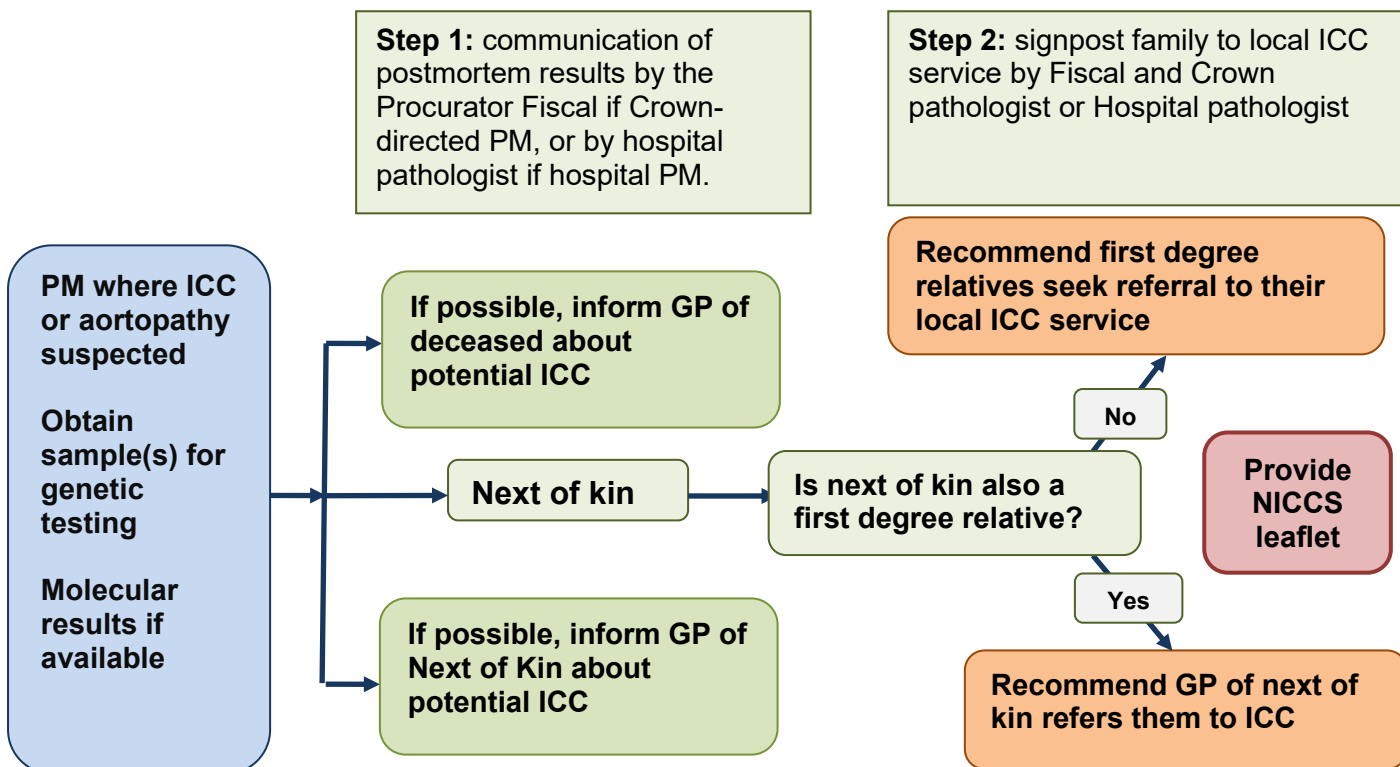
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Pathology Pathway: Next Steps (where SUD/SAD/SCD/Aortopathy suspected)



Molecular autopsy

Sometimes, the pathologist may request genetic testing as part of the post mortem, at other times genetic testing may be requested through the ICC service on behalf of the relatives at a later date.

Communication with next of kin

After a Crown Directed post mortem examination, the Procurator Fiscal communicates directly with the next of kin about the findings, and should also pass relevant information on to the GP of the deceased person and the GP of the next of kin. After a hospital post mortem, this should be undertaken by the Hospital Pathologist.

Suggested letter for next of kin and first-degree relatives

"Please seek further advice from your local genetics service about the implications of the diagnosis in your relative. You should contact your General Practitioner in the first instance to discuss referral and whether any screening investigations may be needed. Please let your GP know the city where your deceased relative's autopsy was carried out. Your GP can refer you to your local genetics service, and they will seek details about the findings for you. A leaflet about this is available from the Network for Inherited Cardiac Conditions Scotland (<https://www.niccs.scot.nhs.uk/>)."

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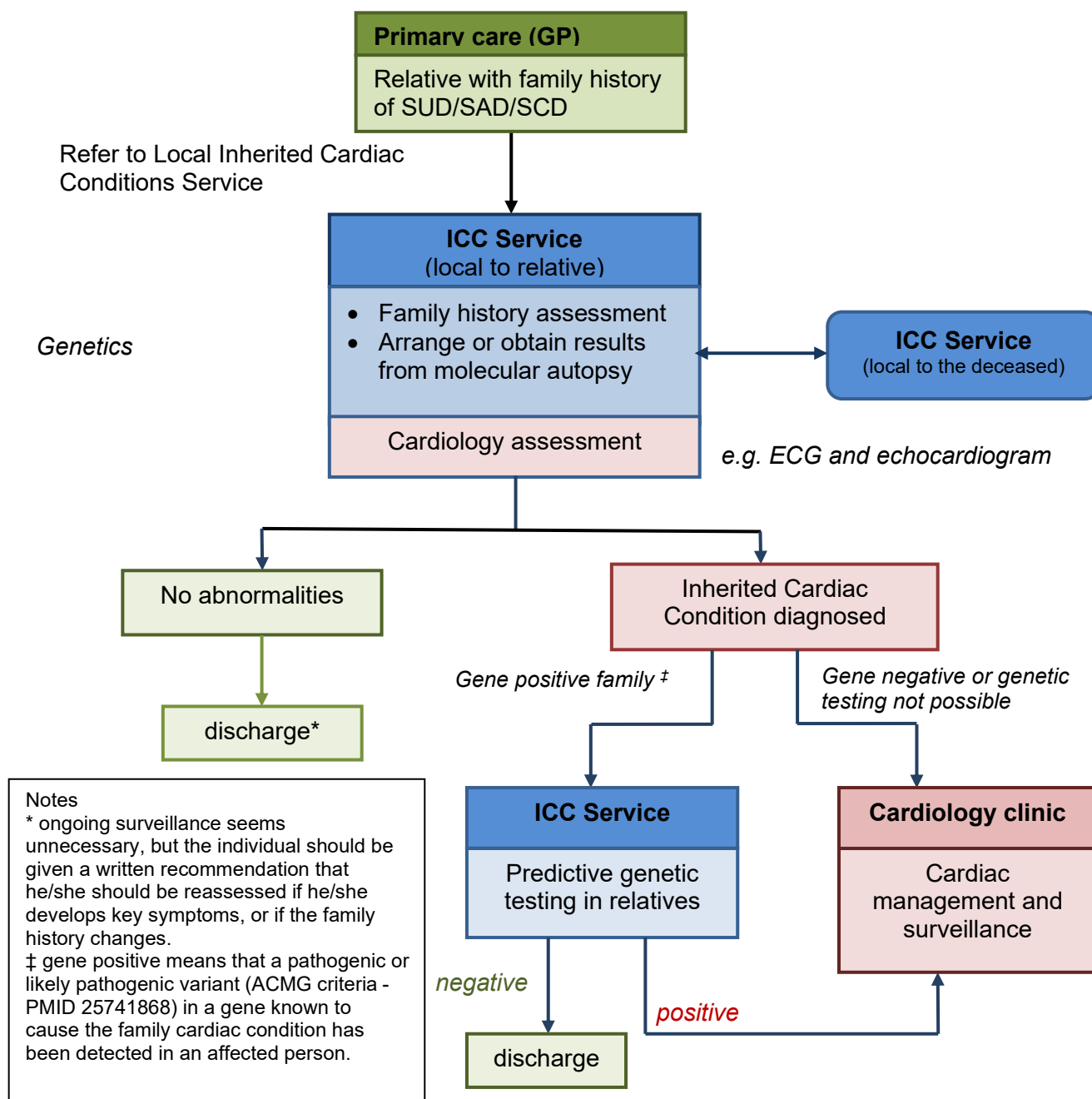
Referral of first-degree relatives

Relatives should be referred to their local ICC service through their local Genetics Service, so that family history information can be collected to inform the need for further genetic or cardiac investigation. Sometimes, cardiology screening (such as clinical assessment, ECG or echocardiogram) may be arranged through the relatives' local ICC service before the results of a molecular autopsy are available. The relatives' local genetics service will liaise with the genetics service local to the deceased person (if this is different) to ensure that information from any molecular autopsy is available to inform the investigation and follow-up of the relatives.

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Relatives' Pathway: First degree relatives of deceased person with SUD/SAD/SCD



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Appendix 1 – Stakeholder Involvement

Guidance Development

This guidance was developed by NICCS and following endorsement by the Crown Procurator Fiscal, it was approved at the NICCS Steering Group on 16th November 2022.

In October 2025, a review of the content was undertaken with only minor typographical/formatting changes required.

Reviewer		
Name	Designation	Organisation
Dr Kerryanne Shearer*	Consultant Forensic Pathologist	NHS Lothian

*Guidance also shared with colleagues for comment.

Approval

This guidance was approved by the NICCS Steering Group on 28 November 2025. The Steering Group comprises of:

NICCS Steering Group		
Name	Designation	Organisation
Dr Paul Broadhurst	Consultant Cardiologist	NHS Grampian
Dr Anna Maria Choy	Consultant Cardiologist	NHS Tayside
Susanne Christie	ICC Nurse Specialist	NHS Tayside
Dr Caroline Coats	Consultant Cardiologist	NHS GG&C
Dr Panayiotis Constantinou	Consultant Geneticist	NHS GG&C
Helena Davison	Clinical Nurse Specialist	NHS GG&C
Richard Forsyth	Health Systems Insights Manager	British Heart Foundation
Dr Duncan Hogg	Consultant Cardiologist	NHS Grampian
Dr Maria Ilina	Consultant Paediatric Cardiologist and Electrophysiologist	NHS GG&C
Dr Zaid Iskandar	Consultant Cardiologist	NHS Highland
Dr Will Jenkins	Consultant Cardiologist	NHS Lothian
Annie Johnes	Genetic Counsellor	NHS Grampian
Dr Catherine Labinjoh	Consultant Cardiologist	NHS Forth Valley
Ms Sarah Latto	Patient Representative	N/A
Debbie Mackin	Registered Genetic Counsellor	NHS Lothian
Ms Audrey McColl	Patient Representative	N/A
Dr Ruth McGowan	Clinical Genetic Consultant	NHS GG&C
Dr Karen McLeod	Consultant Paediatric Cardiologist and Electrophysiologist	NHS GG&C
Dr Catherine McWilliam	Consultant Clinical Geneticist	NHS Tayside
Dr Catherine Mondoia	Nurse Consultant	NHS Forth Valley
Dr Rachel Myles	Consultant Cardiologist	NHS GG&C
Robbie Panton	Patient Representative	N/A
Kirsten Patterson	Genetic Specialist Nurse	NHS Tayside
Mary Porteous	Consultant Clinical Geneticist	NHS Lothian
Lisa Robertson	Consultant Clinical Geneticist	NHS Grampian
Ms Gillian Scott	Principal Genetic Counsellor	NHS Lothian

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Dr Kerryanne Shearer	Consultant Forensic Pathologist	NHS Lothian
Dr Joanne Simpson	Consultant Cardiologist	NHS GG&C
Dr Graeme Tait	Consultant Cardiologist	NHS Lanarkshire
Dr Sylvia Wright	Consultant Forensic Pathologist	NHS GG&C
Dr Esther Youd	Consultant Pathologist	NHS GG&C

NICCS Contact Details

Email: nss.niccs@nhs.scot

Website: www.niccs.scot.nhs.uk

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