



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*

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.

Sudden unexpected death 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.

1) Pathology Pathway: Initial Steps

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

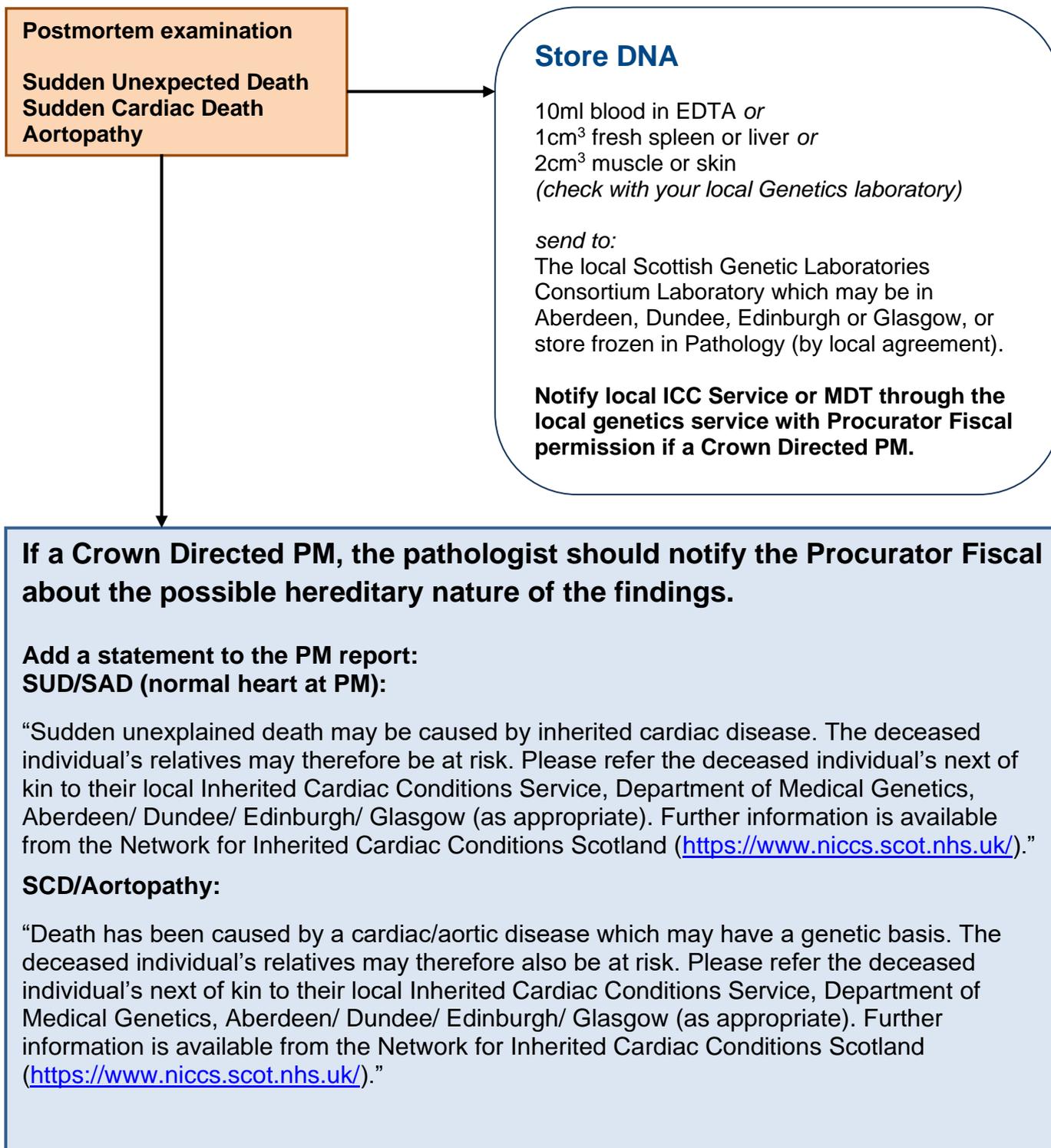
3) Relatives' pathway: first degree relatives of deceased person with SUD/SAD/SCD

**This pathway 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 pathway 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.*

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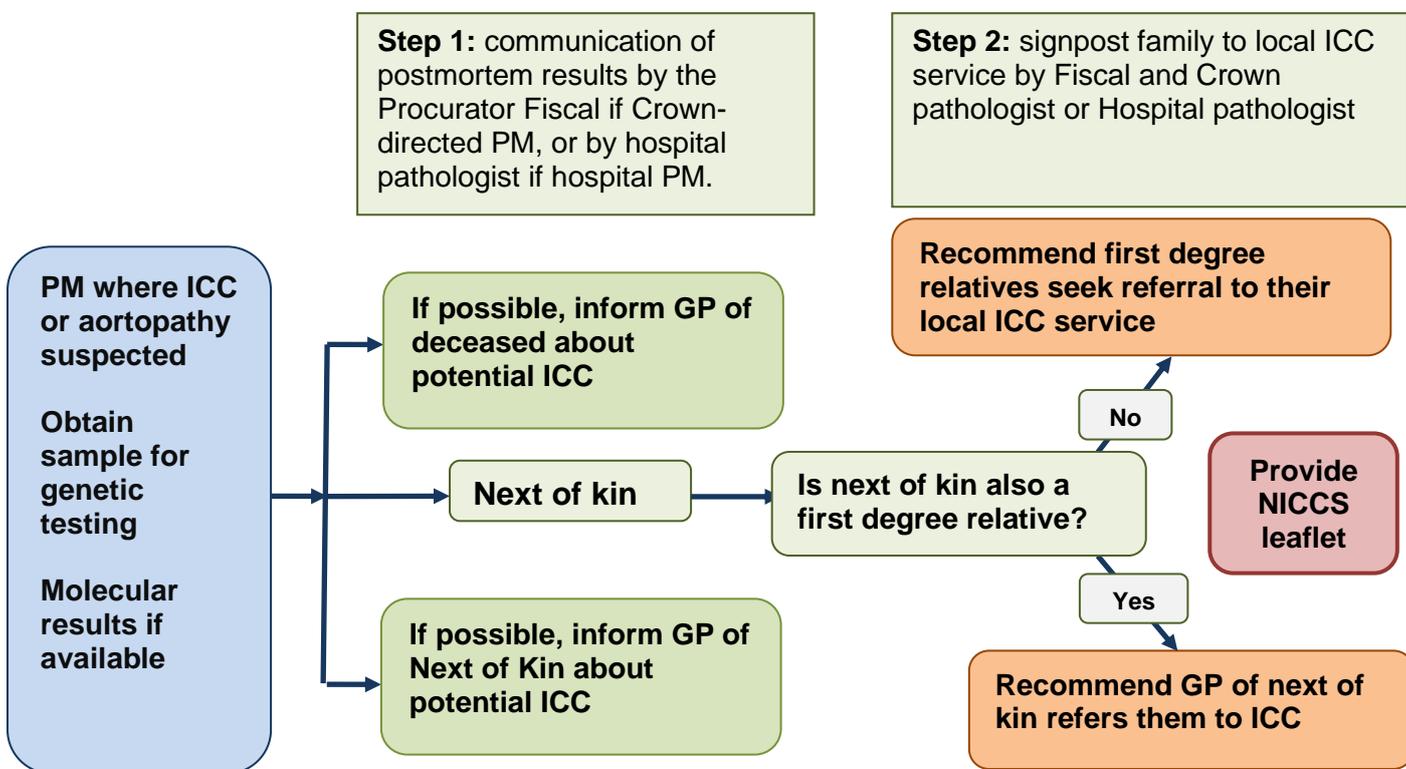
1) Pathology Pathway: Initial Steps



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2) 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.

3) Relatives' pathway: first degree relatives of deceased person with SUD/SAD/SCD

