Sudden Cardiac Death where death occurs in ICU
Operating Guideline

Introduction

Some deaths resulting from out of hospital cardiac arrest (OOHCA) are due to inherited cardiac causes. The 2022 ESC Guidelines for the management of patients with ventricular arrhythmias and the prevention of sudden cardiac death[1] contain some applicable information but are not prescriptive in follow up requirements. However, based on these international guidelines, local pathways, and local protocols the following NHS Lothian guideline has been developed in conjunction with colleagues in Clinical genetics, Cardiology and ICU specifically for patients admitted to ICU with a sudden cardiac death syndrome where there is a strong suspicion of an inherited cardiac condition (ICC). This guideline may be used by other ICU's in South East Scotland within the regional ICC network (NHS Borders, Forth Valley and Fife)

Patients discharged to cardiology from ICU will undergo appropriate screening for underlying cardiac disease including a possible inherited cardiac condition.

This guideline applies to patients who do not survive beyond ICU.

Which patients does this guideline apply to?

OOHCA Patients meeting the following criteria:

- Deaths in general intensive care unit (ICU)
- Patients under 60
- Unlikely to be due to an acute coronary syndrome
- Non-cardiac precipitant excluded
- Sufficient information to complete the death certificate (MCCD)*
- Cardiology review/advice confirms suspicion of ICC

*Please be as specific as possible for the underlying cause of death on the MCCD. A discussion with the cardiology team is advised. Some examples of underlying causes of death on the MCCD that might trigger the application of the guideline may include dilated cardiomyopathy, hypertrophic cardiomyopathy or arrhythmogenic right ventricular cardiomyopathy, the channelopathies (Brugada syndrome, Long QT syndrome, Polymorphic catecholamine induced VT), and less commonly familial aortopathy (acute dissection) which typically end up on cardiac ICU. In many cases this level of specificity may not be possible without further post-mortem investigation. In these cases, less specific terms, provided they appear in ICD11, are permitted.

Which patients does this guideline not apply to?

- Deaths following OOHCA where there is clear rationale to refer to the Procurator Fiscal, typical examples being deaths associated with suspected illicit drug use, deaths following trauma, suicide
- Deaths following OOHCA where there is insufficient information to complete the MCCD
- Both of these cases should be referred to the Procurator Fiscal.
    - Please ring the duty biochemist to store the closest available samples to the time of admission and send sample: Urine, drugs of abuse (all sites).
- For the full list of reasons to refer to Procurator Fiscal please see this link.
- For patients with OOHCA due to coronary heart disease under 60 years, who die in ICU, first degree relatives should be advised to attend their GP for cardiovascular risk assessment.

Family contact: The ICU Team should identify and record contact details of at least one family member who agrees to act as a liaison between the family and the Clinical Genetics team for ongoing communications regarding screening for an inherited cardiac condition. This family member needs to consent for their contact details to be passed to Clinical Genetics. These details should be included in the email sent to Clinical Genetics referring the patient (index case) to the Cardiac Genetics MDT.

Title: NHSL Critical Care Sudden Cardiac Death Where Death Occurs on ICU	
Version 3	**Authors:** T Craven, D Mackin, P Greene, M Denvir
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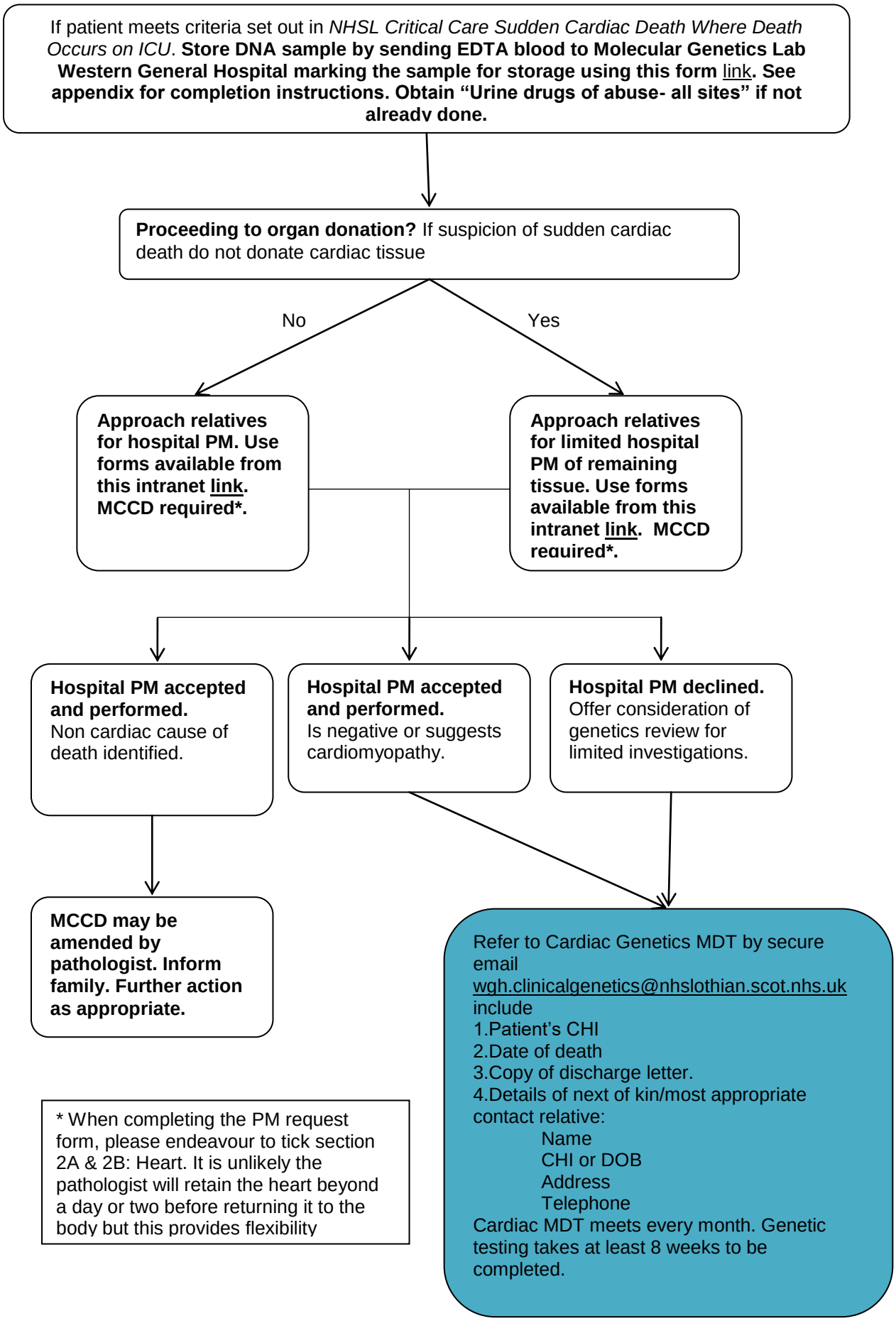
For included patients



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INHERITED CARDIAC CONDITIONS/GENETICS MDT:

This is a regional meeting for South - East Scotland held at 0900h on the last Friday of each month in the Cardiology department at RIE and can be attended on Teams.

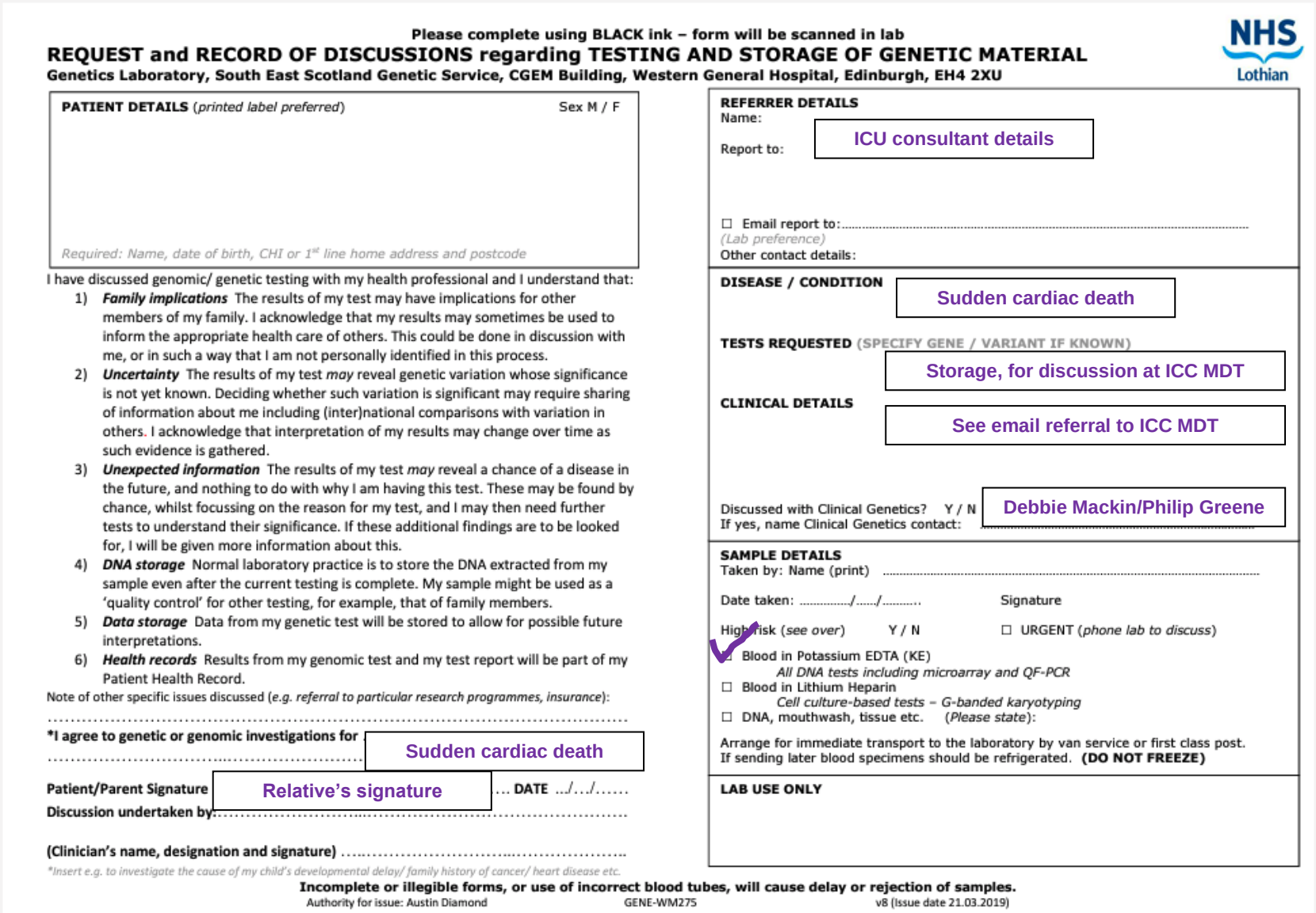
The responsible ICU consultant/doctor will be invited to attend the ICC MDT meeting when the patient is scheduled for discussion. Attendance is not mandatory but would be extremely valuable in providing clinical context. The MDT will review and discuss clinical details and will decide if gene testing is appropriate or not. The MDT will then decide which gene panel analysis should be used. The Clinical Genetics team will contact the family, via the liaison contact, explore family history and consent for testing if appropriate.

The outcome of the MDT and results of any investigations will be reported back to the GP of the family contact by the clinical genetics team. Further necessary genotypic or phenotypic screening of family members will be coordinated through the ICC MDT.

References

1. 2022 ESC Guidelines for the management of patients with ventricular arrhythmias and the prevention of sudden cardiac death | European Heart Journal | Oxford Academic.

Appendix



Please complete using BLACK ink – form will be scanned in lab

REQUEST and RECORD OF DISCUSSIONS regarding TESTING AND STORAGE OF GENETIC MATERIAL

Genetics Laboratory, South East Scotland Genetic Service, CGEM Building, Western General Hospital, Edinburgh, EH4 2XU

NHS Lothian

PATIENT DETAILS (*printed label preferred*) Sex M / F

Required: Name, date of birth, CHI or 1st line home address and postcode

I have discussed genomic/ genetic testing with my health professional and I understand that:

1) ***Family implications*** The results of my test may have implications for other members of my family. I acknowledge that my results may sometimes be used to inform the appropriate health care of others. This could be done in discussion with me, or in such a way that I am not personally identified in this process.
2) ***Uncertainty*** The results of my test *may* reveal genetic variation whose significance is not yet known. Deciding whether such variation is significant may require sharing of information about me including (inter)national comparisons with variation in others. I acknowledge that interpretation of my results may change over time as such evidence is gathered.
3) ***Unexpected information*** The results of my test *may* reveal a chance of a disease in the future, and nothing to do with why I am having this test. These may be found by chance, whilst focussing on the reason for my test, and I may then need further tests to understand their significance. If these additional findings are to be looked for, I will be given more information about this.
4) ***DNA storage*** Normal laboratory practice is to store the DNA extracted from my sample even after the current testing is complete. My sample might be used as a 'quality control' for other testing, for example, that of family members.
5) ***Data storage*** Data from my genetic test will be stored to allow for possible future interpretations.
6) ***Health records*** Results from my genomic test and my test report will be part of my Patient Health Record.

Note of other specific issues discussed (*e.g. referral to particular research programmes, insurance*):

.....

***I agree to genetic or genomic investigations for** Sudden cardiac death

.....

Patient/Parent Signature Relative's signature ... **DATE** .../.../.....

Discussion undertaken by.....

(Clinician's name, designation and signature) .....

**Insert e.g. to investigate the cause of my child's developmental delay/ family history of cancer/ heart disease etc.*

REFERRER DETAILS

Name:

Report to: ICU consultant details

☐ Email report to:.....
(Lab preference)

Other contact details:

DISEASE / CONDITION Sudden cardiac death

TESTS REQUESTED (SPECIFY GENE / VARIANT IF KNOWN)

Storage, for discussion at ICC MDT

CLINICAL DETAILS

See email referral to ICC MDT

Discussed with Clinical Genetics? Y / N Debbie Mackin/Philip Greene

If yes, name Clinical Genetics contact: .....

SAMPLE DETAILS

Taken by: Name (print) .....

Date taken: ...../...../..... Signature

High risk (*see over*) Y / N ☐ URGENT (*phone lab to discuss*)

☑ Blood in Potassium EDTA (KE)
All DNA tests including microarray and QF-PCR
☐ Blood in Lithium Heparin
Cell culture-based tests – G-banded karyotyping
☐ DNA, mouthwash, tissue etc. (*Please state*):

Arrange for immediate transport to the laboratory by van service or first class post.
If sending later blood specimens should be refrigerated. **(DO NOT FREEZE)**

LAB USE ONLY

Incomplete or illegible forms, or use of incorrect blood tubes, will cause delay or rejection of samples.

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