

WEST OF SCOTLAND INHERITED CARDIAC CONDITIONS SERVICE REFERRAL GUIDANCE

The Inherited Cardiac Conditions (ICC) service is for patients with a diverse range of potentially familial conditions, which may present with sudden cardiac death (SCD).

- Cardiomyopathies (hypertrophic, dilated, restrictive, arrhythmogenic)
- Ion channel disorders (long QT, short QT, Brugada, CPVT)
- Aortopathies (syndromic, eg Marfan, Loeys Dietz and non syndromic)
- Neuromuscular disorders (muscular dystrophies, myotonic dystrophy)

ICC SCI-REFERRAL PATHWAYS

All referrals will be reviewed by the core genetics and cardiology team using active clinical review and triage (ACRT). Genetic testing and/or cardiac investigations may be arranged directly, with virtual appointments or written advice given where appropriate.

1) SUDDEN CARDIAC DEATH REFERRAL PATHWAY

- We recognise the profound psychological impact of SCD on family members and endeavour to prioritise these referrals.
- After a sudden cardiac death (SCD) the next of kin or first-degree relative(s) should be referred with relevant details about the deceased to facilitate ACRT.
- Following post-mortem (PM), the pathologist may recommend referral to the ICC service. In these cases, samples may have been retained for genetic investigations in the deceased.
- If several family members are seeking referral, please use this pathway to refer **only** the individual who can provide the relevant family history and consent for genetic investigations. Refer other first-degree relatives using the general ICC referral pathway, referencing the name of the deceased.
- The patient will be sent a letter acknowledging receipt of referral and a leaflet explaining the investigation process. [NICCS Leaflet Sudden Death](#). Clinical investigations may be arranged directly if appropriate.

2) GENERAL INHERITED CARDIAC CONDITIONS REFERRAL PATHWAY

This pathway should be used for referral of any patient with, or at risk of having, an inherited cardiac condition. Please state the reason for referral:

- **Diagnostic evaluation** – ICCs may require a combination of specialist clinical and / or genetic investigation to reach a diagnosis.
- **Genetic testing**
 - i. If the diagnosis of an ICC is established, please send an EDTA blood sample to clinical genetics in parallel with the SCI-referral. DNA will be extracted and stored pending ACRT.
 - ii. If a genetic diagnosis has been made in another relative, please provide details of where the testing has taken place, so that results can be obtained by the genetic team in advance of their appointment.
- **Management advice** – please provide clinical details about specific issues and the urgency of referral.
- **Family screening referrals** – please provide details of the affected relative to facilitate ACRT. In some cases, the ICC service may request referral of the affected relative first.

Further information about inherited cardiac conditions for patients, families and professionals in Scotland is available at <https://www.niccs.scot.nhs.uk> or printable [Scotland ICC Services Leaflet](#).