Phenotype	GP	Referral Point	Investigations	Phenotype identified in relative?	Genetic testing	Follow-up	Therapy?

Pathway direction

SADS: Unexplained SCD

(also consider Sudden Unexplained Death in epilepsy [SUDEP] as SADS until proven otherwise)

Investigations before referral:

Expert autopsy

Retention of fresh tissue or blood for freezing +/- DNA extraction

Refer first degree blood relatives including children

Unexplained syncope or seizures?

Refer urgently

ICC clinic

More distant blood relative: Seek advice from ICC clinic

Refer key relatives who are likely carriers and/ or suffer unexplained syncope or seizures

Expert pathology

Review coronial reports, PMH, old ECGs

Investigations can include: Family history, ECG, Echo, ExECG +/- SaECG, Tape and Ajmaline test

Children to complete investigation as age permits

YES

YES
Appropriate to phenotype
(see recommended pathway)

Molecular autopsy of SADS victim if suitable tissue retained

YES
Appropriate to phenotype and refer at risk relatives

YES
Appropriate to phenotype and risk

NO

Molecular autopsy of SADS victim if suitable tissue retained.

Consider de novo disease.

Follow-up children when able to complete testing and then once during, once after puberty and then once in adulthood, investigating as appropriate.

Discharge adults

Re-refer:

- urgently if symptomatic
- if a phenotype is identified in another blood relative

NO