

# PE2067/D: Improve data on young people affected by conditions causing Sudden Cardiac Death

## Network for Inherited Cardiac Conditions Scotland written submission, 5 April 2024

The Network for Inherited Cardiac Conditions Scotland (NICCS) was established in 2008 (formerly, the Familial Arrhythmia Network Scotland) to address some of the challenges in caring for families affected by sudden cardiac death (SCD) or sudden unexpected death (SUD). [The network has agreed guidance in Scotland](#), but despite this, we know from lived experience that more needs to be done and we continue to hear from families that have had a challenging journey following SUD/SCD to get to the right services at the right time.

When a death is sudden, or unexpected, there are legal requirements to ascertain the cause of death. In 15-20% of SCD/SUD cases unascertained at post-mortem a concealed electrical or heart muscle disorder may be identified through molecular genetic testing (references 1 and 2). At such a devastating time, the process can feel confusing and complicated, and investigations can take a long time (reference 3).

The West of Scotland Inherited Cardiac Conditions Service, based in NHS Greater Glasgow and Clyde received 18 months funding in 2023 for a cardiac nurse specialist to evaluate areas of need and develop better support for families in Scotland. This project has 3 work streams:

1. **Data quality and regional / national audit.** Working with NICCS, the Scottish Cardiac Audit programme (SCAP) and regional genetics and pathology services, we aim to standardise data collection and develop a robust national audit process.
2. **Pilot an integrated care system for SUD/SCD.** By appointing a cardiac nurse specialist we will facilitate early contact with families, which we know is critical to perception of risk and engagement with screening. Focus groups will gather feedback on service needs.
3. **Education, information and bereavement support.** Grief associated with SUD/SCD is particularly complex when people die at a young age and/or when other family members may be affected. We are working with educational and public information to improve access to resources.

The nurse specialist post commenced in February 2024 and has already made important progress by gathering information best practice and registry data form across the world. We look forward to working closely with families and 3rd sector organisations to drive improvement in this area.

### References

1. Lahrouchi et al. Utility of Post-Mortem Genetic Testing in Cases of Sudden Arrhythmic Death Syndrome, JACC 2017, Vol 69 (17) p2134-44

2. Stiles et al. 2020 APHRS/HRS expert consensus statement on the investigation of decedents with sudden unexplained death and patients with sudden cardiac arrest, and of their families' Heart Rhythm Journal, 18 (1)
3. Allan et al. A Qualitative Study of Families' Experiences When a Young Relative Dies of Sudden Cardiac Death. Circ Cardiovasc Qual Outcomes. April 2023, p279-287