

Network for Inherited Cardiac Conditions Scotland

Annual Report 2025/26

The Network is supported by a dedicated programme team within Public Services Delivery Scotland (PSDS), consisting of:

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This document has been prepared by National Services Directorate (NSD) of Public Services Delivery Scotland (PSD Scotland) on behalf of the Network for Inherited Cardiac Conditions Scotland (NICCS). Accountable to Scottish Government, PSD Scotland works at the heart of the health service providing national strategic services to the rest of NHS Scotland and other public sector organisations to help them deliver their services more efficiently and effectively. NICCS is a collaboration of stakeholders involved in care of inherited cardiac conditions who are supported by a PSD Scotland Programme Team to drive improvement across the care pathway.

Introduction

The Network for Inherited Cardiac Conditions Scotland (NICCS) was launched in 2019 following an extension to the scope of the Familial Arrhythmia Network Scotland (FANS) to incorporate inherited cardiomyopathies. The role of the Network is to support improvements in the diagnosis, treatment, and outcomes of people with inherited cardiac conditions (ICCs).

Improving outcomes in patients with ICCs requires specialist clinical management to improve both life expectancy and quality of life. The Network provides a framework to facilitate delivery of standardised quality patient care for patients with ICCs throughout Scotland. The Network monitors that the care delivered meets agreed national standards and supports services in improving standards of care through the establishment of continuous quality improvement.

The network aligns closely with the principles set out in the Scottish Governments Operational Improvement Plan, the core elements of which are; improving access to treatment, shifting the balance of care, improving health and social care services through digital and technological innovation and prevention (ensuring we work with people to prevent illness and more proactively meet their needs).

Current Position

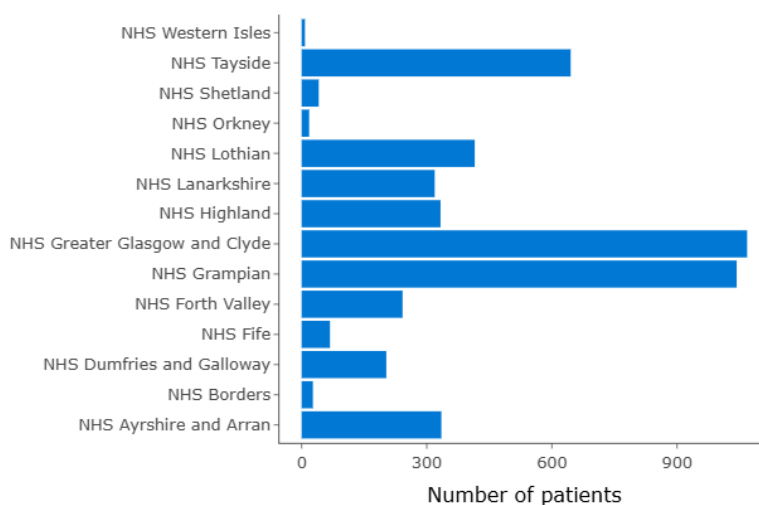
Activity during 2025/26 reflected national prioritisation set during a period of review. Alongside evolving national planning arrangements, Managed Clinical Networks were asked to focus activity on a number of core priorities.

Looking ahead, NICCS will build on its established approach by undertaking a Strategic Needs Assessment to inform the 2026/27 workplan and ensure priorities remain aligned to population need, current pathways, available data and stakeholder perspectives. This remains consistent with the direction set by the Health and Social Care Service Renewal Framework and Scotland's Population Health Framework (June 2025), and recognising that Chief Executive Letter (CEL) 29 (2012) *Managed Clinical Networks: Supporting and Delivering the Healthcare Quality Strategy* remains the extant mandate for Managed Clinical Networks.

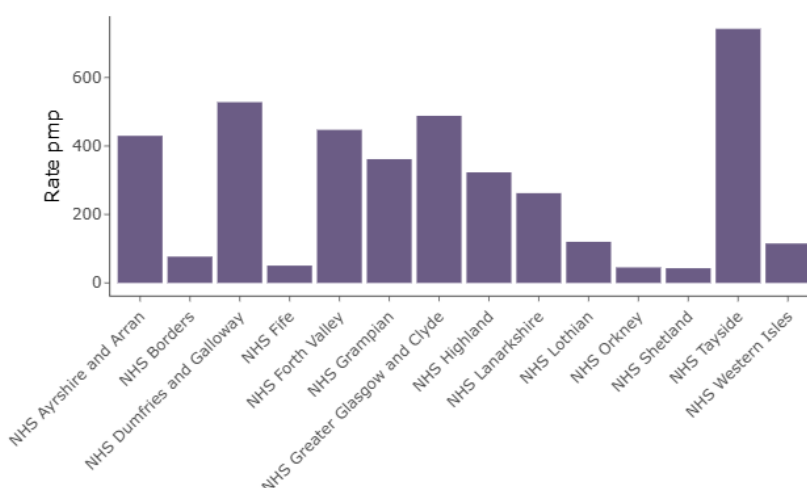
The priorities for NICCS in 2025/26 were:

Priority Action	Progress
Data collection and analysis of the NICCS Annual Audit of Hypertrophic Cardiomyopathy (HCM).	The Network worked with the Scottish Cardiac Audit Programme (SCAP) to link all HCM data collected by the network across the 2025 audit and previous audits with SMR data metrics. The 2024/25 SCAP Annual Report published in November 2025 (scotland.shinyapps.io/phs-scap-annual-report-2024-25/) included information on Inherited Cardiac Conditions for the first time.

The graph below shows the number of patients with HCM collected through the NICCS audits between 2015/16 and 2024/25, by NHS board.



The graph below shows the genotype positive rate per million population (pmp) by NHS board, as at 31 March 2025



Note: Both graphs do not include information from East centre for 2024/25 due to delay in receiving information but will be incorporated into future reports.

Work is ongoing with regional ICC centres and SCAP to ensure the robustness of HCM data collected to date and streamlining of the data collection process for future ICC audits.

Development of guidance on Genetic Screening in Children

'Predictive genetic testing for children (<16 years old) at risk of Inherited Arrhythmias and Inherited Cardiomyopathies' guidance was endorsed by the Steering Group on 18 June 2025 and is available on the NICCS website.

All business-as-usual objectives in the 2025/26 workplan were completed. This included ensuring appropriate network governance, strengthening communication and stakeholder engagement, delivering education, and progressing audit and continuous improvement activities.

The network continued to make use of technology and remote communications to progress work this year. This has continued to be effective, saving time on travel, and promoting economic and climate friendly practices.

Highlights

Guidance

A Task and Finish Group was established to develop guidance on transition from paediatric to adult services for young people with an inherited cardiac condition. This guidance aims to support healthcare professionals in NHS Scotland to deliver a consistent approach. The guidance is expected to be endorsed by the Steering Group in Quarter 1, 2026/27.

The existing NICCS guidance on Sudden Unexpected Death (SUD), Sudden Arrhythmic Death (SAD) and Sudden Cardiac Death (SCD) was reviewed and minor updates made. This was endorsed by NICCS Steering Group on 28 November 2025 and is now available on the Network website.

Education

Education is a core objective for all Managed Clinical Networks. The 2023 - 2026 NICCS Education Strategy outlines the objectives and outcomes of the education the network will deliver.

The NICCS Annual Symposium was held on 14 November 2025 in NHS Education Scotland Westport Offices, Edinburgh. In total, 50 people attended the event with 24 people attending in person and 26 people attending online via Teams.

Evaluation forms were completed by 16 attendees (32% response rate):

- The majority of respondents 'strongly agreed' (75%) or 'agreed' (13%) that the event had met its objective by giving them 'a broader understanding of a range of aspects of inherited cardiac conditions'. One person reported they 'strongly disagreed' that the objective had been met, however their other responses provided very positive feedback. Therefore, it is likely that this response was recorded in error. One person did not answer this question.
- Attendees were asked to score each presentation. The results reflected that the majority of attendees agreed that the 'delivery' and 'content' of each was 'excellent' or 'very good'.
- When asked what people valued most about this event, respondents highlighted the benefit of networking face to face and that the event offered an online option for those unable to attend in person.
- All respondents said the event would be 'very effective' (31%) or 'effective' (69%) in changing their practice.

Some of the ways attendees stated the event would change their practice included:

- Better understanding of pathways and delivery of care to those with inherited cardiac conditions

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- Establish robust local processes for mainstreaming of genetic testing.
- Taking ideas from how things work in other centres.
- Be more vigilant to the red flags for an Amyloid diagnosis.
- Engage with the development of the SCD project across the East of Scotland service.
- Ensure the ongoing development/engagement in audit.
- More awareness of the key contacts involved in caring for families with inherited cardiac conditions

15 respondents would recommend this event to their colleagues. One respondent did not answer this question. 15 respondents said the learning from this session would contribute to their Continuing Professional Development (CPD) requirement for revalidation. The event provided 320 hours of CPD to health care professionals.

The network continued to deliver its programme of virtual education sessions aimed at health care professionals with an interest in ICCs. These sessions take place at lunchtime over Teams. Sessions are recorded to allow people to watch it on the NICCS Education Teams channel which currently has 120 members (as at 31 March 2026).

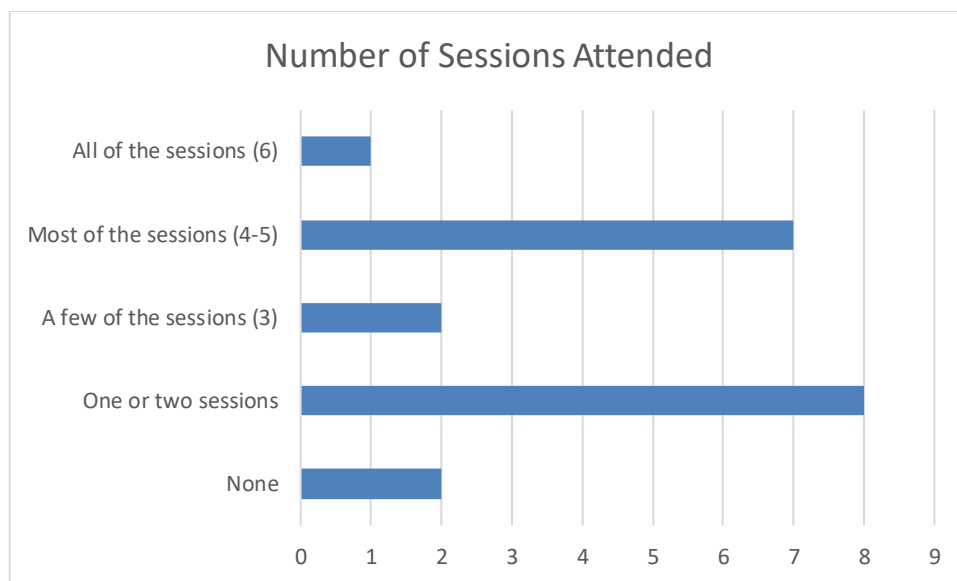
Six sessions were held in 2025/26 - details of each session is provided below:

Date	Topic	Attendees	Views*	CPD
30/05/2025	Cardiac genetic testing in Scotland...where we are and the need for demand optimisation	12	0	12 hours
29/08/2025	Psychological Support for ICD recipients: Insights from a pilot service at the Golden Jubilee National Hospital	18	5	23 hours
31/10/2025	Accessible Patient Information: Experiences from the British Heart Foundation	9	6	15 hours
30/01/2026	Exercise Risk in Cardiomyopathies	24	4	28 hours
27/02/2026	An overview of REDCap from the Scottish Cardiac Audit Programme	23	1	24 hours
27/03/2026	Vascular Ehlers-Danlos Syndrome Services in the UK	21	1	22 hours

*As at 20/04/26

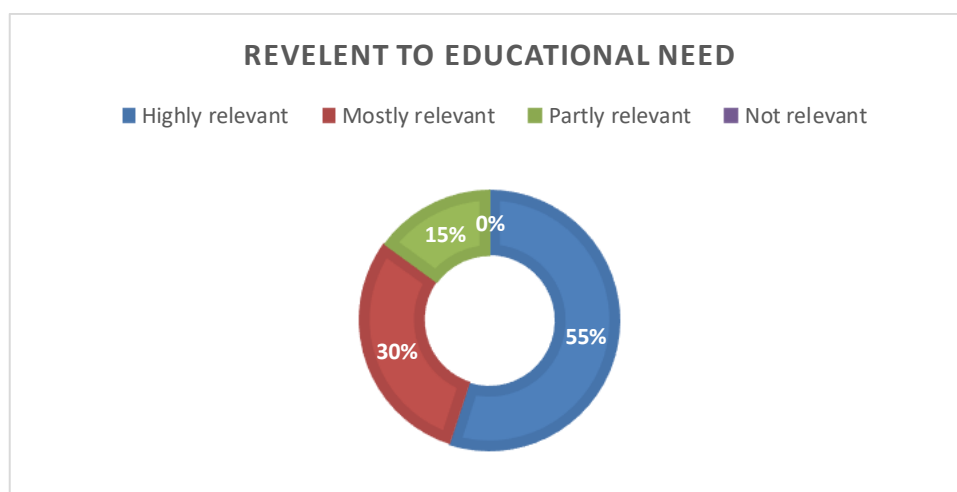
In total, the NICCS Education Sessions in 2025/26 provided 124 hours of CPD to health care professionals.

To gather feedback on the education sessions, and inform future education sessions, an evaluation survey was shared in April 2025 via email and on the NICCS Education Teams channel. In total, 20 people from 8 different health boards responded. The number of sessions attended or viewed by each respondent is noted in the graph below:



Nine people (45%) said they had watched at least on one of the sessions following the session through the NICCS Education Teams channel

In response to how relevant these sessions were to people's educational needs; the following feedback was received:



When asked to rate the overall quality of education provided by the programme of monthly education sessions in 2025/26, 60% of respondents rated these as 'Excellent' and 35% rated these as 'Good'. One respondent who had not attended any of the sessions did not answer this question.

The feedback received from the evaluation of the Annual Symposium and virtual education sessions including suggested topics for future education events, was considered by the NICCS Steering Group to inform planning for future education events.

Patient Engagement

The Patient Engagement Group continued to meet quarterly to support implementation of the 2023 - 2026 Patient Engagement and Patient Experience Strategy. A key activity undertaken by the group this year was the review and update of the following NICCS Patient Information materials:

Patient Information Leaflets	• NICCS Information for patients
	• How the genetics team can help you
	• Inherited cardiac conditions: Services for patients and their families
	• What happens after a sudden unexpected death which may be due to an inherited cardiac condition?
Information Resource Pack	• Inherited cardiac conditions
Alert Cards	• Brugada Patient Information
	• QT Patient Information

Following the 2024/25 pilot of the networks online patient support drop-in sessions, which aimed to provide information and peer support to people affected by inherited cardiac conditions, an additional session was held in June 2025. The focus of the session, Exercise and ICCs, was in response to what patients said would be helpful however only 6 patients attended. Despite positive feedback from patients who had attended one or more of the sessions, the Patient Engagement Group and Steering Group agreed that these should be paused due to the limited attendance, and the network would explore alternative routes to identify and meet patient's needs.

Looking forward – 2026/27

The Network will undertake a strategic needs assessment to inform the workplan for the next 3-5 years and agree clear, evidence-based, and measurable outcomes. Through this we will look at the needs of the patient population to inform future patient engagement activity due to limited attendance at patient events hosted by the network in recent years.

Education will remain a key focus for the Network through delivery of the Annual Symposium and the virtual education sessions. In recognition of the breadth of education that has already taken place within the network and is available on the NICCS MS Education Teams Channel, the virtual education session will move to being held on a quarterly basis. A signposting document will be developed and published on the website to signpost health care professionals with an interest in ICCs to a range of resources/education from NICCS and other sources. Opportunities for peer support will continue through the quarterly National Case Discussion Sessions and meetings of the Nurse/Allied Health Professional subgroup.

The draft Transition Guidance developed by the Task and Finish Group in 2025/26 will be finalised and published on the NICCS website. The NICCS ICC Specification is currently being reviewed and updated to include KPIs for Network and additional ICC Audits to monitor progress are being considered. Partnership working will continue with the Scottish Cardiac Audit Programme to support data collection and analysis of outcome for people with HCM.

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The Network will continue to contribute to the delivery of the SCD/OOHCA Project with a key action to work in partnership to redevelop the existing NICCS Patient Information Leaflet with information on the new pathways and support now in place for families following a Sudden Cardiac Death.

Finance

The network operated within its allocated budget in 2025/26, focusing on low-cost, high-impact activities such as virtual education and digital resource development.