

Network for Inherited Cardiac Conditions Scotland

Annual Report 2024/25

Lead Clinician (Cardiac): Vacant

Lead Clinician (Genetics): Vacant

Programme Manager: Gillian Kinstrie

Programme Support Officer: Aneta Gorczynski (to 30/09/2024)/Leanne Baxter-Ramsay (from 01/10/2024)

This document has been prepared by NHS National Services Scotland (NSS) on behalf of the Network for Inherited Cardiac Conditions Scotland (NICCS). Accountable to Scottish Government, NSS 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 an NSS 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 recently published 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

In light of the ongoing Scottish Government review of national networks, planning has been adapted to focus on core priorities and ensure continuity of essential services. We await further guidance to inform future strategic development. Interim leadership arrangements have been in place during 2024/25, ensuring continuity of activity while formal recruitment is aligned with national review outcomes.

The actions prioritised for NICCS were:

Priority Action	Progress
Completion and evaluation of the pilot to host monthly virtual patient drop-in sessions and host a face-to-face information event for patients.	Pilot and evaluation complete. The Patient Event was paused pending the outcome of the review of networks providing clarity on the role of patient engagement in any future network model. Patient drop-in sessions continued in Q4 2024/25 pending the outcome of the evaluation of the pilot sessions.
Data collection and analysis of the NICCS Annual Audit of Hypertrophic Cardiomyopathy (HCM).	Data has been collected for the 2024 audit. The Network is now being supported by the Scottish Cardiac Audit Programme to link all of the data collected by the network across this and previous audits with SMR data metrics and undertake the analysis of findings. This project has encountered delays due to centres needing to undertake data cleansing and submit additional data not collected as part of the initial audit exercises to provide a more robust dataset. It is anticipated that this will be completed in Q1 2025/26 and will support streamlining of 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 has been drafted and is expected to be endorsed by the Steering Group in Q1 2025/26.
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All business as usual objectives on the 2024/25 workplan were completed.

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

Guideline Development

Following the work undertaken by the Inherited Arrhythmias and Inherited Cardiomyopathies Task and Finish Groups in 2023/24, the network published Diagnosis and Referral Pathways, along with shorter guidance aimed at primary care, for the following conditions:

- Arrhythmogenic right ventricular cardiomyopathy (ARVC)
- Brugada Syndrome (BrS)
- Catecholaminergic polymorphic ventricular tachycardia (CPVT)
- Dilated Cardiomyopathy (DCM)
- Hypertrophic Cardiomyopathy (HCM)
- Long QT Syndrome (LQTS)
- Resuscitated Ventricular Fibrillation (Resus VF)
- Short QT Syndrome (SQTS)

A Task and Finish Group was established this year to develop guidance on 'Predictive genetic testing for children (<16 years old) at risk of Inherited Arrhythmias and Inherited Cardiomyopathies'. Predictive genetic testing in children for inherited cardiac conditions is highly contentious within the cardiac genetics community and therefore 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 Q1, 2025/26.

The NICCS Steering Group was also asked to inform and endorse the guideline 'Investigation pathway for patients with suspected cardiac amyloid' developed by the Heart Failure Hub Scotland,. A link to this guidance is available on the NICCS 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 network continued to deliver its programme of monthly 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

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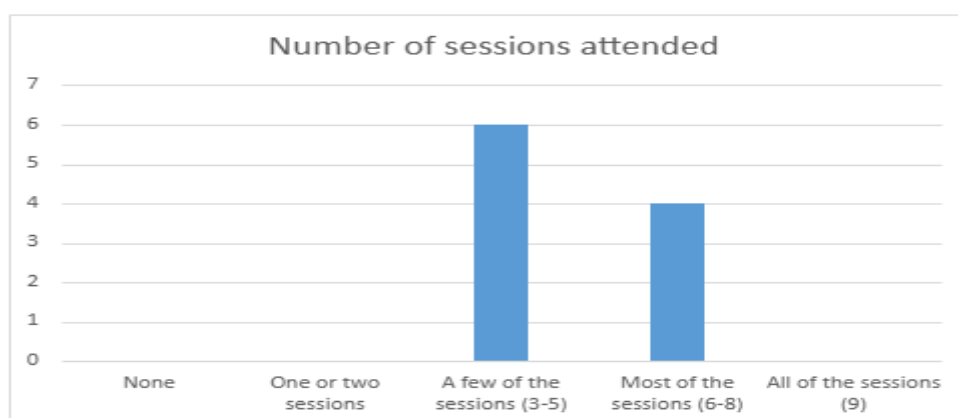
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currently had 107 members (as at 31st March 2025). Nine sessions were held in 2024/25 - details of each session is provided below:

Date	Topic	Attendees	Views*
26/04/2024	Updates in cardiac gene therapy	15	7
31/05/2024	Muscular disorders associated with CMA	22	10
28/06/2024	Case Discussion - North of Scotland	9	0
30/08/2024	MyInsight: Cardiomyopathy UK National Survey	13	5
25/10/2024	Variant interpretation and classification using a cardiac case study	12	7
01/11/2024	The autopsy & SCD	17	9
31/01/2025	Risk assessment in cardiomyopathy	24	12
28/02/2025	Update on GENVID Video testing study	19	5
28/03/2025	Case Discussion – East of Scotland	5	-

*As at 01/04/25

To gather feedback on the education sessions and inform the future education, an evaluation survey was shared in April 2024 via email and on the Teams channel. In total, 10 people responded with the number of sessions attended by each noted in the graph below:



In response to how relevant these sessions were to people's educational needs, 60% of respondents said these were 'highly relevant' and 40% said 'mostly relevant'. When asked to rate the overall quality of education provided by the programme of monthly education sessions in 2024/25 80% of respondents rated these as 'Excellent' and 20% rated these as 'Good'.

The NICCS Annual Symposium was held on 6 December 2024 in NHS Education Westport Offices, Edinburgh. In total, 67 people attended the event with 29 people attending in person and 38 people attending online via Teams.

Evaluation forms were completed by 25 attendees (37.3% response rate):

- All respondents 'strongly agreed' (60%) or 'agreed' (40%) that the event had met its objective by giving them 'a broader understanding of a range of aspects of inherited cardiac conditions'.

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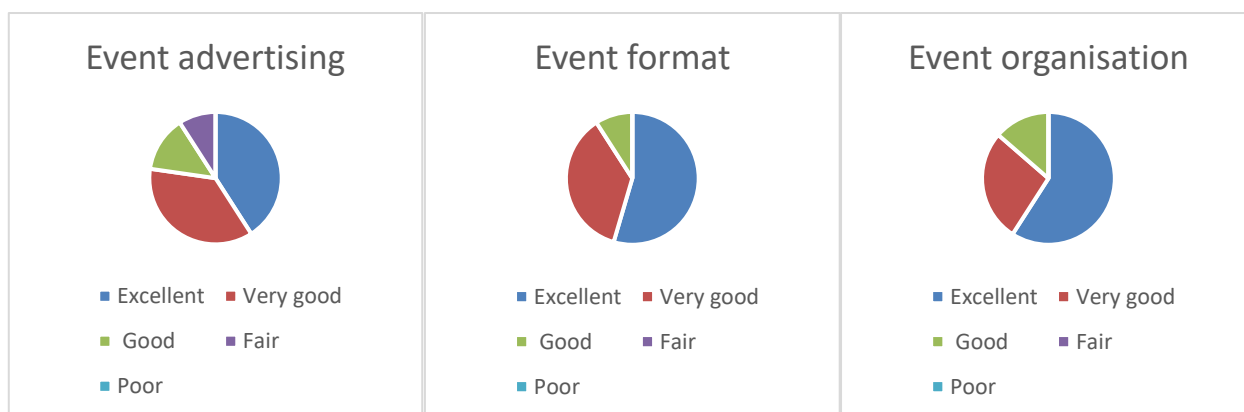
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- Attendees were asked to score each presentation. The results reflected that the majority of attendees agreed that the 'delivery' and 'content' of each was 'excellent' or 'very good'.
- When asked what people valued most about this event, respondents highlighted the benefit of networking face to face and that the event was an opportunity to update their knowledge.
- All respondents said the event would be 'very effective' (44%) or 'effective' (56%) in changing their practice.

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

- Going forward, I will have greater confidence in initial assessment of Out of Hospital Cardiac Arrest (OOHCA) and Long QT syndrome.
- More thoughtful and deal with inherited cardiomyopathies in a holistic way, importance of family screening.
- I feel considerably more confident - I've had some work to do to refresh my knowledge after taking over our Boards ICC Genetic lead role.
- Adopt guidelines and disseminate information to colleagues re genetic testing in children.
- Better patient care.

When asked to rate the event for event organisation, event format and event advertising the responses were:



All 25 respondents would recommend this event to their colleagues. All respondents, where applicable, said the learning from this session to contribute to their CPD requirement for revalidation. The event provided 396 hours of CPD to health care professionals.

The feedback received from the evaluation of the monthly education sessions and annual Symposium 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 continues to meet quarterly to support implementation of the 2023 - 2026 Patient Engagement and Patient Experience Strategy.

In February 2024, in response to patient feedback, the network began piloting online patient support drop-in sessions to provide information and peer support to people affected by inherited

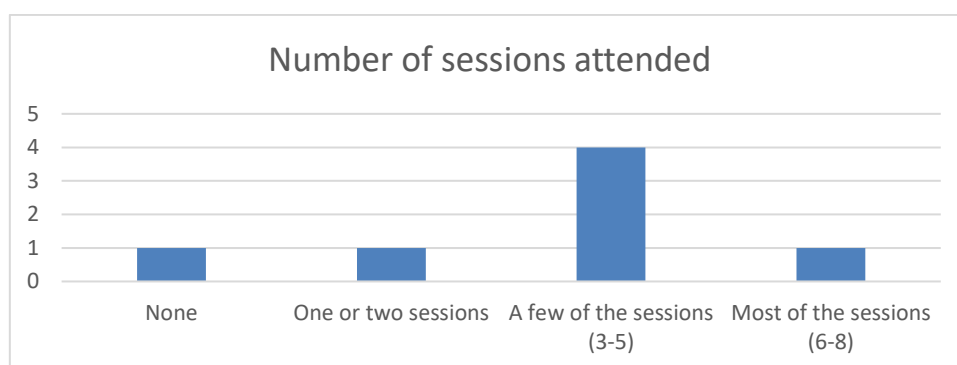
cardiac conditions. Each session is led by a health care professional who presents on a topic of interest to patients and then the session is opened up for general questions/signposting.

In total 9 sessions were held during the pilot - details of each session is provided below:

Date	Topics Discussed	No Patients Invited	No Patients Attended
06/02/2024	ICC Services Overview Familial risks and types of ICCs, Clinical Trials	10	6
05/03/2024	ICC Care from a specialist nursing perspective	15	6
07/05/2024	Understanding Aortopathies	16	3
04/06/2024	Self-Management of Heart Failure	17	6
06/08/2024	The Forensic Pathologist and Sudden Cardiac Death how do we help?	17	3
03/09/2024	Abnormal Heart Rhythms	18	4
01/10/2024	ICC Genetics Team	18	1
05/11/2024	Sudden Cardiac Death & OOHCA Project	18	1
03/12/2024	New Developments treatment/devices	20	6

In December 2024 to gather feedback on the patient drop-in sessions and inform the future of these sessions, an evaluation survey was shared with everyone who had noted an interest in attending. In total, seven people provided feedback through the evaluation survey.

The number of sessions attended by each respondent is noted in the graph below:



In response to why they attended the number of sessions they did, the respondent who had not attended any of the sessions noted that there was a *'mix or reasons'* for this *'from timings and subjects'*. The person who attended one or two sessions only found out about them in November therefore could only attend one session to date. Those who attended a few of the sessions advised that they sometimes forgot about the session, the timing of session was not always suitable, topics were not always of interest and that they only found out about the sessions in the summer. The respondent who attended most of the sessions stated they were *'great sessions to listen too which are informative even if the subject matter isn't relevant at the present time and medical journey'*.

Respondents were asked to provide general feedback on the sessions. Responses included

- The sessions are very useful to ask questions that did not come to my mind when seeing the cardiologist/ nurse and for sharing different experiences across the group of attendees.
- Patient engagement across the group is key to supporting new or old patients on all aspects of ICCs.

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- I find them very interesting and informative. It gives a patient to talk directly to the presenter of the topic.

The survey asked people to rate the patient drop-in sessions overall - four people rated these as 'Excellent' and three rated these as 'Good'. The aim of the sessions was to provide information and peer support to people affected by inherited cardiac conditions and therefore the survey asked if this had been achieved. In response four people said 'Yes', two said 'Partly' and one did not provide an answer. All seven respondents said they would like to see the patient drop-in sessions continue.

The survey asked people to suggest improvement or ideas how we can promote the sessions better. Respondents said that while online event are helpful, 'an in person event is where you also get great support from in an open environment' and there is a need to 'ensure all HCP talk to their patients about NICCS at their consultations and share dates and times of these event. Also for HCP and patients to share on social media about upcoming sessions'.

The NICCS Patient Engagement Group and Steering Group considered the feedback. While limited responses to the survey were received, the feedback demonstrated value in hosting the patient drop-in session and support for these to continue. Ensuring that the sessions are promoted widely to encourage more patient participation was required.

Following the evaluation two further patient drop-in sessions took place in February and March 2025 (details below) and sessions are planned to continue into the new year.

Date	Topics Discussed	No Patients Invited	No Patients Attended
04/02/25	ICC Services Overview	20	5
14/03/25	Psychological support for people with an ICC	22	8

Looking forward – 2025/26

Due to ongoing review of national networks, networks have been asked to only plan activity for Quarter 1, 2025/26. NICCS have agreed the following activities:

Carried forward from 2024/25:

- Publication of 'Predictive genetic testing for children (<16 years old) at risk of Inherited Arrhythmias and Inherited Cardiomyopathies' guidance
- Publication on HCM Audit

Network Business as usual activity:

- Network quarterly meetings - Steering Group, Patient Engagement Subgroup, Data Subgroup, and Nurse/AHP Subgroup
- Monthly Education Sessions
- Evaluation of 2024/25 Education Sessions
- Patient Drop-in Sessions
- Quarterly National Case Discussion Session
- Review and relaunch of NICCS Patient Information

Finance

The network operated within its allocated budget in 2024/25, focusing on low-cost, high-impact activities such as virtual education and digital resource development.”

Risks & Issues

The network recognises the importance of maintaining national coordination in areas such as education, clinical guidance, and quality improvement. Continued support will be essential to sustain these benefits for patients and professionals.

Stakeholders have highlighted the importance of maintaining national coordination to sustain improvements in care. Continued support will be essential to build on existing progress and deliver future benefits.