

# **Network for Inherited Cardiac Conditions Scotland**

## **Annual Report 2022/23**

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### 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 ensures that the care delivered meets agreed national standards and supports services in improving standards of care through the establishment of continuous quality improvement.

### Current Position

The network completed 20 of 26 (77%) of its objectives within its business plan in 2022/23.

The Network planned to endorse and publish its guidance on Hypertrophic Cardiomyopathy this year, however, it was agreed to delay its publication pending the European Cardiac Society's update to their Guideline on Hypertrophic Cardiomyopathy due in August 2023. The objective to consider extending the scope of Network to include Aortopathies was paused during the course of the year. An external research study, supported by the Network, is currently looking at the number of people in Scotland affected by Aortopathies and their clinical outcomes and this will be used to inform the Networks considerations.

The remaining objectives were delayed due to competing priorities but are on track for completion in 2023/24. This includes the development of thematic guidelines for Inherited Cardiomyopathies and Inherited Arrhythmias which will now be taken forward by separate task and finish groups, and the update of the network's education strategy informed by a learning needs analysis. There were delays in collecting, collating and linking data for the 2022 audits for Hypertrophic Cardiomyopathy and Sudden Cardiac Death (due to the former data analyst leaving their post) and this will now be incorporated and published with the 2023 audits. Progress has been made in drafting the clinical quality indicators for ICC services with these expected to be finalised soon with consultation on these taking place over the summer. This will ideally align with the Scottish Cardiac Audit Programme (SCAP) which is part of the Scottish National Audit Programme within Public Health Scotland.

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

### National Case Conference Meetings

In September 2022, the Network began a 12-month pilot to host quarterly National Case Conference meetings to provide a forum for colleagues from Clinical Genetics, Laboratory Medicine and Cardiology across Scotland to discuss complex cases. The cases discussed are referred from the regional MDTs via the Network proforma where the case/family would benefit from review in a national forum (e.g. families across boundaries, variant interpretation and clinical co-segregation). Consensus decisions reached during case conference is advisory and the decision on clinical care remains that of the clinicians providing direct care.

The aim of the National Case Conference Meetings is to

- support high quality diagnostic service and appropriate follow-up for families
- provide data and audit to improve services and outcomes for people with an ICC
- facilitate learning and education

Three meetings have taken place with the final pilot National Case Conference planned for June 2023. The meetings, which last one hour over MS Teams, are chaired by a clinical geneticist across the four ICC centres on a rotating basis. A summary of the meetings held to date is given below:

Case Conference Meeting	14/09/2022	14/12/2022	15/03/2023
Meeting Chair	North of Scotland ICC Centre	East of Scotland ICC Centre	West of Scotland ICC Centre
Number of Attendees	Not Recorded	11	15
Regions Represented	Not Recorded	East of Scotland North of Scotland South of Scotland West of Scotland	East of Scotland North of Scotland West of Scotland
Number of Cases Discussed	3	2	3

Following the final pilot meeting, an evaluation will be undertaken to ensure the National Case Conference is meeting its aims and to inform the guidance around these meetings. Informal feedback from attendees has been very positive to date with representation and cases discussed from each regional ICC centre.

### Sudden Cardiac Death Guideline

In November 2022, the Network published its '*Guidance for Post Mortem investigation into Sudden Unexpected Death (SUD), Sudden Arrhythmic Death (SAD), Sudden Cardiac Death (SCD), and Aortopathy*'.

The guideline, endorsed by the Crown Procurator Fiscal, includes three pathways which should be followed in the event of a sudden cardiac death:

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- Pathology Pathway: Initial Steps
- Pathology Pathway: Next Steps (where SUD/SAD/SCD/Aortopathy suspected)
- Relatives' Pathway: First degree relatives of deceased person with SUD/SAD/SCD

The guidance highlights the importance of exploring if there is a genetic basis to the sudden cardiac death, the risk posed to relatives of deceased individuals, and referral of the next of kin to their local ICC service. Suggested text to include in post mortem reports, and in communication with relatives, is included and supporting information available on the NICCS website is highlighted.

In the coming year, the Network will capture feedback of the level of compliance and impact of this guideline via a stakeholder survey and discussions at the Symposium in September.

### Patient Engagement

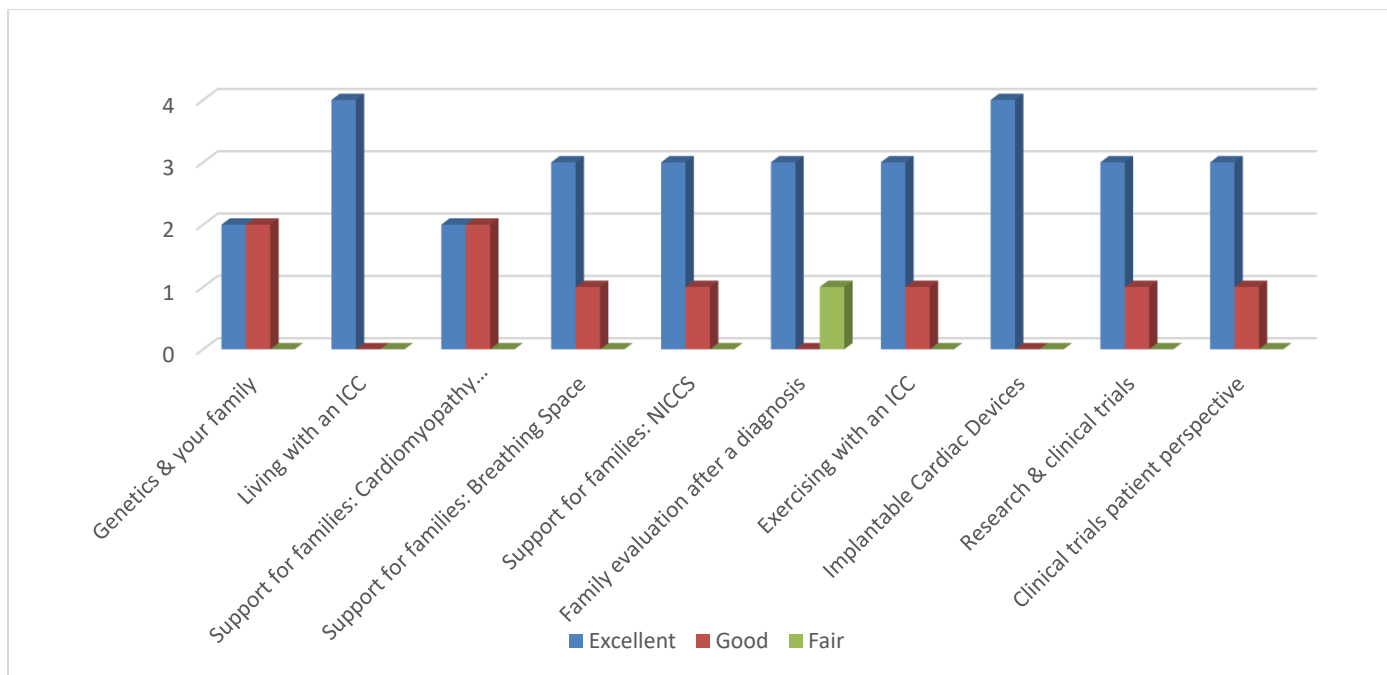
The Network continues to ensure the experiences of people and families affected by ICCs, and understanding what matters to them, informs its activities as outlined in our Patient Experience and Engagement Strategy. Central to this is the direction and feedback provided by the Networks Patient Engagement Group which includes patient and family representatives and voluntary sector organisations with an interest in ICCs.

In March 2023, the Network held an information event for patients, carers and families who have been affected by an ICC. This event included a range of presentations, workshop discussions and networking opportunities. Attendees were asked to share what would help them the most living with an ICC and what they would like from future events to inform future activities of the network.

In total, 22 people attended the event of which 8 were people from families affected by an ICC. The event was promoted widely through network members sharing information to patients, putting up flyers in waiting areas and through social media channels by third sector partners.

Four of the people from families affected by an ICC responded to the evaluation of the event. In response to how people had found out about the event, two people found out via the Network, one person found out about the event through their health care team and the other through social media. When asked if the event have increased their knowledge about ICCs all respondents agreed. Feedback on the presentations shared on the day was positive as noted in the graph below:

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During the event and through their evaluation feedback people affected by inherited cardiac conditions were encouraged to share what matters most to them. A key area raised at the event was the need for access to psychological support and this was echoed in evaluation feedback. Also highlighted was earlier diagnosis and timely appointments, condition specific information and self-help guides, and having a key point of contact within the service to provide support when required.

The feedback from the evaluation and from informal feedback at/following the event was considered by the Networks Patient Engagement Group to inform planning for engagement activities in the coming year.

### Education

Education is a core objective for all Managed Clinical Networks and a key action within the NICCS Education Strategy.

The Network continued to deliver its programme of monthly education sessions aimed at health care professionals with an interest in ICCs. The education sessions which take place at lunchtime over Teams. Sessions are recorded to allow people to watch it on the Networks' dedicated education Teams channel which currently has 99 members. Ten sessions took place this year (see table below).

Date	Topic	Attendees	Views
08/04/22*	Thoracic Aortic Imaging - ICCs	13	13
29/04/22	Exercise and ICCs	12	42
20/04/22*	Heart Disease Action Plan	16	18
27/05/22	Psychological impact of ICCs	8	25
24/06/22	Variants Interpretation	13	45

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26/08/22	Peripartum cardiomyopathy	16	51
30/09/22	ICC in Pregnancy/Contraceptive choices for ICC patients	10	23
28/10/22	Interface between nursing and genetics in ICC care	23	13
25/11/22	Genetic testing for children	20	13
27/01/23	Brugada Syndrome	35	26
24/02/23	Management of Marfan Syndrome and Role of the Marfan Trust	24	14
31/03/23	Case Discussion Session	12	14

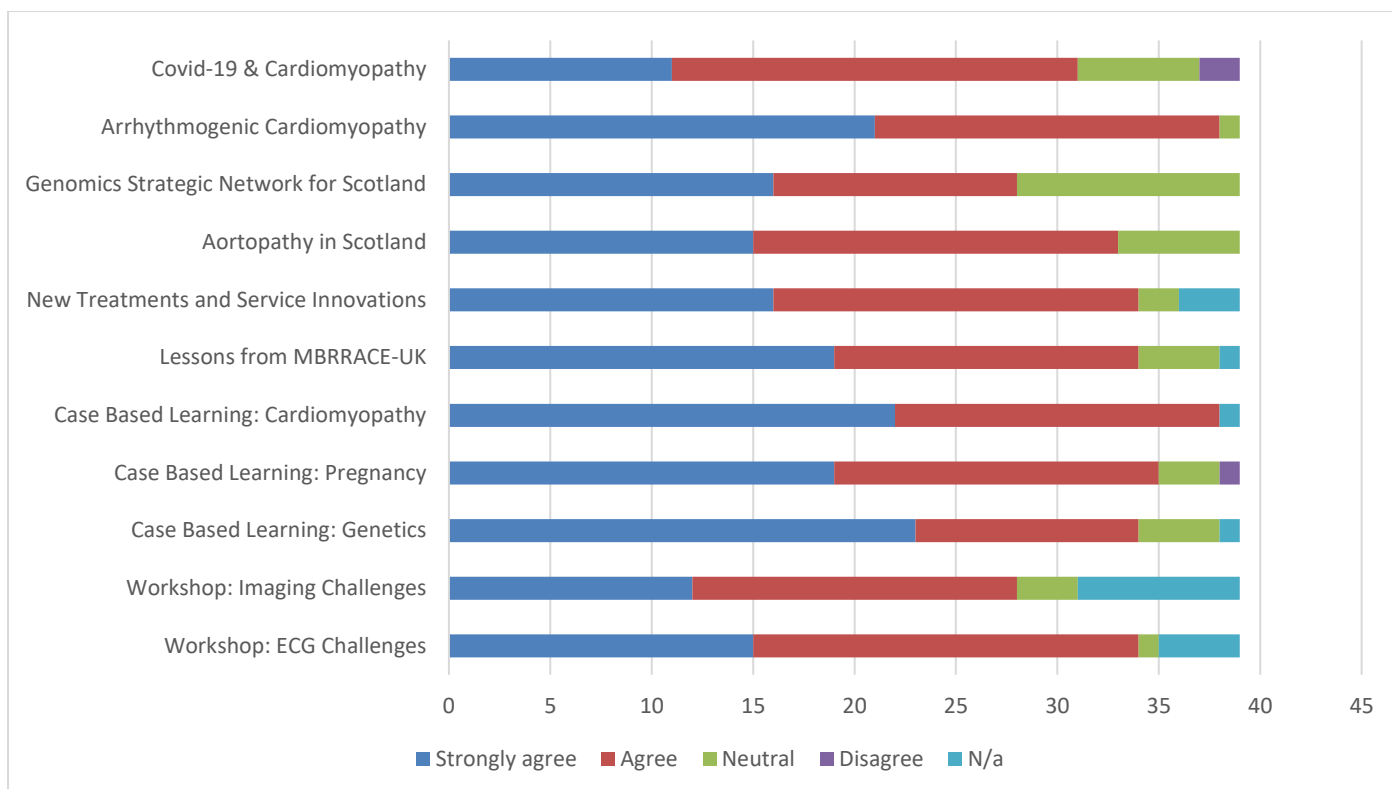
\*Rescheduled Dates from 2021/22 Programme

To gather feedback on the education sessions and inform the programme for 2023, an evaluation survey was shared in November 2022 via email and on the Teams channel. In total, seven people responded to this evaluation. In response to how many session people attended, 3 said '*between 3 and 5 sessions*', 3 said '*between 6 and 9 sessions*', and one person had attended all of the sessions. Six respondents rated the overall quality of education provided as '*excellent*' and one rated this as '*good*'. When asked if each session was relevant to their educational needs five respondents felt the sessions were '*very relevant*'.

The Network's Annual Symposium was held this year in the Perth Station Hotel on 9<sup>th</sup> September 2022 with 40 people attending in person and 45 attending online via Teams. Feedback following the event was provided by 39 attendees (46% response rate) who rated the overall quality of education provided by the event as '*excellent*' (49%) or '*good*' (46%).

The symposium consisted of a range of presentations, cased based learning and workshops with participants asked to rate how relevant each was to their educational needs. The feedback provided is noted below:

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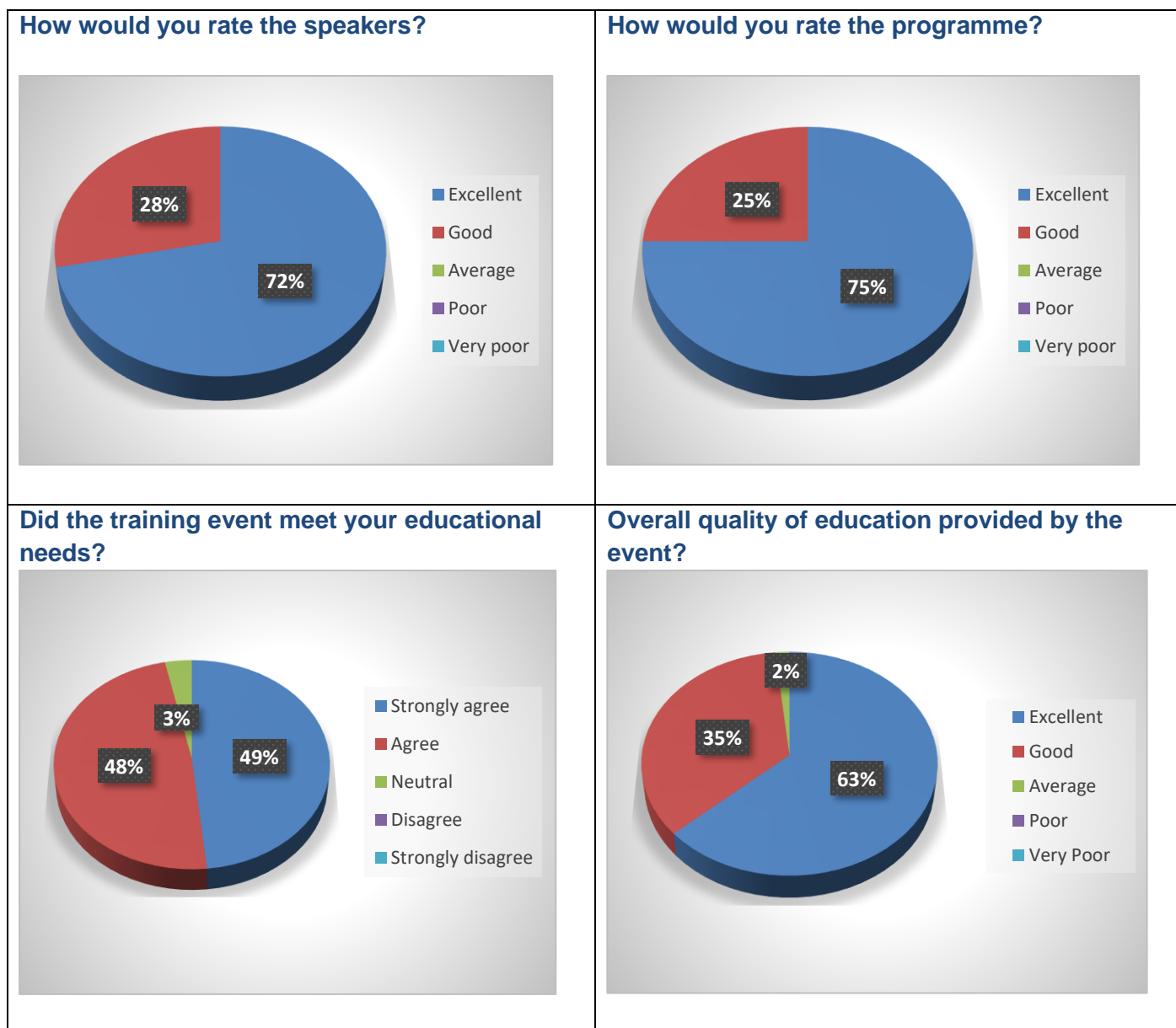


In response to a question on how the event would impact their future practice, respondents highlighted that the event had given them a *'greater understanding of signs and symptoms of ICC and how to manage patients with these conditions'*, they would *'take learning of latest evidence to apply to genetic counselling'* and that the event was *'great for networking'*. For future symposiums, 58% of respondents noted they would like to attend this in person while 42% would like this to be offered on a hybrid basis.

The feedback received from the monthly and annual education events, including format, IT challenges and suggested topics for future education events, was considered by the Networks Steering Group and will inform planning for future education events.

An additional event held by the Network was a training day in partnership with the Association for Inherited Cardiac Conditions (AICC) following their Annual Conference which took place this year in Glasgow. The training event was held at the Golden Jubilee Conference Hotel on 13<sup>th</sup> December 2022. The event was aimed at staff working in ICCs from across the whole of the UK and despite the impact of the national rail strikes and severe winter weather 90 people attended. Of these attendees, 34 people worked within ICC care in Scotland.

In total, 60 people (66%) provided feedback on the event and the results are displayed below:



When asked how the event would inform future practice lots of positive comments were shared. Some of the comments were:

- *There have been a lot a great learning points which I will take home and disseminate to my colleagues who were unable to attend. This will most certainly improve our practice moving forward.*
- *The clinical content was excellent and very enjoyable*
- *The case study approach with the presentations was particularly useful and helpful when applying your learning to real-world scenarios*

### Looking forward – 2023/24

With the tenure of Dr John Dean, Lead Clinician, ending on 31 July 2023, the Network will be recruiting to the post of Genetics Lead over the summer months. The tenure of Dr Caroline Coats will end in March 2024 and therefore recruitment for the Cardiac Lead is planned for early 2024.



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In the coming year the Network will consider the strategic vision for the next 3-5 years and ensure that the structure and representation support it, to meet its objectives. Linked to this a refresh of the Communication, Education, and Patient Engagement Strategies is planned.

Some of the other key activities planned by the Network for the year ahead include:

- Task and Finish Groups to be established to support the development of guidelines for Inherited Cardiomyopathies and Inherited Arrhythmias
- Evaluation of the National Case Conference Pilot
- Supporting health care professionals through Network monthly and annual education events
- Report on the HCM Audit and Sudden Cardiac Death Audits undertaken in 2022 and 2023
- Development of the Network's Quality Improvement Strategy
- Finalise Clinical Quality Indicators for ICCs and undertake the first audit against these

## Finance

The itemised costs and total spend for 2022/23 is given below:

<b>Detail Code</b>	<b>Spend</b>
Exhibition/Conferences <ul style="list-style-type: none"><li>• £1,200 for NICCS Symposium</li><li>• £1,665 for AICC/NICCS Training Day</li><li>• £1,455 for Patient Event</li></ul>	£4,320.00
Travel Subsistence	£164.00
Public Transport	£184.10
Printing/Stationary	£33.00
<b>TOTAL SPEND</b>	<b>£4,701.10</b>

## Risks & Issues

As noted above recruitment for the Lead Clinician posts is planned for early summer and early 2024 and should either of these positions are not filled within these timeframes there may be a risk to the delivery of the network's business plan.