

**Network for Inherited Cardiac Conditions Scotland**

Annual Report

2023/24

**Lead Clinician (Cardiac):** Dr Caroline Coats (April 2020 - March 2024)

**Lead Clinician (Genetics):** Dr John Dean (April 2020 - July 2023)

**Programme Manager:** Gillian Kinstrie

**Programme Support Officer:** Aneta Gorczynski

**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 achieved 30 of 35 (86%) of its objectives within its business plan in 2023/24.

The objectives not completed and reason for this is noted in the table below:

|  |  |
| --- | --- |
| **Undertake HCM Audit to include data to 31 March 2023 and publish findings from 2022 and 2023 audit.** | The HCM Audit was undertaken, however, the publication of the 2022 and 2023 audits has been delayed. This was due to the requirement for a DPIA to enable Public Health Scotland to perform the data linkage aspects of the audit. The DPIA has now been approved and analysis of the data will take place in 2024/25. |
| **Undertake Sudden Cardiac Death Audit to include data to 31 December 2022 and publish findings from 2022 and 2023 audit.** | The Sudden Cardiac Death Audit was undertaken, however, the publication of the 2022 and 2023 audits has not taken place. This was due to inconsistencies in the data submitted. A review of the data requested is underway ahead of the 2024 Audit. |
| **Finalise Clinical Quality Indicators for Inherited Cardiac Conditions** | A network workshop took place in December 2023 to finalise the CQIs. It was agreed that due to external programmes reviewing cardiac data capture across Scotland, finalising the CQIs should be put on hold until there was greater clarity on the data which can be collected. |
| **Audit against Clinical Quality Indicators** | As the CQIs have been put on hold this action was not achievable in 2023/24. |
| **Undertake a review of the NICCS guidelines to assess their impact.** | It was agreed that given the planned launch of multiple NICCS guidelines in April 24 this action would be carried forward to the 2024/25 workplan to assess their impact. |

Dr John Dean’s tenure as Lead Clinician for Genetics ended in July 2023. Following an unsuccessful recruitment exercise in June 2023 the network has continued with clinical leadership provided by Dr Caroline Coats, Lead Clinician for Cardiac. Dr Coats tenure ended in March 2024 and therefore the network enters 2024/25 without dedicated clinical leadership.

In October 2023, following discussions within NSD it was recommended that a transition plan should be developed to bring together the two cardiac managed clinical networks, NICCS and Scottish Obstetric Cardiology Network (SOCN). While initial discussions have taken place between representatives of both networks to consider how this might work in practice this has been unable to progress further given the lack of advertisement for the lead clinician vacancies in both networks.

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

Two Task and Finish Groups met three times each to develop evidence-based guidelines on inherited arrhythmias and inherited cardiomyopathies. Diagnosis and Referral Pathways have been developed 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)

Shorter guidance to support referral from primary care is also being developed for each condition. The guidance is due to be published in May 2024.

The Task and Finish Groups identified the need for guidance in the areas of ICCs and pregnancy, genetic screening in children and transition from paediatric to adult service. These new guidelines will be developed in the coming year through separate Task and Finish Groups.

Evaluation of National MDT Pilot

In September 2022, the network launched a 12-month pilot of facilitating quarterly National MDT meetings for health care professionals working in ICCs across Scotland to discuss complex cases.

The aim of the National MDT was 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.

The National MDT meetings lasted around an hour over MS Teams and were chaired by a clinical geneticist from the regional ICC centres on a rotational basis. In advance of the pilot, guidance and a referral proforma were developed to support the running of the meetings. A summary of the meetings held during the pilot is given below:

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **National MDT**  | **14/09/2022** | **14/12/2022** | **15/03/2023** | **14/06/2023** |
| **Meeting Chair** | North of Scotland | East of Scotland | West of Scotland | North of Scotland |
| **No. of Attendees** | Not Recorded | 11 | 15 | 11 |
| **Regions Represented** | Not Recorded | East of ScotlandNorth of ScotlandSouth of ScotlandWest of Scotland | East of ScotlandNorth of ScotlandWest of Scotland | East of ScotlandNorth of ScotlandWest of Scotland |
| **No. of Cases Discussed** | 3 | 2 | 3 | 1 |

In July 2023, a survey was shared with members of the NICCS Network to gather feedback on the National MDT and inform the recommendations for the future of the National MDT. In total, 8 people responded to the survey. 7 respondents had attended at least one meeting. The respondent who had not attended any noted this was due to meetings taking place when they had clinical commitments.

Respondents were asked to rate the discussion at the National MDT meetings. All 5 respondents who had presented at least one case at the meeting rated the discussion as excellent.

Some respondents highlighted that the meetings provided ‘useful and insightful collective experience in the group’ and were a ‘valuable learning experience’. It was also noted that it was ‘useful to have an input and conversation with other centres to ensure similar care is offered to family members who come from different parts of Scotland’.

The evaluation demonstrated value in having a National MDTs and broad support for these to continue. Ensuring that the meetings are promoted widely to encourage wider participation was a recurring theme of the feedback. The NICCS Steering Group considered the feedback and amended the guidance to reflects suggested areas for improvement. The National MDT meetings resumed in January 2024 and will continue to take place quarterly.

Education

Education is a core objective for all Managed Clinical Networks. In November 2023, the 2023 – 2026 NICCS Education Strategy was endorsed which outlines the objectives and outcomes of the education the network will deliver over the next three years. A review of the previous strategy by Steering Group members and a learning needs analysis with network stakeholders informed the development of this refreshed 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 take place at lunchtime over Teams. Sessions are recorded to allow people to watch it on the NICCS education Teams channel which currently has 98 members. Nine sessions took place in 2023/24 (see table below).

|  |  |  |  |
| --- | --- | --- | --- |
| **Date** | **Topic** | **Attendees** | **Views** |
| 28/04/2023 | ECG and Red Flags | 19 | 16 |
| 30/06/2023 | Case Discussion: North of Scotland | 7 | 8 |
| 25/08/2023 | Paediatric Cardiomyopathies | 10 | 21 |
| 29/09/2023 | Preimplantation Genetic Testing | 22 | 19 |
| 27/10/2023 | Case Discussion: Southeast of Scotland | 13 | 10 |
| 24/11/2023 | Fabry Disease in patients with HCM | 15 | 8 |
| 26/01/2024 | Variant interpretation in ICCs | 10 | 1 |
| 23/02/2024 | Inherited Arrhythmias in Children | 15 | 3 |
| 27/03/2024 | Sudden Cardiac Death (SCD) & Out of Hospital Cardiac Arrest (OOHCA) in ICCs | 23 | 3 |

To gather feedback on the education sessions and inform the programme for 2024, an evaluation survey was shared in December 2023 via email and on the Teams channel. In total, 12 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, 10 respondents said these were ‘highly relevant’. When asked to rate the overall quality of education provided by the programme of monthly education sessions in 2023 all 12 respondents rated these as ‘Excellent’.

The NICCS Annual Symposium was held this year at COSLA Conference Centre, Edinburgh on

Friday 8th September 2023 with 40 people attending in person and 31 attending online via Teams. Feedback following the event was provided by 40 attendees (56% response rate) who rated the overall quality of education provided by the event as *‘excellent’* (83%) or *‘good’* (15%).

Attendees was asked to rate how relevant each presentation was to their educational needs. The feedback provided is noted below:

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 genetic testing and managing families with HCM’, an ‘awareness and education around role of varies professionals in ICC care’ and ‘confidence discussing exercise with ICC patients’.

For future symposiums, 28% of respondents advised they would like this to be an in-person only event while 70% would like this to be offered on a hybrid basis.

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 and will inform planning for future education events.

Patient Engagement

The network reviewed and updated its Patient Engagement and Patient Experience Strategy for 2023-26. The Patient Engagement Group continues to meet quarterly to support implementation of the Patient Engagement and Patient Experience Strategy.

This year, four NICCS patient information leaflets were reviewed and relaunched. In response to patient feedback a patient information leaflet on cardiac screening was developed. All patient facing information from the Network includes a QR code to a ‘Get Involved’ survey for people to tell us how they would like to get involved in the network’s patient activities.

In February 2024, in response to patient feedback, the network began piloting online patient support drop-in sessions which aim to provide information and peer support to people affected by inherited cardiac conditions. Each session is led by a health care professional who speaks for a brief time on a topic of interest to patients and then the session is opened up for general questions/signposting. Informal feedback from patients who have attended the drop-in sessions, and from health care professionals who have facilitated the sessions, has been positive to date. Therefore the sessions will continue in their current format throughout 2024 following which an evaluation will be undertaken to ensure the sessions are meeting the needs of patients and to inform the future of these.

Stakeholder Survey

A stakeholder survey was shared in March 2024 to gather feedback from people who currently work within, are involved in, or are impacted by the network. The survey was shared with 66 stakeholders and 8 responses were received (12% response rate).

While the number of responses was disappointing, a lot of positive feedback was received and highlights the value added by the network:

* 100% responses ‘strongly agreed’ or ‘agreed’ that the network provided a structure to make service improvements in inherited cardiac care.
* 88% responses ‘strongly agreed’ or ‘agreed’ that the networks service development activity adds value to inherited cardiac care.
* 100% responses from staff ‘strongly agreed’ or ‘agreed’ that the networks education offering adds value to inherited cardiac care.

50% responses ‘strongly agreed’ or ‘agreed’ that the networks audit and continuous quality improvement activity adds value to inherited cardiac care.

The survey was also an opportunity for stakeholders to share feedback on network strengths, network challenges, areas for improvement and the priorities for the next few years. The responses are summarised below:

|  |  |
| --- | --- |
| **Strengths** | **Areas for Improvement**  |
| * Many respondents noted a key network key strength was supporting collaboration between multidisciplinary health care professionals to help improve ICC services.
* The commitment from healthcare professionals who care and engage to drive improvements in patient care was also highlighted.
* Adds value through service development by gathering data and developing/reviewing guidelines and pathways.
* Adds value through the programme of education events across the year and through peer support.
* Adds value through audit and continuous quality improvement activities through support to gather/ report data and provides data to inform practice/improvements.
 | * Continue to have dedicated HCPs working together and sharing their experiences.
* More active participation in the subgroups
* An integrated database that allows research and audit at a national level. At present data collection is too slow and labour intensive.
 |
| **Suggested Future Priorities (3-5 years)**  | **Network Challenges/Threats** |
| * Access more families from socially deprived areas, ethnic groups.
* Promote NICCS in every healthcare area.
* Continue to develop guidelines, supporting each other in our clinical roles e.g. ICCs and pregnancy and transition from paediatric to adult services.
* Education and training of HCPs in ICC for succession planning.
* Access and capacity for clinical services i.e. cardiac imaging, echocardiography.
* Ensuring successful collaboration with SOCN.
* Continue to develop patient engagement opportunities.
* Develop staff competencies.
* Engage with Scottish Cardiac Audit Programme (SCAP) to conduct and link national audits.
 | * Staff having limited time to participate in network activities.
* Financial challenges.
* Clinical leadership to continue to drive the Network forward.
* Succession Planning.
* Network admin and management support.
* Data management and analysis.
 |

The feedback received will be considered by the NICCS Steering Group and an action plan to support areas for improvement will be developed.

**Looking forward – 2024/25**

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

* Develop the Networks Strategic Workplan for 2025-2028.
* Reviewing the ICC Service Specification for Scotland. This document outlines how ICC services in Scotland should operate to improve the diagnosis, treatment and outcomes of people with ICCs. The review and update of the service specification will be informed by the review of the ICC specification currently taking place in NHS England.
* Develop guidance on ICCs and pregnancy, genetic screening in children and transition from paediatric to adult services.
* Support improvements in caring for families affected by sudden cardiac death (SCD) or sudden unexpected death (SUD) through involvement in SG funded SCD/Out of Hospital Cardiac Arrest Project.
* Continue to pilot monthly Peer Support Drop-In Sessions for patients and evaluate these to inform future activity.
* Supporting health care professionals through monthly and annual education events, and quarterly MDT case conferences.
* Conduct annual HCM Audit and Sudden Cardiac Death Audits and publish data from all previous audits.

**Finance**

The itemised costs and total spend for 2023/24 is given below:

|  |  |
| --- | --- |
| **Detail Code** | **Spend** |
| Exhibition/Conferences: 2023 NICCS Symposium | £1,426.00 |
| Printing/Stationary: Reprint of NICCS Leaflets | £ 355.36 |
| **TOTAL SPEND** | **£1,781.36**  |

**Risks & Issues**

The network is currently without dedicated clinical leadership which may impact the delivery of the network’s business plan and progress that can be made aligning the cardiac managed clinical networks.

Due to the current financial constraints within NHS Scotland, networks have been asked to hold events virtually to reduce costs to local NHS Boards for staff travel. NICCS members value the opportunity network events offer to meet with staff from a range of specialties supporting inherited cardiac care working across Scotland and have requested that the symposium and patient event planned for 2024-25 take place in person. Should the events take place virtually network members feel they would be of limited value, offer little return from a networking perspective and therefore attendance may be greatly impacted.