



Network for Inherited Cardiac Conditions Scotland (NICCS)

Annual Report 2021/22

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Background

Managed Clinical Networks are defined as co-ordinated groups of health professionals that support clinical services to continuously improve service delivery to ensure equitable provision of high quality, clinically effective services.

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.

Improving outcomes in patients with inherited cardiac conditions (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 has demonstrated good progress against the 2021/22 workplan despite the challenges resulting from the COVID pandemic. Progress against the workplan is detailed in Appendix 1.

Lead Clinician Viewpoint

The Network has delivered much of its planned activity despite the ongoing impact of Covid on outpatient waiting times and staff resource. Many patients have experienced long waits or delays in accessing cardiac investigations, particularly echocardiography. Whilst awareness of inherited cardiac conditions is improving, our audits demonstrate gaps in services and highlight areas of variation across the country.

The Network is committed to expanding the provision of education and patient support in Scotland and we are grateful for the time and enthusiasm from our AHP and patient subgroups. There are new therapies on the horizon for ICCs and the network will have an important role in enabling participation in clinical trials and communicating information to patients and professionals in Scotland. We look forward to working together to ensure national audits are relevant not only to healthcare staff but also national campaigns and directives to deliver the best possible care to patients and their families.

Highlights

Network National Audits

This year, the Network conducted two national audits to evaluate current ICC service provision in Scotland, support identification of areas for improvement and to inform workforce planning.

- *Hypertrophic Cardiomyopathy National Audit*

Hypertrophic cardiomyopathy (HCM) is an inherited disease of the heart muscle, where the muscle wall of the heart becomes thickened. HCM is a genetic condition caused by a change or mutation in one or more genes. The HCM National Audit reviewed data on patients with HCM known to their service between April 2015 and April 2020. Using the CHI number of each individual, the data was linked with information available from Public Health Scotland to understand disease prevalence, results of genetic testing, frequency of hospital admission and mortality.

While the prevalence of HCM in the UK population is 1 in 500 (equivalent to 200 per 100k population), our audit found the prevalence of people with HCM who had been referred to an ICC clinic to be 39.1 per 100k population. While further analysis will take place, our audit demonstrates local and regional variation in numbers of patients with HCM referred to an ICC clinic, use and yield of genetic testing and the yield of testing. All information shared by centres for the HCM audit will be added to the NICCS Clinical Audit System to give a comprehensive national dataset of people affected by HCM and to support future audits.

- *Sudden/Unexpected Cardiac Death National Audit*

Sudden unexpected death can be the first indicator of an inherited cardiac disorder predisposing to arrhythmia in a family. If a cause is identified, this may provide an opportunity for prevention of mortality and morbidity in relatives. The aim of the Sudden Cardiac Death National Audit was to ascertain how many sudden deaths were thought to be indicative of an inherited cardiac condition, how many had samples collected for genetic analysis, how often genetic analysis took place, and how often the genetic analysis identified an inherited cardiac condition.

This audit provided information about sudden death investigation in Scotland and demonstrated variation in processes, data availability, and case detection across Scotland. Standardisation of the process for the investigation of sudden cardiac death, including standardised data collection across Scotland's Health Boards may help improve the detection of inherited cardiac conditions amongst sudden cardiac death victims and their relatives. The Sudden Unexpected Death Pathway developed by NICCS when published should be used to guide and facilitate these processes for the future.

Following these audits, the Network plans to formalise mechanisms for standardised data collection and has suggested minimum data sets to support these audits in future. This will allow the audits to be conducted on an annual basis and monitor progress towards improvements in service quality.

Aortopathies

In October 2021, a short life working group was established to consider whether the scope of the network should be extended to include Aortopathies. Consideration is being given to defining what could be included as part of the NICCS specification, agreeing national thresholds for genetic testing and long-term surveillance of people with Aortopathies in Scotland. To support this, a survey was circulated to group members to identify any gaps in service and areas for improvement.

The short life working group has only met once to date given the COVID pressures over the winter months and so this objective will continue into the 2022/23 workplan. If agreed that extending the scope of the network would have a positive impact in relation to quality of service, clinical outcomes and patient experience, a request will be made through national commissioning governance.

Patient Experience and 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 June 2021, the Network hosted an online engagement event for patients, carers and families who have been affected by an inherited cardiac condition. The event featured a patient, Sarah, sharing her experience of inherited cardiac conditions which affected three generations of her family and provided an opportunity for people to learn more about the range of health care professionals who support people affected by inherited cardiac conditions.

The Network worked in partnership with the NHS National Services Scotland Communications Team to promote the event. A press release sharing Sarah's story was picked up by several media outlets and a social media campaign was conducted to promote the risk of inherited cardiac conditions and the support available. Twenty-six people attended the event and the feedback received was positive with support for condition specific events to take place in the future.

Members of the Patient Engagement Group have also been involved in informing the development and review of the Network's patient information and website to ensure these meet the needs of people attending ICC services. The Group also led on the development of the patient experience survey which was distributed across ICC services and will review the feedback to inform future activities.

Education

This year, the Network launched a programme of education aimed at health care professionals with an interest in ICCs. The lunchtime education sessions are held monthly, led by a range of presenters depending on the topics discussed. The education sessions are recorded to allow people to watch it later on the Networks' dedicated education Teams channel which currently has 52 members. Seven sessions took place this year (see table below). Two sessions planned for early 2022 were postponed due to Covid pressures and will now take place in Spring 2022.

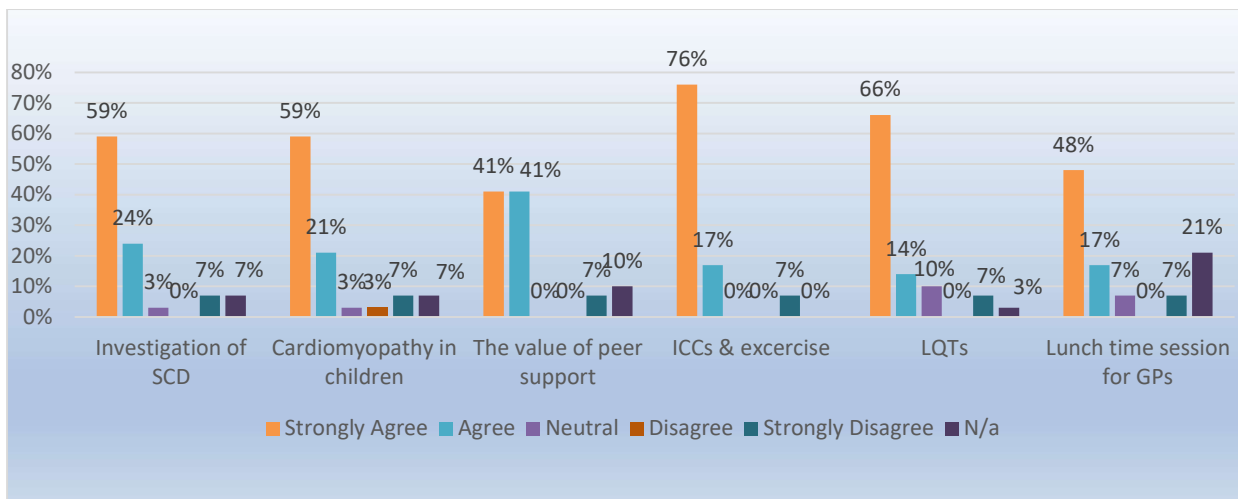
Date	Topic	Attendees	Views
30/04/21	Family History Taking/Screening	13	20
28/05/21	Dilated Cardiomyopathies: red flags and variants	20	18
25/06/21	Device therapy in Inherited Cardiac Conditions	15	15
27/08/21	ECG Interpretation	11	13
29/10/21	Current Clinical Trials in Inherited Cardiac Conditions	8	14
26/11/21	Pathology processes in Inherited Cardiac Conditions	12	9
28/01/22	Highlights from AICC December meeting	15	21

To gather feedback on the education sessions and inform the programme for 2022, in December 2021 an evaluation survey was shared via email and on the Teams channel. In total, nine people responded to this evaluation. Respondents had attended a varying number of sessions with three people advising that they attended all six sessions held to date. Of the eight respondents who attended at least one education session, seven 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 all respondents *'strongly agreed'* or *'agreed'* with this statement for each session they attended.

The Annual Symposium took place virtually on 9th September 2021 with 74 people in attendance. The focus of this event was to share the latest national developments with the ICC community. Topics discussed included Investigation of Sudden Cardiac Death, Cardiomyopathy and Children, Inherited cardiac conditions and exercise, and Peer Support. Network members provided an overview of the work being undertaken in the network and discussed Long QT syndrome to coincide with the launch of the new guideline on this topic.

Following the main symposium event, a lunch time session designed for primary care colleagues was held to share information on how to refer people who may have an inherited cardiac condition and what to expect from the service. The session also featured case studies on Sudden Cardiac Death, Hypertrophic Cardiomyopathy and Long QT Syndrome, and provided the opportunity for people to ask questions to an expert panel.

Of the 29 respondents who returned an evaluation and attended the main symposium session, all agreed that it met its objective of updating the ICC community on the latest national developments. All respondents rated the quality of education provided at the event as excellent (97%) or good (3%). Feedback on each presentation in relation to relevance to attendee's educational needs was very positive as noted in the graph below:



Exceptions

Sudden Cardiac Death (SCD) Pathway

The publication of the Sudden Cardiac Death (SCD) pathway was delayed as further consultation with pathology and the procurator fiscal service was required. While not intended to be 'a one size fits all pathway', as pathology and procurator fiscal services across Scotland operate in different ways, its purpose is to provide guidance on what services should be aiming to achieve. It is anticipated that this pathway will now be published in Spring 2022.

Finance

Due to the restrictions in place and the continued use of virtual meetings, cost normally associated with face-to-face meetings and education events have not been incurred this year.

The Network did use some of its budget to ensure that the redeveloped NICCS patient information leaflets were written in Plain English and to support printing and distribution of Network materials. The itemised costs and total spend is noted in the table below.

Item	Spend
Plain English Review of 3 Patient Information Leaflets	£516.00
Printing and Distribution Costs	
• 2,100 Patient Information Leaflets and 900 Condition Alert Cards	£350.80
• 750 Patient Experience Surveys and Return Envelopes	£355.22
• 4000 Business Cards	£231.60
TOTAL SPEND	£1,453.62

Looking Forward

The Network for Inherited Cardiac Conditions Scotland (NICCS) will continue to support improvements in the diagnosis, treatment and outcomes of people with ICCs through the

delivery of its 2021-24 workplan.

The Network will continue to support colleagues who are taking forward the priorities set out in the Scottish Governments National Heart Disease Action Plan 2021. The Network will work with the Scottish Cardiac Audit Programme as it considers data collection processes and develops clinical quality indicators to ensure that the audit programme supports improved outcomes for people with inherited cardiac conditions. The Networks Nurse/AHP Subgroup is working closely with the Scottish Governments 'Transforming Nursing Roles' Lead to support the development of generic cardiac competencies for advanced nurse specialists working in heart disease.

The 2022/23 Network objectives are outlined in the workplan in Appendix 2. Key priorities for the coming year include:

- Developing the Network's Clinical Quality Indicators and its Quality Improvement Strategy informed by the outcome of the patient experience survey and discussions with staff providing ICC care.
- Repeating the HCM Audit and ensuring all data is added to the NICCS Clinical Audit System to give a comprehensive national dataset of people referred for genetic testing for HCM.
- Repeating the Sudden Cardiac Death Audit and publishing the Sudden Cardiac Death Pathway.
- Using the outcome of discussions from the Aortopathy SLWG to identify the key issues, service gaps and areas for improvement and define how best to support people with Aortopathies in Scotland.
- Undertaking a pilot of a national MDT for ICCs for individuals and families with complex issues that would benefit from cross boundary input from Clinical Genetics, Laboratory Medicine and Cardiology.
- Supporting the continuing professional development of staff directly and indirectly supporting people affected by ICCs.
- Continuing to use the experiences of people and families affected by ICCs and understanding what matters to them to inform the activities of the network.

Appendix 1: Detailed Description of Progress in 2020/21

Core Principle	Activity	End of Year Update	Start Date	End Date	Q4 RAG Status
Effective Network Structure and Governance	Core Team Meets Regularly	Core Team met fortnightly during 2021/22.	01/04/21	31/03/22	C
	Hold 3 Steering Group Meetings	Meetings held on 16th June, 19th November and 23rd February 2022.	01/04/21	31/03/22	C
	Structure and representation within the network support ICC improvements	New structure embedded and continues to meet the needs of the Network. Will be reviewed on an ongoing basis.	01/04/21	31/03/22	C
	Subgroups meet regularly	Subgroups have taken place regularly during 2021/22.	01/04/21	31/03/22	C
	Guideline Governance	Guideline governance discussed at Core Group meetings. Standing item on Steering Group Agenda.	01/06/21	31/03/22	C
	Annual Report	Submitted 31/05/21. APR held on 19/11/21.	01/04/21	31/05/21	C
	Mid-Year Report	Mid-Year Report submitted 31/10/21.	01/09/21	31/10/21	C
	Quarterly monitoring of finance spreadsheet	No finance data provided. Network holds local record for budget spend.	01/04/21	31/03/22	N/A
	Purchase Orders received at the end of each quarter	No finance data provided. Network holds local record for budget spend.	01/04/21	31/03/22	N/A
	2022/23 Workplan Objectives	Objectives agreed at SG in March 22.	01/01/22	31/03/22	C
Service Development and Delivery	Finalise and publish its sudden cardiac death (SCD) pathway	Guideline not yet endorsed as further discussion required with Pathology/Procurator Fiscal. Due to be signed off shortly.	01/04/21	16/06/21	A
	Finalise and publish Long QT Protocol	Guideline endorsed by Steering Group in June 21 and is available on NICCS website.	01/04/21	16/06/21	C
	Virtual management of patients best practice following service/patient feedback.	Survey shared in March 21 with limited response. Recirculated in May 21. Collated results shared with SG on 16 June 21.	20/21	30/06/21	C
	Collate and publish ICD10/READ codes for ICCs along with the guidance on its use	Guidance shared and is available on NICCS website.	20/21	01/09/21	C
	Undertake a national audit on hypertrophic cardiomyopathy.	Report discussed at SG on 19/11/21 and at Data Subgroup on 1/12/21. Comments collated and report now final.	Apr-21	19/11/21	C
	The network will work with Boards to review services against the National Specification for Inherited Cardiac Conditions to highlight any potential gaps in service, share best	Meetings held with Forth Valley, Lanarkshire, NoS and Highland. Survey drafted to gather input from ICC staff where meetings have not taken place but not progressed due to COVID pressures. Survey/further discussions will take place with Boards on 2022/23.	20/21	31/03/22	A

	practice and identify areas where the Network could further support.				
	Consider workforce-planning requirements and develop staff competencies to identify how ICC services can be delivered effectively across Scotland.	Draft competencies and role description drafted. Not progressed further due to COVID pressures and work taking place at SG to transform nursing roles. Will be carried over to 2022/23 workplan informed by output of SG activity.	Apr-21	31/03/22	A
	Support primary care e.g. guidance/referral pathway/education sessions	GP Education Session held at Annual Event (9/09/21). Updated/new guidelines now include 'GP at a glance' documents which are available on NICCS website.	Apr-21	31/03/22	C
	Consider extending the scope of Network to include Aortopathies	A SLWG met in September 21. Survey to collate views conducted and results shared with SLWG. Not progressed further due to COVID pressures. Will be carried forward into 2022/23.	Sep-21	31/03/22	A
	Use outcomes from the patient survey and service audits to improve quality of ICC services across Scotland	Patient survey shared in October 21. Deadline extended due to limited response. Meeting with HBs/Service audits ongoing. Will be carried forward into 2022/23.	Oct-21	31/03/22	N/A
Stakeholder Communication and Engagement	Development of the website	Website review by PEG and Nurse/AHP Subgroup has taken place and website updated. Service Map of ICC services added to website. Will continue to review/update on an ongoing basis.	01/04/21	31/03/22	C
	Issue 4 newsletters	Two newsletters issued in June 21 and November 21.	01/04/21	31/03/22	A
	Develop/Review patient information resources	Three patient leaflets and condition alert cards printed/distributed to all centres in June 21.	01/04/21	30/06/21	C
	Develop Patient Pathway information	Patient Pathway to be developed in conjunction with the Patient Engagement Group. Not yet started due to COVID pressures. Will be carried forward into 2022/23.	01/010/21	31/03/22	N/A
	Hold a patient engagement event	Virtual Patient event held on 23rd June 2021. 26 people attended.	01/04/21	23/06/21	C
	Patient experience survey	Survey developed in conjunction with the Patient Engagement Group distributed to centres (Oct-Dec). Survey extended and is ongoing due to limited response. Collation or survey will continue into 2022/23.	01/09/21	31/12/21	A
Education	Host Annual Educational Event	Virtual Symposium and Primary Care Education session held on 9th September 2021. 74 people attended.	01/05/21	09/09/21	C
	Monthly Education Events	7 Education sessions took place. Evaluation of 2021 programme	01/04/21	31/03/22	C

		conducted. 2022 Programme finalised.			
Audit and Continuous Quality Improvement	Develop and adopt its Quality Improvement Strategy with defined clinical quality indicators	QI Strategy available in draft. Discussion on CQIs has taken place at SG on 19/11/21 and 23/02/22 and first draft CQI discussed at Data Subgroup on 02/03/22. Comments being considered prior to sharing with Steering Group for comment. Will be finalised in 2022/23.	01/04/21	31/03/22	A
	Undertake a first audit of the Clinical Quality Indicators	CQIs to be finalised. Will be carried forward into 2022/23 workplan.	01/09/21	31/03/22	A

Appendix 2: Proposed Workplan for 2022/23

Core Principle	Activity	Start Date	End Date
Network Structure and Governance	Core Team Meets Regularly	01/04/2022	31/03/2023
	Hold 3 Steering Group Meetings	01/04/2022	31/03/2023
	Subgroups meet regularly to drive forward workplan	01/04/2022	31/03/2023
	Structure and representation within the network supports ICC improvements	01/04/2022	31/03/2023
	Ensure governance in place for Guideline/Pathway/PIL review	01/04/2022	31/03/2023
	Ensure all finance requirements are met	01/04/2022	31/03/2023
	Submit Annual Report	01/04/2022	31/05/2022
	Submit Mid-Year Report	01/10/2022	31/10/2022
	Develop 2023/24 Workplan	01/02/2023	31/03/2023
Service Development and Delivery	Guideline Update: Finalise and publish its sudden cardiac death (SCD) pathway	01/04/2022	30/06/2022
	Guideline Update: Finalise and publish the HCM guidance	01/04/2022	31/03/2023
	Guideline Update: Inherited Cardiomyopathies	01/04/2022	31/03/2023
	Guideline Update: Inherited Arrhythmias	01/04/2022	31/03/2023
	Repeat the national audit on hypertrophic cardiomyopathy to include data to 31 March 2022.	01/04/2022	31/03/2023
	Repeat the national audit on sudden cardiac death to include data to 31 March 2022.	01/04/2022	31/03/2023
	Consider workforce-planning requirements and develop staff competencies to identify how ICC services can be delivered effectively across Scotland.	01/04/2022	30/09/2022
	Consider extending the scope of Network to include Aortopathies	01/04/2022	30/09/2022
	Develop and pilot a National MDT meeting for complex ICC patients/geographically spread families.	01/04/2022	30/09/2022
Stakeholder Engagement and Communication	Share findings and develop action plan in response to 2021/22 Patient Experience Survey	01/04/2022	30/06/2022
	Website is useful resource for patients/HCPs	01/04/2022	31/03/2023
	Issue at least 2 Newsletters	01/04/2022	31/03/2023
	Host a Patient/Family Engagement Event and provide peer support opportunities for people with an ICC	01/04/2022	30/06/2022
Education	Host Monthly Education Events for HCPs	01/04/2022	31/03/2023
	Host Annual Educational Event for HCPs	01/04/2022	30/09/2022
	Conduct Learning Needs Analysis and Update Education Strategy	01/10/2022	31/03/2023
	Promote education opportunities and increase support to non-ICC specialists including GPs	01/04/2022	31/03/2023
Audit and Continuous Quality Improvement	Continue to work with boards to review services against the National Specification for Inherited Cardiac Conditions to highlight any potential	01/04/2022	31/03/2023

	gaps in service, share best practice and identify areas where the Network could further support.		
	Develop and adopt its Quality Improvement Strategy with defined clinical quality indicators	01/04/2022	30/09/2022
	Undertake a first audit of the Clinical Quality Indicators	01/10/2022	31/03/2023

