Updating the RCN Children and Young People's Cardiac Nursing Guidance: A survey of roles and career pathways

Corresponding author:

Dr Kerry L Gaskin, Associate Professor of Nursing, Three Counties School of Nursing and Midwifery, University of Worcester WR2 6AJ

k.gaskin@worc.ac.uk, twitter @GaskinKerry, ORCID: 0000-0002-1179-4921

Lynda Shaughnessy, Lead Nurse for Paediatric Cardiology / Co-Clinical Director for Lifelong CHD Network, Evelina London Children's Hospital, ORCID: 0000-0002-5194-9633

Amanda Daniels, Associate Lecturer, Three Counties School of Nursing and Midwifery, University of Worcester WR2 6AJ

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Abstract

Aim: to explore implementation of nursing roles within children's cardiac services

Background: The Congenital Cardiac Nurses Association (CCNA) and Royal College of Nursing (RCN) first published guidance on roles, career pathways and competencies for children's cardiac nursing in 2011 to enhance and standardise clinical nursing care for children, young people, and their families. Over the last 12 years children's cardiac nursing has changed, reflecting advances in health care.

Method: A cross-sectional survey design, using JISC Online surveys, circulated to CCNA membership (N=150) via email, social media (August 2019) and CCNA conference (November 2019).

Results: Participants (n=32) deemed that guidance was well implemented and underpinned education, job descriptions and competency development. Conversely, implementation of NHSE Standards and Service Specifications was more challenging.

Conclusion: Some implementation of key roles, such as the Lead Nurse for the Network, had occurred. There had been some progress with the new innovative nursing roles vision since 2014.

Background:

Over the last 10 years, nursing roles within the children's cardiac specialty in the United Kingdom (UK) and Ireland have changed reflecting advances in health care. The Congenital Cardiac Nurses Association (CCNA) and Royal College of Nursing (RCN) first published guidance on roles, career pathways and competencies for children's cardiac nursing in 2011 (RCN 2011), updated in 2014 (RCN 2014). The initial aim being to enhance and standardise the clinical nursing care for Children and Young People (CYP) with congenital heart disease (CHD) and their families. The original guidance was informed by 'Modernising nursing careers: setting the direction' (DH 2006) career pathway and it was anticipated that the development of health care services would reflect the needs of service users.

After a long review of CHD services, NHS England published the CHD standards and service specifications (NHSE 2016), which specifies the care for adults and children with CHD across Networks including Level 1-3 care, from the point of diagnosis to palliative and end of life care. Health Improvement Scotland (2019), NHSS 2018 and the North-South Inter-Parliamentary Association (2015) published standards for Scotland, and an all-island CHD Network for Ireland, and Northern Ireland.

From a nursing perspective, key roles defined within the standards were informed by work conducted by the CCNA and the resulting RCN document (RCN 2014). Key Nursing roles included: The Lead Nurse for the Network, providing clinical and professional leadership for the nursing workforce (NHSE 2016, section 4.2, p. 156), cardiac nurse educators and children's cardiac nurse specialists (to include fetal nurse specialists and transition nurse specialists).

Given that these standards had been in place for four years, it was an appropriate time to explore the breadth of implementation of the key nursing roles across the UK and whether these roles meet the standards (NHSE 2016) and the RCN/CCNA guidance (RCN 2014).

The aim of this project was to explore the implementation of key nursing roles within CHD services across the UK and whether they met the CHD standards (NHSE 2016) and the RCN guidance (2014).

Secondary Objectives

- Explore consistency of role descriptors for key roles (Lead Nurse, Nurse Educator, Nurse Specialists) across the networks
- Explore the implementation of Advanced Clinical Practice roles and Consultant Nurse roles
- Explore the implementation of Nurse Research roles in CHD (Reader/Professor)
- Explore nurses' perceptions of their roles

Methods

An online cross-sectional survey design was used to answer the question:

Have key nursing roles been implemented within children's cardiac services across the UK, in line with the CHD standards and service specifications (NHSE 2016) and the RCN guidance (2014)?

Participants were children's cardiac nurses working in the UK or Ireland. The hyperlink was circulated via an invitation email in August 2019 to the CCNA Membership distribution email list (150 members from across the UK and Ireland) and via email to

known Lead Nurses and Cardiac Nurse Specialists for circulation to their colleagues. The survey URL was also made available on the CCNA website www.ccn-a.co.uk and via the CCNA Twitter (@CongentialCNA). A reminder email was sent out to CCNA members at the end of September and delegates at the CCNA conference, held in November, were informed of the survey and how to access it. The survey was closed at the end of November 2019.

The questions were developed based on the roles defined in the 'CYP cardiac nursing: RCN guidance on roles, career pathways and competence development' document (RCN 2014) and the CHD Standards and Service Specifications (NHSE 2016). The questions were split into eleven sections (table1) and participants were directed to answer questions pertinent to their role and the type of centre that they worked in. Most of the questions were quantitative, with some open-ended questions for further comments or explanations. The questionnaire was developed by the CCNA Executive Committee and piloted (n=3) for ease of access, speed, and convenience; the final version of the questionnaire was made available via JISC Online surveys (https://www.onlinesurveys.ac.uk/).

Quantitative data were analysed using descriptive statistics, due to the small number of responses. The qualitative comments were thematically analysed (Braun & Clarke 2006) within the sections.

Ethical approval was obtained from the Health, Life & Environmental Sciences Research Ethics Panel at the University of Worcester. The first question of the online survey asked participants to consent and was mandatory to continue with the questions. Due to the anonymous nature of the survey, participants were informed that if any potentially serious problems were reported through the questionnaire, we were unable to individually feedback to the Trust involved. Therefore, participants were

advised to report any serious concerns through the 'Raising Concerns' procedure in their place of work.

Findings

There were 32 responses (21%), which was low given the number of nurses invited to participate in the survey (N=150). Whilst 26 respondents worked in a Specialist Cardiac Surgical Centre (SCSC), section 3 was answered by 30 respondents; section 4 was answered by up to 21 respondents yet only 8 respondents worked in a Specialist Children's Cardiology Centre (SCCC) and 11 respondents answered section 5 despite none of the participants working in a Local Children's Cardiology Centre (LCCC). The responses demonstrate that participants have an awareness of roles and service specifications in their area and across the network. However, the responses do not quantify or identify how many roles are currently set up across each of the networks. Fourteen respondents (45.2%) had over 10 years cardiac nursing experience; twelve had or were working towards a master's degree (39%), two had a PhD and most respondents worked in the Specialist Cardiac Surgical Centre (n= 26, 87%) in a range of nursing roles (table 2). Not all participants answered all demographic questions, and some answered more than one category.

Within sections 3-5, participants were asked about educational opportunities, implementation of the RCN (2014) guidance and NHSE (2016) standards and implementation of key nursing roles.

Educational opportunities

Unfortunately, there were no responses from cardiac nurse educators. Participants were asked what specialist cardiac educational opportunities were available, and three

types were identified: in-house/locally available; University courses/nationally available; conference attendance (table 3).

Implementation of RCN guidance (2014)

Participants deemed that the RCN guidance was well implemented and used to underpin education, job descriptions and competency development, as these responses demonstrate:

"They are well implemented; we have pathway for every role. From new to the ward, to band 6, ECMO then band 7 pathways" (P2)

"We have developed cardiac competency book at level 1 and level 2 from the RCN competencies" (P20)

"They are frequently referred to as a gold standard in education and service delivery" (P28)

Implementation of CHD standards and service specifications (NHSE 2016)

The standards (NHSE 2016) state that there should be a Lead Nurse for each of the networks within six months (standard A23, L1, p. 178) and 'sufficient cardiac nurse educators' for the networks (standard E6, L1, 199); furthermore, it was expected that cardiac nurse specialist teams including a fetal nurse specialist and a transition nurse specialist would be in place within one year (standard B29, L1. p.185).

Overall, a theme of *'challenging'* emerged, which focused on the lack of recruitment or slow progress of setting up key roles including the Lead Nurse for Network, Cardiac Educator and Clinical Nurse Specialist roles. Political and financial factors were also impacting factors on recruitment and retention

"After 3 years no network lead nurse. Level 2 & 3 centre training variable. Not enough staff to meet demands" (P4)

"Well implemented but challenges of nursing recruitment, and political and financial challenges affect retention" (P7)

"There is slow progress in setting up the network leads" (P8)

"Quite well but we don't have enough cardiac nurse specialist in a network, no lead nurse a present yet and educator does not work in a network" (P20)

"CHD standards for Cardiac Nurse specialists have been implemented in my area just this year. prior to this we did not meet the required standard for Fetal Nurse specialist and transition nurse specialist" (P26)

Implementation of Key Roles

Sections 7-11 of the questionnaire referred to specific roles. However, some of these sections were answered by respondents who had different roles, these responses were, therefore, removed from the data analysis in this section.

Lead Nurse for the Network (section 7)

One Lead Nurse completed the survey, they commenced the role 14 months after the standards were published (NHSE 2016, A23, L1), thereby not meeting the standard of implementation within 6 months. The role descriptor matched the RCN job descriptor (RCN 2014, appendix 1) except for maintaining their own clinical practice, aiming for 20 per cent of their time over the period of a month.

Nurse Specialists (section 8)

Six (19%) children's cardiac nurse specialists (CCNS) completed the survey, three of whom were fetal nurse specialists (FNS) and three were transition nurse specialists (TNS). Four were already in the role before the standards were published, two

commenced the role about two years after. Four stated that their role descriptors matched the RCN job descriptor (RCN 2014, appendices 2,5,7).

All stated they met standard F19, L1 (NHSE 2016), provided support and advice to nursing staff within intensive care, high dependency care and inpatient wards. Four responses (although one said this was minimal due to resources) confirmed standard B5, L3 (NHSE 2016), '*do your CCNS team provide support, education and a link to the outpatient and ward nursing staff at the LCCC?*' was met. Participants indicated that a local link nurse (standard B4/5, L3) was only available in some LCCC (n=5).

The responses indicated that their CCNS teams included between 5 to 7.8 whole time equivalents (WTE), and that none met the standard B29, L1 (NHSE 2016), which is a minimum of 1 WTE per 600,000 catchment population. Agenda for Change (AfC) Banding in their CCNS teams ranged from band 6 (2.8WTE) to 8 (1WTE), with the majority being band 7 (10.2 WTE). Business cases (n=4) had been submitted to increase the number of nurses in some of the teams.

Within the CCNS teams, specific leadership roles included: FNS, TNS, patients with a single ventricle, pre-admission, elective admission pathway, education, parent/patient information, home monitoring programme, anti-coagulation, young person clinic, palivizumab, palliative care and bereavement. Additional education undertaken to support the service (maps to RCN Appendix 4 and NHSE standard E6, L1) included: advanced health assessment, independent and supplementary prescribing, counselling, and immunisations.

The main workload pressures identified for the CCNS teams were capacity, complexity, recruitment and retention, and geographical pressures.

'Workload just keeps getting bigger, numbers, more complex cases, more nurse led services' (P28)

'Understaffing, developing the service with no time available, team expertise-developing team members. Too many patients and not enough nurses, geographical pressures, being unable to attend our peripheral clinics because we just can't get there. Transition patients not getting an equal service because of this' (P32)

Cardiac Nurse Educators (section 9)

There were no responses for this section as none of the children's cardiac nurse educators completed the survey.

Advanced Nurse Practitioners (section10)

Two cardiac advanced nurse practitioners (ANP) responded to the survey, both of whom had job descriptions that matched the RCN role descriptor (RCN 2014, appendix 9). One commented that the role now also fully matched the Multi-professional ACP framework (NHSE 2017). Comments regarding the positive changes implemented in practice since 2016 included:

"Focus on discharges, which are of high quality and link in with the larger network. Consultant and nurse led discharge ward round. A robust warfarin service" (P8)

"Bridging medical and nursing roles. Excellent clinical pathway for nursing. Well received by children, young people, and families" (P7)

Three main factors impacted on their roles and workload: *Political and financial pressures*; *Clinical capacity* – time, case load size, volume, and nature of work; *Coaching and guidance* – follow up with families, medical supervision

However, this quote summarised their ANP role:

"An innovative and visionary role. More than the 4 pillars of practice. A way to develop new services, deliver new models of care and change care delivery for the better" (P7)

Nurse Researchers/Reader/Professor (section 11)

The RCN guidance (2014) did not include the research nurse role. However, three (9%) participants were research nurses, two with an MSc. Section 11 of the survey referred to the Reader/Professor roles (RCN 2014, Appendix 10, 11). Two respondents (6%) had been in senior academic roles for the last 4 years, and whilst not in roles directly matching the RCN role descriptor, were both leading and collaborating in research in a SCSC. The CHD Standards (NHSE 2016) have not directly influenced the ongoing development of either of these roles, although both are developing national and international research portfolios.

"There is not currently a drive to support this role within networks or nationally, any progression in a research capacity needs to be self-driven" (P32)

Discussion

The main finding from this survey was that the RCN guidance (2014) had been used to inform role descriptors, underpin education and training; and cardiac competency booklets have been developed to support role pathways. Conversely, implementation of the CHD Standards and Service Specifications (NHSE 2016) had been more challenging, perhaps in part due to the political and financial landscape. The results indicated that there had been some implementation of key roles such as the Lead Nurse for the Network. However, the results of the survey did not enable quantification of how many networks had implemented this key leadership role, therefore, we were unable to clarify that professional and clinical leadership was in place nationally at the

time of the survey. The Lead Nurse role was supposed to have been implemented within six months (NHS 2016, p.178), as this role is critical to shaping the network vision, developing services, and driving innovation for cohesion of services across the Network Care Levels.

Secondly, the findings indicated that some progress had been made with the innovative nursing roles vision within the specialty since 2014. The findings demonstrated employment and growth of advanced nurse practitioner roles across several specialist children's surgical centres, the first consultant nurse in electrophysiology and inherited cardiac conditions, cardiac research nurses and an honorary cardiac nurse researcher (career framework level 8). Advanced clinical practitioners need to demonstrate achievement of knowledge and skills to the standard outlined in the 'Multi-professional Framework for Advanced Clinical Practice' (NHSE 2017) meeting the four pillars underpinning this level of practice: clinical practice, leadership and management, education, and research. In the future, children's cardiac nurse consultant roles may focus in specific areas, such as surgery, transplant, electrophysiology, arrhythmias, inherited cardiac conditions, pulmonary hypertension, and cardiac intensive care. Nurse consultant roles are expected to differ from other advanced practice roles, clinical nurse specialists and nurse practitioners; with over half of the nurse consultant's time being spent in providing expert practice and the remaining time divided between leadership and consultancy; education and training; and service development, research, and evaluation (Gerrish, McDonnell, Kennedy 2013). Specialist capability documents have been developed in other children's nursing speciality roles, such as oncology and haematology (Woodman & Spencer 2022) and this may be the way forward for specialist CHD advanced practice and consultant roles.

Thirdly, although anecdotally we know that there were some educators in post at the time of the survey there were no responses from cardiac nurse educators, which may have reflected a lack of education roles in some networks at the time of the survey and would have been a significant deficit in provision. Education is a key requirement across the network (NHSE 2016), with the emphasis on '*all health professionals maintaining continuing professional development as required by their registering body and/or professional associations*' and '*this should include both specialist education and training*' (NHSE 2016, E1, L1, p. 198). The standards state that '*Specialist Children's Surgical Centres must provide sufficient Cardiac Clinical Nurse Educators to deliver standardised training and competency-based education programmes across the Congenital Heart Network including linked neonatal units, within 6 months'* (NHSE 2016, p.199). Whilst there was some indication of a range of specialist cardiac educational opportunities, the survey was unable to extrapolate the extent to which education had been implemented as no nurse educators responded. The participants gave limited insight into the available educational opportunities. The results indicated an emphasis on 'in-house' and 'local' educational forums. However, there was no indication of sharing across the networks or nationally and it was not clear whether this was because there were no educators in post or whether the educators were concentrating on local educational provision.

The findings informed the third edition of the RCN guidance (RCN 2021) by including new roles that had been developed since 2014, for example, the research nurse role. However, as research features within the CHD Standards (NHSE 2016) as each SCSC is expected to engage in research and to be linked to at least one academic

department in Higher Educational Institutes (standards G1-4, L1), inclusion of this research nurse role in the third edition was an important addition. Skills in research and audit are expected to be part of the educational programme for nurses across the network (standard E6). The recent development of research nurse posts demonstrates a commitment to clinical research and is a positive step for nursing careers. Furthermore, development of a CHD Reader, Associate Professor (Appendix 12) or Professorial post (Appendix 13) would reflect NHS and academic collaboration, leading and developing congenital cardiac nursing research and implementation of evidence-based practice across all children's cardiac networks.

It was envisaged that the third edition (RCN 2021) would continue to facilitate appropriate and structured workload planning based on the CHD Standards and Specifications (NHSE, 2016). Clinical competency documents have already been developed in some centres based on earlier editions of the RCN document. However, to reflect the changing needs of CYP, their families and the services required, career pathways need to be contemporaneous.

In addition to the CHD standards and specifications, which cover the UK and Ireland (Health Improvement Scotland, 2019; NHSE, 2016; NHSS, 2018; North-South Interparliamentary Association, 2015), the needs of infants, children and young people are also at the forefront of the NHS Long-Term Plan (NHSE, 2019a) with development of a Children and Young People's Transformation Programme alongside a Maternity Transformation Programme, to oversee the delivery of commitments to the NHS Long Term Plan (NHSE, 2019a). The future emphasis on children's cardiac care provision should be though integrated care management and delivery. Therefore, additional nursing roles are required to assist the CYP cardiac team.

The CHD Standards and Service Specifications (NHSE 2016) indicate that the identified teams and the relationships will include nurses and other professionals who will be working with and linking to the cardiac nursing teams across the three network levels and into the community.

A key capability of the cardiac nursing team will be to develop collaborative working so that the CHD service is more joined-up and coordinated in its care (NHS 2019a), with the aim of **"***breaking down traditional barriers between care institutions, teams and funding streams so as to support the increasing number of people with long-term health conditions, rather than viewing each encounter with the health service as a single, unconnected 'episode' of care"* (NHS 2019. p.12). Furthermore, by 2028 the aim is to move to person-centred and age-appropriate service models; implementing a selective '0–25 years' service model to improve children's experiences of care, outcomes, and continuity of care (NHSE, 2019a p.55).

Thus, the wider nursing teams will need to be informed and skilled in working within the partnership approach to care (NHSE 2016, standard D10 (L1) – D46 (L1) p. 193-197; D5 (L2); D44 (L2) p. 237-241 and A10 (L3) p. 269). Different roles require variable levels of competence related to the nature of the work and responsibility. Consequently, the RCN (2021) document features roles spanning levels 5–9 of the career pathway (DH, 2006; 2007a; 2007b; Skills for Health, 2010; RCN, 2007) and provides a competency framework reflecting the key roles outlined within the CHD standards (NHSE, 2016) and from which a CYP nurse can work within the principles of nursing practice and their professional standards (RCN, 2010; NMC, 2018a).

A vision for how people working in the NHS will be supported to deliver care and the actions that will be taken are identified in the Interim People Plan (NHSE, 2019b). A

review of '*how to increase both national and local investment in continuing professional development (CPD) and workforce development, with the aim of achieving a phased restoration, over the next five years, of previous funding levels for CPD*' (p.31) is the key action identified to inform 'We are the NHS: People Plan for 2020–21 – action for us all' (NHSE, 2020). Nurses need assistance to develop their careers, including a varied range of options for career progression, such as, advanced practitioners within multi-professional teams or as academics and educators of the next generation (NHSE, 2019b, p.40). For nurses currently working within CYP cardiac services there are clear opportunities for progression both academically and professionally in the third edition of the RCN (2021) document.

Conclusion

Whilst the survey findings did not clarify the implementation of roles across each cardiac network, there was some evidence of inclusion of the RCN (2014) and NHSE (2016) guidance and standards in the development of roles.

The findings from this survey contributed to a contemporaneous third edition of the RCN guidance (2021), enabling inclusion of new roles developed since 2014 to inform future delivery and development within CYP cardiac nursing.

Limitations

There are limitations to the survey. Firstly, there was no existing validated tool to explore the phenomenon of interest (Latour and Tume, 2021), therefore, this was developed by the study team. Secondly, maximising the response rate to surveys is notoriously difficult, and despite the invitation email being sent to a minimum of 150 nurses only 32 responded (21% response rate). The response rate is not consistent with a recent meta-analysis of online surveys, in which the average online survey

response rate was identified as 44.1% (Wu et al 2022). Reasons for the low response rate ~~It~~ may have been that people do not check email accounts due to being busy or mass delete emails before reading them or it may have reflected the altered relationship between centres following the service review. Additionally, most respondents worked in the SCSC and therefore, not getting responses from the LCCC was a limitation.

Thirdly, due to the relatively small number of key nursing roles within the CHD speciality and to maintain anonymity, participants were not asked the geographical location in which they worked, this was to meet the ethical approval. Anecdotally, there are few post holders for some roles and despite the survey being anonymous they may have felt that they were easily identifiable and, therefore, may have felt vulnerable answering the questions. It could be that the 32 respondents worked in a variety of units spread across the UK, or the responses could have been from just a few centres; thereby, not giving a true representation of the national picture. The responses, therefore, provided insight but did not enable us to ascertain the exact implementation of roles in each network, for example the number of Lead Nurses or Clinical Educators in post.

Finally, whilst the questionnaire was piloted for question design, order, and ease of completion; some of the questions did not generate the responses expected. As we were unable to ask location of the network in which the participant worked, due to anonymity, the responses to these questions did not fully support the aim of the survey. The survey was changed following the pilot to include a 'skip to' direction to avoid participants having to answer all questions. However, some participants still gave answers to sections that they could have skipped, so perhaps did not find the survey easy to navigate. This confusion may have deterred their peers from participating.

Implications for Practice and Future Recommendations

- The third edition of the RCN document was published in June 2021 to inform future delivery and development within nursing.
- Cardiac Networks should focus on ensuring the RCN (2021) and NHSE 2016) standards for nursing care are met.
- Nurse researcher roles should be further developed in response to the Chief Nursing Officer's research strategy (NHSE 2021).
- The findings from this survey will inform the design of a future questionnaire to identify a better way of ascertaining how many roles have been implemented.
- Future surveys should target network Lead Nurses, who should be able to provide details for LCCC and SCCC and improve responses.

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Table 1 Questionnaire Sections

Section Page	Section topic
1	Participant Information
2	Consent
3	Answer if you work in a Specialist Cardiac Surgical Centre (SCSC)
4	Answer if you work in a Specialist Children's Cardiology Centre (SCCC)
5	Answer if you work in a Local Children's Cardiology Centre (LCCC)
6	Details of your role
7	Answer if you are a Lead Nurse
8	Answer if you are a Cardiac Nurse Specialist
9	Answer if you are a Cardiac Nurse Educator
10	Answer if you are a Consultant Nurse/Advanced Nurse Practitioner
11	Answer if you are a Reader/Associate Professor/Professor in Children's Cardiac Nursing

Table 2 Participant demographics

	criteria	n (%)
Time working in Children's Cardiac Speciality	0-1 1-3 3-5 5-10 Over 10	2 (6.5) 6 (19.4) 5 (16.1) 4 (12.9) 14 (45.2)
Academic level	Diploma Bachelor Degree Bachelor degree (honours) PG Cert PG Dip MSc PhD	7 (22.6) 2 (6.5) 12 (38.7) 3 (9.7) 2 (6.5) 7 (22.6) 2 (6.5)
Centre	SCSC SCCC Other (University)	26 (86.7) 8 (26.7) 2 (6.7)
Role	Lead Nurse Cardiac Clinical Nurse Specialist Fetal Nurse Specialist Transition Nurse Specialist Cardiac Advanced Nurse Practitioner Ward Nurse Nurse (other- CICU x3, Community x1) Research Nurse Reader/Professor Other	1 (3.2) 5 (16.1) 3 (9.7) 3 (9.7) 2 (6.5) 13 (41.9) 4 (12.9) 3 (9.7) 1 (3.2) 2 (6.5)

Table 3 Types of educational opportunity	
In-house/locally available	Study days/education Short learning bursts by CNS team Unit Practice Educators Foundation course Competency document
University courses/nationally available	Cardiology module Advanced (L7) High dependency Intensive care ECMO/VAD Introduction to Congenital Heart Disease week
Conferences	national and international self-funded education fund