# cambridge.org/cty

# **Original Article**

**Cite this article:** Wolfe KR, Caprarola SD, Clark C, Davidson J, Everitt MD, Faul L, Hageman C, Kelly SL, Maloney E, Patteson H, Scott S, Talbot A, Tong S, and DiMaria KL (2023) Implementation of the Cardiac Inpatient Neurodevelopmental Care Optimization (CINCO) programme: an interdisciplinary, generalisable approach to inpatient neurodevelopmental care. *Cardiology in the Young* **33**: 2581–2588. doi: 10.1017/ S1047951123000562

Received: 20 December 2022 Accepted: 1 March 2023 First published online: 12 April 2023

#### **Keywords:**

Cardiac neurodevelopment; inpatient neurodevelopmental care; cardiac intensive care; quality improvement

#### Author for correspondence:

Kelly R. Wolfe, PhD, ABPP-CN, 13123 E 16th Ave, B155, Aurora, CO 80016, USA. Tel: +1 720 777 5511; Fax: +1 720 777 7895. E-mail: Kelly.Wolfe@childrenscolorado.org

© The Author(s), 2023. Published by Cambridge University Press.



Implementation of the Cardiac Inpatient Neurodevelopmental Care Optimization (CINCO) programme: an interdisciplinary, generalisable approach to inpatient neurodevelopmental care

Kelly R. Wolfe<sup>1</sup>, Sherrill D. Caprarola<sup>1</sup>, Caelah Clark<sup>2</sup>, Jesse Davidson<sup>1</sup>, Melanie D. Everitt<sup>1</sup>, Laura Faul<sup>2</sup>, Colton Hageman<sup>2</sup>, Sarah L. Kelly<sup>1</sup>, Emily Maloney<sup>2</sup>, Hilary Patteson<sup>2</sup>, Sarah Scott<sup>2</sup>, Alyse Talbot<sup>2</sup>, Suhong Tong<sup>1</sup> and Kimberly L. DiMaria<sup>1</sup>

<sup>1</sup>Department of Pediatrics, University of Colorado School of Medicine, Aurora, CO, USA and <sup>2</sup>Children's Hospital Colorado, Aurora, CO, USA

## Abstract

Background: Children with CHD are at risk for neurodevelopmental delays, and length of hospitalisation is a predictor of poorer long-term outcomes. Multiple aspects of hospitalisation impact neurodevelopment, including sleep interruptions, limited holding, and reduced developmental stimulation. We aimed to address modifiable factors by creating and implementing an interdisciplinary inpatient neurodevelopmental care programme in our Heart Institute. Methods: In this quality improvement study, we developed an empirically supported approach to neurodevelopmental care across the continuum of hospitalisation for patients with CHD using three plan-do-study-act cycles. With input from multi-level stakeholders including parents/caregivers, we co-designed interventions that comprised the Cardiac Inpatient Neurodevelopmental Care Optimization (CINCO) programme. These included medical/ nursing orders for developmental care practices, developmental kits for patients, bedside developmental plans, caregiver education and support, developmental care rounds, and a specialised volunteer programme. We obtained data from the electronic health record for patients aged 0-2 years admitted for at least 7 days to track implementation. Results: There were 619 admissions in 18 months. Utilisation of CINCO interventions increased over time, particularly for the medical/nursing orders and caregiver handouts. The volunteer programme launch was delayed but grew rapidly and within six months, provided over 500 hours of developmental interaction with patients. Conclusions: We created and implemented a low-cost programme that systematised and expanded upon existing neurodevelopmental care practices in the cardiac inpatient units. Feasibility was demonstrated through increasing implementation rates over time. Key takeaways include the importance of multi-level stakeholder buy-in and embedding processes in existing clinical workflows.

Children born with CHD are at risk for lifelong neurodevelopmental delays, which impact longterm educational, vocational, and psychosocial outcomes as well as overall quality of life.<sup>1–5</sup> While the aetiology of these neurodevelopmental delays is multifactorial, longer duration of post-surgical hospitalisation has been consistently shown to predict poorer long-term neurodevelopmental outcomes, even when controlling for medical complexity and comorbidities.<sup>6,7</sup> There are multiple aspects of inpatient hospital care, particularly in an ICU, that are suboptimal for neonatal and infant neurodevelopmental. These include spending much of the day in bed with limited stimulation, reduced holding/skin-to-skin contact due to mobility limitations or lack of caregiver confidence, and frequent sleep interruptions for medications or vital sign assessments.<sup>8–10</sup> The surgical hospitalisation impacts the child and the caregiver; up to 80% of parents will experience post-traumatic stress symptoms after their child's surgery, which may persist for years and have been shown to impact the child's neurodevelopmental outcomes.<sup>11,12</sup> Importantly, many of these factors are modifiable, yielding an exciting opportunity to potentially improve neurodevelopmental outcomes by altering standard cardiac inpatient care practices and bolstering support for patients and families.

Existing scientific literature recommends incorporating neonatal ICU-like developmental care practices into cardiac ICU care<sup>10,13-15</sup> and describes site-by-site variations in cardiac ICU developmental care,<sup>16,17</sup> but there is less guidance around the practicalities of developing and implementing comprehensive, interdisciplinary cardiac inpatient developmental care



programmes. At our centre, we had many inpatient clinical team members providing aspects of neurodevelopmental care at an individual patient level, but we lacked a systematic, integrated, universal approach to providing neurodevelopmental care in the cardiac ICU and cardiac progressive care unit settings. To bring this important element of care front of mind and improve integration of neurodevelopmental interventions, we created the Cardiac Inpatient Neurodevelopmental Care Optimization (CINCO) programme. We sought to include interventions that could be easily and reliably integrated into existing clinical roles and workflows that would be generalisable to other paediatric cardiac inpatient care settings.

# **Materials and methods**

We implemented a prospective, single-site quality improvement interventional study at Children's Hospital Colorado, a tertiary care academic paediatric hospital, and reported according to SQUIRE 2.0 guidelines.<sup>18</sup>

# Context

The overarching goal of the CINCO programme was to systematise, standardise, and augment the existing neurodevelopmental care practices in our cardiac inpatient units. CINCO was designed to be low cost, with processes that could be integrated into existing clinical team members' established workflows while reducing redundancy and increasing efficiency. Important contextual factors included an existing, highly invested interdisciplinary team including physical therapy, speech/language pathology, occupational therapy, psychologists, nurses, social workers, child life specialists, physicians, and advanced practice providers. Furthermore, CINCO built upon enthusiasm for neurodevelopmental care demonstrated through our participation as a founding institutional member of the Cardiac Neurodevelopmental Outcome Collaborative.

With respect to institutional size and resources, the inpatient cardiology service includes a 22 bed cardiac ICU and a 24 bed cardiac progressive care unit (that can flex up to 34 beds). Within the Heart Institute, we have dedicated physical therapy, occupational therapy, and speech/language pathology providers, with a total of 8.0 clinical full time equivalent (FTE), as well as two full-time inpatient cardiac child life specialists, three full-time cardiac social workers, and a chaplain. We also have a clinical psychologist and neuropsychologist with a total of 1.6 FTE dedicated to clinical care, programme development, and research.

# Preparation

The first step in designing the Cardiac Inpatient Neurodevelopmental Care Optimization programme was creating a steering team of interdisciplinary<sup>19</sup> content experts and clinicians who understood and valued the importance of integrating neurodevelopmental interventions into inpatient care for patients with CHD. The team reviewed existing literature on inpatient cardiac neurodevelopmental care and facilitated focus groups to obtain input and buy-in from clinical team members and parents/caregivers. These discussions elucidated the current state and future ideal state of neurodevelopmental practices across the Heart Institute (Table 1).

With input and buy-in from clinical team members and parentcaregiver representatives, the Cardiac Inpatient Neurodevelopmental Care Optimization steering team created five categories of interventions that together united an interdisciplinary team to implement evidence-based neurodevelopmental intervention at key time points along the continuum of care for patients in the cardiac ICU/cardiac progressive care unit. Executive leadership buy-in was obtained, and internal grant funding was secured for the minor costs associated with CINCO. Most of this funding supported the Developmental Kits, described below, with the remainder used for informatics and biostatistics support for tracking CINCO implementation. Three plan-do-study-act cycles, each lasting six months, were completed (Phase I occurred from 9/1/20 to 2/ 28/21; Phase II from 3/1/21 to 8/31/21; and Phase III from 9/1/21 to 2/28/22).

# Intervention

#### CINCO order panels

Towards the goal of facilitating a "home-like" environment for our youngest cardiac inpatients, Order Panels were designed for the cardiac ICU and cardiac progressive care unit in the electronic medical record (Epic Hyperspace; Fig 1A). The goals of the orders were to safely increase time spent out of bed, cluster cares and medicine, and minimise sleep disruptions.

A preliminary barrier when creating these Order Panels was our institution's nursing informatics team's impression that the instructions were redundant with standard clinical care and did not require a separate order set. We met with nursing informatics to discuss the importance of consistent, standardised neurodevelopmental care practices in the cardiac ICU and cardiac progressive care unit, and the Order Panel was ultimately approved. Important to this discussion was the concept that placing orders for neurodevelopmental care interventions engages medical and nursing providers in considering neurodevelopmental implications of multiple aspects of the inpatient environment and can reset expectations around traditional practices (e.g., that holding/skin-to-skin is always unsafe in the cardiac ICU).

Another barrier was the concern from cardiac progressive care unit physicians and advanced practice providers around skipping overnight every 4-hour hands-on vital sign assessments in children based on diagnosis or surgical stage rather than clinical stability. To address this concern, the CINCO team augmented education for providers, particularly around the options to select/unselect specific order options for individual patients. For example, all infants, irrespective of specific CHD diagnosis or surgical stage, could benefit from being out of bed during waking times and having their medications bundled in the cardiac progressive care unit, even if overnight vital signs were still important to obtain. During Phases I and II of CINCO, there was a high need for frequent re-education of cardiology inpatient providers, nursing, and clinical support staff, due to turnover and conflicting priorities. To this end, nursing neurodevelopmental care champions were identified for the cardiac ICU and the cardiac progressive care unit, who helped drive and reinforce neurodevelopmental education and nursing buy-in for the CINCO programme.

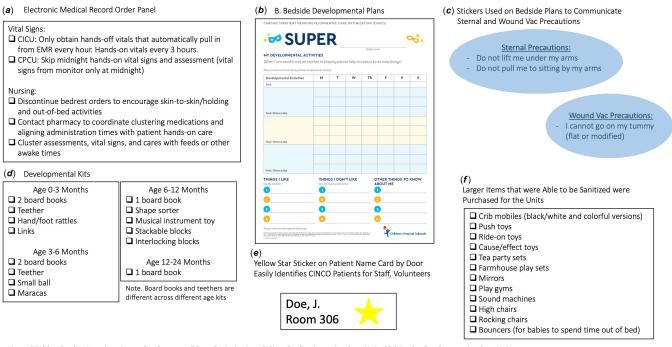
### Developmental plans and kits

The physical therapy, occupational therapy, and speech/language pathology team led the creation of bedside Developmental Plans (Fig 1B), with the goal of clearly communicating (e.g., to a volunteer, parent/caregiver, or clinical team member) suggestions for individualised, developmentally appropriate, and medically safe activities to promote the patient's neurodevelopmental. Goals were included for each patient, one from each therapy discipline and a

### Table 1. Stakeholder focus groups

2583

Focus group members	Key questions	Take-home points	
Multidisciplinary Clinical Team <ol> <li>Physical therapists</li> <li>Speech/language pathologists</li> <li>Occupational therapists</li> <li>Social workers</li> <li>Child life specialists</li> <li>Psychologists</li> <li>Nurses</li> <li>Cardiology inpatient attending physicians and advanced practice providers</li> </ol>	What are you already doing in your respective roles, in terms of cardiac ND care, that we can build upon?	Team members valued ND-centred care and provide it on an individual level Implementation of ND care sometimes varied among different providers even within the same specialty Clinical acuity or patient instability was <i>not</i> identified as consistent barriers to providing ND care	
	What are the biggest challenges you face in your role to provide consistent ND care in the CICU/CPCU, and what are your ideas to overcome these challenges		
<ul> <li>Parents/Caregivers</li> <li>10 parents (9 mothers, 1 father)</li> <li>All had children aged 0-2 years of age who had recently extended hospitalisations in our cardiac units</li> <li>Parent sociodemographic data were not collected at the time of the focus group</li> </ul>	When your child was hospitalised, were you thinking about their ND?	Parents/caregivers were concerned about their child ND even during the most critical CICU time periods Cardiac-specific volunteer training would significant increase parent/caregivers' comfort level with the volunteers interacting with their child at bedside	
	Would you have liked more information or activities to do to help their ND?		
	If you couldn't be present at bedside, how would you have felt about trained volunteers providing ND activities for your child?	J ANNA	



Note. CINCO = Cardiac Inpatient Neurodevelopmental Care Optimization; CICU = Cardiac Intensive Care Unit; CPCU = Cardiac Progressive Care Unit

#### Figure 1. Illustrations of selected CINCO interventions.

fourth goal to promote time spent out of bed, with a daily schedule to check off when each activity was completed. Examples of goals included "hold me chest to chest," "talk, read, and sing to me," "help me bring my hands to midline," and "help me look to the left." The plan was displayed in the patient's room to encourage team members and parent/caregivers to integrate neurodevelopmental care into the daily care routines.

Identification of patients who would benefit from a Developmental Plan was integrated into an existing weekly therapies team meeting by reviewing a census list of the units. Developmental Plans were hung by the team and updated weekly. Additionally, stickers with information specific to patients with sternal or wound vac precautions were developed to easily communicate activity adaptations to caregivers, staff, and volunteers (Fig 1C). A unique Smart Phrase in the electronic medical record was entered into the routine therapy progress note when a patient first received a Developmental Plan, to track implementation, and each week when Developmental Plans were updated, the old Plan was scanned into the electronic medical record as a mobile photo.

The physical therapy, occupational therapy, and speech/language pathology team designed Developmental Kits to complement the Developmental Plans and provide patients with developmentally appropriate toys, books, and activities (Fig 1D). Developmental Kits were distributed at the time of therapists' first meeting with the parent/caregiver and were for the family to keep (per epidemiology policy and also to provide opportunity for home enrichment). A unique Smart Phrase in the electronic medical record was added to the therapy progress note to track Developmental Kit distribution. In addition, larger items that were able to be sanitised were purchased for the units (Fig 1F). Barriers to implementation of the Developmental Kits in Phase I included identifying the most appropriate team member for ordering and restocking the kits, supply chain issues related to the COVID-19 pandemic, and initially only purchasing board books in English. These were addressed in Phase II by a therapy aide staff member taking ownership of ordering and adding board books in Spanish (the most common language other than English spoken in our region) to the Developmental Kits.

# Volunteers

A key concept of the initial CINCO programme design was to develop a specially trained cadre of volunteers who could provide developmental stimulation to appropriate patients. The first step was to meet with our hospital-wide Association of Volunteer leadership to present the rationale and obtain buy-in. Cardiac Inpatient Neurodevelopmental Care Optimization volunteers underwent the Association of Volunteer screening and training for hospital volunteers, plus additional cardiac-specific training with our cardiology child life specialists. We also obtained autonomy to schedule and direct the activities of our CINCO Volunteers. After completing general hospital Association of Volunteer screening and orientation, CINCO Volunteers-in-training attended a presentation from a cardiology child life specialist about cardiac neurodevelopment and medical aspects of cardiac ICU/cardiac progressive care unit care (e.g., sternal closures). Cardiac Inpatient Neurodevelopmental Care Optimization Volunteers-in-training then shadowed an existing CINCO Volunteer (or child life specialist) for two 4-hour shifts, before volunteering independently.

Patients were identified as ready for a CINCO Volunteer if they had a CINCO Developmental Plan at bedside. This served to eliminate patients who were not medically stable enough for developmental activities (particularly in the cardiac ICU). As such, the CINCO Volunteers acted as "therapy extenders," completing Developmental Plan activities and using Developmental Kit materials at bedside. A yellow star (Fig 1E) was placed on the door nameplate of patients with CINCO Developmental Plans, so Volunteers could easily identify them. In Phase II, we additionally created a Patient List in the electronic medical record that was shared among clinical staff including nursing, child life specialists, physical therapy, occupational therapy, speech/language pathology, and psychology providers and used to communicate to the Volunteers which patients would benefit from Volunteer interaction.

# Parent/caregiver education and care

Although the impact of having an infant with critical CHD on caregiver mental health is well-documented in the literature, the caregivers in our focus group and more broadly in our clinical experience identified gaps in family support and education around caregiver mental health. We developed two educational handouts to inform and empower caregivers in the inpatient units. The first handout discussed the importance of parental presence, ways to promote bonding and development in the hospital setting, strategies for self-care, and advocacy along with the Care Partnership Pyramid.<sup>20</sup> The second handout focused on parent/caregiver mental health, including normalising symptoms of distress in this context, statistics on the incidence of clinically significant anxiety, depressive, and traumatic stress symptoms, and guidance on seeking help. The handouts were reviewed by our hospital Health Literacy department for accessibility and translated into Spanish. The handouts were incorporated into a folder with additional resources given to families by social work at admission, and a Smart Phrase in the electronic medical record was used to document distribution.

## Developmental care rounds

During Phase II, the team initiated weekly bedside Developmental Care Rounds in the cardiac ICU and cardiac progressive care unit, with the goals of providing intensive developmental education and support to a few patients/families each week, as well as driving overall CINCO programme implementation and uptake. Developmental Care Rounds was designed to include a 30-minute interdisciplinary team pre-meeting and then one hour conducting Developmental Care Rounds at bedside with parents/caregivers. To pilot the process, Developmental Care Rounds initially launched in the cardiac progressive care unit and included two patients/families per week. With experience, Developmental Care Rounds was able to progress to include 3-4 patients/families per week and to include patients in both the cardiac ICU and cardiac progressive care unit. Interdisciplinary team participation routinely includes nursing, physical therapy, occupational therapy, speech/language pathology, and psychology representation, often with additional disciplines. During the pre-meeting, the census lists of the cardiac ICU and cardiac progressive care unit are reviewed for patients who might be appropriate for CINCO interventions (Order Panels, Developmental Plans and Kits) but do not yet have them. Followup messages to medical providers from Developmental Care Rounds are sent to request consideration for placing CINCO Orders, and our physical therapy, occupational therapy, speech/language pathology team directly provides the Developmental Plans and Kits, as well as additional activities, interventions, education, and handouts as appropriate. In this way, Developmental Care Rounds acts as both an educational intervention with both families and team members, and a driver of other CINCO interventions.

# Analysis

Approval for the present study was obtained from Children"s Hospital Colorado's Organizational Research Risk and Quality Improvement Review Panel. The target population for the present implementation study included patients 0–2 years of age who were admitted to the cardiac ICU or cardiac progressive care unit for at least seven days. The first plan-do-study-act cycle (implemented 9/ 1/2020) included the Order Panels, Developmental Plans and Kits, and Caregiver Support Handouts. Due to hospital COVID-19 policies, the volunteer programme implementation was delayed to 9/1/2021. A total of three plan-do-study-act cycles were completed at 6-month intervals to regularly assess implementation and overcome barriers to successful integration.

Process aims for initiating Cardiac Inpatient Neurodevelopmental Care Optimization programme were developed as follows: Aim 1: To implement and increase utilisation of the Cardiac Inpatient Neurodevelopmental Care Optimization Order Panels, Developmental Plans and Kits, and Caregiver Support Handouts from 0 to 50% by 3/1/2022; and Aim 2: To reach at least 500 hours of specialised Cardiac Inpatient Neurodevelopmental Care Optimization Volunteer direct patient contact, performing neurodevelopmental interventions and supportive cares, by 3/1/2022. To assess for unintended consequences of the increased normalisation of routines, which included more time out of bed and fewer sleep interruptions to perform physical assessments, the team also began to track dislodgements of medical devices (e.g., Gastric tubes, peripheral lines, Nasogastric tubes) as a balancing measure. From the initiation of the CINCO programme, we instituted twice-monthly virtual meetings for CINCO interdisciplinary team members, to facilitate communication around successes and barriers to implementation.

Patient descriptive data and implementation metrics for Aim 1 were obtained via automatic data extractions from the electronic medical record and uploaded to Research Electronic Data Capture (hosted at Children's Hospital Colorado).<sup>21</sup> Race and ethnicity were gathered as reported in the electronic medical record and were collected because of research showing adverse cardiac, and neurodevelopmental outcomes have been associated with non-White race and non-Hispanic ethnicity for infants with CHD.<sup>22-24</sup> Volunteer tracking data for Aim 2 were obtained via a Research Electronic Data Capture survey that each volunteer completed at the end of each shift, by scanning a QR code attached to their volunteer badge. The survey assessed the duration of the shift, the number of patients with whom the volunteer made contact, and the developmental interventions or activities performed with each patient. A statistical process control chart was used to track utilisation of process measures over time. Pairwise comparison of utilisation across the three plan-do-study-act cycles was also used to evaluate changes in implementation over time. Additional exploratory bivariate analyses examined whether CINCO utilisation differed by patient sociodemographic or medical characteristics, including sex, race, ethnicity, prematurity (yes/no), age at admission, history of extracorporeal membrane oxygenation, Society of Thoracic Surgeons-European Association for Cardio-Thoracic Surgery surgical score, and hospital length of stay. Missingness was dealt with using pairwise deletion and was assessed to determine if it occurred at random. Wilcoxon rank sum test was used to compare the median of continuous variables, while chi-squared test was applied to compare the categorical variables. P-values less than 0.05 were considered statistically significant. Statistical process controls were created using QI Macros software (KnowWare International, Inc., Denver, Colorado). All other statistical analyses were performed using SAS V9.4 (Cary, NC).

#### Results

During the 18-month study period, there were 619 admissions of patients aged 0-2 years to the cardiac ICU or cardiac progressive care unit lasting at least seven days (Table 2). A proportion of race/ethnicity data was missing from the electronic medical record, but was determined to be missing at random. Statistical process control charts demonstrated increased utilisation of CINCO interventions over time with both an increased trendline and a centreline shift for CINCO cardiac ICU/cardiac progressive care unit Order Panels (Fig 2). CINCO Order Panel utilisation increased from 0 to 55% by 3/1/2022, for a total of 279 Order Panels activated. Pairwise comparisons of Order Panel utilisation in plando-study-act I to plan-do-study-acts II and III demonstrated significant increases (p = 0.0163, and p = 0.0007, respectively). Developmental Plans were implemented for 182 patients (reaching 51% of eligible patients in Phase III), and Developmental Kits were

Exploratory examination of Cardiac Inpatient Neurodevelopmental Care Optimization utilisation by demographics revealed that younger patients with longer length of stay, particularly in the cardiac ICU, were more likely to receive CINCO interventions (all p-values <0.01). Additionally, patients who had been born prematurely, received extracorporeal membrane oxygenation, or had a higher STAT score (indicating more severe disease) were more likely to receive CINCO interventions (all p-values <0.01). CINCO utilisation did not differ by patient sex, race, or ethnicity. There were 10 dislodgements of medical devices in the 619 admissions post-CINCO implementation. Case review of each event revealed that CINCO orders were active in five of the 10 affected patients (specifically, for three gastronomy tube dislodgements, one transpyloric nutrition tube dislodgment, and one peripherally inserted central catheter line dislodgement).

# Discussion

The CINCO programme was designed to ensure that patients receive a systematic, evidence-based, and optimal approach to neurodevelopmental care in cardiac inpatient units while undergoing necessary medical management and surgical planning. CINCO builds upon previous research on inpatient cardiac neurodevelopmental care by adding descriptions of iterative, interdisciplinary implementation, and improvement processes that can be generalisable to other centres and teams. Many paediatric care centres with cardiac surgery programmes have clinical team members who could potentially add elements of the CINCO programme to their existing clinical workflows. Based on our experiences, our primary recommendations for sites considering implementing inpatient cardiac neurodevelopmental interventions include the following: 1) Embed interventions into existing clinical workflows and documentation templates to the greatest extent possible; 2) Involve key stakeholders and patient/family input, starting in the design phase; 3) Consider designing interventions that are interrelated/interdependent (e.g., our CINCO volunteers reference the Developmental Plans for activities to complete with the patient, and Developmental Care Rounds is a check-in time to ensure CINCO Orders are in place if appropriate); and 4) Frequent staff and provider re-education is critical to maintain momentum.

Along with tracking progress towards goals, quality improvement science emphasises the importance of tracking balancing measures to ensure that programme implementation is not also causing harm.<sup>25</sup> We found that 1.79% of patients receiving CINCO interventions experienced dislodgements during our study period. This balancing metric lacks baseline data at our institution, but is well below reported rates of dislodgments in paediatric settings.<sup>26–28</sup> The Cardiac Inpatient Neurodevelopmental Care Optimization team will continue to monitor this balancing measure to assess for unintended consequences of the CINCO interventions, specifically increased holding of patients and volunteer involvement.

There are several important limitations to the present study, as well as the overall CINCO programme. Implementing a multifaceted, interdisciplinary quality improvement programme during the height of the COVID-19 pandemic was challenging and Table 2. Demographics and medical characteristics

	Total cohort (n = 619)	Participants receiving CINCO intervention(s) (n = 292)	Participants not receiving CINCO intervention(s) (n = 327)	p-value
Age at admission (days)	104 (1.0, 223.0)	62.5 (0.0, 160.5)	131 (18.0, 285.0)	<0.0001
Sex				0.5385
Male	363 (58.6%)	175 (59.9%)	188 (57.5%)	
Female	256 (41.4%)	117 (40.1%)	139 (42.5%)	
Race				0.9661
American Indian or Alaska Native	17 (2.8%)	8 (2.7%)	9 (2.7%)	
Black/African American	26 (4.2%)	14 (4.8%)	12 (3.7%)	
Hawaiian/Pacific Islander	18 (2.9%)	8 (2.7%)	10 (3.1%)	
Multiracial/Other	94 (15.2%)	42 (14.4%)	52 (15.9%)	
White	346 (55.9%)	162 (55.5%)	184 (56.3%)	
Unknown	118 (19.1%)	58 (19.9%)	60 (18.3%)	
Ethnicity				0.5552
Hispanic/Latino	171 (27.6%)	75 (25.7%)	96 (29.4%)	
Non-Hispanic	333 (53.8%)	163 (55.8%)	170 (52.0%)	
Unknown	115 (18.6%)	54 (18.5%)	61 (18.6%)	
Premature birth				0.0037
No	393 (73.7%)	202 (79.5%)	191 (68.5%)	
Yes	140 (26.3%)	52 (20.5%)	88 (31.5%)	
Hospital length of stay (days)	9.5 (5.3, 29.0)	22.7 (8.3, 48.3)	6.2 (3.4, 11.0)	<0.0001
CICU length of stay (days)	3.8 (1.9, 11.0)	10.1 (3.7, 21.8)	2.1 (1.1, 4.1)	< 0.0001
History of ECMO support				0.0024
No	574 (92.7%)	261 (89.4%)	313 (95.7%)	
Yes	45 (7.3%)	31 (10.6%)	14 (4.3%)	
STAT category				<0.0001
1	114 (25.6%)	41 (17.8%)	73 (34.0%)	
2	140 (31.5%)	56 (24.3%)	84 (39.1%)	
3	47 (10.5%)	25 (10.9%)	22 (10.2%)	
4	99 (22.3%)	68 (29.6%)	31 (14.4%)	
5	45 (10.1%)	40 (17.4%)	5 (2.3%)	

Note. CINCO = Cardiac Inpatient Neurodevelopmental Care Optimization; CICU = Cardiac ICU; ECMO = Extracorporeal Membrane Oxygenation; STAT = Society of Thoracic Surgeons-European Association for Cardio-Thoracic Surgery).

impacted some elements of CINCO more than others (particularly the Volunteer Program, which could not begin until volunteers were allowed back in the hospital). The initial design of CINCO did not include every possible aspect of cardiac neurodevelopmental care, such as light/noise reduction or formal Newborn Individualized Developmental Care and Assessment Program (NIDCAP)<sup>29</sup> interventions. The data we present are not a direct measure of Cardiac Inpatient Neurodevelopmental Care Optimization implementation, but instead reflect documentation of implementation, an imperfect proxy in the context of a busy clinical setting. Finally, while CINCO was designed to be low cost, the Developmental Kits require funding.

The next steps for the CINCO programme include sustaining and improving on implementation rates of CINCO interventions through ongoing staff and provider education, continued monthly CINCO interdisciplinary team meetings, and implementation data tracking. We plan to add more specific environmental and carebased interventions, such as NIDCAP-informed cares and light/ noise reduction. We also plan to build upon recent work in the broader field of paediatric cardiology with respect to health equity, to ensure neurodevelopmental interventions are prioritised for our most vulnerable populations.<sup>22,24,30</sup> We plan to add more Cardiac Inpatient Neurodevelopmental Care Optimization interventions that are developmentally appropriate for patients age 3-18, such as increased individual and group educational opportunities while on the unit. Finally, we will track neurodevelopmental assessment scores for complex cardiac patients at our centre, through our centre's clinical neurodevelopmental evaluation data in the Cardiac Neurodevelopmental Outcome Collaborative clinical registry, to evaluate the potential downstream impact of the CINCO programme interventions on intermediate and long-term neurodevelopmental outcomes.

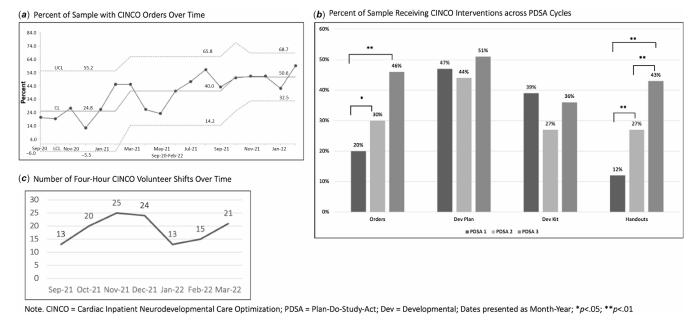


Figure 2. CINCO implementation over time.

# Conclusions

We created and implemented a low-cost, interdisciplinary programme that systematised and expanded upon existing neurodevelopmental care practices in the cardiac intensive care and stepdown care unit settings. The programme demonstrated feasibility through increasing implementation rates over time as well as acceptability to families, providers, and staff. Key takeaways include the importance of multi-level stakeholder buy-in across parents/caregivers, institutional leadership, and interdisciplinary team members, embedding processes in existing clinical roles and workflows, and designing interventions to be interrelated and interdependent in order to drive implementation.

Acknowledgements. The authors thank Adel Younoszai, MD, for contributions to the initial design of CINCO; members of the CINCO clinical team, including Meghan Booth, LSW; Chelsie Lawson, LSW; Betsy Long, LSW, Foster Rosemund, CCLS; and Kathleen Clark, CCLS; and our dedicated CINCO Volunteers for their time and effort spent nurturing and encouraging our cardiac patients' neurodevelopment.

**Financial support.** The University of Colorado School of Medicine/Children's Hospital Colorado Center for Clinical Operations and Patient Safety.

### Conflicts of interest. None.

# References

- Idorn L, Jensen AS, Juul K, et al. Quality of life and cognitive function in Fontan patients, a population-based study. Int J Cardiol. 2013; 168: 3230–3235.
- Ilardi D, Ono KE, McCartney R, Book W, Stringer AY. Neurocognitive functioning in adults with congenital heart disease. Congenit Heart Dis. 2017; 12: 166–173.
- Neal AE, Stopp C, Wypij D, et al. Predictors of health-related quality of life in adolescents with tetralogy of Fallot. J Pediatr. 2015; 166: 132–138.
- Sananes R, Manlhiot C, Kelly E, et al. Neurodevelopmental outcomes after open heart operations before 3 months of age. Ann Thorac Surg. 2012; 93: 1577–1583.

- Sugimoto A, Ota N, Ibuki K, et al. Risk factors for adverse neurocognitive outcomes in school-aged patients after the Fontan operation. Eur J Cardiothorac Surg 2013; 44: 454–461, discussion 461.
- Mahle WT, Lu M, Ohye RG, et al. A predictive model for neurodevelopmental outcome after the Norwood procedure. Pediatr Cardiol. 2013; 34: 327–333.
- Newburger JW, Sleeper LA, Bellinger DC, et al. Early developmental outcome in children with hypoplastic left heart syndrome and related anomalies: the single ventricle reconstruction trial. Circulation. 2012; 125: 2081–2091.
- Lisanti AJ, Cribben J, Connock EM, Lessen R, Medoff-Cooper B. Developmental care rounds: an interdisciplinary approach to support developmentally appropriate care of infants born with complex congenital heart disease. Clin Perinatol. 2016; 43: 147–156.
- Peterson JK. Supporting optimal neurodevelopmental outcomes in infants and children with congenital heart disease. Crit Care Nurse. 2018; 38: 68–74.
- Torowicz D, Lisanti AJ, Rim JS, Medoff-Cooper B. A developmental care framework for a cardiac intensive care unit: a paradigm shift. Adv Neonatal Care 2012; 12 Suppl 5: S28–32.
- McCusker CG, Doherty NN, Molloy B, et al. A controlled trial of early interventions to promote maternal adjustment and development in infants born with severe congenital heart disease. Child Care Health Dev. 2010; 36: 110–117.
- Woolf-King SE, Anger A, Arnold EA, Weiss SJ, Teitel D. Mental health among parents of children with critical congenital heart defects: a systematic review. J Am Heart Assoc 2017; 6.
- Butler SC, Huyler K, Kaza A, Rachwal C. Filling a significant gap in the cardiac ICU: implementation of individualised developmental care. Cardiol Young. 2017; 27: 1797–1806.
- Lisanti AJ, Vittner D, Medoff-Cooper B, Fogel J, Wernovsky G, Butler S. Individualized family-centered developmental care: an essential model to address the unique needs of infants with congenital heart disease. J Cardiovasc Nurs. 2019; 34: 85–93.
- LaRonde MP, Connor JA, Cerrato B, Chiloyan A, Lisanti AJ. Individualized family-centered developmental care for infants with congenital heart disease in the intensive care unit. Am J Crit Care 2022; 31: e10–e19.
- Miller TA, Lisanti AJ, Witte MK, et al. A collaborative learning assessment of developmental care practices for infants in the cardiac intensive care unit. J Pediatr. 2020; 220: 93–100.
- Sood E, Berends WM, Butcher JL, et al. Developmental care in North American Pediatric Cardiac Intensive Care Units: survey of current practices. Adv Neonatal Care. 2016; 16: 211–219.

- Goodman D, Ogrinc G, Davies L, et al. Explanation and elaboration of the SQUIRE (Standards for Quality Improvement Reporting Excellence) Guidelines, V.2.0: examples of SQUIRE elements in the healthcare improvement literature. BMJ Qual Saf 2016; 25: e7.
- Choi BC, Pak AW. Multidisciplinarity, interdisciplinarity and transdisciplinarity in health research, services, education and policy: 1. Definitions, objectives, and evidence of effectiveness. Clin Invest Med. 2006; 29: 351–364.
- Klug J, Hall C, Delaplane EA, et al. Promoting parent partnership in developmentally supportive care for infants in the pediatric cardiac intensive care unit. Adv Neonatal Care. 2020; 20: 161–170.
- Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap) – a metadata-driven methodology and workflow process for providing translational research informatics support. J Biomed Inform. 2009; 42: 377–381.
- 22. Bucholz EM, Sleeper LA, Goldberg CS, et al. Socioeconomic status and long-term outcomes in single ventricle heart disease. Pediatrics 2020; 146.
- Flanagin A, Frey T, Christiansen SL, AMA Manual of Style Committee. Updated guidance on the reporting of race and ethnicity in medical and science journals. JAMA. 2021; 326: 621–627.
- 24. Peyvandi S, Baer RJ, Moon-Grady AJ, et al. Socioeconomic mediators of racial and ethnic disparities in congenital heart disease outcomes:

a population-based study in California. J Am Heart Assoc 2018; 7: e010342.

- 25. Toma M, Dreischulte T, Gray NM, Campbell D, Guthrie B. Balancing measures or a balanced accounting of improvement impact: a qualitative analysis of individual and focus group interviews with improvement experts in Scotland. BMJ Qual Saf. 2018; 27: 547–556.
- 26. Waterhouse J, Bandisode V, Brandon D, Olson M, Docherty SL. Evaluation of the use of a stabilization device to improve the quality of care in patients with peripherally inserted central catheters. AACN Adv Crit Care. 2014; 25: 213–220.
- Naiditch JA, Lautz T, Barsness KA. Postoperative complications in children undergoing gastrostomy tube placement. J Laparoendosc Adv Surg Tech A. 2010; 20: 781–785.
- Thiagarajan RR, Ramamoorthy C, Gettmann T, Bratton SL. Survey of the use of peripherally inserted central venous catheters in children. Pediatrics 1997; 99: E4–e4.
- 29. Westrup B. Newborn Individualized Developmental Care and Assessment Program (NIDCAP) - family-centered developmentally supportive care. Early Hum Dev. 2007; 83: 443–449.
- Lopez KN, Morris SA, Sexson Tejtel SK, Espaillat A, Salemi JL. US mortality attributable to congenital heart disease across the lifespan from 1999 through 2017 exposes persistent racial/ethnic disparities. Circulation. 2020; 142: 1132–1147.