



Original Article

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Development of an Equity, Diversity, and Inclusion Committee for a collaborative quality improvement network: Pediatric Cardiac Critical Care Consortium (PC⁴) Equity, Diversity and Inclusion (EDI) Committee: white paper 2023

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Abstract

Racial and ethnic disparities are well described in paediatric cardiac critical care outcomes. However, understanding the mechanisms behind these outcomes and implementing interventions to reduce and eliminate disparities remain a gap in the field of paediatric cardiac critical care. The Pediatric Cardiac Critical Care Consortium (PC⁴) established the Equity, Diversity, and Inclusion (EDI) Committee in 2020 to promote an equity lens to its aim of improving paediatric cardiac critical care quality and outcomes across North America. The PC⁴ EDI Committee is working to increase research, quality improvement, and programming efforts to work towards health equity. It also aims to promote health equity considerations in PC⁴ research. In addition to a focus on patient outcomes and research, the committee aims to increase the inclusion of Black, Indigenous, and People of Color (BIPOC) members in the PC⁴ collaborative. The following manuscript outlines the development, structure, and aims of the PC⁴ EDI Committee and describes an analysis of social determinants of health in published PC⁴ research.

Racial and ethnic disparities in medicine have been consistently reported across several specialties and illnesses, including asthma, research funding, pain management, and cancer outcomes.^{1–4} In paediatric cardiology and cardiac critical care, these disparities are evident in a range of outcomes, including failure to rescue, post-operative mortality, and post-transplant outcomes.^{5–7} Despite recognising these disparities, the field of paediatric cardiac critical care and associated specialties continue to struggle to understand the many modifiable factors that contribute to disparities and ways to mitigate these factors in the current social and medical environment. Similar to other fields in medicine, the paediatric cardiac critical care workforce has a poor representation of minority racial and ethnic groups, which may be another contributing factor to disparate patient outcomes.^{8–10} Broad systemic changes are necessary to dismantle structural racism inherent to the institution of medicine, especially as the non-White population continues to grow. According to the United States Census Bureau, White non-Hispanic race composed 57.8% of the United States population, compared to 63.7% in 2010.¹¹ Local and multi-centre research and quality improvement efforts are needed to help centres identify and address disparities.

Formed in 2009, the Pediatric Cardiac Critical Care Consortium (PC⁴) aims to improve critical paediatric acquired and CHD care across North America through a collaborative learning model that supports scientific research and quality improvement. At the core of PC⁴ is a strong commitment to the purposeful collection of clinical data and collaborative learning. Through its strengths in patient-level data collection, analytics, research, and quality improvement, PC⁴ provides a framework and infrastructure for initiatives to work towards health equity for minority racial and ethnic populations. For this reason, PC⁴ has formed the PC⁴ Equity, Diversity, and Inclusion (EDI) Committee to address health disparities in paediatric critical cardiac illness. This paper outlines the development, mission, goals, and structure of the PC⁴ EDI Committee to further the PC⁴ aim of improving patient care and outcomes for this population. Additionally, we describe an analysis of the integration of race and ethnicity in published PC⁴ research.

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PC⁴ EDI Committee initiation

Until recently, PC⁴ publications have not primarily focused on examining disparities within the paediatric cardiac critical care population. Within the field of paediatric cardiac critical care, investigators, including those at PC⁴ centres, have evaluated health disparities within the paediatric cardiac critical care patient population, including outcomes such as extracorporeal membrane oxygenation and post-surgical mortality. As in other fields of medicine, disparities were apparent in these studies.^{12–15} In 2021, the PC⁴ Executive Committee unanimously decided that a PC⁴ EDI Committee was necessary to understand these health inequities and begin to change outcomes. The PC⁴ EDI Committee convened its first meeting in May 2021.

PC⁴ EDI Committee mission

The mission of the PC⁴ EDI Committee is to address disparate outcomes in critically ill children with heart disease through the multiple avenues of PC⁴. Broadly, this mission promotes equity, diversity, and inclusion throughout the existing PC⁴ committees. By incorporating EDI principles into the structure and workflow of PC⁴, the EDI Committee aims to make the lens of health equity fundamental to all PC⁴ operations. Additionally, this committee works to promote equity, diversity, and inclusion among the institutional participants of PC⁴, as this principle is integral in addressing disparities in healthcare. The committee also aims to ensure that quality science within PC⁴ directly examines and addresses diversity and health disparities.

PC⁴ EDI Committee structure

PC⁴ consists of 75 paediatric critical care units providing care to patients with critical heart disease across North America that contribute patient-level data to the consortium registry. Each site has a clinical champion to serve as the liaison between PC⁴ and their institution. The structure of PC⁴ is made up of eight committees: Executive, Quality Science, Scientific Review, Public Relations, Program, Database, Finance, and Audit. Any interested clinician from PC⁴ institutions can join PC⁴ committees (with the exception of the Executive Committee), submit scientific proposals, and participate in quality improvement initiatives. The strength of the PC⁴ collaborative is patient-level data collection and sharing in an unblinded fashion to promote benchmarking and collaborative improvement, which requires a rigorous audit process. Data are available for single centre and collaborative-wide research and quality improvement. The EDI Committee actively participates in all aspects of PC⁴. As such, the EDI Committee delegates designated members to serve on individual PC⁴ committees to ensure that all PC⁴ activities are performed with a lens of equity and diversity. The initial PC⁴ EDI Committee structure included chair, committee liaisons to each of the above PC⁴ committees, and specific workgroups to support EDI-related quality improvement and research (Fig 1).

PC⁴ EDI Committee goals and objectives

PC⁴ will address disparities and promote equity, diversity, and inclusion in all aspects of PC⁴. The aims of the EDI Committee include:

1. Active participation of equity, diversity, and inclusion in each of the PC⁴ committees;
2. Improving data collection of social determinants of health and providing tools for centres to identify disparities among their patient population;
3. Identification and engagement of experts in the field of Health Equity;
4. Advancing research and quality improvement science in EDI;
5. Producing informative webinars to advance EDI education;
6. Partnering with other registries within Cardiac Networks United for joint projects;
7. Promoting mentorship in the paediatric cardiac critical care community.

Active participation in PC⁴ Committees

EDI Committee members with an interest, prior experience, or current members on one of the PC⁴ committees act as EDI liaisons to their respective committees. We currently have 1–2 EDI members on each committee to promote an EDI lens in each committee's work.

1. **Executive Committee:** EDI Committee chair(s) and other EDI Committee members will bring attention to the importance of diversity when electing new members. Executive Committee candidates are selected from active committee members. As such, the EDI Committee encourages clinicians with diverse backgrounds from PC⁴ centres to join PC⁴ committees of their interest.
2. **Scientific Review:** EDI liaison members on the Scientific Review Committee will encourage non-disparity-focused research proposals under review to give adequate attention to reporting relevant social determinants of health. For example, liaisons will promote reporting of race/ethnicity for all studies and examine outcomes by race/ethnicity when applicable. Oversight will include review and ranking of proposals, functioning as committee liaison for specific analyses and critical manuscript review.
3. **Quality:** EDI liaison members to the Quality Committee will work to identify and promote quality improvement initiatives that work to achieve health equity. These initiatives can be local projects, multi-centre collaborations, or collaborative-wide initiatives. Additionally, the EDI liaisons will provide insight and support to ensure that collaborative quality improvement projects examine goals and outcomes through a health equity lens. Because quality improvement projects can potentially exacerbate health disparities, EDI liaisons will review QI projects and monitor them to ensure appropriate balancing measures are also included.
4. **Public Relations:** EDI liaisons to the Public Relations Committee will work to promote diversity and inclusion in the public-facing efforts of PC⁴. This goal can be accomplished by public promotion of research in health equity, quality initiatives that address disparities, and highlighting diversity in our workforce. EDI liaisons will also strive to increase the visibility of investigators from underrepresented populations and speakers/presenters with diverse backgrounds. EDI liaisons will also encourage imaging and wording that promotes principles of health equity in public relations communications. Finally, EDI liaisons can partner with patient advocacy groups to promote and align efforts that address disparities in the PC⁴ patient population.

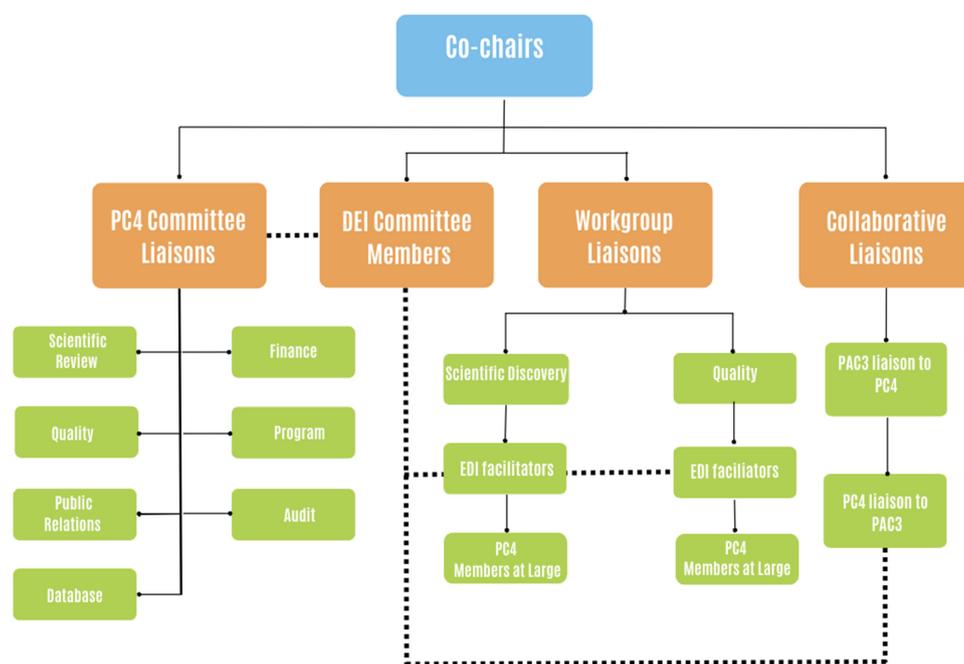


Figure 1. PC⁴ EDI initial committee structure and organisation. The Pediatric Cardiac Critical Care Consortium (PC⁴) EDI Committee is led by 1–2 (co-)chair(s) (current co-chairs: Titus Chan, Yuen Lie Tjoeng). The committee is open to all members of PC⁴. One to two committee members then sit on each PC⁴ committee to lend a health equity lens to all aspects of PC⁴. The Scientific Discovery and Quality workgroups are housed under the DEI Committee and facilitated by two EDI members, with open participation by PC⁴ members at large. Additionally, work across collaboratives is encouraged; the DEI Committee currently has liaisons to and from the Pediatric Acute Care Cardiology Collaborative (PAC³).

5. **Database:** EDI liaisons will work with the Database Committee to construct tools to aid hospitals in identifying disparities within their population and across the collaborative. Specifically, EDI Committee members will work with the Database Committee to identify variables and analytic tools that will not only seek to uncover health disparities, but the mechanisms by which populations experience these disparities. A closer look at these mechanisms can be achieved by constructing measures of hospital disparities which can be visualised on the PC⁴ reporting platform to facilitate evaluation of institutional outcomes and unblinded benchmarked comparisons to other institutions. EDI members will help develop appropriate risk-adjusted metrics that address diversity. Finally, the EDI members will work to improve accuracy and consistency on how race, ethnicity, and social elements are captured in the PC⁴ registry.
6. **Program:** EDI liaison members will help the Program Committee select and develop themes and presentations that draw attention to health disparities and promote equity, diversity, and inclusion. This work may include presentations at the annual PC⁴ conference and various presentations throughout the year. The EDI Committee members will also help guide the Program Committee to promote diversity and inclusion when identifying potential speakers.
7. **Finance:** EDI liaisons will also work with the Finance Committee to apply for funding that supports equity and diversity programmes and initiatives.
8. **Audit:** EDI liaison members on the Audit Committee will work to identify areas of disparities in care that are deemed important domains of information accuracy during institutional audits. Similar to the goals with the Data Committee, EDI members will promote a better understanding, uniformity, and accuracy of race and ethnicity data populating the institutional electronic medical record. In addition, EDI members may examine disparities in data accuracy and, if existing, interventions to address these disparities will be suggested.

Improving data collection and providing tools for centres to identify disparities

Race and ethnicity are social constructs, meaning that there is no evidence that racial or ethnic groups have a distinct unifying biologic or genetic basis.¹⁶ Instead, race and ethnicity are intricately linked to access to healthcare and institutional policies and procedures that are embedded in structural racism. Differences in outcomes by race and ethnicity have been demonstrated in critically ill children with CHD^{5,7,17}, and the collection of high-quality, accurate data surrounding race/ethnicity and social determinants of health is paramount to advancing the field towards equitable health outcomes.

To assist PC⁴ centres in identifying disparities in their patient outcomes at their centre, the EDI Committee has partnered with the PC⁴ Database Committee to enhance the PC⁴ reporting platform. Race and ethnicity filters have now been applied to unadjusted outcomes and adjusted risk models. The models have been retested to ensure that filtering by race/ethnicity has a similar concordance statistic as previous risk-adjusted models. Observed to expected ratios demonstrate how a particular race/ethnicity's outcome at a specific centre compares with the entire PC⁴ population and provides a method for institutions to benchmark their respective outcomes by race/ethnicity. This feature was added in early 2022. Looking forward, additional social determinants of health data, including language preference and neighbourhood characteristics, will be considered for incorporation into the PC⁴ reporting platform.

An active topic of debate is whether comparative analyses of outcomes based on race and ethnicity using registry data are appropriate due to concerns of validity of the data uploaded from the electronic medical record.¹⁸ How race/ethnicity data are collected and subsequently reported to large databases varies from centre to centre, and prior studies have demonstrated discordance between database entries and self-reported race/ethnicity.¹⁹ Additionally, current race/ethnicity groupings are inadequate to describe the growing number of patients who identify with

multiple racial and ethnic groups or with groups that include multiple race/ethnicities, such as “Asian.”^{20,21}

The PC⁴ EDI Committee will continue to work closely with PC⁴ champions and the Database and Audit Committees towards understanding and establishing best practices for collecting race/ethnicity data as a first step. Through high-quality comprehensive data collection, PC⁴ would then have the tools to accurately identify disparities in outcome, implement interventions, and measure progress in reducing inequities over time. Additional measures will be undertaken by the committee to work with data analysts to offer risk-adjusted outcomes by race/ethnicity, insurance and other social determinants of health, examination of additional social determinants of health as potential predictors of risk-adjusted outcomes, and ensuring appropriate use and interpretation of these models by PC⁴ institutions to prevent unintended harmful consequences (such as aversion to higher risk cases).²²

Identification and engagement of an expert(s) in the field of Health Equity

The PC⁴ EDI Committee will identify a few scientists in the field of Health Equity who agree to actively participate on the EDI Committee. Their roles will help direct and focus research, quality improvement, public relations, and data science/management efforts to reduce health disparities in our patient population. The respective individual(s) will be appropriately recognised in PC⁴ publications.

Advancing research and quality improvement science

The PC⁴ EDI Scientific Discovery and Quality Improvement Working Group will function as a forum to promote EDI-related projects. Each working group will be facilitated by 1–2 EDI members and open to all PC⁴ members to join. These working groups will generate proposals that originate from EDI Committee members in addition to helping other EDI Committee members and PC⁴ investigators to develop proposals or incorporate a health equity lens into their existing research or quality improvement project. These projects can be single-centre, multi-centre, or collaborative-wide projects. Research and QI projects supported by the PC⁴ EDI Scientific Discovery and Quality Improvement Working Group will be submitted to and be evaluated by the appropriate PC⁴ committee in the standard fashion for all research/QI projects. Additionally, proposals from the Scientific Review Committee and Quality Improvement Committee may be referred to the appropriate EDI work group to add a health equity lens to the proposal and analysis. If multiple proposed studies examine health equity, the working group will help prioritise studies and coordinate studies/investigators to ensure a cohesive series of work is produced. The PC⁴ EDI Scientific Discovery and Quality Improvement Working Group will also promote and encourage diversity among investigators through mentorship (guidance and advice from more experienced researchers) and sponsorship (promoting specific individuals for opportunities).

Producing informative webinars to advance EDI education

The EDI Committee will work on educational and interactive education relevant to equity, diversity, and inclusion that can be accessed by all members of PC⁴ and, potentially, other receptive audiences. These activities will be primarily led by the EDI members who are liaisons to the Public Relations and Program Committees. These activities may include seminars/lectures from

outside health equity experts and discussions that examine PC⁴ data on disparities or possible interventions. Additionally, the EDI Committee will work to foster collaboration and sharing across institutions to promote equity and diversity through centre-level and individual-level mentoring and collaboration on EDI-related activities.

Partnering with other collaborators

The PC⁴ EDI Committee will encourage collaboration with other registries to produce cross-collaborative quality and research science that addresses disparities and promotes health equity. This collaboration can be facilitated by Cardiac Networks United.

Mentorship and sponsorship

The PC⁴ EDI Committee will increase participation and visibility of underrepresented populations in PC⁴, including as members in the collaborative, as investigators submitting proposals to the Scientific and Quality Improvement Committees, and as members of the paediatric cardiology and critical care profession. To achieve this goal, the committee will create a mentorship model or join an existing mentorship network to pair senior members with junior members as career and research mentors, with an emphasis on supporting underrepresented groups. Sponsorship of early career or trainee Black, Indigenous, and People of Color (BIPOC) PC⁴ members for committee work, leadership opportunities, research and quality project participation, and other PC⁴ activities will be encouraged and will be the responsibility of senior committee members. Encouraging PC⁴ participants who represent diversity to be active members of PC⁴ committees will accelerate enhanced diversity in the PC⁴ Executive Committee.

Committee expectations and accountability

The Committee meets bi-monthly via electronic conference call to discuss objectives, completed goals, and accomplishments and to set goals for the next quarter. Because of the inherent complexity involved in promoting EDI issues, these meetings also serve as an opportunity for members to work through complex issues and gain input from the larger group. Committee members are expected to attend at least 75% of PC⁴ EDI Committee calls and 75% of subgroup committee calls, be actively engaged in their individual committee/subgroup responsibilities, and be responsive to electronic communications. EDI Committee work will be tracked by its leadership and documented to ensure that the committee's goals are being met. If any EDI goals are not progressing, the leadership may shift prioritisation and attention to those areas in most need or that are most impactful to improving outcomes and mitigating disparities in our patients.

Previous inclusion of race/ethnicity in PC⁴ research and quality improvement publications

An important step in understanding the role of PC⁴ data in EDI-related research is understanding how race and ethnicity have been considered in previous PC⁴ publications to inform best practices for the use of race and ethnicity in future PC⁴ studies. A group of authors (DKW, CA, PN, and SB) analysed all previously published PC⁴ manuscripts to describe whether race and ethnicity data were included, how it was reported and analysed, and identify any missed opportunities. In instances where analytic methods were unclear, primary authors and statistical personnel were contacted

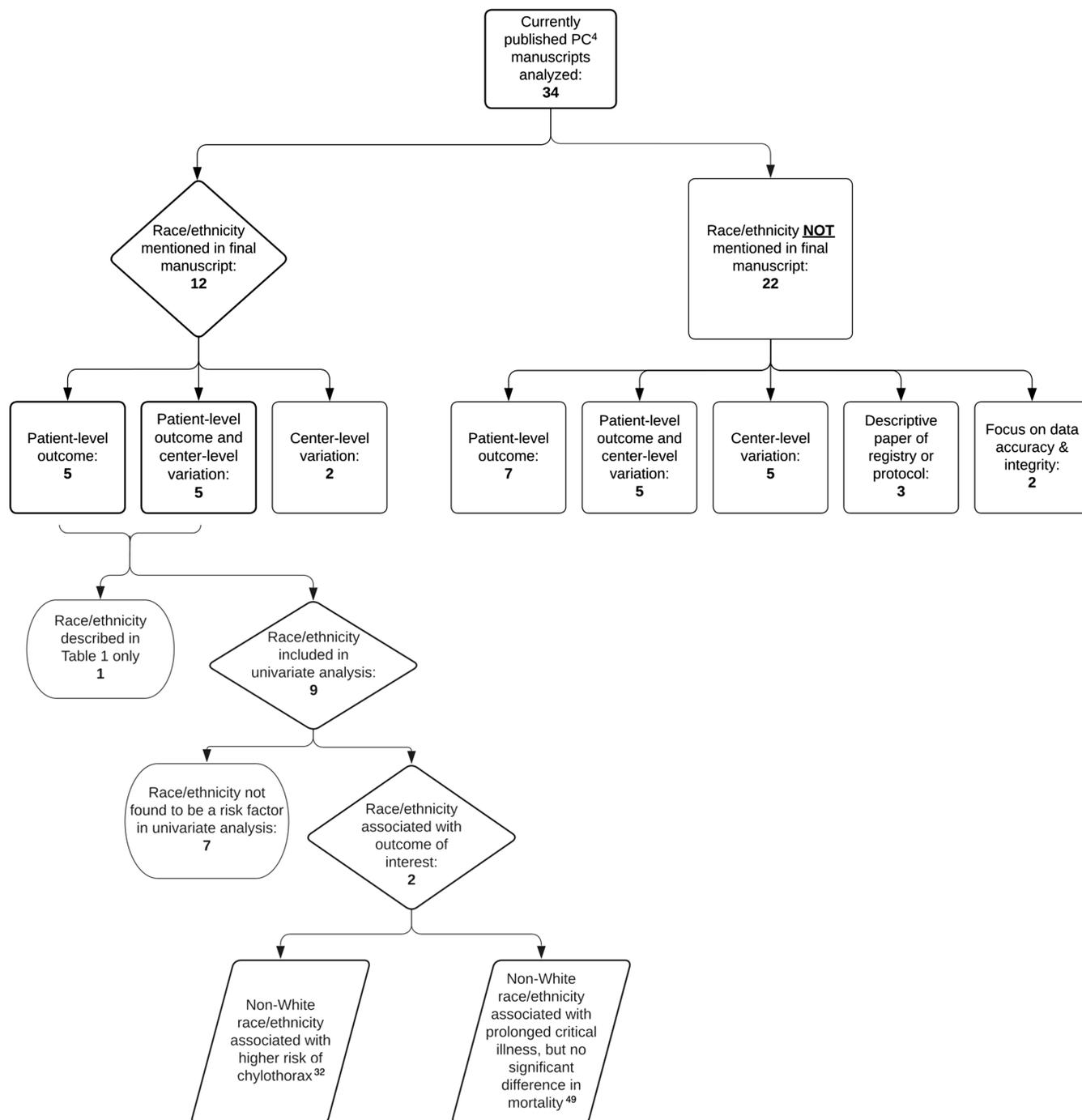


Figure 2. Summary of race and ethnicity and relevant findings in currently published PC⁴ research. A flow diagram of all currently published PC⁴ research (further detailed in Supplemental Table 1) summarises the use and mention of race and ethnicity in each of the PC⁴ analyses and findings.

to adjudicate (DKW and KS). The findings of this analysis are described in Figure 2 and Supplemental Table 1. We acknowledge that our analysis is limited, as we do not have insight into reasons why race/ethnicity may not have been reported in a study. However, we report these numbers as a baseline for applying a health equity lens for future PC⁴ publications.

Of 34 currently published PC⁴ manuscripts, 22 studies did not mention race/ethnicity in the final manuscript. Five of these studies were either describing a registry/protocol or focused on data integrity and accuracy. The remaining 17 studies included

patient-level outcomes, centre-level variation, or both. For these 17 studies, race/ethnicity may have been included in univariate analysis but was not reported in the final manuscript. Of the 12 studies that included race/ethnicity in the manuscript, 10 studies had a patient-level outcome or both patient-level outcome and centre-level variation reported. The researchers of the two studies that focused on centre-level variation mentioned race/ethnicity in supplemental tables or appendices, but not in the body of the manuscript. Of the remaining 10 studies, 9 reported outcomes by race/ethnicity in univariate analysis, and 2 studies found race/

ethnicity to be risk factors for the outcome of interest. Therefore, 13 of 22 studies (59%) that included a patient-level outcome did not describe the association between race/ethnicity with the outcome of interest. In addition, there were several studies where race/ethnicity were not found to be associated with the outcome of interest in univariate analysis. The researchers did not include the implications of these findings in the discussion where it might have been relevant. For instance, in several studies about acute kidney injury, race and ethnicity were either not described in the analysis or not associated with acute kidney injury in univariate analysis. However, equations to calculate the estimated glomerular filtration rate often include a race coefficient, introducing systemic bias and possible misclassification of renal function.²³ The absence of race/ethnicity in these studies may represent a missed opportunity to address EDI-related outcomes, particularly for papers that included patient-level outcomes.

Current state

In the first 2 years of operation, the EDI Committee has dispatched 10 members across all PC⁴ Committees, reviewed and enhanced multiple scientific projects and QI projects, and created parent and patient-focused materials through the Public Relations Committee. The Committee has also joined efforts with the Pediatric Acute Care Cardiology Collaborative (PAC³) Inclusion, Diversity, and Health Equity Advocates (IDHEA) Committee to form the Joint EDI (JEDI) Committee and is focused on four quality improvement efforts across collaboratives to address language access, underrepresented in medicine diversity and inclusion efforts, educational webinars, and forming a network of EDI champions at participating institutions. The JEDI Committee has also distributed a diversity survey to better understand the demographic makeup of PAC³/PC⁴ physicians and advanced practice providers.

Conclusion

To more formally address health disparities, inequity, and lack of diversity and inclusion in paediatric cardiac critical care, the PC⁴ EDI Committee was established and charter developed in 2021. Through increased awareness and representation across PC⁴ committees and operations, as well as an enhanced focus on EDI in all PC⁴ quality, science, education, and programming, the EDI Committee aims to ultimately improve the outcomes of children with cardiac disease and mitigate the inequity and disparities that they experience.

Supplementary material. The supplementary material for this article can be found at <https://doi.org/10.1017/S1047951123002950>.

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