



HHS Public Access

Author manuscript

Semin Fetal Neonatal Med. Author manuscript; available in PMC 2022 February 02.

Published in final edited form as:

Semin Fetal Neonatal Med. 2021 February ; 26(1): 101198. doi:10.1016/j.siny.2021.101198.

Using rising tides to lift all boats: Equity-focused quality improvement as a tool to reduce neonatal health disparities

Vicky Reichman, MD, MPH*,

Department of Pediatrics, Lenox Hill Hospital, New York, NY

Sandhya S. Brachio, MD,

Department of Pediatrics, Division of Neonatology, Columbia University Medical Center, New York, NY

Chinonyerem R. Madu, MPH,

Children's Hospital of Philadelphia, Center for Healthcare Quality and Analytics

Diana Montoya-Williams, MD,

Children's Hospital of Philadelphia, Philadelphia, PA; University of Pennsylvania Perelman School of Medicine, Philadelphia, PA; CHOP PolicyLab, Philadelphia, PA

Michelle-Marie Peña, MD

Children's Hospital of Philadelphia, Philadelphia, PA; CHOP PolicyLab, Philadelphia, PA

Abstract

Evidence of health disparities affecting newborns abounds. Although quality improvement (QI) methodology is often suggested as a tool to advance health equity, the impact of QI initiatives on disparities is variable. QI work may mitigate, worsen, or perpetuate existing disparities. QI projects designed without an intentional focus on equity promotion may foster intervention-generated inequalities that further disadvantage vulnerable groups. This article reviews disparities in perinatal and neonatal care, the impact of QI on health disparities, and the concept of "Equity-Focused Quality Improvement" (EF-QI). EF-QI differs from QI with an equity lens in that it is action-oriented and centered around equity. EF-QI initiatives purposely integrate equity throughout the fabric of the project and are inclusive, collaborative efforts that foreground and address the needs of disadvantaged populations. EF-QI principles are applicable at every stage

*Corresponding Author: vicky.reichman@gmail.com, (tel) 917-691-3490, (fax) 212-434-3374.

Vicky Reichman, Address: Department of Pediatrics, Lenox Hill Hospital, 100 E. 77th Street, New York, NY 10075

Sandhya S. Brachio, Address: Columbia University Medical Center, Division of Neonatology, 622 W. 168th Street, PH17, New York NY 10032

Chinonyerem R. Madu, Address: Roberts Center for Pediatric Research at the Children's Hospital of Philadelphia, 2716 South Street, 12th Floor, Philadelphia, PA 19146

Diana Montoya-Williams, Address: Roberts Center for Pediatric Research at the Children's Hospital of Philadelphia, 2716 South Street, 19th Floor, Suite 19361, Philadelphia, PA 19146

Michelle-Marie Peña, Address: Roberts Center for Pediatric Research at the Children's Hospital of Philadelphia, 2716 South Street, 19th Floor, Suite 19390, Philadelphia, PA 19146

Conflict of Interest: None reported.

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

of project conception, execution, analysis, and dissemination, and may provide opportunities for reducing disparities in neonatal care.

Keywords

Quality Improvement; Health Equity; Health Status Disparities; Healthcare Disparities; Minority Health; Racism; Quality of Health Care; Social Determinants of Health; Vulnerable Populations; Health Services Research; Perinatology; Neonatology; Neonatal Intensive Care Units

Introduction

Health disparities are prevalent, costly, and consequential^{1–5}. Sustained improvements in neonatal care over the past decade have not equitably benefited all neonates, with ample evidence that infants of color suffer excess morbidity and mortality^{1–4,6,7}. Such inequities in care may alter the lifetime trajectory of infants' and their families' wellbeing and create ripple effects within their communities. Additionally, health disparities exact a \$300 billion annual toll in economic losses⁵. Quality improvement (QI) methodology is conceptually well-suited and frequently posited as a means of progressing from describing towards eliminating disparities, but in practice may inadvertently exacerbate existing gaps. This article aims to provide a broad overview of neonatal health disparities scholarship, review the potential impact of QI work on health disparities, and provide a framework for centering neonatal QI endeavors around equity.

I. Disparities in Perinatal and Neonatal Care

Disparities represent variation relating to disadvantage. Health disparities are “avoidable, systematic differences adversely affecting economically or socially disadvantaged groups”⁸. Disparities in neonatal outcomes are very well documented. The Socio-Ecological model, a framework that conceptualizes health status as stemming from multiple influences (including individual predisposition, health behaviors, relationships, community and societal factors), is a useful lens to elucidate intersectional sources of variation that may cumulatively and longitudinally contribute to inequities within neonatal care^{9,10}. Disparities may occur within any of the layers of the Socio-Ecological model; demographic attributes, health system factors, and geographic location can all provide a fulcrum for inequities.

The largest body of literature describes disparities relating to parental (nearly universally maternal) race/ethnicity. Infants of color are overrepresented within low birthweight rates, preterm birth rates¹¹, and neonatal mortality rates^{12,13}. In 2018, the infant mortality rates in the United States for infants of non-Hispanic Black (10.75 per thousand live births), Native Hawaiian or Pacific Islander (9.39 per thousand live births), and American Indian or Alaska Native women (8.15 per thousand live births) were approximately double that of infants of non-Hispanic White (4.63 per thousand live births) and non-Hispanic Asian (3.63 per thousand live births) women¹³. Furthermore, underserved newborns suffer an excess burden of neonatal morbidities. For example, Janevic et al. found higher rates of intraventricular hemorrhage, retinopathy of prematurity, necrotizing enterocolitis, and bronchopulmonary dysplasia in Black and Hispanic infants under 32 weeks in New York City⁷.

Temporal Evolution—Racial and ethnic neonatal disparities are impacted by temporal, local, and regional contexts. For instance, disparities in preterm birth and neonatal mortality rates have shown a temporal evolution. As the overall preterm birth rate has continued to increase, disparities in both overall preterm birth rates^{11,14,15} and very low birthweight (VLBW) rates are widening, with VLBW disparities increasing for seven decades¹². In 2019, non-Hispanic Black women had an overall preterm birth rate of 14.39% compared to 9.26% in non-Hispanic White women; the difference in early gestations was even starker, with a rate of 4.94% very preterm births in non-Hispanic Black women compared to 2.27% in White women¹⁴. However, gaps in other neonatal outcomes have changed differently over time; between 2006–2016, when examining infants under 30 weeks, Boghossian found that disparities between African American and White infants in in-hospital mortality, necrotizing enterocolitis, late onset sepsis, and hypothermia had narrowed². In addition, there is evidence that disparities may temporally evolve even within individual hospitalizations; in a statewide QI collaborative addressing provision of mother’s own milk for VLBW infants, Parker et al. found that disparities in mother’s milk provision did not emerge among infants of Hispanic, non-Hispanic White, and non-Hispanic Black mothers until their third week of life^{16, 62}.

Geographic Influences—Infants’ geographic location of birth may also be a source of variation leading to inequities. Mortality may vary with urbanization, with emerging evidence of higher infant mortality rates nationally in more rural areas when compared to more urban counties¹⁷. In addition, large differences in neonatal mortality have been documented within urban areas, even between neighboring communities. For instance, in New York City, the neonatal mortality rate in the Central Harlem neighborhood in 2015 was 7.2 per 1000 live births,¹⁸ more than double the rate in the adjacent Upper West Side neighborhood (2.6/1000) over the same period¹⁹. Neonatal Intensive Care Unit (NICU) quality and breastmilk usage of urbanization, region of care has also been associated with striking variation in multiple neonatal quality measures, including overall NICU quality and breastmilk usage. Horbar et al. described wide census region differences in Baby-MONITOR scores, a robust hospital-level composite metric of overall NICU quality care delivery comprising mortality, two process measures, and six neonatal morbidities¹. NICUs in hospitals in the Pacific region scored highest when compared to NICUs in the Mountain and East South Central regions¹. Differences exist in breast milk utilization between and within regions²⁰. VLBW infants in the South have been shown to have the lowest receipt of breast milk at discharge, whereas VLBW infants in the West had the highest rates.²⁰ Within each census region, Native American and non-Hispanic Black VLBW infants had the lowest receipt of breast milk at discharge, though the size of this disparity varied regionally.²⁰

The site of care delivery is also an important mediator of variation; racial and ethnic disparities in outcomes exist both between and within hospitals that care for parents and infants. An important contributor to these disparities appears to be the relationship between racial/ethnic segregation within and between hospitals and associated differences in the overall measured quality of hospitals¹. For instance, it is well-documented in some localities that mothers and infants of different racial/ethnic groups predominantly receive care at different centers^{1,21,22}. Hebert et al. found that regardless of proximity, Black mothers in

New York City were 40% less likely than White mothers to deliver at hospitals in the lowest tertile for maternal mortality²². In addition, non-Hispanic Black infants were found to be more likely to receive care at lower-quality hospitals, while Asian infants were more likely to receive care at higher-quality hospitals than White infants¹. Between-hospital quality differences are consequential; for infants in New York City, they accounted for 35% of the Black-White disparity in VLBW mortality rate⁴. They also accounted for 40% of the Black-White disparity and 30% of the Hispanic-White disparity in a composite outcome of severe morbidity and mortality for infants under 32 weeks gestational age²³. Between-hospital disparities in outcomes may be influenced by hospital volume; when compared to non-Hispanic White infants delivered at high-level, high-volume hospitals, non-White infants demonstrated a smaller increase in the odds of neonatal morbidities²⁴. Finally, within-hospital disparities by race/ethnicity may coexist with between-hospital disparities. Disparities by race/ethnicity both between and within hospitals have been found in metrics such as overall NICU quality, as measured via Baby-MONITOR scores²⁵, and in mother's milk provision¹⁶.

Demographic Nuance—While these studies illuminate the critical challenges facing parents and infants of color, they may underestimate risk. Because individuals in the majority of these studies have been collapsed into broad US-census defined categories of race and ethnicity, heterogeneity within each racial and ethnic category has been understudied. As such, important signals within groups may be underestimated or completely overlooked. A study of neonatal mortality in California from 1991–2001 revealed significant heterogeneity in risk of neonatal mortality among different Asian subgroups²⁶. When compared to White infants, for instance, Thai infants had a 90% excess adjusted risk, while Japanese infants had a 33% lower adjusted risk of neonatal mortality²⁶. Subgroup differences in mortality reflecting differential risk relating to natality have also been demonstrated in New York City, where in 2017, infants born to Puerto Rican mothers had a neonatal mortality rate of 6.3 per thousand live births, while other Hispanic-origin infants had a neonatal mortality rate of 4.3 per thousand live births²⁷, reflecting national findings of higher infant mortality for infants of Puerto Rican women among Hispanic origin-subgroups¹³. Subgroup differences within Hispanic infants have also been documented for preterm birth rates and low birthweight^{13,28}. Unfortunately, most registries and other administrative datasets do not typically collect such nuanced race, ethnicity, and natality data²⁸. As a result, neonatal disparities work is often predicated solely on maternal race and ethnicity, which may not accurately capture infants' race and ethnicity or the impacts of natality and/or immigration status. Relying solely on maternal race and ethnicity may also obscure the intersectional effects of birth partner race/ethnicity, which is less often collected and/or reported²⁹. Finally, ethnicity is often reported as a substitute for race, potentially obscuring differences within an ethnic group by race.

In addition to race and country of origin, other parental attributes are often understudied but may contribute to variation. For example, the pediatric and adult literature has identified alarming disparities in the care of patients who prefer a language other than English, though this effect is under-investigated within neonatology^{30–32}. Additional important parental attributes, such as gender identity, sexual orientation, differently-abled status, and

immigrant acculturation, may also contribute to inequitable outcomes but have been largely undescribed in the neonatal literature and merit further inquiry. Indeed, the current rich knowledge base of disparities faced by infants of color serves to suggest how critical it is to explore whether disparities exist by other attributes.

II. Threats to Health Equity During Quality Improvement Work

Health equity, defined by Montoya-Williams et al. as “the principle, goal, or process that motivates or underpins efforts to eliminate health disparities”, is integral to quality work³³. Equity considerations, like patient safety, must undergird all quality improvement projects, because any change in patient outcomes either reinforces or alters existing disparities. Quality improvement projects without explicit attention to equity risk worsening existing disparities or generating new ones^{34,35}.

Quality improvement may affect an existing disparity via three possible trajectories (Figure 1). It may improve outcomes:

1. for all populations evenly, preserving and perpetuating the existing disparity (Figure 1 Panel b);
2. for all populations, but with greater impact for the more advantaged group, widening the existing disparity (Figure 1 Panel c);
3. for all populations, but with greater impact for the less advantaged group, diminishing or eliminating the existing disparity (Figure 1 Panel d).

In the absence of proactively tracking variations in response to interventions, a QI project may improve care overall while simultaneously maintaining (Figure 1, Panel b) or widening (Figure 1, Panel c) the quality gap and thus further disadvantaging already vulnerable groups^{34,35}. An “intervention-generated inequality (IGI)” is more likely to occur when interventions disproportionately benefit advantaged groups in terms of accessibility, adoption, adherence, or efficacy³⁶. Thoughtful, robust interventions are not immune to the generation of IGIs; this has been most strongly shown in adult literature. For example, public health smoking cessation campaigns, which radically reduced smoking rates nationally, introduced a dramatic disparity in smoking rates, favoring individuals with higher educational attainment³⁵. Similarly, the introduction of adult sepsis care protocols in New York was associated with improved sepsis performance overall but a widened Black-White disparity in protocol adherence, a difference that was driven by worse protocol adherence in higher “minority-serving” hospitals³⁷. Additionally, the publication of surgeon report cards for coronary artery bypass graft (CABG) surgeries in New York widened the existing disparity in CABG utilization with a 19% reduction in CABG use for Black and Hispanic patients³⁸. This disparity took nearly a decade to narrow to baseline³⁸.

IGIs may arise at multiple junctures including during project design, intervention creation and implementation, data collection, and data dissemination. The subsequent section provides a discussion of issues for QI practitioners to consider during each stage of project development and implementation.

Project Design Considerations—The design of most QI projects is observational, with the generation of time series data, as metrics are tracked longitudinally before and after the introduction of interventions. This model cannot separate the effects of secular trends and local context³⁹. Other models, such as the stepped-wedge approach, interrupted time series, cluster randomization, and crossover designs, may be better suited to clarifying contextual influences and eliminating potential sources of bias^{39,40}. Considering these approaches and other analytic tools will allow for more robust evaluation of changes in data and a deeper investigation of IGIs that might otherwise be overlooked.

Data Collection Considerations—Even prudent analytic design will neither identify nor eliminate IGIs if data collection does not include participant characteristics that may precipitate disparities. Patient characteristics, especially race and ethnicity, are inconsistently, inaccurately, or incompletely collected within medical records^{41,42}. For instance, an observational study of a national healthcare database of 160 million participants found that race or ethnicity were unknown for 25% of patients⁴¹. Furthermore, data collection may not guarantee fidelity; in the same study, 57% of patients within a health system serving 2.4 million patients had unknown race or ethnicity; and for 66% of patients, their self-reported information was discrepant with the medical record⁴¹. Furthermore, a survey of 93 pediatric hospitals revealed marked heterogeneity in their definitions and practices for the collection of REaL (*R*ace, *E*thnicity and *L*anguage) data⁴³. The tension between the benefits of standardization versus those of customization and granular detail make collection of demographic variables challenging, as do the idiosyncrasies of individual electronic medical record systems and healthcare systems. Federally endorsed categories for race and ethnicity are standardized; however, these large buckets may cloak important subgroup differences and do not permit individuals to precisely define themselves, including as being multiracial. The converse - intricately customized data collection - may be difficult to parse for trends or evaluate for generalizability. Neonatology may face a particular challenge, as REaL data may enter infants' records from linked maternal charts, lack partners' characteristics, and propagate imprecision. Finally, even if obtained in detail, REaL data represents a floor, rather than a ceiling, of patient descriptors; other frameworks such as PROGRESS-PLUS (*P*lace of residence, *R*ace/ethnicity/culture/language, *O*ccupation, *G*ender/sex, *R*eligion, *E*ducation, *S*ES, *S*ocial capital, and other personal and relational features such as sexual orientation, differently-abled status, age, immigration status, educational attainment), are more comprehensive and may be more revealing of underlying risk profiles^{36,44}.

Even when available, demographic data may be underused. Despite evidence of variation in hospital processes, disease outcomes, adverse events, and patient satisfaction by race, ethnicity, and primary language, Cowden et al. found few pediatric institutions utilized those variables in stratifying analyses⁴³. In addition, when racial differences *are* reported, it is usually without attention to or explanation of contextual factors⁴⁵. Since race is a social construct that serves as a proxy for various forms of racism, incomplete reporting of racial/ethnic differences may lead to the perpetuation of disparities or the entrenchment of the drivers of systemic racism⁴⁵. This is especially likely if evidence of variation leads to conclusions based on the incorrect assumption that biological differences exist by race⁴⁵.

Indeed, the use of race-correction in algorithms such as clinical calculators is increasingly being understood as a mechanism by which inequities sometimes get perpetuated through systematic underscoring of risk and differential access to important medical treatments⁴⁶.

Considerations for Implementation—Some QI interventions may be more prone to IGIs during the implementation phase. Technology-focused interventions, such as telehealth or those employing social messaging campaigns, may be especially susceptible to widening disparities^{36,47,48}. Innovations in technology, including medical devices, first spread to those with greatest resources³⁶. A study of more than four million hospitalizations between 2002–2008 revealed that the utilization of a new technology, drug eluting stents, varied by insurance type (rather than patient or hospital characteristics), with privately insured patients more likely to receive the drug eluting stents than those with Medicaid, Medicare, or no insurance⁴⁹. Broadly available interventions may also have poor penetrance to vulnerable populations. In one study of New York-based federally qualified health centers, patients in underrepresented racial and ethnic groups, those without commercial insurance, and those with limited English proficiency were less likely to receive access codes to their electronic patient portal⁵⁰. Finally, even universal access to an intervention has the potential to reinforce inequities. For instance, freely available mass media campaigns may reinforce culturally entrenched stereotypes and further stigmatize or divide subgroups⁵¹.

This literature describes misimplementation of interventions, but it is important to remember that both types of misimplementation - overuse and underuse - could perpetuate or widen health disparities. In adult patients, some studies demonstrate variation in misimplementation by race, ethnicity, and socioeconomic status; patients with higher socioeconomic status were more likely to experience overuse, such as unnecessary screening tests, while patients with lower socioeconomic status may be more likely to experience underuse⁵². Patients of underrepresented racial and ethnic backgrounds may experience both overuse and underuse simultaneously^{52,53}.

A final consideration is that erosions in QI intervention efficacy may occur at multiple points and together may coalesce to widen disparities. Tugwell et al. describe this ‘staircase effect’ as occurring for less advantaged populations due to differences in “awareness, access, or coverage, screening, diagnosis, or targeting, compliance of providers, and adherence of consumers”⁵⁴. Each of these steps represents an opportunity for diminution in intervention efficacy, and cumulatively, these steps further increase inequity⁵⁴. Low-efficacy care, especially within a context of resource scarcity, may create IGIs that occur beyond the scope of the initial QI project. These opportunity costs may be great, in terms of reallocated financial and human resources, and may be coupled with a loss of faith in QI methodology^{39,40,51}.

III. Defining “Equity-Focused Quality Improvement”

Despite these threats to validity and equity, QI interventions do have the potential to improve disparities and further health equity. Interventions that target ‘upstream’ factors contributing to health outcomes within the Socio-Ecological model, such as policy, community-level, and environmental projects, may be more likely to reduce disparities than those focused on

‘downstream’ factors such as hospital process measures and individual behavior^{36,47,55}. For instance, Beck et al. partnered with healthcare providers, care coordinators, social workers, community health workers, pharmacies, and teachers to address multiple ‘upstream’ determinants of health to successfully reduce pediatric hospitalizations in two disadvantaged neighborhoods⁵⁶.

Thus, the use of QI methodology in reducing health disparities requires careful attention to Socio-Ecological principles, data quality, intervention properties, and local healthcare delivery context. Green et al. frame the considerations of equity within QI into three categories: (1) standard QI work, which does not specifically address equity a priori, and thus may possibly improve disparities (but may also maintain or worsen them); (2) group-targeted QI work, which preferentially targets disadvantaged groups, and thus may reduce disparities, and (3) culturally competent QI work, which addresses ‘upstream’ barriers to care that perpetuate disparities, and thus may improve care for all while reducing disparities³⁵. The term “cultural competency” has raised concerns in recent years, as it may lead to the perception that providers can become competent in others’ cultures, which has been associated with culturally reductionist beliefs and curricula³³. Therefore, we introduce the term “Equity Focused-Quality Improvement” or EF-QI.

EF-QI refers to QI initiatives that integrate equity throughout the fabric of the project and are inclusive, collaborative efforts that prioritize and address the needs of disadvantaged populations. EF-QI differs from traditional framing such as Green’s, and differs from QI with an equity lens in that it is action-oriented and centered around equity.³⁵ More than a nod to equity through the post-hoc stratification of analyses by race/ethnicity, EF-QI principles are applicable at every stage of project conception, execution, analysis, and dissemination, and may provide opportunities for reducing disparities in care affecting disadvantaged populations.

IV. Recommendations for Performing Equity Focused-QI (EF-QI)

This section describes eight foundational concepts to guide practitioners in designing and executing Equity Focused QI (EF-QI) projects. Table 1 summarizes these concepts and their practical applications.

Concept 1: Foster a Culture of Equity.—Fostering a culture of equity is critical to initiating and carrying out a successful EF-QI initiative. Similar to safety, equity should be integrated into all existing and future initiatives, processes and policies.³³ As the National Quality Forum (NQF) describes, “a culture of equity recognizes and prioritizes the elimination of disparities through genuine respect, fairness, cultural competency, the creation of environments where all individuals, particularly those from diverse and/or stigmatized backgrounds, feel safe in addressing difficult topics, e.g., racism, and advocating for public and private policies that advance equity”⁵⁷.

EF-QI requires time, personnel and expertise to effectively design a project that addresses elements pivotal to narrowing disparities. Those leading EF-QI efforts need protected time and funding to do this work, including the time to start new initiatives, collect and analyze

data, tailor interventions to local sub-populations, and collaborate with multidisciplinary teams that include patients, families and community partners.

Concept 2: To Address a Disparity, It Must First be Identified.—In order to address local disparities, it is first necessary to identify them. EF-QI initiatives should be built on a foundation of data collection strategies that capture local disparities, needs, and resources. To start, existing QI outcome measures can be stratified by race, ethnicity, language, and other PROGRESS-Plus variables to evaluate for disparities. To do this, collection of demographic data should prioritize as much detail as possible. It is also critical to understand how race/ethnicity and other sociodemographic data are locally collected.

The National Quality Forum (NQF) also provides guidance for the selection of equity-focused QI measures. NQF recommends focusing on one of the following “disparities-sensitive” measures: (1) measures with a known disparity, (2) measures of care decisions impacted by provider behavior and discretion, (3) communication-sensitive processes, and (4) measures impacted by social determinants of health⁵⁸.

Concept 3: Incorporate Equity into the Design of QI Initiatives.—Equity should be incorporated into QI initiatives from the start, from the selection of measures to integration as part of the SMART aim(s), root cause analyses, key driver diagrams, and study design. This “define phase” of QI work should be patient-focused, interprofessional, and collaborative. Furthermore, ongoing Plan-Do-Study-Act (PDSA) cycles should be designed to address ongoing or worsening disparities strategically and in real-time. This is demonstrated in Figure 2, which in contrast with Figure 1 Panel d, depicts PDSAs designed to specifically target improvement for disadvantaged populations. QI research methods evaluating disparities-focused interventions may include analytical techniques such as statistical process control charts, interrupted time series analysis, or stepped wedge design to isolate the intervention effect from contextual factors and secular trends, as previously described³⁴. Furthermore, attention should be paid to the operational definitions of equity-focused QI measures. For example, outcomes can be reported as raw stratified data, gaps or differences between groups, or as a ratio comparing a specific outcome between 2 or more groups.

Concept 4: Involve Families and Community Partners as Critical Stakeholders.—Families and community partners are essential in this work. QI teams should lead with curiosity to learn from families and the expansive work being performed by community coalitions. Rather than assuming what patients and families need and know, qualitative methodologies such as focus groups, semi-structured interviews, or surveys may be utilized to tailor initiatives around families’ needs. Investing in partnerships with families and community members can validate and inform the team’s framework and contribute to the success of change ideas and PDSA cycles. Importantly, teams should make a strong effort to compensate families and community partners for their time.

Concept 5: Consider Alternative Comparator Groups.—Typically, at least two groups are compared to evaluate for a disparity. Historically, White patients are the default comparator group, as White patients typically make up the largest group and have been

considered historically advantaged in many domains. However, for equity-focused QI work, a different reference group can be selected based on specific criteria, such as size of group (i.e. largest group) and performance (i.e. highest performing group), which may differ depending on the measure evaluated and the stratification variable. Local data can also be compared to regional or national data or data from a similar hospital or unit.

Concept 6: Focus Work on Root Causes and Modification of Systems and Processes.—Caution should be exercised to ensure that race-stratified data analyses and discussions highlight the root causes of inequities, such as sources of structural racism. These analyses should address the systems or processes that have resulted from these root causes, rather than work within systems that propagate upstream drivers of inequities. Teams should utilize problem-solving approaches that evaluate and intervene on modifiable systems and processes, rather than focusing on individual behaviors. Specifically, brainstorming the role of implicit or explicit bias, systemic racism, and social determinants of health can provide a framework and language to evaluate the root causes of disparities.

Teams should also consider evaluating problems using QI tools such as cause and effect diagrams (also known as “fishbone” or Ishikawa diagrams), Pareto charts, the 5 Why’s⁵⁹, and simplified failure modes effects analyses (sFMEA) to inform the selection of areas of focus for process improvement⁶⁰. For instance, team members could use the 5 Why’s to brainstorm the ways in which different forms of structural racism are contributing to outcomes or shaping healthcare processes. Together, the combination of systems thinking, evaluation of root causes, and input from families and community partners can help QI teams design and prioritize effective change ideas centered around the patient and family voice.

Concept 7: Adapt Existing Data Visualization Tools to Emphasize Disparity Trends over Time.—Data should be presented as clearly as possible to capture and effectively communicate existing disparities to stakeholders and sponsors. Teams can consider displaying stratified run charts or statistical process control charts in one figure to visually show disparities, as shown in our example Figure 2. Hospital systems or regions may consider designing “disparities dashboards” to automate this work and efficiently identify and track disparities. Multi-center quality initiatives, especially those run by state or regional perinatal center collaboratives, should preserve the ability to disaggregate data by center in order to track, investigate, and possibly intervene on emerging between-hospital and within-hospital variation that may contribute to disparities.

Concept 8: Approach Dissemination of Data from an Equity Perspective.—Data describing underserved communities and findings of the QI initiative should also be disseminated to those communities and organizations using plain-language summaries. Dissemination of learnings via non-traditionally academic formats, such as lay media, social media, and community partners, should be considered to ensure all stakeholders have access to knowledge that may impact their healthcare. This also helps establish community members as partners rather than subjects.

Established frameworks such as the Standards for Quality Improvement Reporting Excellence (SQUIRE 2.0) guidelines challenge QI researchers to move beyond working on improving local outcomes to investigating how that knowledge can better healthcare on a larger scale⁶¹. The SQUIRE 2.0 guidelines do not currently mandate a separate category for capturing the effects of initiatives on health equity; however, consistently including this pivotal dimension in published endeavors should prompt future guideline iterations to move equity from optional to structurally integral.

QI leaders must disseminate lessons learned, best practices, and contextual details to improve generalizability, which can be especially helpful to lower-resourced settings with limited QI infrastructure and support. Evaluations of efficacy and descriptions of human and institutional resources may be useful for adaptation to other settings considering these components as part of their calculus of available resources and opportunity costs. Given the concentration of vulnerable patients at lower-resourced hospitals, such sites may be the loci of both greatest need for EF-QI and least available resources to perform it, thus benefiting from scalable or adaptable interventions.

Conclusion

Equity in healthcare must be stewarded as carefully and collaboratively as antibiotic utilization. Equity-focused QI ensures that the needs and voices of historically marginalized populations are respected and central at every step of QI initiative design, implementation, analysis, and dissemination. As such, EF-QI can be a powerful tool to combat existing health disparities and prevent the emergence of new disparities.

Acknowledgments

Funding source: Dr. Michelle-Marie Peña was supported by the National Institutes of Health (T32HL098054-11 Training in Critical Care Health Policy Research).

References

1. Horbar JD, Edwards EM, Greenberg LT, et al. Racial segregation and inequality in the Neonatal Intensive Care Unit for Very Low-Birth-Weight and very preterm infants. *JAMA Pediatr.* 2019;173(5):455–461. doi:10.1001/jamapediatrics.2019.0241 [PubMed: 30907924]
2. Boghossian NS, Geraci M, Lorch SA, Phibbs CS, Edwards EM, Horbar JD. Racial and ethnic differences over time in outcomes of infants born less than 30 weeks' gestation. *Pediatrics.* 2019;144(3). doi:10.1542/peds.2019-1106
3. Sigurdson K, Mitchell B, Liu J, et al. Racial/Ethnic Disparities in neonatal intensive care: A systematic review. *Pediatrics.* 2019;144(2). doi:10.1542/peds.2018-3114
4. Howell EA, Hebert P, Chatterjee S, Kleinman LC, Chassin MR. Black/white differences in very low birth weight neonatal mortality rates among New York City hospitals. *PEDIATRICS.* 2008;121(3):e407–e415. doi:10.1542/peds.2007-0910 [PubMed: 18267978]
5. LaVeist TA, Gaskin D, Richard P. Estimating the economic burden of racial health inequalities in the United States. *Int J Health Serv Plan Adm Eval.* 2011;41(2):231–238. doi:10.2190/HS.41.2.c
6. Lorch SA. A Decade of improvement in neonatal intensive care: how do we continue the momentum? *JAMA Pediatr.* 2017;171(3):e164395. doi:10.1001/jamapediatrics.2016.4395 [PubMed: 28068439]

7. Janevic T, Zeitlin J, Auger N, et al. Association of race/ethnicity with very preterm neonatal morbidities. *JAMA Pediatr.* 2018;172(11):1061–1069. doi:10.1001/jamapediatrics.2018.2029 [PubMed: 30208467]
8. Braveman PA, Arkin E, Orleans T, Proctor D, Plough A What Is health equity? And what difference does a definition make? Robert Wood Johnson Foundation; 2017.
9. Bingham D, Jones DK, Howell EA. Quality improvement approach to eliminate disparities in perinatal morbidity and mortality. *Obstet Gynecol Clin North Am.* 2019;46(2):227–238. doi:10.1016/j.ogc.2019.01.006 [PubMed: 31056125]
10. Beck AF, Edwards EM, Horbar JD, Howell EA, McCormick MC, Pursley DM. The color of health: how racism, segregation, and inequality affect the health and well-being of preterm infants and their families. *Pediatr Res.* 2020;87(2):227–234. doi:10.1038/s41390-019-0513-6 [PubMed: 31357209]
11. Manuck TA. Racial and ethnic differences in preterm birth: a complex, multifactorial problem. *Semin Perinatol.* 2017;41(8):511–518. doi:10.1053/j.semperi.2017.08.010 [PubMed: 28941962]
12. Matoba N, Collins JW. Racial disparity in infant mortality. *Semin Perinatol.* 2017;41(6):354–359. doi:10.1053/j.semperi.2017.07.003 [PubMed: 28864275]
13. Ely DM, Driscoll AK. Infant mortality in the United States, 2018: Data from the period linked Birth/Infant death file. National Vital Statistics Reports, vol 69 no 7. Hyattsville, MD: National Center for Health Statistics; 2020.
14. Martin JA, Hamilton BE, Osterman MJK. Births in the United States, 2019. NCHS Data Brief, no 387. Hyattsville, MD: National Center for Health Statistics, 2020.
15. Martin JA, Hamilton BE, Osterman MJK. Births in the United States, 2018. NCHS Data Brief, no 346. Hyattsville, MD: National Center for Health Statistics. 2019.
16. Parker MG, Burnham LA, Melvin P, et al. Addressing disparities in mother’s milk for VLBW infants through statewide quality improvement. *Pediatrics.* 2019;144(1). doi:10.1542/peds.2018-3809
17. Ehrenthal DB, Kuo H-HD, Kirby RS. Infant mortality in rural and nonrural counties in the United States. *Pediatrics.* 2020;146(5). doi:10.1542/peds.2020-0464
18. Hinterland K, Naidoo M, King L, et al. Community Health Profiles 2018, Manhattan Community District 10: Central Harlem; 2018:1–20.
19. Hinterland K, Naidoo M, King L, et al. Community Health Profiles 2018, Manhattan Community District 7: Upper West Side; 2018:1–20.
20. Parker MG, Greenberg LT, Edwards EM, Ehret D, Belfort MB, Horbar JD. National trends in the provision of human milk at hospital discharge among Very Low-Birth-Weight infants. *JAMA Pediatr.* Published online September 3, 2019. doi:10.1001/jamapediatrics.2019.2645
21. Howell EA, Egorova NN, Balbierz A, Zeitlin J, Hebert PL. Site of delivery contribution to black-white severe maternal morbidity disparity. *Am J Obstet Gynecol.* 2016;215(2):143–152. doi:10.1016/j.ajog.2016.05.007 [PubMed: 27179441]
22. Hebert PL, Chassin MR, Howell EA. The contribution of geography to black/white differences in the use of low neonatal mortality hospitals in New York City. *Med Care.* 2011;49(2):200–206. doi:10.1097/MLR.0b013e3182019144 [PubMed: 21239954]
23. Howell EA, Janevic T, Hebert PL, Egorova NN, Balbierz A, Zeitlin J. Differences in morbidity and mortality rates in black, white, and Hispanic very preterm infants among New York City hospitals. *JAMA Pediatr.* 2018;172(3):269. doi:10.1001/jamapediatrics.2017.4402 [PubMed: 29297054]
24. Yannekis G, Passarella M, Lorch S. Differential effects of delivery hospital on mortality and morbidity in minority premature and low birth weight neonates. *J Perinatol Off J Calif Perinat Assoc.* 2020;40(3):404–411. doi:10.1038/s41372-019-0423-9
25. Profit J, Gould JB, Bennett M, et al. Racial/Ethnic disparity in NICU quality of care delivery. *Pediatrics.* 2017;140(3). doi:10.1542/peds.2017-0918
26. Baker LC, Afendulis CC, Chandra A, McConville S, Phibbs CS, Fuentes-Afflick E. Differences in neonatal mortality among whites and Asian American subgroups: evidence from California. *Arch Pediatr Adolesc Med.* 2007;161(1):69–76. doi:10.1001/archpedi.161.1.69 [PubMed: 17199070]
27. Li W, Onyebek C, Huynh M, et al. Summary of Vital Statistics, 2017. New York, NY: New York City Department of Health and Mental Hygiene, Bureau of Vital Statistics; 2019.

28. Montoya-Williams D, Williamson VG, Cardel M, Fuentes-Afflick E, Maldonado-Molina M, Thompson L. The Hispanic/Latinx perinatal paradox in the United States: a scoping review and recommendations to guide future research. *J Immigr Minor Health*. Published online October 31, 2020. doi:10.1007/s10903-020-01117-z
29. Tullius Z, Rankin K, DeSisto C, Collins JW. Adverse birth outcome across the generations: the contribution of paternal factors. *Arch Gynecol Obstet*. 2020;302(5):1151–1157. doi:10.1007/s00404-020-05712-1 [PubMed: 32748050]
30. Lion KC. Caring for children and families with limited English proficiency: current challenges and an agenda for the future. *Hosp Pediatr*. 2017;7(1):59–61. doi:10.1542/hpeds.2016-0186 [PubMed: 27979993]
31. Obregon E, Martin CR, Frantz ID III, Patel P, Smith VC. Neonatal Intensive Care Unit discharge preparedness among families with limited English proficiency. *J Perinatol*. 2019;39(1):135–142. doi:10.1038/s41372-018-0255-z [PubMed: 30341402]
32. Miquel-Verges F, Donohue PK, Boss RD. Discharge of Infants from NICU to Latino Families with limited English Pproficiency. *J Immigr Minor Health*. 2011;13(2):309–314. doi:10.1007/s10903-010-9355-3 [PubMed: 20490681]
33. Montoya-Williams D, Peña M-M, Fuentes-Afflick E. In pursuit of health equity in pediatrics. *J Pediatr X*. 2020;5:100045. doi:10.1016/j.ympdx.2020.100045 [PubMed: 33733084]
34. Lion KC, Raphael JL. Partnering health disparities research with quality improvement science in pediatrics. *PEDIATRICS*. 2015;135(2):354–361. doi:10.1542/peds.2014-2982 [PubMed: 25560436]
35. Green AR, Tan-McGrory A, Cervantes MC, Betancourt JR. Leveraging quality improvement to achieve equity in health care. *Jt Comm J Qual Patient Saf*. 2010;36(10):435–442. doi:10.1016/S1553-7250(10)36065-X [PubMed: 21548504]
36. Veinot TC, Mitchell H, Ancker JS. Good intentions are not enough: how informatics interventions can worsen inequality. *J Am Med Inform Assoc*. 2018;25(8):9.
37. Corl K, Levy M, Phillips G, Terry K, Friedrich M, Trivedi AN. Racial and ethnic disparities In care following the New York State Sepsis Initiative. *Health Aff Proj Hope*. 2019;38(7):1119–1126. doi:10.1377/hlthaff.2018.05381
38. Werner Rachel M, Asch David A, Daniel Polsky. Racial Profiling. *Circulation*. 2005;111(10):1257–1263. doi:10.1161/01.CIR.0000157729.59754.09 [PubMed: 15769766]
39. Berenholtz SM, Needham DM, Lubomski LH, Goeschel CA, Pronovost PJ. Improving the quality of quality improvement projects. *Jt Comm J Qual Patient Saf*. 2010;36(10):468–473. doi:10.1016/s1553-7250(10)36069-7 [PubMed: 21548508]
40. Auerbach AD, Landefeld CS, Shojania KG. The tension between needing to improve care and knowing how to do it. *N Engl J Med*. 2007;357(6):608–613. doi:10.1056/NEJMs070738 [PubMed: 17687138]
41. Polubriaginof FCG, Ryan P, Salmasian H, et al. Challenges with quality of race and ethnicity data in observational databases. *J Am Med Inform Assoc JAMIA*. 2019;26(8–9):730–736. doi:10.1093/jamia/ocz113 [PubMed: 31365089]
42. Klinger EV, Carlini SV, Gonzalez I, et al. Accuracy of race, ethnicity, and language preference in an electronic health record. *J Gen Intern Med*. 2015;30(6):719–723. doi:10.1007/s11606-014-3102-8 [PubMed: 25527336]
43. Cowden JD, Flores G, Chow T, et al. Variability in collection and use of race/ethnicity and language data in 93 pediatric hospitals. *J Racial Ethn Health Disparities*. 2020;7(5):928–936. doi:10.1007/s40615-020-00716-8 [PubMed: 32056162]
44. O’Neill J, Tabish H, Welch V, et al. Applying an equity lens to interventions: using PROGRESS ensures consideration of socially stratifying factors to illuminate inequities in health. *J Clin Epidemiol*. 2014;67(1):56–64. doi:10.1016/j.jclinepi.2013.08.005 [PubMed: 24189091]
45. Boyd R, Lindo EG, Weeks LD, McLemore MR. On racism: a new standard for publishing on racial health inequities. *Health Affairs Blog*. doi:10.1377/hblog20200630.939347
46. Vyas DA, Eisenstein LG, Jones DS. Hidden in plain sight — Reconsidering the use of race correction in clinical algorithms. Malina D, ed. *N Engl J Med*. 2020;383(9):874–882. doi:10.1056/NEJMms2004740 [PubMed: 32853499]

47. Lorenc T, Petticrew M, Welch V, Tugwell P. What types of interventions generate inequalities? Evidence from systematic reviews. *J Epidemiol Community Health*. 2013;67(2):190–193. doi:10.1136/jech-2012-201257 [PubMed: 22875078]
48. Cahan EM, Mittal V, Shah NR, Thadaney-Israni S. Achieving a quintuple aim for telehealth in pediatrics. *Pediatr Clin North Am*. 2020;67(4):683–705. doi:10.1016/j.pcl.2020.04.015 [PubMed: 32650867]
49. Epstein AJ, Ketcham JD, Rathore SS, Groeneveld PW. Variations in the use of an innovative technology by payer: the case of drug-eluting stents. *Med Care*. 2012;50(1):1–9. doi:10.1097/MLR.0b013e31822d5de9 [PubMed: 22167062]
50. Ancker JS, Barrón Y, Rockoff ML, et al. Use of an electronic patient portal among disadvantaged populations. *J Gen Intern Med*. 2011;26(10):1117–1123. doi:10.1007/s11606-011-1749-y [PubMed: 21647748]
51. Lorenc T, Oliver K. Adverse effects of public health interventions: a conceptual framework. *J Epidemiol Community Health*. 2014;68(3):288–290. doi:10.1136/jech-2013-203118 [PubMed: 24336237]
52. Helfrich CD, Hartmann CW, Parikh TJ, Au DH. Promoting health equity through de-implementation research. *Ethn Dis*. 29(Suppl 1):93–96. doi:10.18865/ed.29.S1.93
53. Kressin NR, Groeneveld PW. Race/Ethnicity and overuse of care: a systematic review. *Milbank Q*. 2015;93(1):112–138. doi:10.1111/1468-0009.12107 [PubMed: 25752352]
54. Tugwell P, de Savigny D, Hawker G, Robinson V. Applying clinical epidemiological methods to health equity: the equity effectiveness loop. *BMJ*. 2006;332(7537):358–361. doi:10.1136/bmj.332.7537.358 [PubMed: 16470062]
55. Chin MH. How to achieve health equity. *N Engl J Med*. 2014;371(24):2331–2332. doi:10.1056/NEJMe1412264 [PubMed: 25494273]
56. Beck AF, Anderson KL, Rich K, et al. Cooling the hot spots where child hospitalization rates are high: a neighborhood approach to population health. *Health Aff Proj Hope*. 2019;38(9):1433–1441. doi:10.1377/hlthaff.2018.05496
57. National Quality Forum (NQF). A roadmap for promoting health equity and eliminating disparities: The four I's for health equity. NQF; 2017:1–119. https://www.qualityforum.org/Publications/2017/09/A_Roadmap_for_Promoting_Health_Equity_and_Eliminating_Disparities_The_Four_I_s_for_Health_Equity.aspx
58. Weissman J, Betancourt JR, Green AR, et al. Commissioned paper: healthcare disparities measurement. Published 2011. Accessed October 19, 2020. <https://mghdisparitiessolutions.files.wordpress.com/2015/10/dsc-commissioned-paper.pdf>
59. Card AJ. The problem with '5 whys.' *BMJ Qual Saf*. 2017;26(8):671–677. doi:10.1136/bmjqs-2016-005849
60. Institute for Healthcare Improvement. Quality improvement essentials toolkit. Institute for Healthcare Improvement; 2017. <http://www.ihf.org/resources/Pages/Tools/Quality-Improvement-Essentials-Toolkit.aspx>
61. Ogrinc G, Davies L, Goodman D, Batalden P, Davidoff F, Stevens D. SQUIRE 2.0 (Standards for QUality Improvement Reporting Excellence): revised publication guidelines from a detailed consensus process. *BMJ Qual Saf*. 2016;25(12):986–992. doi:10.1136/bmjqs-2015-004411
62. Parker MG, Gupta M, Melvin P, et al. . Racial and ethnic disparities in the use of mother's milk feeding for very low birth weight infants in Massachusetts *J Pediatr*, 204 (2019), pp. 134–141.e1, 10.1016/j.jpeds.2018.08.036 [PubMed: 30274926]

Practice Points:

- QI work designed without an intentional focus on equity may mitigate, worsen, or perpetuate existing disparities.
- Equity-focused QI (EF-QI) initiatives intentionally integrate equity throughout the project to address the needs of disadvantaged populations. This approach may effectively combat disparities.
- Important EF-QI principles include stratifying data by selected sociodemographic variables, partnering with family and community stakeholders, selecting comparator groups and measures to illuminate and address disparities, and disseminating learnings to professional and lay audiences.

Research Directions:

- The use of QI to address disparities needs to be more rigorously studied; learnings from both successful and unsuccessful initiatives should be published.
- The influence of parental/community attributes beyond race/ethnicity (such as sexual orientation, English proficiency, differently-abled status) on infant outcomes and health disparities must be investigated.
- The optimal strategy for disseminating learnings to parents, community partners, and low resource settings merits further study.

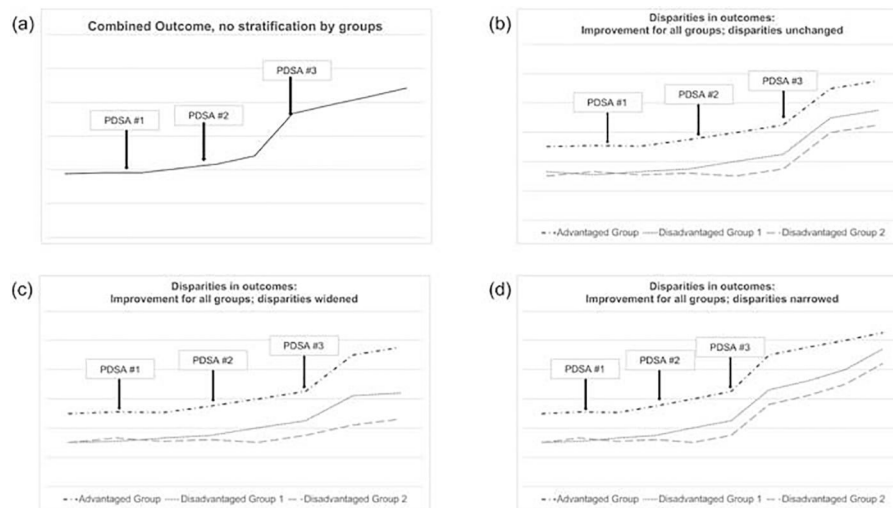


Figure 1.

This figure presents possible impacts for a hypothetical quality improvement (QI) project on disparities between populations. Displaying the outcome for all populations combined (a) may show overall improvement and obscure existing disparities. Separating the run chart into multiple populations may reveal that despite overall improvement the QI project resulted in perpetuated (b), widened (c), or narrowed (d) disparities. (Modified from Green et al.)

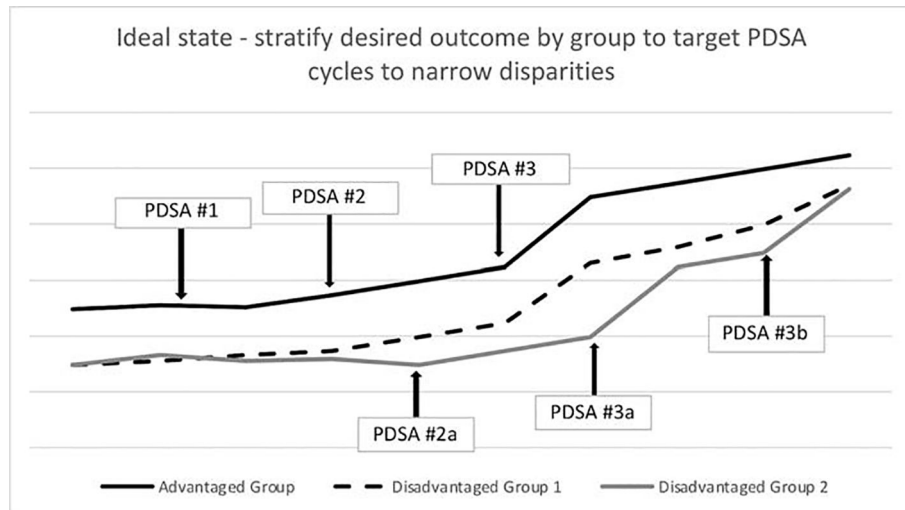


Figure 2.

This figure presents the ideal outcome for a hypothetical Equity-Focused QI project. PDSA cycles have been specifically targeted to the needs of disadvantaged populations and have led to both overall improvement in the desired outcome and to narrowed disparities between populations.

Table 1.

Applying equity-focused quality improvement concepts to practice.

Concept	Practical Application
1. Foster a culture of equity.	<ul style="list-style-type: none"> • Incorporate equity into all discussions about existing and future initiatives. • Similar to safety, striving for equity should be everyone's work.
2. To address a disparity, it must first be identified.	<ul style="list-style-type: none"> • Analyze data considering PROGRESS-Plus variables including race/ethnicity, preferred language, country of origin or neighborhood. • Investigate how race, ethnicity and sociodemographic data are locally collected.
3. Incorporate equity into the selection of measures, development of SMART aim, root cause analysis, key driver diagram, and study design.	<ul style="list-style-type: none"> • Incorporate equity into the selection of measures, SMART aim, root cause analysis, key driver diagram, and study design.
4. Families and community partners are critical stakeholders.	<ul style="list-style-type: none"> • Families and community partners should have a seat at the table to provide input on project design and planning. • Conduct qualitative work to allow family and community voices to inform SMART aims, key driver diagrams and change ideas.
5. Consider alternative comparator groups.	<ul style="list-style-type: none"> • The reference group can be selected based on specific criteria, such as size of group and performance of the group depending on the EF-QI measure.
6. Focus of work should be on the evaluation of root causes and modification of systems and processes.	<ul style="list-style-type: none"> • Be careful when analyzing race-stratified data and ensure you understand what the race variable is serving as a proxy for. • Approach disparities using systems thinking and QI tools to evaluate root causes and systemic contributors to problems. Avoid focusing on individual behaviors.
7. Adapt existing data visualization tools to emphasize disparity trends over time.	<ul style="list-style-type: none"> • Display run charts and statistical process control charts stratified by REaL data at a minimum and other characteristics as defined by project aims.
8. Approach dissemination of data from an equity perspective.	<ul style="list-style-type: none"> • Disseminate data and findings to all involved stakeholders using plain language summaries to increase community capacity-building. • Share lessons learned and best practices with other units and organizations, acknowledging limitations in generalizability.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript