EXAMINING PATIENTS’ REPRESENTATIVENESS IN HCAHPS SURVEYING: A MIXED-METHOD APPROACH IN HEALTHCARE

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Abstract

Alyncia Bowen, Advisor

This study examined the representation of racial minorities in the demographic subpopulation of Hospital Consumers Assessment of Healthcare Providers and Services (HCAHPS) survey respondents. These survey scores are the basis for a substantial portion of financial compensation from the Centers for Medicare and Medicaid Services; they are used to drive the process improvement of patient-centered care. Considerable previous research has focused on factors that affect HCAHPS scores and made adjustments to the scores of many other demographic factors. However, none has focused specifically on race and representativeness, which is needed to ensure benefits for all health care consumers. Reliance on this mechanism as the single measure of patient experience on which financial decisions are made and improvement efforts are centered may be a further example of systemic racism in a system with an established history of racism. This study examined the use of a representative sample from a social justice perspective utilizing Rawls' framework from *A Theory of Justice*. Following the logic of this work, most people would not choose failing to hear diverse patient voices at a representative rate when blinded to their own identity, as this would not represent the choice most likely to result in patient-centered care for all health care consumers. This mixed-method, convergent parallel design study compared the sample of patients returning HCAHPS surveys, the inpatient population, and contextualized those results with semi-structured interviews with patient experience professionals to provide context to the need for a representative sample.

Keywords: HCAHPS, racism in health care, patient-centered care, patient experience, process improvement

This work is dedicated in loving memory to my husband Arlan, who taught me that I can do hard things; to my mother Renee Gumins Knight and my grandmother Reva Forman Gumins, who were among the wisest women I have ever known and never let me take for granted the power of my mind when I am determined to achieve.

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Chapter 1: Introduction

This mixed-method study examined how effectively the Hospital Consumers Assessment of Healthcare Providers and Services (HCAHPS) represents the needs of all health care consumers in the United States. At the end of the last century, health care leaders began to vigorously examine issues of health care quality both in the United States and across the world. In the United States, the Institute of Medicine (IoM) captured the attention of the industry with its landmark publication *To Err Is Human*. The report, which focused on error reduction and quality, established a firm link between health outcomes and how health consumers experience their care, positioning patient experience as one of four quality quadrants (Brown & Patterson, 2001). This report also introduced the concept of paying for performance to motivate health providers to improve care quality (Cohen et al., 2017). For the first time, conversations of health care quality meaningfully and significantly included the lens of how patients experience care (Epstein & Street, 2011). In 2011, pay for performance moved from concept to policy when value-based purchasing (VBP) was included in the Affordable Care Act (ACA), colloquially referred to as “Obamacare” after then President Barack Obama, who passed the landmark health care reform. Not only did patients' experience of care begin to influence hospitals financially, but it also drove quality improvement measures and ratings and provider compensation. To evaluate experience of care, the Centers for Medicare and Medicaid Services (CMS) partnered with the IoM to develop a validated tool to measure patients’ experience of care: the HCAHPS surveys.

HCAHPS surveys used voluntary responses of patients discharged from acute care hospitals to rate patient-centered care. Since its inception in 2006, several patient mix adjustments have been applied to the resulting data, allowing for variation in scores based on key demographics outside the hospital's control. Adjustments are important as the factors adjusted for have been shown to impact patients’ perception of their care experience and are outside of the hospital’s control. These factors include age, gender, economic status, and geographic location; however, race is not included. Because financial and quality improvements in hospitals are solely based on the scores from these surveys, it is important to understand how well the scores represent the perspectives of all hospital consumers. American philosopher John Rawls posits that the fairest ethical decisions stem from the *original position*, a standpoint where individuals are unaware of their societal roles. This research endeavored to apply Rawls' theory to the question of HCAHPS respondents' representativeness and the fairness of employing this measure. This study aimed to elucidate the extent to which HCAHPS scores accurately reflect the experiences of all hospital consumers, with a particular focus on the consideration of racial factors.

Problem Statement

It is not known how well the subpopulation of HCAHPS survey respondents reflects the racial and ethnic diversity of admitted hospital patients and how well the survey represents the issues that are important to health care consumers. Currently, HCAHPS scores are adjusted for many demographic factors, including age, gender, and economic and education levels; however, they do not include race or ethnicity. This problem impacts health care consumers, hospitals, and health care employees because hospitals receive substantial financial incentives based on these scores and the metric is widely used in hospitals to measure and drive experience quality. Among the many factors contributing to this problem are funding structures that encourage hospitals to cater to White patients, patients’ disregard for experiences of discrimination, and lack of information for minority patients to make health care decisions based on the experiences of their peers. This study contributes to the body of knowledge needed to address this problem by exploring the HCAHPS through the lens of race and ethnicity.

Purpose of the Study

Quantitatively, the purpose of the study was to establish if the HCAHPS scores are representative of the entire population of health care consumers admitted to hospitals. Qualitatively, it sought to understand the perspectives of patient experience professionals, issues with the survey they consider to be significant, and the role of HCAHPS in their understanding of their work. Specifically, the aim was to understand the patient experience professionals' insights regarding race and ethnicity and if or how these insights are factors in how patients experience their care. These goals were accomplished through a mixed-method, convergent parallel design. Qualitative data were obtained from 11 semi-structured interviews with patient experience professionals. Quantitatively, available demographic information from HCAHPS surveys returned to the health system were compared to demographic information from the electronic medical records of congruent time frames. A dependent *t* test was conducted using the two data sets to determine the similarity of racial and ethnic subgroups. When comparing participants that are linked, such as admission to a health system and survey respondents (independent variables), which are being evaluated on a single measure such as race (dependent variable), the dependent t-test is a suitable analysis (National University, 2024). Both quantitative and qualitative data were collected and analyzed at the same time.

By combining the two types of data when examining the results, this study used the qualitative findings to both authenticate and provide context for the effects of race and ethnicity on HCAHPS scores. Creating a robust understanding of how race and ethnicity impact HCAHPS scores and how the scores impact the hospitals enables the introduction of any changes indicated by Rawls' original position. According to Rawls, the choices made behind the veil of ignorance (the original position) are the fairest and the most rational choices, made without the distraction of self-interest (Ekemekci & Arda, 2016, p. 4).

Research Questions

This convergent parallel design study utilized the following quantitative hypotheses:

H_1: There is a statistically significant difference between the response rate of non-White patients to the HCAHPS survey and the admission rate of non-White patients to a health system during the same time.

H_{01}: There is not a statistically significant difference between the response rate of non-White patients to the HCAHPS survey and the admission rate of non-White patients to a health system during the same period.

H_2: Patient race is a statistically significant factor in how patients score their hospital experience.

H_{02}: Patient race is not a statistically significant factor in how patients score their hospital experience.

The qualitative central research questions were:

RQ: How well do patient experience professionals believe HCAHPS scores capture the experiences of patients who identify as racial minorities?

RQ2: How do patient experience professionals describe the impact of HCAHPS scores on hospital operations and quality improvement?

The perspectives of patient experience professionals regarding the HCAHPS survey response data and their perceptions of the experiences of racially and ethnically diverse patient populations were used to provide a basis for approaching discrepancies. The semi-structured interviews informed the importance of HCAHPS scores to hospital leaders and the use of this metric to drive experience quality improvement. The sample size for the semi-structured interviews was 11; as this study employed data from the semi-structured interviews to support understanding and provide background for the quantitative findings, this sample size was sufficient to reach saturation. Lastly, this study aligns with Franklin University's Doctor of

Healthcare Administrations program learning outcomes—analyze organizational health care problems, develop solutions, measure their impact, and demonstrate ethical leadership and management theory in health care organizations.

This study provided definitive research regarding the representativeness of the sample of HCAHPS respondents relative to race and ethnicity. Ultimately, for the survey results to be valid, the sample must be representative of the hospital's inpatient population. Because these survey results are utilized as a basis for VBP and impact the financial wellbeing of hospitals and health systems, it is critical to ensure that safety net hospitals are not being negatively impacted by the very system that was proposed to support the infrastructure to improve social determinants of health. This study will further the conversation about what it means for health care to be patient-centered and to listen to and act upon the voice of the patient.

Ideally, this study challenges the prevailing perceptions regarding patient experience and how HCAHPS is used in the United States to universally measure all patients. This study could also support the efforts aimed at providing more equitable funding and process improvements as it expands the perspectives being considered in experience quality metrics. Most importantly, this study creates space to revisit the HCAHPS survey and understand if additional mix adjustments or other changes should be applied. Moreover, the study considers the analysis of organizational health care problems and measures, as well as how the industry demonstrates ethical leadership and management theory in health care organizations.

Definition of Terms

HCAHPS: Hospital Consumer Assessment of Healthcare Providers and Systems survey is the first national, standardized, publicly reported survey of patients' perspectives of hospital care. HCAHPS (pronounced "H-caps"), also known as the CAHPS Hospital Survey, is a survey instrument and data collection methodology for measuring patients' perceptions of their hospital experience (CMS, 2021).

CMS: Center for Medicare and Medicaid Services: Federal health insurance program for:

- Medicare
    - People who are 65 or older
    - Certain younger people with disabilities
    - People with end-stage renal disease (permanent kidney failure requiring dialysis or a transplant, sometimes called ESRD)”
- Medicaid
    - Eligible low-income adults
    - Children
    - Pregnant women
    - Disabled people (CMS, 2021)

Quality of Care: “Quality of care is the degree to which health services for individuals and populations increase the likelihood of desired health outcomes” (WHO, 2023).

Value-Based Purchasing: “The Hospital Value-Based Purchasing (VBP) Program is part of our ongoing work to structure Medicare’s payment system to reward providers for the quality of care they provide” (CMS, 2021).

WHO: The World Health Organization was established in 1948 by the United Nations to advance health globally for all people (WHO, 2023).

Patient Experience: This term involves what happened or failed to happen while a health care consumer received care (Kumah, 2019, p. 173).

Patient Satisfaction: It describes how a health care consumer feels about what happened or did not happen while receiving care (Kumah, 2019, p. 173).

Social Determinants of Health: They are “the non-medical factors that influence health outcomes. They are the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life. These forces and systems include economic policies and systems, development agendas, social norms, social policies and political systems” (WHO, 2024).

The Veil of Ignorance: It refers to the hypothetical curtain that prevents actors from realizing the individual attributes or roles they may have in any social institution (Follesdal, 2014, p. 8).

The Original Position: This is the place where actors step behind the veil of ignorance and decide the most just outcome in any social challenge (Follesdal, 2014, p. 8).

Chapter 2: Literature Review

When President Barack Obama signed the Patient Protection and Affordable Care Act into law on March 23, 2010, health care consumers in the United States for the first time had the opportunity to access information about how other health consumers perceived their care experience as admitted hospital patients. The CMS-hosted website, Hospital Compare, made it possible to view data from HCAHPS surveys detailing the experiences of previous consumers (Giordano et al., 2010). These surveys were designed to capture information regarding various aspects of care to allow comparison of the experience from the patient's perspective (Elliot et al., 2010). Additionally, these scores are the basis for approximately one-quarter of the financial bonuses and penalties that U.S. hospitals receive under the federal VBP program (Tanenbaum, 2016). This literature review explored the history and aspirations of the HCAHPS survey and assessed current knowledge about the efficacy of these scores as a base for VBP. It examined how well the survey represents the total population of health care consumers through the exploration of previous research and identified gaps. Consideration was also given to current knowledge about the validity and reliability of these data and the fairness of using this metric from Rawls' original position.

Search Strategies and Procedures

The studies for this literature review were selected using the search feature of Google Scholar, Business Source Complete, Medline, and PubMed databases (see Table 1). Studies were selected for inclusion based on timeliness, with priority given to research published within the last 5 years, foundational research, most frequently cited research, and peer-reviewed materials. Extensive search also occurred on government and non-profit websites, including CMS, Agency for Healthcare Research and Quality (AHRQ), and the World Health Organization (WHO).

Table 1

Literature Search Phrases and Databases

Search Terms	Database	Literature Returned	Literature Reviewed
Patient Experience	Business Source Complete	1589	29
HCAHPS and Value Based Purchasing	Business Source Complete	16	9
Patient Experience	Google Scholar	5,160,000	87
HCAHPS and Value Based Purchasing	Google Scholar	1,220	18
Patient Experience and Demographics	Google Scholar	60,300	10
Patient Experience	Medline	14,644	34
HCAHPS Validity	Medline	7	1
Patient Experience Measurement	PubMed	13,902	17
HCAHPS Alternatives	PubMed	2	2
HCAHPS and Patient Mix	Open Dissertations	17	6

Research documents were reviewed and assessed based on relation to topic, frequency of citation by others, and contribution of foundational or novel information.

HCAHPS and VBP

As an impetus to provide high-quality care to all U.S. health care consumers, VBP purported to reward or penalize individual hospitals based on key performance measures (Lee et al., 2020). One such key measure was a tool that compared patients' care perception in a standardized, validated way both for performance assessment and for health care consumers to make informed choices (Giordano et al., 2010). The VBP program was, at its core, designed to link the amount of financial compensation that hospitals receive to their performance on specific quality measures (Chatterjee et al., 2012). A key component of these measures is the patient's experience of care. Approximately 25% of the VBP dollars are linked to HCAHPS, which is the only measure not based on a physical health outcome (Kelley, 2015).

As a method that informs quality of care assessment, VBP uses HCAHPS scores as the base data for its conclusions (Ramirez et al., 2018), following global discussion that began just after the turn of the century regarding person-centered care. Person-centered care refers to the extent to which patients, their preferences, histories, and individual choices are centralized to individualized goal planning when designing treatment courses (Eklund et al., 2018). This perspective of quality became relevant when the WHO, an international authority charged with defining the global priorities for health and measuring attainment of these goals, released its recommended framework for a high-quality health system, identifying six optimal building blocks (Manayazewal et al., 2017). Patients' perspective of their care was propelled to an international topic in the health care community by the inclusion of this metric as a crucial element of measurement in the WHO Building Blocks of Health (WHO, 2010). Almost simultaneously, CMS and the AHRQ, both agencies under the umbrella of the U.S. Department of Health and Human Services, joined forces to develop the HCAHPS survey (AHRQ, 2020), an innovative approach that created a forum for health care consumers to publicly evaluate their experience of care so that others could compare hospitals (HCAHPS, 2021).

HCAHPS as an Improvement Driver

In order for HCAHPS to be a viable tool to inform health care decisions, its efficacy in improving experience quality must be considered. The VBP program was implemented to encourage hospitals to improve the quality of their care and allow patients to choose care based on quality (Carter & Silverman, 2016). In 2017, Papinicolas et al. compared hospitals that participated in VBP to those that did not over three years and found no statistically significant difference in experience quality between the groups, leading the researchers to question the use of VBP as an improvement driver. This finding was consistent with Ryan et al. (2017), who were unable to pinpoint a single improvement in patient experience, clinical process, or mortality through the difference-in-difference testing method using public data obtained from the CMS website. A 2014 study of the validity and reliability of HCAHPS results examined HCAHPS scores from a behavioral psychological perspective; it found significant concerns regarding the validity of the relationship between the factor being measured and the health care quality it intended to measure. (Westbrook et al., 2014).

What the HCAHPS Survey Measures

The HCAHPS survey is designed to measure the patients' experience of care by asking questions regarding what did and did not happen during their hospital stay and how frequently (Kumah, 2019). The survey asks about six distinct types of experiences: care from nurses, care from doctors, the hospital environment, general experiences, discharge, and overall experience. (HCAHPS, 2023). Additionally, the survey includes a few questions about the patient. Most questions are designed to capture how frequently specific care activities, such as responding to call lights, explanation of care, and assistance with toileting occurred during the hospital experience, asking patients to indicate never, sometimes, usually, or always or indicate strongly disagree, disagree, agree, or strongly agree to capture data on a Likert scale. The *overall score* and *the likelihood to recommend* are top box measures, with health systems striving to receive the highest rating in each category (HCAHPS, 2023). Appendix A offers an example of the HCAHPS survey. Health systems may also ask supplemental questions at their discretion and leave space for patients' comments.

HCAHPS and Disparity

"A health disparity should be viewed as a chain of events signified by a difference in: (1) environment, (2) access to, utilization of, and quality of care, (3) health status, or (4) a particular health outcome that deserves scrutiny" (Carter-Pokras & Baquet, 2002, p. 427). Presumably, there may be many types of disparity in the population of health care consumers; for this study, the central focus was racial disparity, specifically between Black and non-White Hispanic populations and the majority Caucasian population. In Rawls' conception of the original position, he suggests that actors step behind the veil of ignorance to determine the fairest way to distribute social goods; however, he does not include health in these goods, as according to Rawls, health is considered a primary good. “Primary goods may be defined as the things free and equal citizens need all through their lives to live as a normal and social member of the society” (Ekmekci & Arda, 2015, p. 229). However, the experience of receiving health care and using HCAHPS as its measure could be considered a social good. Patient experience quality is the recognition that what is being measured is the interpersonal interactions that occur during care and how care providers interact with patients and one another (Larson et al., 2019).

Purportedly introduced to both promote experience quality and support the equity of health care access by avoiding financial penalties for safety net hospitals (serving predominantly minority patients; Elliot et al., 2016), VBP has been questionably successful. In research conducted over a 4-year period, hospitals earned points by both progressing toward and attaining higher top box scores on HCAHPS. Some research has found that safety net hospitals showed identifiable improvement (Elliot et al., 2016). Notably, this research did not compare these results to non-safety net hospitals or hospitals not serving predominantly minority patients, making it impossible to know if improvement was the same or greater for those hospitals and if ultimately, the VBP bonuses were equitably distributed. Separately, the research team of AbuDagga and Weech Moldonado (2016) used Pearson correlations to identify relationships between patient demographics, including age, gender, and insurance status; hospital attributes such as staffing levels, occupancy, and teaching vs. non-teaching; as well as community characteristics like income, minority rates, health care availability, and experience data. These researchers were able to link some positive correlations between identified attributes and HCAHPS scores, illustrating the potential existence of a relationship between these scores and some aspects of health equity (AbuDagga & Weech-Maldonado, 2016). However, without specific consideration of race as a characteristic, it is not possible to understand the relationship between these scores and potential benefit to all health care consumers. Hence, considering the use of these scores from behind the veil of ignorance would be unwise, since without knowing how all groups are impacted and which individual attributes actors hold, HCAHPS would be insufficient to inform a just distribution.

Racism in Health Care

In order to assess how representative the sample of HCAHPS survey responses is of American health care consumers, one must assume that each person living in the United States is a potential consumer of health care services. Despite this truth, research has shown that minorities and particularly non-White health consumers are more likely to suffer from many conditions, with more significant negative outcomes, due to inequitable care, biased treatment, and systemic racism (Benkert et al., 2006). Notably, the link between the position held in society and the health of that individual is an often-discussed phenomenon, known as the social determinants of health (SDH). Vicente Navarro, a health policy expert, addressed the *Eighth European Conference of the International Union of Health Promotion and Education* in 2008, highlighting the ways in which a person's health is impacted by the specifics of their position in the social and economic order. He shared that he had researched and documented this phenomenon globally and over many years:

> In the United States, as in any other country, the highest number of deaths could be prevented by interventions in which the mortality rate of all social classes was made the same as the mortality rate of those in the top income decile. (Navarro, 2009, p. 5)

Structural Racism in Health Care

Research has established that simply being born male and Black in America results in a shorter life expectancy than any other population (Powell et al., 2019). While this finding is likely a complex issue, it may in part be attributable to racism in health care, which has been shown, for a wide variety of reasons, to diminish the participation and compliance of minority consumers while weakening their perception of the quality of care received (Ben et al., 2017). Understanding the extensive history of structural racism in health care requires a diligent and thorough investigation of all health care initiatives to ensure that efforts are benefitting rather than further harming already vulnerable populations.

Structural racism refers to the ways that social resources such as health care, education, housing, employment, and institutions such as banking and public health are built and maintained to benefit and oppress specific subpopulations (Yearby, 2020). Inherent to U.S. health care is a long history of constructs and practices that blatantly harmed or subversively denied access to minority patients. Feagin and Bennefield (2014) provide an overview of atrocities perpetrated on both enslaved and free Black research subjects in graphic detail. The outrages committed against minority populations include the sale of the bodies of Black slaves for use as anatomical specimens in medical schools in the name of medical science, enforced sterilization programs on Native American reservations and other minority populations, and the harvested cancer cells of Henrietta Lacks, used without permission or even notification to the patient or her family in the 1950s (Nuruddin et al., 2020). Perhaps one of the best-known examples of the White-controlled establishment of health care research sacrificing the well-being of Black subjects is the Tuskegee Airmen study. This 40-year U.S. public health study withheld penicillin from syphilis patients to learn about long-term effects. Like much of the research conducted on Black subjects, these experiments were performed without informed consent (Jaiswal & Halkitis, 2019). While there is a myriad list of examples of abuses committed against minority populations by the American medical community, not all of the known abuses have been blatant; many have resulted in policies and structures that caused and perpetuated immeasurable harm. As recently as January 2023, policies for kidney transplant eligibility were updated to allow Black patients to qualify for placement on the registry as early as their more privileged counterparts. When the list was developed, a racial adjustment was applied, which effectively meant Black Americans had to be sicker longer and have more advanced diseases to be eligible for transplants (Organ Procurement and Transplant Network, 2023). This policy was rescinded following research that revealed that the original criteria had been largely predicated on the erroneous belief that there is a biological difference between how the organs of Black bodies and other races function. This belief was eventually disproven after evidence of the effects of laws and rule-making regarding defining race in America revealed that social policies (self-identification) rather than any biological construction (genetic make-up) were most frequently used to define race (Lujan & DiCarlo, 2021). Abuse and exploitation of minorities in health care give context to the distrust of many minority health consumers of health care in general.

In Oakland, California, a group of researchers measured the willingness of Black male patients to participate in preventative screening both before and after meeting with their provider. They found that those patients who met with a Black male provider were more likely to engage in preventative procedures and specifically invasive procedures that are likely to lead to earlier identification and intervention of serious health conditions (Alson et al., 2019). This finding presents a substantial disadvantage, as Black physicians are underrepresented by more than 50% in the workforce, with only 6% of medical school graduates being Black despite Black Americans forming approximately 13% of the total population (Poole, 2019). This discovery is particularly concerning given research findings that have shown that the quality and frequency of interactions with providers may be the single most significant factor contributing to patient experience (Burns & Pauly, 2018).

Systemic Racism

A 2014 study used a systemic racism theory to conduct a literature review aimed at understanding historic racism in U.S. health care and its effects on Black Americans. The researchers identified that systemic racism is subtler and more difficult to isolate yet no less real; harmful actions taken without thought and supported by decision-makers fundamentally harm minority patients (Feagin & Bennefield, 2014). These researchers concluded that a crucial step in addressing health disparity is "comprehensive research and other educational efforts to publicly voice experiences of people of color within situationalized racism in health-related institutions" (Feagin & Bennefield, 2014, p. 13). While giving voice to the patient is the express goal of the HCAHPS survey, failing to analyze the efficacy of this program through the lens of race represents a further example of constructive harm to minority populations and arguably willful ignorance on the part of decision-makers who have regularly adjusted the scores based on the mode of administration, age, gender, education level, self-rated health, and primary language of respondents without considering race (Elliot et al., 2009).

Effects of Marginalization

Research has established that the systemic marginalization of minority populations in U.S. health care has caused both suffering for individual health care consumers and endemic health challenges for overall minority populations (Baah et al., 2019). Additionally, separate research has established that health outcomes are also linked to the proximity of health care services to health consumers' homes and the dearth of such services near minority populations (Stine et al., 2013). The recent COVID-19 pandemic has spotlighted, if not exacerbated, the impact of health disparity on Black Americans. Minority populations were notably infected and died of the virus at twice the rate of their Caucasian and Asian neighbors (Bibbins-Domingo, 2020). Using county-level data from across the United States, researchers utilized a binomial regression model to examine the relationships between racial segregation in housing patterns or residential segregation, racial inequity in poverty rates, racial disparity in incarceration rates, and reported COVID-19 cases and deaths (Tan et al., 2021). This study found that even when these indicators of racism within the community were controlled for, Black Americans were still disproportionately more likely to suffer more serious or fatal health outcomes, suggesting the urgent need to understand how these consumers experience and access health care (Tan et al., 2021). Moreover, researchers attempting to understand vaccine hesitancy noted the effects of marginalization and abuse of health care: "Mistrust and lack of confidence in vaccines and vaccination stems from the fact that 'for too long, too often, African Americans have been used as test subjects. People don't forget that and don't feel comfortable' (Program participant: 210421_003)" (Majee et al., 2023, p. 467).

HCAHPS Inconsistencies

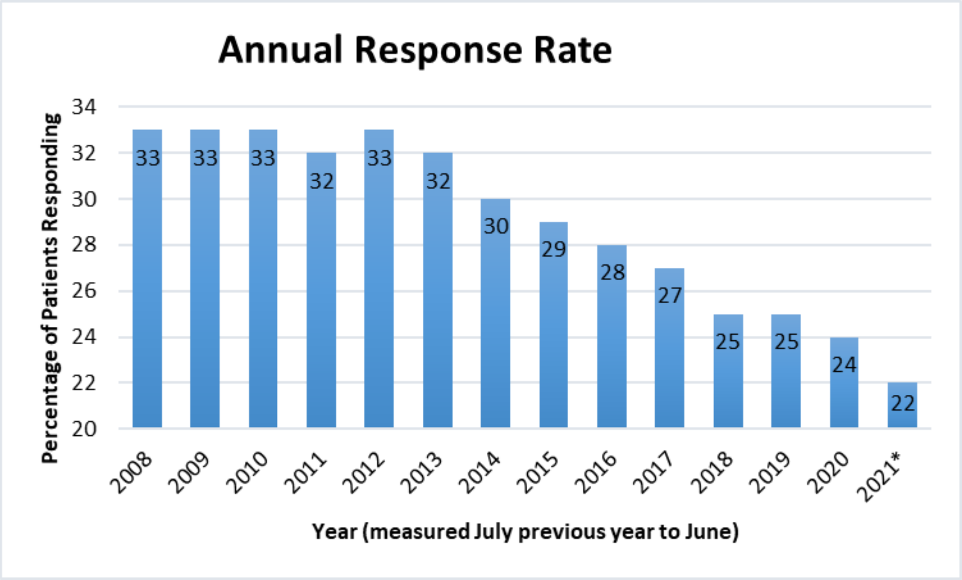
Despite the established reality of racism in health care and the compelling evidence of the effects of that racism on minority communities, there is no specific research aimed at understanding how representative the HCAHPS scores are of racial minorities. Notably, concerning patients, survey respondents who are White, female, and over the age of 65 with at least a high school education are most likely to respond (Boissey, 2020). Without tackling the representativeness of the HCAHPS, a unique study attempted to measure equity in patient experience using HCAHPS. This study used a Health Equity Summarized Score (HESS), which was a performance measure they estimated and standardized from the HCAHPS scores, to determine that minority patients tended to receive care most frequently at hospitals with high scores on this measure, concluding that greater equity could be achieved by using this tool to identify hospitals where interventions are most needed (Beckett et al., 2023). Although this finding offers evidence of a disparity in the scores and even insight on solutions to address it, it does not quantify the underrepresentation in the scores, which is needed to discuss racism in this sector of health care. Discussion of racism in U.S. health care is critical based on Rawls' original position: "Including health equity (i.e., the distribution of health outcomes within the group) in the definition of population health signifies that justice and health disparities are essential considerations, not after thoughts" (DeCamp et al., 2018).

Validity Concerns

Research has established that both response rates and the categories measured represent potential challenges to the HCAHPS utility. Upon introduction in 2006 and for roughly the next six years, the response rate for the HCAHPS survey was approximately 33.35% until 2014, where a marked drop was observed, a trend that has continued in each subsequent year (Godden et al., 2019; see Figure 1).

Figure 1

Annual HCAHPS Response Rate



Note. Percentage of responses to HCHAPS surveys from 2008 to 2020 from publicly available data from HCHAPS Online. *2021 data represents only 2 quarters of data, as January–July 2020 were deemed optional for data submission by hospitals (HCAHPS Online, 2023).

In 2019, researchers attempted to understand the relationship between response rates and scores using Pearson's correlations. Researchers compared the relationship between response rates and the dimension scores for a set of hospitals over multiple quarters, hypothesizing that if the sample of respondents were representative of the total hospital population, there would not be a correlation between the response rate and the dimension scores. However, they found that there was greater correlation between the response rate and the score in hospitals with low response rates than those with high response rates, suggesting that lower response rates indicate lower representativeness of the patient population (Godden et al., 2019). Additional research has centered on identifying which patients might be most likely to return the survey. Using chi-square to test multiple demographic groups confirmed that White women aged 65 or higher with a minimum of a high school degree were most the most probable respondents (Malpini et al., 2020). Because this quality metric is linked to improved medication and follow-up compliance from patients, lower malpractice risk, and increased loyalty for health systems, there is significant financial and social implications to these scores (AHRQ, 2020). Based on these studies, which have established that there are demographic subpopulations that are more or less likely to respond, the HCAHPS scores show evidence of response bias. An identifiable difference between the responders and non-responders occurs when there is a pattern to the responses; hence, those who have not completed the survey tend to be different from those who have, causing specific groups to be overrepresented or underrepresented (Denscombe, 2017). While non-response bias appears to be a factor in both the Malpini et al., and Denscombe studies, they were both completed on small scales, one state-wide and the other within a single service line at a single hospital. Given the impact of HCAHPS scores on hospital systems, it would be helpful to have larger scale studies to confirm these findings before considering the impact of response rate from behind the veil of ignorance. These scores are used to inform decisions regarding quality improvement, which are reflected in financial bonuses and penalties for hospitals and inform physician compensation. Hospitals have made efforts to improve how patient experience, measuring almost exclusively through this metric because of the funds tied to them. “Simply stated, money is a catalyst that motivates providers to invest significant organizational resources—mostly leadership focus and staff time—to optimize the patient experience” (Padilla, 2017, p. 229). Additional efforts include changes to the way patients are evaluated and cared for in the hospital, including the use of interdisciplinary teams who see patients together in an effort to increase understanding and consistency in distributing costs and financial benefits (Wilson et al., 2020). These efforts build upon previous findings that show that HCAHPS scores affect how providers engage with patients, specifically regarding how they communicate regarding a patient’s expectations (Birkelien, 2017). While these efforts may improve the experience for patients represented by the HCAHPS scores, one must understand the effect they may have on patients whose experiences are not reflected in the scores.

Alternatives

Currently, HCAHPS is the singular measure of experience quality for the VBP program. However, researchers have determined that there may be value in utilization of qualitative data regarding experience quality in addition to the quantitative data gathered by the surveys. Using natural language analysis, a research team analyzed all social media comments for hospitals participating in VBP for a one-year period and found that in addition to comments on all HCAHPS domains, health care consumers remarked on 12 additional topics (Ranard et al., 2016). Four years after the original study, another research team utilized the data set and conducted Spearman’s Rho analysis to determine that there is a statistically significant relationship between the topics identified on social media, the HCAHPS scores, and characteristics of hospitals, including profit vs. non-profit and teaching vs. non-teaching (Chakraborty & Church, 2020). These findings suggest that there may be some value in exploring social media comments regarding experience of discrimination in health care and the impact on HCAHPS scores.

While all hospitals in the United States are required to participate in HCAHPS surveying, many voluntarily use patient satisfaction surveys as well. These surveys, which are frequently administered by the same companies as HCAHPS, acquire slightly different information; they focus on understanding how patients felt about the care they received during a hospital admission as opposed to concentrating on what did or did not occur during the admission (Browne et al., 2010). Lee (2019) opines that a person’s judgement is comprised of their unique history and life experiences. While patient experience and patient satisfaction are similar but unique measures, they are frequently confused or interchanged, making the utility of patient experience or HCAHPS scores questionable as a driver of experience quality improvement (Kumah, 2019).

Finally, to gain a full understanding of experience quality and patient-centeredness, patient engagement might be of more use than either patient experience or patient satisfaction. (Boissey, 2020). Understanding patient engagement would involve analyzing how frequently health consumers participate in activities aimed at specifically affected health outcomes (Manta et al., 2020).Use of patient engagement as a metric may be promising if viewed by subpopulations, coupled with an understanding of the cause of behavioral choices, which currently does not exist.

Relevant Dissertations and Research

Given their less than 20-year history, there is limited research regarding HCAHPS and VBP. Results from searches for HCAHPS and race on the Open Access Theses and Dissertations database returned only a single study focused on Hispanic patients in one hospital. The same search on Open Dissertations returned no results. As previously discussed, research has established that demographics influence how patients experience care, with race and ethnicity being linked to how patients respond to the survey. Mazurenko et al. (2017) conducted a meta-analysis and systemic review of previous literature reviews, which analyzed the criteria that could predict how a patient might respond to HCAHPS questions. More than a quarter of the studies they examined concluded that patient race was a factor, with minority patients being less satisfied. A 2021 study conducted over a 5-year period, however, concluded that Spanish-speaking Hispanic patients were more likely to rate their experiences higher than White patients at a California hospital (Donaldson et al., 2021). While not all studies agree on the impact of minority status and HCAHPS scores, there seems to be an agreement that race and ethnicity influence how patients experience care. However, these studies do not indicate how closely the subset of HCAHPS respondents matches the inpatient hospital populations. Given the pervasive use of HCAHPS data to drive quality improvement, impact the financial standing of hospitals, and drive health care consumers' choices about care, it is important to understand the representativeness of the HCAHPS sample as it relates to racial minorities. As described, race appears to be the only characteristic which has not been considered in evaluating HCAHPS scores and their validity and utility. If, like age, education level, and income, race is also a factor that influences how a patient experiences care and patients do not return the survey at a representative rate, then stepping into the original position, HCAHPS is unlikely to be a useful tool to inform health care quality or improvement.

Theoretical Framework

In 1971, American philosopher John Rawls published his seminal work *A Theory of Justice*. This work established a way of considering political, economic, and legal dilemmas through a philosophical lens aimed at determining the most just outcomes (Nussbaum, 2001). Rawls asserted that people are sensible, thoughtful beings and would therefore not agree to a solution that would potentially put them at risk. He proposed that justice is served when the greatest advantage from any inequality is received by the least advantaged members of a population (Follesdal, 2014). He further asserted that a useful way of determining how to resolve dilemmas regarding the fairest distribution of benefits in a society is to consider alternatives to what he describes as the *original position*, which according to Rawls, is when members of a society or actors choose the best solution without having any knowledge of their own individual attributes of status in society (Dworkin, 1973). Rawls refers to the hypothetical structure that blocks individuals from knowing their attributes as *the veil of ignorance* and asserts that the choice from behind this veil will always be the most just choice, as actors do not know their position in society and it would be illogical for them to put themselves at unnecessary risk (Fritz & Cox, 2019). This idea of making decisions from behind the veil of ignorance has been used to consider a myriad of diverse issues, including end-of-life care for prison inmates; examination of what is owed to what is given up when crimes are committed (Cohn, 1999); regulation of the internet with global impacts and interested individuals, corporation, and governments (Douglas, 2015); and even fossil fuel rights and what is owed and faired for the taking of lands containing these resources (Stone, 2020).

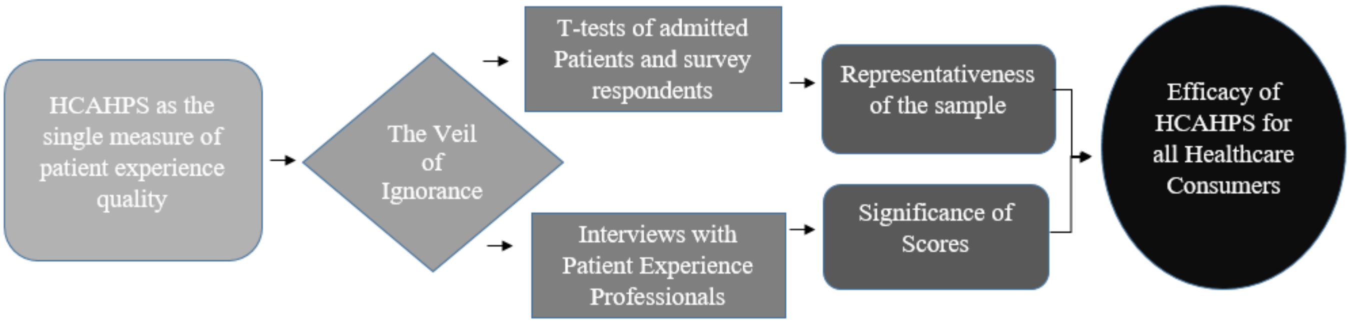
Introduced as a tool for health care consumers to compare hospitals based on the care experiences of their patients and as a tool for paying for performance, the HCAHPS survey represents another opportunity to use the Rawlsian framework. Stepping into the original position allows consideration of how universally the experiences of all health care consumers are represented in the HCAHPS survey data. Examination of the HCAHPS survey data from this vantage also allows consideration of how effectively that data represent the information that all health care consumers need to make decisions.

Conceptual Framework

Validated during its creation in 2008, the HCAHPS tool has experienced significant challenges. In 2014, a significant decline in response rates was observed, and this trend has continued annually since (Godden et al., 2019). Beginning in 2016, and updated in both 2019 and 2021, patient mix adjustments to age, gender, and economic status were applied to the survey results due to variations in hospital populations; however, race was specifically excluded from these factors (HCAHPS Online, 2023). This study attempted to begin to respond to the seeming gap in research created by this exclusion. Using the Rawlsian veil of ignorance informed how the efficacy of the HCAHPS as a tool to drive improvement of care that benefits the total population of health care consumers was be evaluated, as illustrated in Figure 2.

Figure 2

Veil of Ignorance to Evaluate the Efficacy of the HCAHPS Tool



Summary

Considerable funding is allocated to collecting HCAHPS data, and even more funding is dependent on the outcomes of these data. With nearly 30% of VBP dollars dependent on this metric, these dollars can impact the availability of services for communities and the ability of hospitals to compensate providers (influencing where they practice) and drive quality and improvement efforts. As discussed, SDH can be substantially impacted by the availability and quality of health services. For minority patients who most likely live in areas with limited access to health services, have limited ability to travel for these services, and have historic distrust of the health system, understanding how well they are represented in these scores is a critical step in improving health services and outcomes.

Chapter 3: Methodology

To step behind Rawls' wall and consider the use of the HCAHPS as the source of truth for measuring American health care consumers' experience in hospitals, the scores should represent both the population of people admitted to those hospitals and also what that population cares about. Nearly 20 years after VBP was signed into law and the HCAHPS survey was identified as the tool for awarding 25% of the bonuses and penalties associated with these scores (Pro & Zaller, 2020), it remains unknown how representative the sample of respondents is to the actual health care consumer population. This study examined the HCAHPS response sample of a midwestern health system in the United States to understand how well the subset of survey respondents quantitatively represented the race and ethnicity of patients admitted to the health system at the same time. Additionally, it aimed to understand if there was a statistical indication that race or ethnicity may be a factor in how patients rate their experience of care. Qualitatively, context for how well these scores represented the populations served were explored through interviews with patient experience professionals. These interviews attempted to explain how pervasively and in what ways these scores are used by hospitals.

Research Design

In order to evaluate the efficacy of the HCAHPS survey in rewarding and penalizing hospitals to encourage patient-centered care, it is necessary to understand how well the sample of survey respondents represents the population of patients and their concerns. Stepping behind the veil of ignorance and considering the HCHAPS tool from Rawls' original position, for choices to be made about the value of HCAHPS scores in evaluating care experiences for the population of health care consumers, the questions regarding representativeness of the sample and how well the survey allows consumers to rate what matters to them become critical.

Description of Research Participants

This study focused on a small health system in Central Ohio; it is a regional part of a larger national health system and comprises three primary care hospitals and one specialty hospital. Additionally, outpatient services are offered through their medical group, with approximately a million patients each year receiving services from this health system. The largest of the three facilities also offers level-two trauma care, and the smallest is a specialty surgical-only hospital. Quantitative data from the health systems' returned HCAHPS surveys were compared to registration data from the health systems' electronic medical records of self-disclosed patient demographics during 2018 and 2019. Furthermore, a convenience snowball sampling method was employed to identify 11 patient experience professionals from across the United States. However, to ensure that findings are generalizable beyond the health system and selected region, this study will need to be duplicated in additional regions.

Justification for Methodology

Understanding the sample's representativeness was achieved using a mixed-method convergent parallel design. Mixed method was used to identify how representative the subpopulation of respondents is of the admitted patients quantitatively and qualitatively within at least one health care system to explore why disparities in representation for specific demographics matter. According to Schoonenboom and Johnson (2017), mixed-method studies are employed by researchers to create rich and meaningful conclusions that expand the knowledge base regarding the topic. For this study, the two types of research occurred at the same time, with collection and analysis occurring independently. Results of the two sets of analysis were compared to obtain a robust understanding of how the HCAHPS scores measure patient experience for all health care consumers and whose experiences may be underrepresented. This is an established method "to compare results or to validate, or corroborate quantitative results with qualitative findings. The purpose of this model is to end up with valid and well-substantiated conclusions about a single phenomenon" (Creswell & Clark, 2017, pp. 64–65).

Quantitatively, this study compared the published HCAHPS demographics for a 2-year period of a midwestern American health system to the demographic data from registration at the same health system during the same period. The data sets were compared utilizing a dependent *t* test to understand if the racial makeup of the subpopulation of HCAHPS respondents was statistically significantly different from the racial makeup of the admitted patients in a U.S. health system for the same time period. The choice of dependent *t* test is most appropriate for this study as this test is used when participants in both groups are paired in some way—in this case, admitted to the same health system—and are being tested on one measure—in this case, race (National University, 2024). For this study, the independent variable was health care consumers admitted to the health system and the dependent variable was race, as other variables including age, economic status, gender, education level, and general health status have been previously studied. For the purpose of this study, race was operationalized as White/Caucasian, Black/African American, American Indian/Alaska Native, Asian, Native Hawaiian/Other Pacific Islander, and ethnicity was operationalized as Non-Hispanic/Latino or Hispanic/Latino.

Qualitatively, 11 interviews were conducted with patient experience professionals to understand the anecdotal evidence related to how well they believe the HCAHPS scores represent minority health care consumers and how the HCAHPS data are utilized. By exploring both the quantitative element of how well racial groups are represented in the HCAHPS data and the qualitative data of how HCAHPS are used to drive quality improvement, this research strove to provide confirmation to the anecdotal impression of health care workers that the HCAHPS scores are not representative of the patient populations served. This study is a beginning to filling the critical gap in research regarding how representative of race the sample is for the HCAHPS tool while simultaneously assessing how effective the tool is for identifying and measuring the aspects of care that inform health care consumers' perceptions of their care.

Reliability, Validity, and Researcher's Bias

As the single validated and standardized measure of patient experience data in the United States, it is imperative that HCAHPS measures the entire population of health care consumers. At the time of development, it was also an industry-first opportunity for health care consumers to offer direct feedback and for the public to use that feedback to make decisions about where to receive care (HCAHPS, 2023). Initial validation occurred when the survey was introduced in 2006. However, although the most recent reevaluation of patient mix occurred in 2019, brace was again excluded in the patient-identifying characteristics.

Quantitatively, the HCAHPS questions are generally given face validity. This study challenged that assumption by introducing the question of representation of the sample based on race, which has historically been specifically excluded. Qualitatively, semi-structured interviews were transcribed, coded, and themed by the researcher under the supervision of a well-respected, tenured methodologist. Ideally, these steps will support the validity of findings, although there is potential for bias in interpreting descriptions of discriminatory behavior.

The findings from this study will need further evaluation through additional research to establish if they remain consistent in all regions of the country and within the various categories of acute care hospitals. In the United States, social norms and laws traditionally and continually allow for wide variations in practice of how minority groups are perceived and treated. Hence, it may be necessary to examine various areas of the country to completely validate the study results. Additionally, as the research was designed and conceived by a patient experience professional, some research bias may exist based on anecdotal evidence regarding the representativeness of HCAHPS response subpopulation.

Data Collection Plan and Procedures

For the quantitative strand, data regarding the HCAHPS respondents were acquired from the selected health system as received from their survey vendor for 2018 and 2019. All demographics for the inpatient population were extracted from patients' self-disclosed race during registration, as documented in the health systems' electronic medical records.

For the qualitative strand, professionals were invited to participate through the professional networking of the researcher, with one participant suggesting other networks. An interview protocol was developed for consistency and to ensure the anonymity and safety of all participants (see Appendix B). Each interview used the interview protocol, lasted approximately 45 minutes, and was recorded using Microsoft teams or Zoom.

Prior to beginning the study, institutional review board approval was obtained from Franklin University. While the data collection procedures were fairly straightforward, one vulnerability may be related to the selection of the 2018 and 2019 calendar years, which were before the unprecedented impact of the COVID-19 pandemic on the health care industry, The pandemic was noted to have more serious and pervasive negative outcomes for Black Americans (Tan et al., 2021) and may have also impacted their perception of their health care experience.

Data Analysis Procedures

Quantitative data were analyzed using the SPSS platform, with a dependent *t* test performed to determine statistically significant similarities between the populations with hospital admission being the independent variable and race serving as the dependent variable. Interviews were themed and coded using the ATLAS.ti platform. All data analyses were processed and shared with the methodologist for review; the details are presented in Chapter 4.

Summary

This study provided definitive research regarding the representativeness of the sample of HCAHPS respondents relative to race and ethnicity in a midwestern health system. Ultimately, for the results of the surveys to be valid, the sample must be representative. Because these survey results are utilized as a basis for VBP and impact the financial wellbeing of hospitals and health systems, it is critical to ensure that the hospitals that serve the most vulnerable consumers are not being negatively impacted by this system. By framing this research through Rawls' theory of justice and examining the quantitative representativeness of the data and the qualitative reflectiveness of the data to determine what is important to health care consumers, actors positioning themselves behind the veil of ignorance should be able to judge the worthiness of HCAHPS to measure patient experience. As revealed in the next chapter, both the quantitative and qualitative findings create more questions than answers regarding racial and ethnic minority patients and how the health care system measures and improves their health care experience quality.

Chapter 4: Findings

This chapter presents the data collected and analyzed using a mixed-method convergent parallel design. Convergent designs are utilized to obtain a robust understanding of a research problem (Creswell & Clark, 2017). Quantitatively, the racial and ethnic breakdown of a Midwestern American health system's admitted patients to their acute care hospitals during 2018 and 2019 were analyzed to understand the population make-up. The data were compared to the HCAHPS survey respondents for the same health system during the same time frame to determine how representative the sample was of the racial and ethnic diversity served. Qualitatively, 11 patient experience professionals participated in semi-structured interviews that sought to explain how well these scores represent the experience of racial and ethnic minority patients and how the scores impact hospital operations and quality improvement. Because a convergent parallel design was used, interviews occurred during the same time period as the quantitative analysis. The perspectives of the interview participants, who spoke knowledgeably, candidly, and passionately about their work, provided a rich context for understanding the impact of the quantitative findings. The themes that emerged during multiple rounds of coding created even more questions when juxtaposed against the quantitative findings while simultaneously offering distressing and heartfelt anecdotal evidence that suggests there is more to be learned. Quotes from semi-structured interviews have been included but edited for readability, while meticulous attention has been paid to preserving the spirit of the participants' intended meaning. According to a study on presenting qualitative research, this practice, while controversial, is acceptable: "…authors should aim to find a balance in editing quotes and maintaining the integrity of the participants' own words, because participants are the authors' 'partners' in telling the story of the data" (Goldberg & Allen, 2015, p. 14). Ultimately, the null hypotheses could not be rejected, but when contextualized with the qualitative data, the research reveals the HCAHPS to be a flawed tool with limited utility and questionable validity.

Quantitative Analysis

The hypotheses for this research were:

H_1: There is a statistically significant difference between the response rate of non-White patients to the HCAHPS survey and the admission rate of non-White patients to a health system during the same time.

H_{01}: There is not a statistically significant difference between the response rate of non-White patients to the HCAHPS survey and the admission rate of non-White patients to a health system during the same time period.

H_2: Patient race is a statistically significant factor in how patients score their hospital experience.

H_{02}: Patient race is not a statistically significant factor in how patients score their hospital experience.

Selected Health System

This research utilized data from a Midwestern health care organization in the United States that currently operates four hospitals, each of which provides varying levels of care and serves slightly different patient needs, as illustrated in Table 1. All data used were obtained from the health system for quantitative analysis and were utilized as aggregate data containing no patient identifiers. Data were voluntarily collected from patients at the time of admission and entered into individual electronic medical records by registration employees. Patients or their support persons voluntarily specified racial/ethnic identifiers when completing the HCAHPS survey. During both hospital admission and completion of the HCAHPS survey, patients had the opportunity to decline to provide this information.

Understanding the characteristics of the hospital provides vital clues regarding the patients who may receive care. Hospitals with emergency departments (ED) and neonatal intensive care units (NICU) provide some pediatric services on at least a limited basis. Trauma hospitals and hospitals with special care units draw from larger geographical areas, as they can care for patients with specific needs. Smaller hospitals with fewer specializations are more likely to be frequented by patients who intentionally selected the hospital and location, while nonprofit hospitals are frequently associated with a higher percentage of uninsured patients or patients who are economically vulnerable. Similarly, teaching hospitals can have considerable fluctuation in terms of when patients self-select their care due to the seasonality of experienced providers. Table 2 illustrates the characteristics of the hospitals in the selected health system; all hospitals in the system are not-for-profit.

Table 2

Characteristics of Hospitals

	# of Beds	Teaching	Trauma Services	# Specialty Units	ED	NICU
Hospital A	210	X		1	X	X
Hospital B	270	X		3	X	X
Hospital C	400		X	4	X	
Hospital D	60			0		

According to the de-identified patient data from the electronic medical records of the selected health system, patients self-identified as illustrated in Table 3 for the 2018 and 2019 calendar years at the times of admission. Data were provided based on admission; hence, patients with multiple hospital stays were counted as an additional demographic each time they were admitted.

Table 3

Patient Race and Ethnicity

		2018	2019
Race	White/Caucasian	39,604	37,420
	Black/African American	10,427	9,795
	American Indian/Alaska Native	74	85
	Asian	1,129	1,201
	Native Hawaiian/Other Pacific Islander	16	31
	Unknown	7,039	6,130
	Total	58,289	54,662
Ethnicity	Non-Hispanic/Latino	51,470	48,592
	Hispanic/Latino	1,043	977
	Unknown	5,776	5,093
	Total	58,289	54,662

Examining the data from this table reveals that in 2018, there were a total of 58,289 patient admissions and that the largest subpopulation demographics were White/Caucasian at 68% and African American/Black at 18%. In 2019, 54,662 patients were admitted, of which the largest subpopulations were again White/Caucasian at 68% and African American/Black at 17%.

HCAHPS Survey Sampling

The HCAHPS survey is administered using a random cross-sectional design. This survey qualifies as a cross-sectional design because patients following discharge are only asked to complete one survey regarding their experience in the hospital, with no follow-up, therefore meeting the definition (Pajo, 2022). All admitted patients who are discharged home (as opposed to another facility to receive additional care or expired in the hospital) are eligible to and have an equal chance of being selected to receive the survey. Patients in this health system are not surveyed more than once each 30 days for hospital admissions. The data from HCAHPS survey respondents are received and stored as an aggregate for the health system; Table 4 illustrates the breakdown of HCAHPS survey respondents. If a patient is admitted to the hospital, discharged home, and then re-admitted and discharged home a second time within 30 days of the first discharge, they are ineligible to receive a survey. The impact of the demographic breakdown of readmission to the hospitals during these calendar years or even the percentage of readmissions are not known; however, the national average readmission rate is approximately 14%. Because of the equal opportunity for selection, a simple random sampling method was used (Pajo, 2022).

Table 4

Respondents' Race and Ethnicity

		2018	**2019**
Race	White/Caucasian	9,834	9,233
	Black/African American	954	799
	American Indian/Alaska Native	103	101
	Asian	178	137
	Native Hawaiian/Other Pacific Islander	21	9
	Unknown	317	390
	Total	11,407	10,669
Ethnicity	Non-Hispanic/Latino	8,980	9,973
	Hispanic/Latino	197	197
	Unknown	230	499
	Total	9,407	9,233

Note. Demographic breakdown of respondents from health systems' HCAHPS surveys for 2018 and 2019.

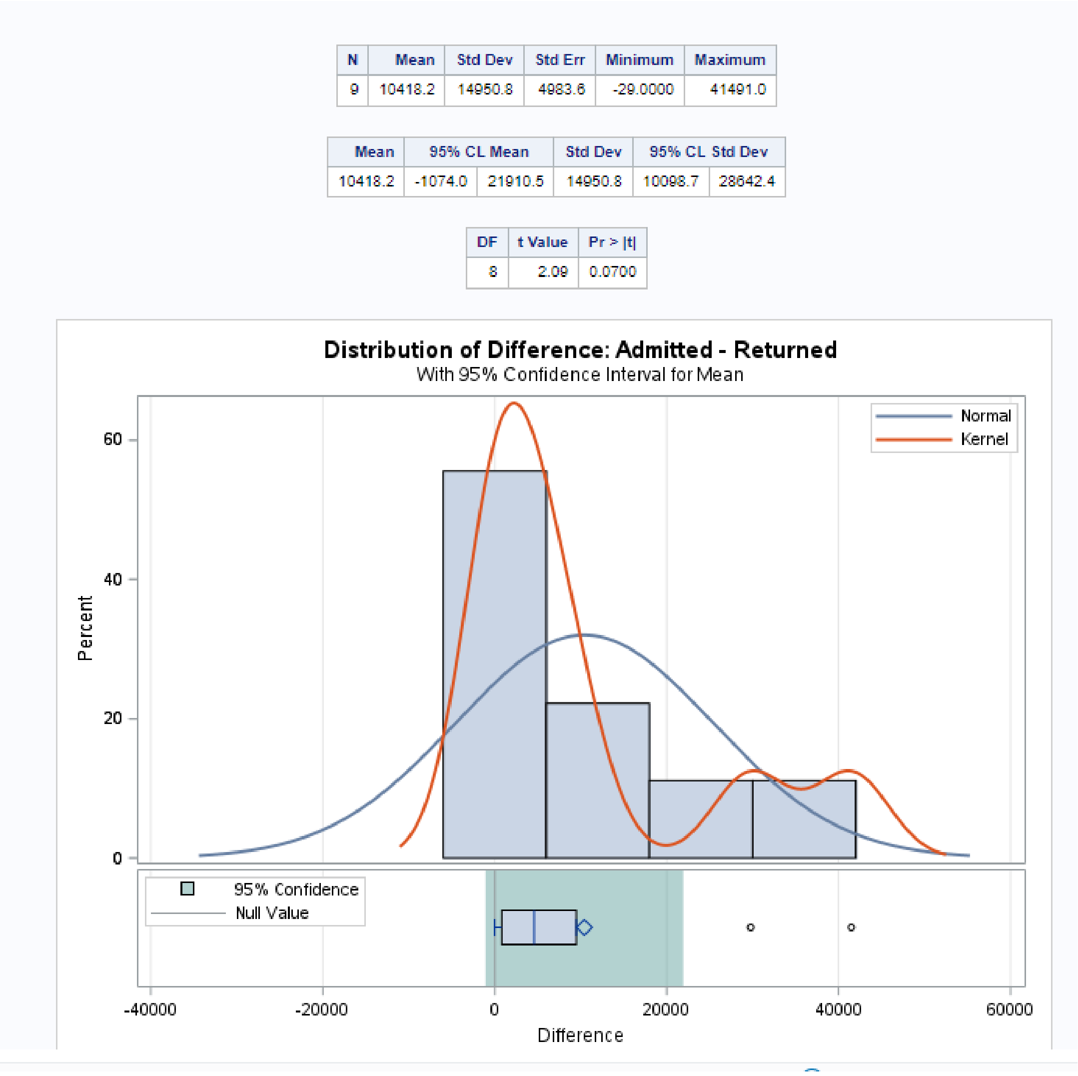
Statistical Tests

To determine if the null hypothesis could be rejected, the first step was to determine how well the subpopulation of HCAHPS survey respondents matched the racial and ethnic demographic of the admitted patients' population. This measure was determined by conducting paired *t* tests, with the independent variable being the patient being admitted to the health system during 2018 or 2019 and returning the HCAHPS survey and the dependent variable being self-identified race or ethnicity. For each of the paired *t* tests performed for the 2018 and 2019 data, the number of admitted patients in each racial or ethnic category was paired to the corresponding number of responses in the same demographic.

The paired *t* test showed the difference between the admitted population and the respondent population for each racial and ethnic group when analyzed using SPSS. Figure 3 illustrates the true relationship of response rate distribution between the expected response rate and the actual response rate when analyzed by race and ethnicity for the 2018 calendar year. In this instance, with a 95% confidence level and a standard deviation of 14950.8, the true value of the comparison should have a mean between -29.0000 and 41491.0 but shows an actual mean of 10418.2, putting the actual mean above the confidence limits. However, with a *p* value of .0700, which is greater than .05, the null hypothesis cannot be rejected.

Figure 3

Analysis of Expected vs. Actual Responses by Racial/Ethnic Demographic for 2018



N	Mean	Std Dev	Std Err	Minimum	Maximum
9	10418.2	14950.8	4983.6	-29.0000	41491.0

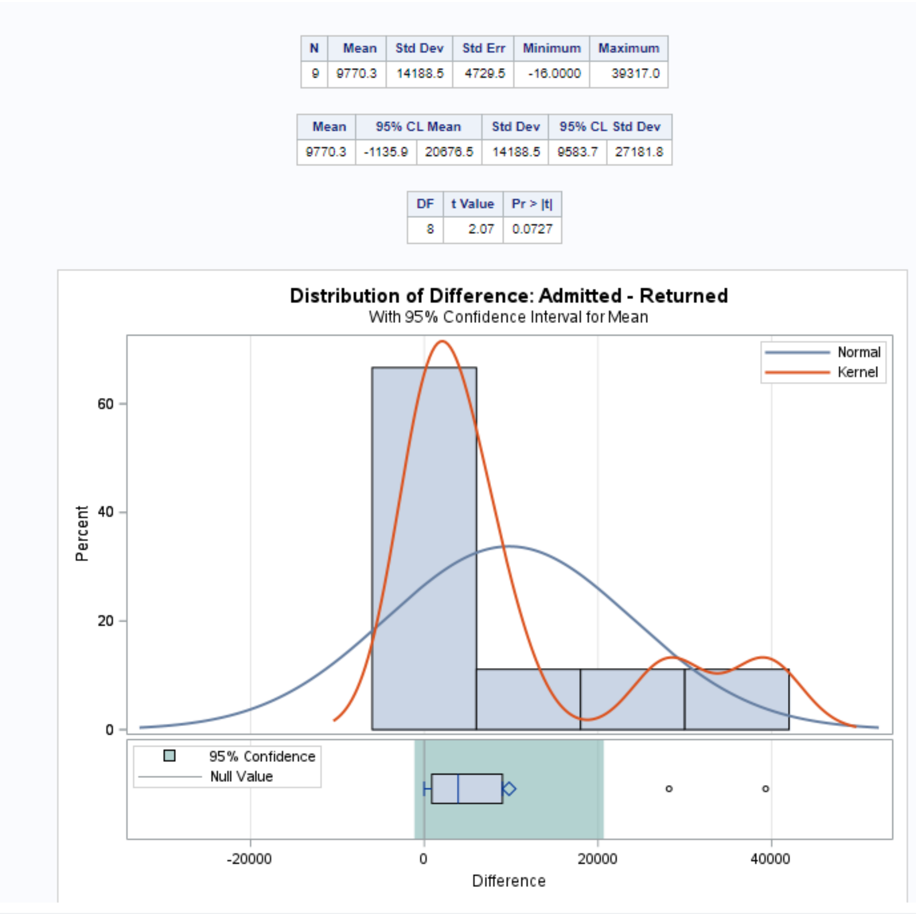
Mean	95% CL Mean		Std Dev	95% CL Std Dev	
10418.2	-1074.0	21910.5	14950.8	10098.7	28642.4

DF	t Value	Pr > |t|
8	2.09	0.0700

For the 2019 calendar year, the SPSS software was again used to analyze the difference between the self-identified race and ethnicity of patients and self-identified race and ethnicity of patients returning surveys. Figure 4 illustrates the true relationship of response rate distribution between the population of admitted patients and the subpopulation of survey respondents when analyzed by race and ethnicity for the 2019 calendar year. In this instance, with a 95% confidence level and a standard deviation of 14188.5, the true value of the comparison should have a mean between -16.0000 and 39317.0. In this analysis, the actual mean is 9770.3, above the confidence limits. Again, at .0727, the *p* value is greater than .05, and the null hypothesis failed to be rejected.

Figure 4

Analysis of Expected vs. Actual Responses by Race/Ethnic Demographic for 2019



N	Mean	Std Dev	Std Err	Minimum	Maximum
9	9770.3	14188.5	4729.5	-16.0000	39317.0

Mean	95% CL Mean		Std Dev	95% CL Std Dev	
9770.3	-1135.9	20676.5	14188.5	9583.7	27181.8

DF	t Value	Pr > |t|
8	2.07	0.0727

Based on the *t*-test analysis, the mean did not fall within the confidence limits in either year; however, both years had a *p* value greater than .05, indicating that the null hypothesis is not rejected.

Although utilizing the selected methodology does not warrant rejecting the null hypothesis, the consistent adamancy of the participants in the qualitative research regarding the inequities in the HCAHPS warranted further exploration of the data. In full disclosure, the inability to reject the null hypothesis was devastating and caused considerable additional examination of the quantitative data. Fortunately, the selection of a convergence parallel design meant that the quantitative and qualitative strands be considered together, and doing so allowed the triangulation of results in such a way that the lack of normal distribution and the effect of this lack was dent. A side-by-side examination of the data reveals interesting and concerning information. By dividing the total number of patient admissions or responses under each demographic by the total number of patient admissions or responses for that calendar year, the percentage for each subpopulation was determined. Table 5 illustrates a disproportionate distribution of respondents by demographic, which is consistent across the calendar years examined and which may offer some evidence of the participants' anecdotal impression of representation within the HCAHPS scores. Notably, for calendar year 2018, White/Caucasian represented 68% of patient admissions and 86% of respondents, while Black/African American comprised 18% of patient admission and only 8% of respondents. The results for calendar year 2019 were almost exactly the same, with White/Caucasian representing 68% of patient admissions and 87% of respondents and Black/African American comprising 18% of patient admission and only 7% of respondents.

Table 5

Percentage Based on Race and Ethnicity

		2018 % OF PATIENT ADMISSIONS	**2018 % OF RESPONSES**	**2019 % OF PATIENT ADMISSIONS**	**2019 % OF RESPONSES**
RACE	White/Caucasian	68%	86%	68%	87%
	Black/African American	18%	8%	18%	7%
	American Indian/Alaska Native	0%	1%	0%	1%
	Asian	2%	2%	2%	1%
	Native Hawaiian/Other Pacific Islander	0%	0%	0%	0%
	Unknown	12%	3%	11%	4%
	Total	100%	100%	100%	100%
ETHNICITY					
	Non-Hispanic /Latino	88%	79%	89%	93%
	Hispanic /Latino	2%	2%	2%	2%
	Unknown	10%	20%	9%	5%
	Total	100%	100%	100%	100%

Additionally, the expected and actual response rates were calculated by dividing the number of survey responses by the total number of admitted patients. The expected response rate for each category was determined by multiplying the number of admitted patients in each racial or ethnic subpopulation (see Table 3) by the response rate. Table 6 reveals that for both calendar years, the number of White or Caucasian patients who actually returned a survey is higher than the numbers that were expected by 2,229 in 2018 and 2,299 in 2019, while the number of African American or Black patients who actually returned the survey were lower than the expected number each year by 1,030 and 1,043 in 2018 and 2019, respectively. For all other racial and ethnic groups, both population and subpopulation were substantially smaller (except non-Hispanic or Latino), but in all samples other than Asian, the number of surveys returned exceeded the number expected in 2018.

Table 6

Expected vs. Actual Responses by Racial/Ethnic Demographic for 2018 and 2019

		2018 Expected	2018 Actual	2019 Expected	2019 Actual
Race	White/Caucasian	7535	9834	6849	9233
	African American/Black	1984	954	1793	799
	American Indian/Alaska Native	14	103	16	101
	Asian	201	178	220	137
	Native Hawaiian/Other Pacific Islander	3	21	6	9
	Unknown	1408	197	1122	390
Ethnicity	Non-Hispanic or Latino	10294	8980	8894	9973
	Hispanic or Latino	5215	209	5338	179
	Unknown	28880	1155	54662	932

The second null hypothesis was evaluated by a simple calculation of averages. H02 stated that patient race is not a statistically significant factor in how patients score their hospital experience. The calculation revealed a minuscule difference between the average HCAHPS ratings of the hospitals in the selected health system when those averages are viewed by race or ethnicity of the respondent, as shown in Table 7.

Table 7

Average Hospital Rating Based on Race or Ethnicity for 2018 and 2019

Race or Ethnicity	Average Rating 2018	Average Rating 2019
White/Caucasian	9.9	9.07
African American/Black	9.67	8.89
American Indian/Alaska Native	9.85	8.85
Asian	9.86	9.44
Native Hawaiian/Other Pacific Islander	9.72	9.22
Non-Hispanic or Latino	9.88	9.06
Hispanic or Latino	9.88	9.06

However, given the extremely low percentage of respondents in any demographic, it is difficult to determine a causal relationship. From the qualitative data from the semi-structured interviews, it appears that some relationship may exist and further exploration may be warranted. In this research, it is not possible to reject the second null hypothesis.

Qualitative Analysis

Participants

Semi-structured interviews were conducted with 11 patient experience professionals with various levels of experience and responsibility in leading patient experience in U.S. hospitals. Participants were selected using a convenience snowball sampling method and were required to have a minimum of two years' experience. Despite the use of a convenience sampling method, participants were intentionally selected to include insight from a broad range of professionals with varied backgrounds. Effort was made to include professionals who possessed a wide range of experience in the field, supported hospitals across different geographic locations in the United States, and possessed varied characteristics in the hope of capturing the most encompassing perspective possible. Qualitatively, the central research questions were:

RQ1: How well do patient experience professionals believe HCAHPS scores capture the experiences of patients who identify as racial or ethnic minorities?

RQ2: How do patient experience professionals describe the impact of HCAHPS scores on hospital operations and quality improvement?

Each participant has worked in the field of patient experience for a minimum of four and up to 30 years. Participants currently hold roles that vary from leading patient experience at a single hospital (three participants) to consulting with health systems across the United States (three participants), as illustrated in Figure 3. Although some participants have evolved professionally to national roles, all have led patient experience efforts at one or more hospitals at various points in their careers. Table 8 offers a breakdown of participants' years in the field, current roles, and parts of the country they support.

Table 8

The Participants

Participant	Years in Patient Experience	Hospitals supporting	State
P1	6 years	National Consultant	National
P2	11 years	4 hospitals	California
P3	14 years	2 hospitals	D.C.
P4	15 years	2 hospitals	New York
P5	10 years	1 hospital	Wisconsin
P6	8 years	National Consultant	National
P7	10 years	2 hospitals	Texas
P8	15 years	1 hospital	Ohio
P9	8 years	2 hospitals	Ohio
P10	6 years	1 Hospital	Michigan
P11	30 years	National Consultant	National

Hospitals supported by participants represent the full scope of hospital characteristics, including urban/suburban/rural, teaching/non-teaching/academic teaching, profit/non-profit, adult only/pediatric/combined, specialty care units, trauma, and specialty hospitals. Table 9 offers a breakdown of the number of participants who have led patient experience in each type of hospital.

Table 9

Types of Hospitals Supported

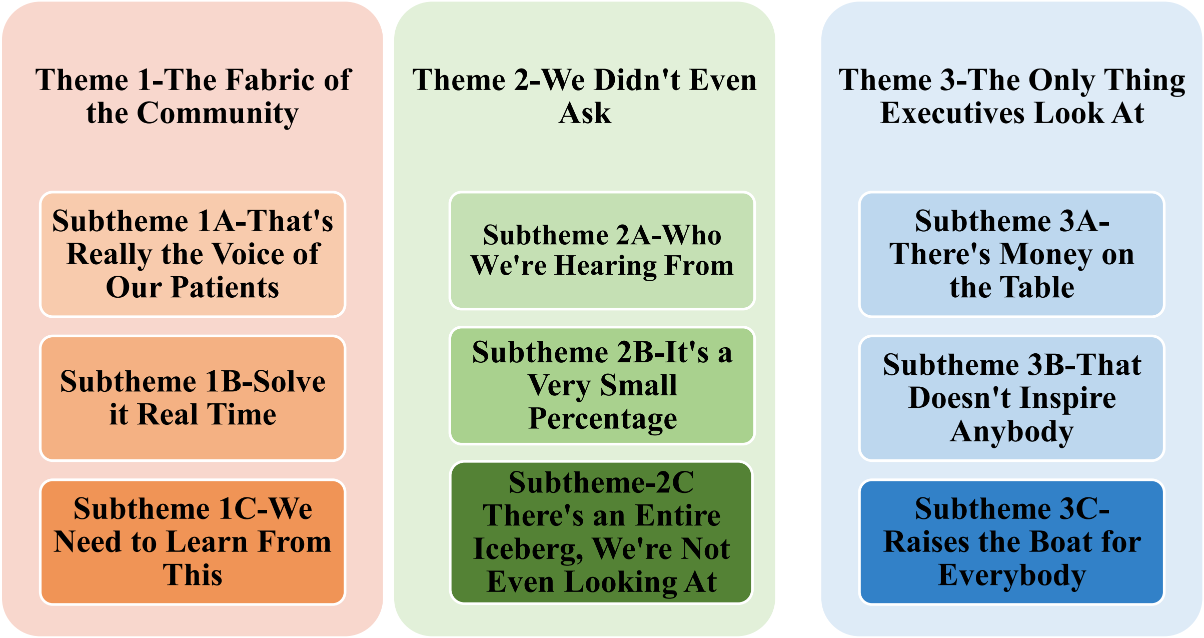
Characteristic	# of Participants
Urban	9
Suburban	8
Rural	4
Teaching	8
Non-Teaching	7
Academic Teaching	5
For Profit	10
Non-Profit	4
Adult Only	8
Pediatric	3
Combined Populations	9
Specialty Care Units	11
Trauma	5
Specialty Hospitals	3

Each semi-structured interview was conducted over Zoom or Microsoft Teams, lasted approximately 45 minutes, and was transcribed before being coded using ATLAS.ti. Coding was done using an inductive method, which is the process of deriving themes from the transcripts of the interviews rather than fitting the quotes from the transcripts into themes created ahead of the research (Brinkmann & Kvale, 2018). Consistent with the inductive method, this exercise was repeated at least three times. The first round was a simple open coding, where the data were examined for in vivo codes derived from the words that participants chose and how they were expressed. This step was followed by axial coding, which sought to examine how codes related to one another and started to form themes; the final round of selective coding allowed the data to be shaped into themes that told the story of the interviews. Throughout this process, the codes were viewed next to the quantitative data; deeper analysis and scrutiny of themes led to additional perspectives and insights into participant comments as well as additional exploration of the quantitative findings. Ultimately, three primary themes were identified: Theme 1—*The*

*Fabric of the Community w*hich looked at the myriad ways that participants receive and seek patient feedback and was subdivided into: subtheme 1A—*That's Really the Voice of Our Patients, s*ubtheme 1B—*Solve It Real Time,* and subtheme 1C—*We Need to Learn From This.* Theme 2—*We Didn't Even Ask* which explores populations and topics missing or disproportionately represented in the survey data and was subdivided into: subtheme 2A—*Who We're Hearing From, s*ubtheme 2B—*It's a Very Small Percentage* and subtheme 2C—*There's an Entire Iceberg We're Not Looking at.* Finally, Theme 3—*It's the Only Thing Executives Look at* which provided discussion of how the data from the surveys is utilized and was subdivided into: 3A—*There's Money on the Table,* 3B—*That Doesn't Inspire Anybody,* 3C— *Raises the Boat for Everybody.*

Each of the themes were discussed by all participants, and under each theme, patterns emerged regarding the utility and completeness of the HCAHPS data. All but one participant consistently and sometimes frequently discussed concerns about racial bias and lack of representativeness of racial challenges in the HCAHPS data. The pervasive use of the scores and dichotomy of these concerns seemed consistent with the quantitative finding that while the *t*-test analysis of representation did not allow for rejecting both the null hypotheses, the distribution of responses seemed dubious. Patterns were identified when two or more participants mentioned issues in similar and sometimes identical language. Themes were consistent across participants and when examined in conjunction to the quantitative findings, suggest a disconnect between the HCAHPS data and those tasked with using the data to promote improvement in patient experience in U.S. hospitals. Figure 5 illustrates the themes and subthemes identified.

Figure 5 Themes from Semi-Structured Interviews



Theme 1: The Fabric of the Community

This theme portrays the various methods used by participants to capture a full picture of the patients in U.S. hospitals and explores how each type of information is woven together to form the fabric of the community or patient population to analyze the pattern of their experiences. Patient experience is defined by the Beryl Institute (2024), a global non-profit committed to advancing patient-centered care and studying and improving the patient experience, as “the sum of all interactions, shaped by an organization’s culture, that influence patient perceptions across the continuum of care.” The patient experience professionals interviewed shared that a critical part of their work is understanding how the patients in their hospitals judge their care experience. They shared universally that to understand the perspectives of all the health care consumers they serve, they require strategies in addition to the HCAHPS survey that capture the breadth, specificity, and the totality of patients’ experiences in their individual hospitals. This requirement highlights the need to fully understand how representative the subpopulation of survey respondents is to the population of the admitted patients. Participants share a collective understanding that health consumers' needs and perspectives vary and are reflective of the communities they serve.

> I want it to be representative of the typical, um, fabric of the community. So what is right in Ohio in one city is one fabric, and what's in Philadelphia is another fabric, and what's in Indiana is another fabric. So, I wanted to be representative not of what the global United States people say it should be. I want it to be customized to this town or this county or, you know, whatever you wanna pick. (P11)

This sentiment—that it is imperative to understand the community that one is serving and that the patients draw from in order to understand who is in one's hospital and how they may be experiencing their care—was common, with multiple participants sharing a similar sensibility.

> So, I think if you're not capturing the information from all groups and all demographics, then you're really missing a good chunk of your portion, especially because I mean you have to look at the community population as well and see who's living in your community, how many people, different demographics are there, and you are you capturing a good percentage of those patients in your information. (P6)

Participants equated a sample that represents the diversity of the community with the first step of understanding experience quality and how well their hospitals meet patient needs.

> I think it's paramount because we serve the community at large and so what is the community made up of when we think about the community at large, it's gonna be diverse and so having good representation from that diverse population is important to ensure that the quality-of-care experience is optimal. (P8)

P4 agreed that the specific needs of the patients in their hospital are crucially linked to the communities served; they further shared that this is an important perspective as hospitals develop tools to work with patients:

> In fact, who are our patients again, whether it be, you know ages or genders or English as a second language or you know race, again, who really are those that we serve. And the reason I think it's so important is again the tools that we use, we have to make sure that they fit with those we serve that they work for those we serve. (P4)

In addition to developing tools, P10 mentioned that processes and strategies can often be adversely affected by missing feedback from groups of patients:

> It matters because if we use all of that input to guide our processes to guide our strategies to guide the way that we care for patients, and if we are not hearing from certain populations from a diverse group and getting that feedback, we really run the risk of developing processes and solutions that maybe work for part of our community but don't work for everybody. (P10)

While a critical component of understanding the voice of the patient includes understanding the make-up of the community and ensuring that the diversity of the patients served is completely represented in the perspective gathered, P9 shared that understanding patient experience requires gathering perspective, especially a broad range of perspectives: "Obviously, the voice of the customer is our biggest opportunity, right, like that is our patients, but that's also our families, guest, our colleagues in some aspects." This perspective suggested a link between patient experience and colleague experience. Recognizing that health care is an industry of humans caring for other humans, it is important to understand the impact of the working environment and the ways in which that may impact the care provided.

> Oftentimes I try to really tap into the nurses because I'm trying to understand the behaviors that are happening on the unit from a nursing perspective, from a physician perspective, so I'm getting the side of the patient, but I'm trying to understand, to see what gaps there that we have in process. (P7)

Subtheme 1A: That’s Really the Voice of Our Patients.

This subtheme explores the value and use of comments received as part of the HCAHPS surveys to understand the experiences and needs of health care consumers. Patient experience professionals identified multiple strategies for understanding their patients’ experiences of care. All 11 professionals identified surveys as an important strategy.

> Yeah, it’s the, you know, one of the main quantifiable ways we can assess customer experience and satisfaction and between the two, between Qualtrics and and HCAHPS and bring that same kind of hard data to uhm, a lagging indicator that you know we, organizations want in terms of key performance indicators and it's, that's the best we can do probably on the lagging indicator standpoint in terms of I'm trying to gain that that insight. (P9)

Despite all participants acknowledging the importance of surveys, they quickly identified that the HCAHPS surveys alone were insufficient to obtain the totality of the experience. Participants mentioned many other ways to hear the voice of the patient, sharing that in addition to HCAHPS, many also use surveying from vendors, including Qualtrics, Press Ganey, and NCR—all organizations that have developed surveys to supplement HCAHPS scores with related but slightly different questions. A participant explained:

> We use what we call an integrated survey, which contains both the HCAHPS and a patient satisfaction survey with supplemental questions. Many of those questions align with similar areas of the HCAHPS survey, so that it focuses, whereas HCAHPS more or less focuses on, how often things happen, the patient satisfaction survey that we use more or less looks at how well those things are taking place. (P8)

Three of the 11 participants mentioned other, grassroots-type surveying as a valuable way to gain additional insights as well: “You could do QR codes or different things like that to get more real time feedback outside the HCAHPS" (P6). Moreover, participants repeatedly shared that it is crucial for them to receive timely feedback from patients because it makes the information actionable.

> And you know, depending on how they're treated, I really think that patients you know may not be as engaged because they're like, you know, I don't wanna go there. I feel that the staff doesn't truly understand me as a person in my needs, so I don't wanna go there. So, I mean I think it's important that we understand again not only who we serve but how they feel. (P4)

Nearly universally, participants identified the importance of the comments that patients submit qualitatively in combination with the quantitative ratings of their care as critical to understanding their perspectives regarding their care experience. P3 stated, "I also find tremendous value within the comments. The comments to me are gold." Similarly, P4 shared, "I feel that whether it's on the HCAHPS or the the modern surveys, those comments to me are gold." The comments can offer participants information about why patients select a particular rating and what was most significant for them during their time in the hospital.

> But I think to get to the true meat is to get to those comments. And so, after you have identified what are your greatest opportunities, it's really looking at, digging deep into those comments to really understand OK, the why behind it or the what is it? (P7)

Similar sentiments were heard throughout the interview process, with participants sharing not only the importance of reading these comments but also how they are used strategically within their hospitals: "I want to use them to recognize and celebrate staff and then also read the comments from people that are pointing out opportunities. That's really the voice of our patients" (P4).

> I feel and that's where when you think about just solely looking at (HCAHPS) data, it can be underrepresented and misrepresented in some cases because even though I, I I score you favorably, I'm sharing with you my voice and how I really feel, because how I really feel is gonna impact how I'm going to be, let's say, compliant with my care, how I'm going to recommend a hospital or, you know, the care to someone else based upon exactly what happened to me, what my experience was. And so, I feel like that is where we get the most bang for our buck is to what are we hearing real time and then how is that driving our decisions for improvement and strategy? (P8)

One participant discussed the value of survey comments as opposed to what may be said on social media:

> We get information from social media, Google Reviews, Yelp reviews, that's usually more in the domain of uh marketing, because very frequently we don't have the ability to trace that back to an actual patient, you know, because they don't give us a handle that gives them actual contact information. So, there's not much we can do about that, but it does still give us the ability to identify trends. (P5)

P5 worried that despite finding tremendous value in comments, it can sometimes be difficult to interpret exactly what a patient is trying to convey: “I think the relative scarcity of patient comments, ugh, that really give you a clear understanding of what they're saying. It is one of the things that you know kind of muddies the water.” In addition to helping to guide strategy and the work of the patient experience professionals in hospitals, patient survey comments are used by participants to help make patient experience a priority for hospital employees at all levels.

> Now you're gonna dig deeper into the comments that come back, uh, to understanding the trending and to properly and diligently sharing that feedback. If we don’t, the people that

> are at the bedside or the food side or the wherever have no access to what was said, not just a number. The numbers you know, to the cleaning people, the number is not that valuable, but they need to be meaningfully connected to the feedback. (P11)

Participants discussed multiple ways in which they incorporate comments into their work and poignantly shared how the comments sometimes help them see issues more clearly than the numbers.

> We've seen a lot of comments in terms of opportunity and indicating racial issues. I remember one of the survey comments was, you know, don't don't they realize why there's such a mistrust? You know, don't they remember, Henrietta Lacks, you know, and you just, you don't really realize when we're not even partnering to try to understand. (P2)

Subtheme 1B: Solve It Real Time.

This subtheme analyzes the various methods that participants use to gather information while patients are at the hospital and improve experience while the patient is still admitted. Participants shared that in addition to both the quantitative and qualitative data from surveys, they employ several additional strategies to gather information regarding patients' perspective of their care. They discussed perspectives on exploring consistency and the processes of communication from and to consumers.

> I'm looking at the performance of the actions that are being taken in the interaction with the patient. So, at that bedside, wherever the care is being provided, even if it's that initial, even if it's whatever contact point that is. So, if it's that initial phone call. All the way through looking at physical environment are we, you know, do we have capability for communicating for patients to communicate with staff appropriately in the appropriate manner and then using the data to determine how well we were doing all of that. (P1)

A specific and common strategy mentioned by seven of the 11 participants for capturing and measuring how patients experience care is through leader rounding, a widespread practice in hospitals. Members from the nursing or administrative leadership teams visit patients to have conversations that help them understand the quality and safety of the care they are receiving; it is also used to gather feedback regarding their care team members (Morton et al., 2014).

> But I think you know really getting the the direct voice of the customer is the most challenging and I'll mention one other input and that is a leader rounding. Actually, the leader going out or somebody in the leadership, you know, perception of authority going out and asking questions of customers in regard to how's it going today really makes a difference. And that's one of the most important things that needs to be done on a regular basis in order to, to get the voice of the customer. Then if you've got a problem, you can solve it real time. (P5)

P9 identified this as an important practice because it allows hospital staff to understand what is happening from the patient’s perspective while the patient is still there as opposed to waiting for the survey to be returned after the experience has ended.

> Another way we get the feedback from our patients, is right now, is primarily on the inpatient and ED, and in terms of actually rounding on patients and their family, a sampling of them, to gain insight on how things are going in the moment. (P9)

In addition to the important perspective gained by visiting patients in their rooms and speaking to them directly, five of the 11 participants spoke about patient and family advisory councils.

> Patient and family advisory councils (PFACs) are an excellent way to help health care institutions and providers better understand the perspective of patients and families while

> also helping caregivers better identify the needs of their patient population and bring patient and clinicians views closer together. (The American Hospital Association, 2024)

Participants shared the practices of utilizing both PFACs, which is an ongoing group that meets regularly and the mobilization of more specific ad hoc groups as needed.

> Rounding feedback that we get from our patients and families and then I would say pulling together the family advisory council too, leveraging that to get the feedback that we need and getting their input. So, there are two things. There's the family advisory board where you know you can meet every month, and then there's those specialized focus groups for uhm certain maybe opportunities that you may have. So, let's say women's health, you have a special project that you want to work on or need feedback for women's health. You pull together that focus group that is diverse to get to, to capture every voice of the patient. (P7)

Strategies to better understand how patients experience care included gathering and evaluating many additional data points, as illustrated in Figure 8. These data points included feedback from leader rounding, audits of how frequently nurses checked on or provided care to patients as documented in the electronic medical record, and the use of technology to record and evaluate the length of time patients wait to have needs met when they use their nurse call button to request assistance.

> I think that's as important as if it's looking at, you know what interactions you have with the patient, if it's assessing are we communicating with the patients are we meeting and rounding on the patient and how are we looking at that data of what interactions are we having with them? To me, that's a little bit more real time data and audits the performance and then yes, I do look at the HCAHPS data. (P1)

Subtheme 1C: We Need to Learn From This.

This subtheme discusses how the complaint and grievance process informs the work of participants and the methods used to understand how patients experience care. Several participants spoke about the importance of correspondence from patients—not only letters of appreciation but also complaints and grievances reported by patients and families. At least one participant cited these as even more critical than patient comments received via survey:

> If I can call that patient and follow up and say, hey, talk to me, we need to learn from this. We need to get better as an organization. I think that is what's going to advance the voice of the customer even more. Sometimes it is hard, a big challenge or barrier is just taking a comment for what it is. A static comment and not truly being in that person's shoes that wrote that comment and understanding what happened and what could we have done differently. (P10)

P9 explained that complaints from patients can evoke strong responses and serve as a catalyst to explore issues; although they struggled, almost seeming to try to distance themselves from the feedback in the telling.

> We had a a patient and they said at the end of the, they go, you go sit in our, you go sit in your ER at the end of a night right around midnight and you'll see the only people in there; Black people. And because, they're, everyone else is getting taken before us, that was their, you know, that was, that perspective. But you don't see, we don't see that in the comments, right? We don't see that in the surveys because we don't often probably get the right number of people responding back. So, but that came, by way, at least voiced out in terms of a complaint and grievance. So that was beneficial, uh, beneficially there. (P9)

Patient-initiated complaints and grievances can help to identify issues that might otherwise be missed. Like the participant above, P4 noted, “Through our grievance process, patients will (sometimes) share that they feel there was something different about their care uhm because of their race.” In some instances, patients may express these concerns in a process external to the hospital; P3 shared, “Usually we have one or two civil rights cases brewing at any given time.”

The patient experience professionals interviewed were explicit about the importance of hearing the voices of their patients and their perception that multiple strategies and tools were necessary to do so. “I think the data about what is collected is accurate but doesn’t accurately demonstrate the experience that patients are having in a health care setting” (P7). This adamancy from participants when examined next to the failure to reject the null hypotheses suggests that perhaps the HCAHPS tool itself needs to be re-examined, as there is clearly more information to understand from the perspective of those who do the work. “We take it for what it's worth we try to use statistically significant data to be able to look at that to drive change, not understand fully” (P8).

Participants consistently articulated that seeing the full picture of how their patients experience care requires them to think continually about where and how they can collect feedback. “I think that there is a lot more technology available to be able to gather more information outside of HCAHPS” (P7). Considering the information that actors might require to base decisions on in Rawls’ original position, it is important to have other sources of patients’ experiences of care available in addition to HCAHPS, as the participants present a compelling case for the need to use additional strategies to hear the voice of patients.

Theme 2: We Did Not Even Ask

This theme examines what or who participants believe are missing from the HCAHPS data that they receive and illustrates the anguish of the participants as they attempt to reconcile the pervasive use of the scores in hospital operations with their own innate fear of what is missed. In addition to discussing their strategies to understand how patients experience care, another major theme that emerged from the semi-structured interviews was the incompleteness of the HCAHPS data—a perception that there were specific aspects missing. These concerns repeatedly revolved around the representativeness of the sample, response rates, and the topics of the surveys.

> Patient experience is not an easy feat because we come from diverse backgrounds, cultures, beliefs, expectations, and so you can have two people with the same diagnosis with the same doctor and even health care team. But how they are maneuvered? Throughout their care, experience can look and feel quite different, and so. I think that that's a challenge in and of itself. How we can? Look at what we're consistent with is important, but above that is how we individualize and personalize the care and finding out what matters to that patient and addressing that first and foremost with safe, high-quality care. Safety comes first. I think that that is where we're at. Is, kind of that foundation is where we need to be. (P8)

Subtheme 2A: Who We're Hearing From.

This subtheme addresses the impressions from participants of who does and does not respond to the survey and why that matters to their work. Concerns regarding the representativeness of the sample seemed most closely poised to help address the first central research question: How well do patient experience professionals believe HCAHPS scores capture the experiences of patients who identify as racial minorities? P10 directly shared, "I see very, very low response rates in all other race and ethnic groups outside of Caucasian white." This observation was substantiated by the quantitative research—over 85% of all responses came from White patients despite those patients comprising fewer than 70% of the patient admissions. Another participant stated, "I'm constantly really surprised at the difference in who we were hearing from, who we were overhearing from and who we were under hearing from" (P3). P1 added, "For the person who answered the survey, I'm confident in the reflection of their experience, or at least their perception of the experience. But it's problematic to sort of generalize it to the entire population."

A third participant shared that they struggled to use the data to quantify their demographics and racial division: "It's sort of the sense based on lived interactions more than the data that there's there are some challenges there and some opportunities" (P4), while yet another participant had spent more time exploring the actual data and shared:

> In fact, in the data that I look at, 85 to 88% responses are white Caucasian. So that's where I do have concerns about our data because I know for a fact more than 10/12% of the population we serve are outside of White Caucasian. (P10)

Some participants shared the efforts that they had made to try to understand or even quantify the underrepresentation of specific groups.

> I think we have a huge opportunity to figure out how do we keep, hearing that voice from minority patients a lot better. We did a study, a big effort right after George Floyd at the ED here and one of the things we looked at was that we had 19% of our patients coming through the ER are African American, yet only 6% of our responses from the ED survey were from African Americans. And that's a national trend, too, that there's this underrepresentation of that population. They don't fill out surveys, for many reasons for historic reasons and feeling that it's going to fall on deaf ears. Feeling that nothing's going to be done or fear of it being used somehow against them. (P9)

Participants expressed their concerns about this inequity: "Their (minority patients') voices are being drowned out by others" (P3). A participant explained that one of their concerns centered on the view of the large score without consideration of the individual responses:

> Umm, I would I would, perceive that it would be a minute percentage of the whole. When we look at our diverse population, umm and I, would be afraid anecdotally, I mean, I mean I have not looked at a demographic breakdown for quite some time, you know by race or ethnicity. I know in in my career over time I have looked at that. From what, what we have received, and it was it was minimal to the whole, when we think about white versus nonwhite on patient that percentage is low. I don't know all the nuts and bolts and ways in how those are randomly distributed, and I think it has a lot to do with those of the minority populations that are actually represented as a whole. I think that those factors sometimes really translate into other issues such as access, being able to even access health care, being able to afford health care. You know some of the perceptions and fears of the groups that are underrepresented may face. So, there could be a lack of, full representation. I think it's a very small percentage of the whole (returning the survey) when we think about our minority or ethnically diverse groups. (P8)

Other participants explained why it is important to ensure that all subpopulations are included: “If we truly value diversity, equity and inclusion, I want to hear from everybody and what's important to you culturally may not be important to another group of individuals” (P3). Participants also expressed that understanding subpopulations is a key step in developing processes that meet individual patient needs.

> So, you wonder if we can do a better job partnering with our demographics and our personal preferences to really be able to understand we're missing with the, for example, the, Islamic woman's patient population here or we could do a better job with and you know I think I think we could do a better job there. You know, with the African American or people that identify as Black, you know, this is how we're feeling here. You know, I

> think there's different combinations that can happen with that data to give us a a better idea and maybe analyze trends in a more meaningful way. (P2)

"I am a huge proponent of personalizing care for each individual. But in order to do that, we need to know who somebody is and what they value and what's important to them" (P4). However, not all participants believed that race was a delineating factor in how patients experience care. One stated the lack of influence clearly: "I don't believe their race, but I do believe their language issues (influence how they rate the experience)" (P11).

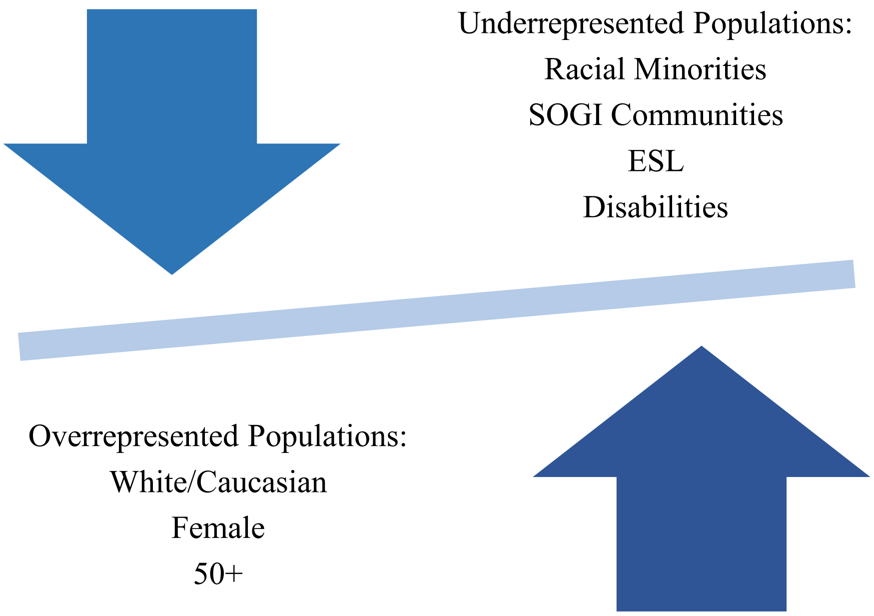
In addition to concerns about racial minorities, participants also identified many other subpopulations they believed to be underrepresented in the HCAHPS scores, as illustrated in Figure 6. The populations mentioned included sexual and gender identity (SOGI) community members, English-as-a-second-language speakers, and patients with disabilities. A participant shared the following concern about the HCAHPS responses: "I don't think that it reflects the experience of our Hispanic population because we don't get that many back from that group and any other (diverse) populations, you know, we're completely blind to gender identity and sexual orientation" (P5). Similarly, P2 said regarding the importance of recognizing challenges for the SOGI community:

> And if you don't even feel courtesy and respect, by the way, you're answering the question because of pronouns or because of, you know, whatever whatnot, then you've already shut the door even before we've started to try to ask how can we be better?

In addition to identifying underrepresented groups in their HCAHPS responses, participants were quick to discuss who they do hear from. "We had certain voices that were very underrepresented and certain voices that were very overrepresented, and I have to tell you, highly educated women 45 + are the worst critics" (P3). The overrepresentation of White patients was revealed in the quantitative data and was a re-occurring theme in the interviews. When asked about how well HCAHPS data reflect the diversity of their hospital population, P5 responded, “I think, yeah, I think it reflects the diversity of white patients.” Figure 6 illustrates how participants view the representativeness of the data based on demographics.

Figure 6

Participants' Perspective of Subpopulations' Representation in HCAHPS



Participants discussed other instances of how failing to understand the individual needs of a subpopulation, such as religion and other subtler indicators, can adversely affect their perspective of their care experience. P2 offered a heartfelt example of how preference and demographic factors can impact what happens in hospitals.

> I think also the time of death. Different religions have different customs, you know? And and maybe you don't mean to offend somebody. I remember at one time we had somebody shave somebody and that was a very bad thing in that culture, you know, and it

> was just very hurtful, you know? And so, I think and I don't think anybody meant to hurt anybody, but it's just we didn't even ask. (P2)

Subtheme 2B: It's a Very Small Percentage.

This subtheme examines the survey response rates and the overall concerns of the participants related to the utility of survey data. The most common issue mentioned regarding the HCAHPS data was the response rate, with all 11 participants raising the concern.

> It's a very small percentage of the population that is responding to give feedback and you know, when you look at response rates of 20 percent, 15%, that means that 85% of the patients that are being cared for and receiving health care are not represented in those numbers. (P1)

This same estimate was offered from another participant working in another part of the country, whose concerns articulated not just the general issue but also that this issue exacerbates the challenge of representativeness for diverse patients: "85% of the population that we are serving that we are not hearing from and there are bigger gaps in different patient populations based off of either race, age or gender is kind of our focus right now" (P10).

P8 spoke passionately about response rates and the importance of a response from every patient, while stressing the value of representation:

> Human connection. Human to human does it matter? Your ethnicity or background, you you are a human being and you are deserving of high quality, safe, personalized care, and your voice matters. And that's what is. That's what. That's what's important. That's what's important that your voice is heard and that it is. It is represented in a way that's meaningful that can affect change. (P8)

Despite the inherent value participants attach to every individual response, response rate and subsequent sample size can impact the utility of the data to drive change for specific groups.

"And then consider sample size and if this is all I have or with certain diagnosis and if we're really trying to dive deep, it's just not enough of a pool to make it actionable" (P2). For participants, there seemed to be a push and pull with the HCAHPS data and being able to use it confidently.

> The data that yeah, the data that comes back, I think, um, you know, just even looking at it from doing a data analysis, looking at if I look at the surveys and look at, I I've never had a concern that what was returned was not accurate, but it's not representative. (P1)

Even when response rates were higher, participants expressed concern about maintaining that level: "Return rates can be a problem. So, response rates, in every health system I've ever worked with or for, they're volatile. Response rates are volatile." (P11)

Subtheme 2C: There's an Entire Iceberg We're Not Even Looking at.

This subtheme explores all the additional issues related to patient experience that are missing from the HCAHPS surveys. Participants expressed concern regarding the ability of the data to reflect the aspects of the experience that patients care about most. "It only scratches the surface of what a good patient experience is all about. In order to get a more complete picture, we would need to have a whole bunch more questions (added to HCAHPS survey)" (P3).

> So, there's the quantitative data versus the qualitative data. And sometimes when you're trying to dig into it and you're like, well, how can I look at that with the data and you just really can't, you know, you're it's you're limited by that. (P10)

Participants suggested that many additional subjects of relevance were not even considered in the HCAHPS survey.

> So, I think high level it gives a tip of the iceberg of here's a small percentage of your population giving you a very generalized answer of a subjective thing that we're asking. And there is an entire iceberg we're not even looking at. (P1)

Participants not only identified that more questions are needed but also claimed that despite growing concern and awareness of the impact of race on patient experience, it has not been addressed. “So, if you know that there is this issue. This racial divide. Why wouldn't you have questions that address that on a survey?” (P6).

Many participants offered other abstract factors that could impact patients’ experience of care. Only one participant identified them as social determinants of health (SDH), but they clearly fell under that category when considered within the context of coding. The WHO (2024) defines SDH as “the non-medical factors that influence health outcomes. They are the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life.”

> But I think that that's true (the survey is) for people that can read at a certain level and that, people that speak English as a primary language and that, people that have had a great education or at least an adequate education. (P5)

While education is certainly an example of SDHs and reveals how they impact HCAHPS scores, other participants shared additional factors, although many struggled with how to talk about the issue, seeming uncomfortable with their own observations.

> Umm, especially African American patients, umm, that you know, the assumption that they are under educated or lack of appropriate preventative health care, there are assumptions made about certain populations. And the communication styles different and I think the level of care that patients receive is absolutely impacted by their umm. Especially when there's a difference in the health care providers and them, whether it be language, social, color, creed whatever it is. (P1)

Race can undoubtedly be an SDH by definition, but there are other relevant factors as well. Participants described this phenomenon and articulated the multi-layered bias that can exist:

> What I noticed …. was how the nurse, who was white, she's rounding on her patients and really engaging with the patient's just talking to them. Hey, what do you need? And went to the next room. There was this African American man who was, I mean, just he, I don't know if he was homeless or not, but he just didn't speak well. He didn't look up to par, hair wasn't combed and things like that. And she just brushed over him? Didn't ask him if he needed anything. I was just like, wow. So, I took a mental note of that, but as we went on, we went to another room, a Caucasian lady who was, I think she deemed her as being less as classy as the others, and treated, and treated her the same as she did the African American male. So, in my head I'm like, OK, so it's not about race, it's about class. If she feels you can't speak well, if you don't have an education, it was just a brush and really did not go through. We were doing bedside shift report and it was just a quick check in check in and out. So, I think class has a huge, huge take on it. (P7)

P5 summed up concerns about SDHs that were echoed in part by multiple other participants, sharing a laundry list of factors that can impact how patients experience care.

> There there's differences in regard to communication and their fluency in regard to health care and navigating health care and being able to navigate health care. You know, assuming that everybody's got a car and everybody's got a phone and everybody's got a home, that's a bias and you know, kind of removing those and that everybody's got good insurance and that just because you have public aid doesn't mean that there's some kind of a personal failure on your part. (P5)

Participants focused on their ability to see and address the SDH, the needs of patients that influence their experience in the hospital, and their overall health, with a huge focus on language. All but one participant mentioned language and the inherent challenges of multilingual patients in hospitals.

> So, whether you're an immigrant, whether you have a language barrier or whether you know if you're if English is not your dominant language. You know how well are you able to understand what is being communicated with you, ahh, even though you know we have devices and resources to kind of help to support that. It may not always carry the same impact. Umm, because things get lost through translation. That feeling? That emotional connection piece, I feel sometimes is lost through translation. (P8)

A participant explained that understanding language preference is critical to the care received and to long-term compliance and health post discharge.

> A third of our patient population does not speak English. Knowing (if English is a) first or second language so that when we are explaining things to a patient, explaining their medications, explaining procedures, we are certain that they are able to understand. (P4)

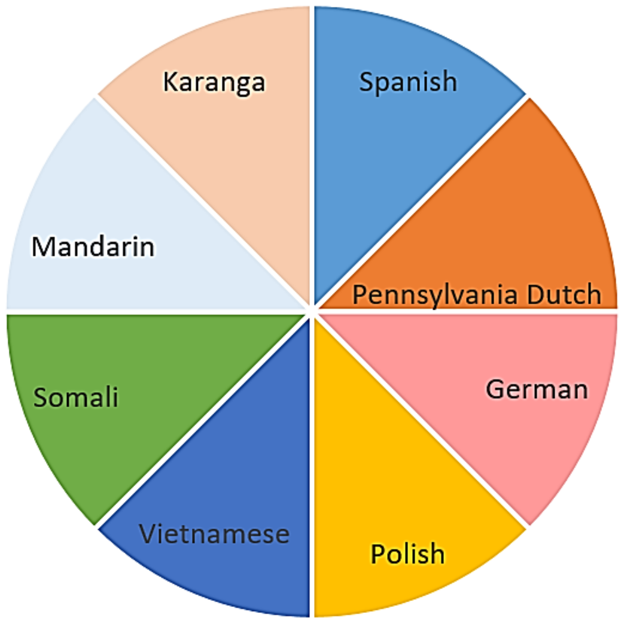
A common sentiment among participants was the need for the survey to be offered in additional languages and the importance of language in the hospital. However, the function of language and concept of fluency can be complicated and can further impact surveying.

> People are not necessarily fluent in spoken English, but they may be functional in spoken English. OK, so they would be illiterate in terms of reading a survey, maybe even in their own native language, but they can get by right, because they've, they're here in the US enough or they're functional with being able to travel around, and they can certainly have a conversation with the nursing staff. (P3)

Figure 7 illustrates the specific languages mentioned by participants as being needed to fully understand how patients in their hospitals experience care.

Figure 7

Languages in Participant Hospitals



Currently, the languages that HCAHPS surveys may be accessed in depends on which mode of survey is being utilized. Each hospital is required to select a survey mode every calendar year. Different modes entail varying costs to administer and are associated with different response rates. The available modes of survey are paper survey administered by United States postal mail, voice survey administered by a person over the telephone, and survey administered by interactive voice command over the telephone. Interactive voice command requires patients to use the number keys on their phone to respond to pre-recorded voice prompts. Some health systems may also choose a hybrid of mail and phone call for non-responders. CMS mitigates the variances in response rate for these modes of survey administration with their patient-mix mode adjustment, which is calculated annually. Table 10 shows a breakdown of languages available per mode and how they match with the language needs identified by participants. This table clearly shows that while most of the nine languages mentioned by the 11 participants to serve their health care consumers are available in at least one format, four (nearly half) are simply not available at all.

Table 10

Breakdown of Survey Language Needs and Availability by Mode

Language	**Needed by a Participants' Patients**	**Available for Postal Mail Survey**	**Available for Phone Survey (Human to Human)**	**Available for Interactive Voice Response Survey (Automated Phone)**
English	X	X	X	X
Spanish	X	X	X	X
Chinese	X	X	X	
Russian		X	X	
Vietnamese	X	X		
Portuguese		X		
German	X	X		
Tagalong		X		
Arabic				
Karanga	X			
Pennsylvania Dutch	X			
Polish	X			
Somali	X			

Data integrity, or the extent to which data are true, encompassing, and valuable, no matter when or how they are viewed (Cote, 2021), is important as decisions are made as a result of the data. As the HCAHPS data are described by participants through this lens, there is considerable question regarding the truth of the data representing all health care consumers. Additionally, ample concerns were raised about how encompassing HCAHPS is in terms of the numbers of health care consumers who respond, the rate at which diverse groups of consumers respond, and how well the questions asked capture the concerns of health care consumers. Patient experience failures occur because the industry cannot personalize care and attend to preference if it never asked.

Theme 3: The Only Thing Executives Look At

This theme presents the participants' views of how the HCAHPS data are valued and prioritized by the organizations they support. The final theme and subthemes center on how hospitals use the HCAHPS data. These themes helped to answer the second central research question: How do patient experience professionals describe the impact of HCAHPS scores on hospital operations and quality improvements? Moreover, these themes are easily divisible into several smaller themes. Subthemes include fiscal impact to the hospital and the many layers of hospital employees, reputation of the hospital affecting its ability to attract patients and physicians, and experience quality improvement processes within the hospital. Participants identified that at the executive level, HCAHPS scores are among the only patient experience data that matter. “So, the strategic core scorecard level is our surveys, it is it is 100% our experience survey metric” (P7).

Subtheme 3A: There’s Money on the Table.

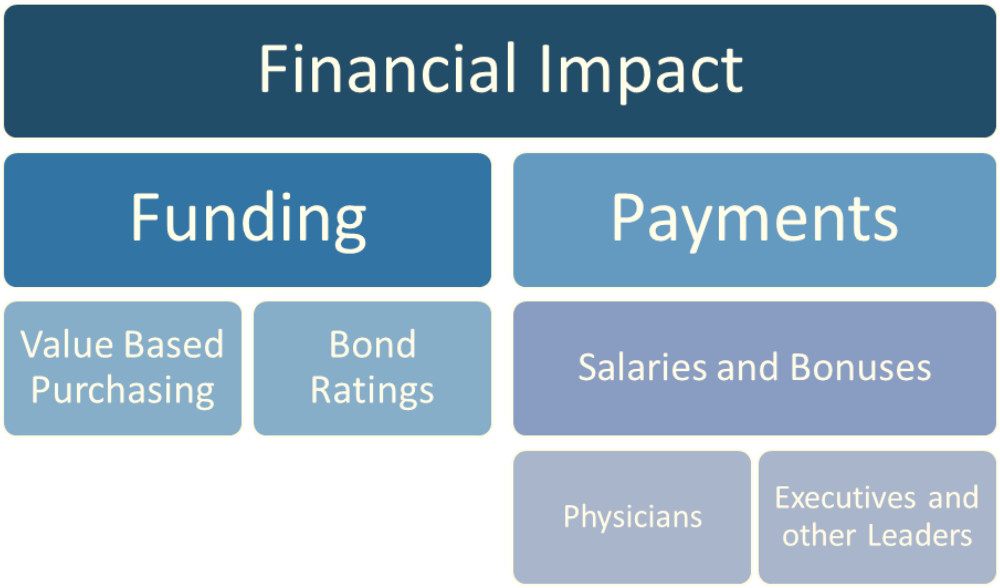
This subtheme discusses the various financial implications of HCAHPS scores to hospitals. Participants described the fiscal impact of HCAHPS scores as critical to the hospitals they support. “Because much of the value-based purchasing is based on HCAHPS, we sometimes prioritize what we're doing by what's going to get us the best HCAHPS score rather than what our patients most need” (P3). The CMS (2021) provides financial bonuses and penalties to hospitals based on performance of specific metrics; approximately 30% of these are based on HCAHPS scores. “There's money on the table, and that's the connection we're trying to make” (P5). A participant who supports hospitals across the country mentioned, “In many, they are used as a punitive dink, and the CFO drives that, typically, and it's to show they put much more attention on who's failing than celebrating who's doing great” (P11). Fiscally, participants shared that HCAHPS scores impact funding by affecting VBP bonuses and penalties and impacting how the long-term financial health of the hospital is rated, known as a hospital’s bond rating (Rangnekar et al., 2015).

> “I think organizations value it (HCAHPS survey data) because it drives a financial impact to the organization. but does it truly drive care? No. Really looking at that star rating and in correlation to you know, bond ratings. And so that's what they're looking at, they're highly focused on those.” (P1)

Significantly, many participants mentioned that HCAHPS performance was tied to salaries and bonuses at executive, physician, and consultant levels. “I think it's about bonuses and branding and just your brand. And so they want to look good and they want to get paid for looking good” (P7). Figure 8 illustrates the numerous ways participants identified these impacts.

Figure 8

Financial Impacts of HCAHPS Scores on Hospitals

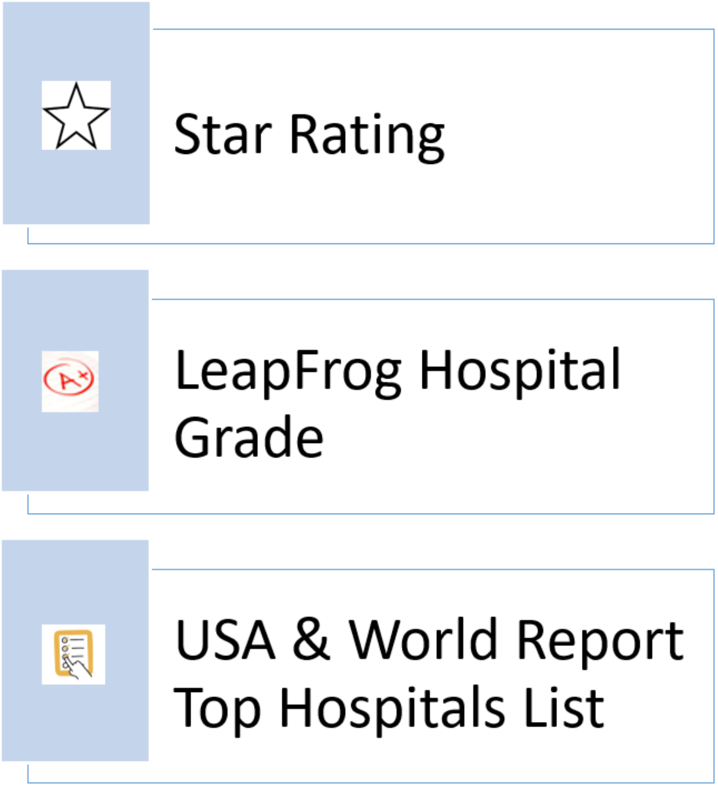


Subtheme 3B: That Doesn't Inspire Anybody.

This subtheme explores the impact of the scores on hospital reputation. As mentioned by a participant, another common theme regarding the organizational impact of HCAHPS is to branding. "A brand is a promise to consumers that the hospital will deliver on the kind of care needed" (Kemp et al., 2014, p. 126). Participants indicated that the reputation of the hospital is another important consequence, with HCAHPS driving multiple public-facing rankings, as illustrated in Figure 9.

Figure 9

Public-Facing Branding Associated With HCAHPS Scores



"Striving to be in the bottom decile that does not inspire anybody and nobody would want to bring their loved one to the organization where they're going to get that kind of treatment" (P5).

> “I mean, there's not dollars tied to it or hard dollars, but obviously having an “A” leapfrog rating is great for your reputation for recruitment of staff, you know, all of that. So I think there's so many things, again tied to HCAHPS, there's a lot at stake.” (P4)

Participants discussed multiple ways that executive teams from their hospitals focused on data, reputation, rankings, and the impact to the organization. For some participants, it was a simple matter of understanding their status in reference to their peers. P2 stated, “I think you just need to know how you're performing,” while P5 added, “So that's the other thing that's important about HCAHPS is that it can tell us not only how we're doing, but how we're doing compared to everybody else.” Others had more complex insights regarding reputation and the long-term impact of patient experience.

> But I think there's more of a recognition that it's not just about the money we lose from CMS, but this is as a company that is a consumer driven company worried about creating an experience is essential. Like we're not a commodity. We're, I think there used to be a view that we're just a commodity industry like we're here, so people come, and we're gonna have patients no matter what, and I don't think that's the case anymore. And I think that's that recognition I think is finally syncing in at the senior level that uhm, we really do need to look at how we're building trust, how we're impacting customer experience because that we can lose patients when perception of our hospital isn't good. (P9)

The concept of branding—of earning trust from consumers and understanding how health care organizations are rated—was mentioned by six participants, with most offering a pessimistic or, perhaps, realistic view that ranking matters most. “Umm, so for organizations, I think they highly value the HCAHPS performance and they are merely looking at it from where does it put us in our ratings” (P1). However, not everyone shared this view. P5 offered a more altruistic twist:

> There's no doubt in my mind that the heart of the executive team is that they want an exceptional experience for the patients that come in, but the only thing that we're really reporting out on a regular basis is one (HCAHPS) metric, you know, and that that only gets you so far.

Subtheme 3C: Raises the Boat for Everybody.

This subtheme examines how HCAHPS scores are used to drive experience quality improvement in hospitals. The semi-structured interviews revealed that HCAHPS scores in the hospitals of the participants are primary drivers of quality improvement. Participants expressed that particularly from an executive perspective, HCAHPS scores serve as a primary barometer of experience quality improvement.

> They want to see us be a five-star hospital, CMS, five star. They want to not lose money, and have penalties against us because of value based purchasing. I yeah, I mean, I think they just look at it globally as that's why they should focus on experience. (P9)

However, HCAHPS scores are not relevant to only executives; HCAHPS performance is used to drive change at a nursing unit level. One participant explained that HCAHPS scores are a primary way to coach and work with the teams they support. “But where are our opportunities and then from there, we break it down by unit and when we have, can point to the units that have the greatest opportunity, that's where we focus our education” (P4). Connecting the HCAHPS data to the frontline hospital staff is sometimes done in ways that bring the financial implications of the scores forward to the direct care workers: “And so now with our dashboards, instead of just making it a standalone metric, we're also saying we lost $8 million, because this many people walked out, and sharing our performance in regard to HCAHPS” (P5).

Participants shared that the HCAHPS scores do more than just measure performance; they also provide data that can be used to detect opportunities. “We dive in develop our key drivers, see where we need to focus on, and then make action plans and things around that to support the work moving forward" (P6). Participants shared various levels of sophistication in how their hospitals tackle experience quality improvement. "It's a journey. It's a continual message and how we're keeping it top of mind around the work" (P8).

> We do an analysis at a unit level as well. So we kind of have, you know our strategy A3 that guides our organization. But then within that, we coach at the unit level like what is this particular unit's gaps and how does what we do here obviously help move the organizational gaps that we've identified. So that not every unit works on the same things, but we always try to have a direct line of sight into doing work that's ultimately gonna move our organizational gaps. (P10)

One participant shared not only a current tactic of the organization but also a vision of how the data can be used to positively impact experience quality.

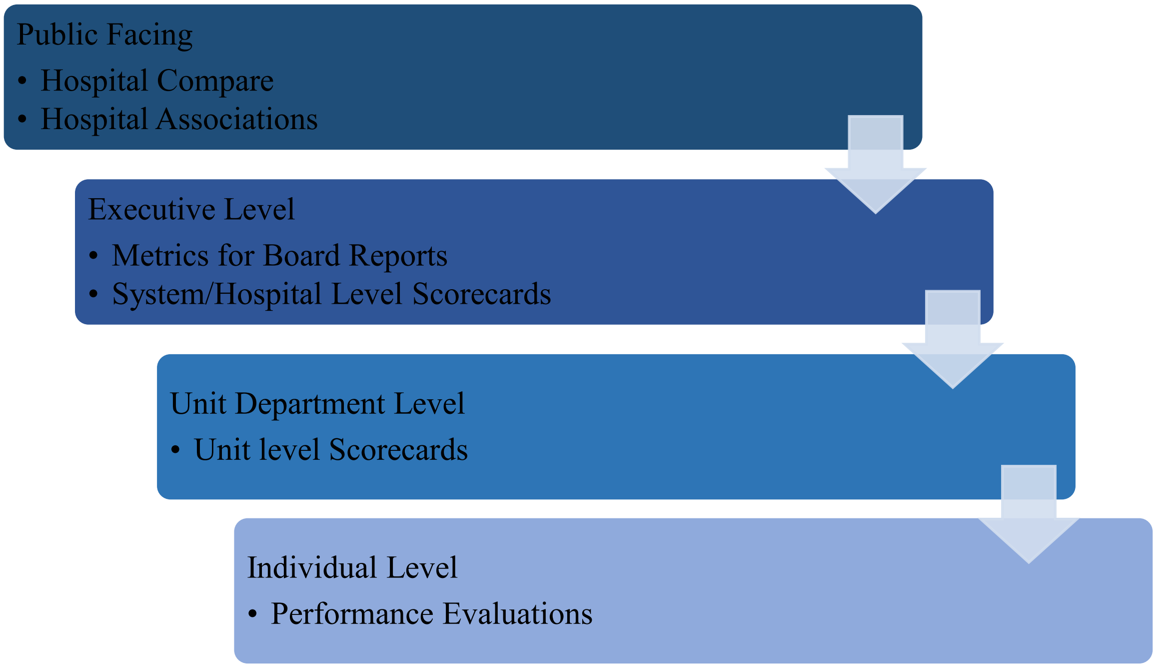
> We approach with an ACA mindset of what could we, what are the, people, processes, structures, technology that have broken down to let this event occur. In a future state approaching with a design standpoint. I mean I like, I'd love to work with our providers to say there should be a standard, there should have structure and so and if we did that then that would that would apply to whoever we're, whether it be a white patient and Black patient right, an Indian patient, like that doesn't matter, the demographic then we've designed a system that uh recognizes some of these just basic things that all people want. Uh, in terms of being cared for. So, uh, I think like, like interventions that raise all boats, right? (P9)

While survey data may be one of several data points that experience professionals employ, it is clearly a critical tool in improvement. Improving experience is simultaneously a group and individual effort and accountability. "Eventually, the staff want to know and they're involved in it, engaged in it, because that trickles all the way down to their department level huddle and it's part of their performance appraisal" (P5). "It's an incredibly team linked sport. Health care is just so team based and so you know we use that data to show you know you know the fluctuations" (P2).

Figure 10 illustrates the way participants described the role of HCAHPS as a metric in experience quality improvement.

Figure 10

How Hospitals Use the HCAHPS Metric



Summary

The quantitative analysis of a single health system's patient admissions and HCAHPS response data were combined with qualitative data generated through semi-structured interviews with 11 patient experience professionals in an attempt to understand how well HCAHPS surveys represent the diversity of patients and reflect the experiences of those patients in U.S. hospitals.

Although neither of the null hypotheses were rejected in the statistical analysis, an examination of the quantitative data revealed concerns regarding the distribution of responses. The themes revealed in the qualitative data provided a context to understand these findings; they explain how the participants struggle to use the HCAHPS tool as their primary measurement. The themes also illustrated how participants understand the populations they serve; the various methods they employ in addition to the HCAHPS tool; who and what are missing, overrepresented, or underrepresented in the HCAHPS responses they receive; and the value and significance of the HCAHPS scores to hospitals, health care workers, and experience quality improvement efforts.

Regarding the need for a way to discuss experience quality and access the same metric across hospitals and health systems nationwide, participants in the semi-structured interviews expressed belief in the value of the HCAHPS survey. “In lieu of another mechanism, I don’t have another mechanism that I can reliably use to tell me if any of my interventions have had any impact” (P3). P1 added, “It helps health care organizations use a standard language about what they’re asking.” Although all participants agreed that this type of measurement is a reality, a few were dismissive of the actual value, expressing that utilizing these data is expected, if not overly useful. “To me, the scores themselves are 33% valuable. They're a necessity. I can look at them over time to see some dips and rises or hopefully some consistency” (P11). Despite this sentiment, participants shared the reality of needing a way to understand how the improvement efforts are affecting patients and the reality of needing to make the tool work.

> It is the, how do I want a word this? It really is the biggest chunk of patient voice that I have and all transparency, you know through our survey comments I can be hearing from thousands of patients a month across our different service lines and there's no, there is no other process or mechanism I could put in place to capture that much information without a ton of resources. (P10)

At times, participants seemed to struggle with their own ambivalence when asked about the reliability of the HCAHPS data.

> I kind of go back and forth. UM, because I feel if I complete a survey, you have a question, you ask me, how do I feel about this particular experience? I I complete that score, I rate it, give it to you. Umm, I think they're reliable to a certain extent. Why do I say that? Because there's a huge bucket that we're missing, there's a gap in collecting all of this data. (P7)

The quantitative data were challenging to analyze statistically due to the extremely small subpopulations, and the participants observed the dearth of information that they seemed to passionately and relentlessly seek as they tried to support patients. The question to be considered from the Rawlsian lens is if these data are enough. P6 summed up their thoughts by sharing, “Good start. I think you know realistically like yes, it's good, the information is good.”

> I think that some of our diverse populations are underrepresented, but if you set that aside, I think in general it's a fairly accurate reflection of the patient experience because it's not like we're hearing different things from all of our different touch points. (P5)

Ultimately, what emerges from using the context of the qualitative and quantitative findings imply that while widely accepted, the HCAHPS may be nothing more than a good start.

Chapter 5: Conclusions and Recommendations

This chapter discusses the results and findings of this study, with particular attention on the limitations of the findings. The discussion also centers on understanding what the findings mean, particularly as a mixed-method study enables examining how both types of findings provide meaning in the context of one another. The chapter also explores how well the findings support or contradict the existing literature, what that reveals, and if it suggests the need for further inquiry. Additional attention is paid to understanding how this research contributes to understanding the field of patient experience, how patient experience is measured in the United States, and how well that measurement represents U.S. health care consumers. This chapter concludes with recommendations for further study in the area of patient experience scores by patient race/ethnicity and the implications of the findings to the field, policymakers, and U.S. health care consumers.

Summary of the Study

The study addresses how effectively the HCAHPS reflects the care experiences of racially and ethnically diverse patients admitted to hospitals in the United States. The HCAHPS survey, a requirement for all hospitals that participate in Medicare billing, is described by the CMS as a primary tool to drive high-quality care improvements in U.S. hospitals. By basing portions of the payments to those hospitals on specific quality measures, a structure known as VBP, CMS financially rewards or penalizes hospitals for their performance. Among these measures is patient experience, which is measured solely by HCAHPS surveys (CMS, 2021). This study sought to understand how well this measurement method captures the performance of experience quality for racial and ethnic minorities. The lengthy and pervasive history of racism in U.S. health care requires diligent investigation of every tool introduced to ensure the lack of intentional and unintentional discrimination.

This study investigated the efficacy of the HCAHPS survey to provide a basis for driving experience quality improvement that benefits all health care consumers. A review of the literature regarding HCAHPS scores revealed that the program has been studied since its inception to understand how numerous factors, including patient-level demographics such as age, gender, and ethnicity, may impact the scores. Studies also examined social factors, including patients' education level, employment, and insurance status. However, the influence of race was missing from the existing literature on HCAHPS scores. This research sought to begin the discussion of the relationship between race and the HCAHPS survey and offer a starting point for filling the dearth of research on this topic. The delivery of high-quality health care and services to minority patients in the United States requires diligent examination of all practices and measurements to ensure fair and equitable treatment that does not perpetuate historical ills. Considering the U.S. health care system from Rawls' original position suggests that these examinations are not simply good practice but obligations.

In order to ascertain how well the HCAHPS survey captures the experiences of racial and ethnic minority patients, a mixed-method convergent parallel design was employed. Aggregate patient admissions by race and ethnicity data were collected from a midwestern American health system for 2018 and 2019. Understanding how representative the survey sample is for race and ethnicity, even in a single health care system, represents a beginning to fill the existing gap in knowledge regarding the relationship between race or ethnicity and patient experience, as measured by the HCAHPS scores. This study employed a mixed-method design to better understand the HCAHPS data in the context of race and ethnicity affecting patient experience. To provide this context, 11 patient experience professionals from across the country participated in semi-structured interviews that focused on understanding the central research questions: How well do patient experience professionals believe HCAHPS scores capture the experiences of patients who identify as racial or ethnic minorities? How do patient experience professionals describe the impact of HCAHPS scores on hospital operations and quality improvement?

The collection and analysis of the quantitative data and all semi-structured interviews occurred over two-and-a-half weeks. All the participants were working in the field of patient experience, holding roles from national consultant to system level or regional patient experience leader and patient experience leader at a single hospital or group of hospitals. A convenience snowball sampling method was used, with participants suggesting other professionals who might also like to participate. The health system selected for the quantitative data is located in the Midwest, comprising four hospitals varying from a level two acute care trauma hospital to a specialty surgical hospital. All four hospitals primarily serve adults but treat pediatric patients in all emergency departments as required by law and in nurseries or neonatal intensive care postpartum. The hospitals serve a predominantly urban/suburban population in one of the top 15 largest cities in the United States. The convergent parallel design was selected to mix the data at the interpretation phase so that findings could be used to explain and interpret each other, resulting in practical, clear conclusions regarding the representativeness of the HCAHPS tool. Statistical analysis of quantitative data was conducted using the SPSS SAS package. All semi-structured interviews were conducted over Zoom or Microsoft Teams and stored and transcribed according to Franklin University data protection guidelines. All video and audio recordings were destroyed following transcription, and no identifying information regarding participants or the hospitals they support has been shared. Qualitative analysis was conducted using ATLAS.ti software, and an inductive method of identifying codes and themes through analysis instead of fitting coded data into pre-identified themes was employed.

Discussion of Findings

This study furthers the conversation about what it means for health care to be patient-centered and to listen to and act upon the voice of the patient. This study produced multiple findings related to the HCAHPS surveys and racial and ethnic minorities' care experiences in U.S. hospitals. However, the most explicit and critical finding is that the HCAHPS survey is not an effective tool to promote health care that encourages experience quality for racially and ethnically diverse Americans. The qualitative findings indicate that patient experience leaders hold widespread beliefs about the inability of the HCAHPS surveys to provide sufficient feedback from diverse patients. Participants insightfully shared their impressions of patients who did not respond—impressions that were confirmed by the quantitative data. This combination of mixed findings provided substantial evidence of the themes that emerged from the qualitative analysis—*The Fabric of the Community, We Didn't Even Ask,* and *The Only Thing That Executives Look At*—these themes suggest that racism and being able to address the needs of diverse patients are significant to patient experience professionals. Not only were participants mostly able to correctly describe the disparity in the scores' representativeness as shown in the quantitative data but they also eloquently shared concerns about the challenges of capturing the perspectives of diverse patients.

Quantitatively, the scarcity in responses confirmed the anecdotal impressions of participants: "I think it is an extremely high-level snapshot of a very small portion of a population that's being served" (P1). Existing literature supports this view—nonresponse rate error becomes a significant and concerning issue when there is an overrepresentation of specific subpopulations in the group of non-responders (Sivo et al., 2006). Like all high-level snapshots, the details seem to be missing from HCAHPS, and the qualitative themes and subthemes reveal that these details are significant. While this analysis of the HCAHPS from the lens of representativeness for racial and ethnic minorities may be unique, the findings are consistent with previous research, which has identified that improving experience quality is dependent on building relationships between patients and caregivers that are built on communication, trust, and confidence that stems from seeing patients as individuals and recognizing individual needs (Wyn, 2016). Aggregate data by race and ethnicity of patients returning the HCAHPS survey were collected from the same health system for the same calendar years. While the use of a simple *t* test did not allow the rejection of the first null hypothesis—H01: There is not a statistically significant difference between the response rate of non-white patients to the HCAHPS survey and the admission rate of non-white patients to a health system during the same period—the sample sizes were so small for all populations other than White/Caucasian and Non-Hispanic/Latino that meaningful analysis to test the second null hypothesis was not possible—H02: Patient race is not a statistically significant factor in how patients score their hospital experience.

Qualitative analysis revealed that patient experience professionals invest considerable time and energy in gathering feedback from racially and ethnically diverse patients. The participants expressed anguish regarding the discord between the population of patients returning surveys and those that they see in their hospitals; they compassionately described issues of bias in their hospitals and impacts on individual patients.

> I think we can to help heal and so I think when we realize that we're hurting and where the basics of dignity and respect or courtesy and respect are not there and we don't feel like they're not, we're not even listening to you. How can we possibly be treating you well? You know, we talk about that correlation and that's gonna end up in a readmission. (P2)

Participants collectively and individually described, with passion, the challenges faced by minority patients in their hospitals. These findings build upon existing research, which suggests that improving experience quality is incumbent on understanding patients’ needs and preferences and providing health care professionals with the skills to meet those needs (Kumah, 2019). They also add to depth to the perspective that the social construction of race in health care requires identifying trends and mindfulness of bias that shadows a preponderance of decisions and behaviors (Poole, 2019). While most participants discussed the link between patient race and care experiences, all could articulate varied additional demographics of import. The collective list of demographics that influence experience of care that participants produced contained varied factors, including race, ethnicity, language, sexual orientation and gender identity, education level, and housing status. This list is consistent within the context of previous knowledge about hospitals that serve a greater percentage of disadvantaged patients performing worse on the HCAHPS metrics (Cleary, 2016).

All participants agreed that, ultimately, HCAHPS scores were the only measure of patient experience that was relevant to their executive leadership, which they identified was linked to the relationship between the scores and the financial well-being and reputation of the hospital. While this relationship was repeatedly and universally mentioned by participants, this finding is inconsistent with the existing knowledge regarding HCAHPS and VBP, specifically that nearly 20 years after the program was introduced, there has been no notable improvement to patient experience scores that can attributed to the program; hospitals that do not participate have improved at the same and sometimes faster rate (Ryan et al., 2021). Despite this inconsistency, all participants expressed the importance of understanding how patients experience care, shared innovative strategies for gathering patient feedback that was both inclusive and timely, and seemed to feel that it was imperative for them to do so.

Findings and the Theoretical Framework

Inherent to Rawls's theory of justice is the idea that justice is fairness. Rawls suggests that what is just is what provides the greatest opportunity to the least advantaged and that in the original position, actors will always select the option that offers the greatest opportunity for the least advantaged in case that is the position they hold in society when they step out from behind the veil of ignorance. Rawls does not include discussions of health in his original theory, considering it to be a natural primary good. Natural primary goods are attributes randomly assigned as part of the organic condition of being human as opposed to being a social primary good, which can be distributed strategically from the original position (Rawls, 1971). Since the introduction of this theory, others have re-interpreted and offered the perspective of inclusivity for health care as a social primary good on the basis of SDH, understanding that access to health care that meets individual needs would be a condition in which agreement from behind the veil of ignorance is appropriate (Ekmekci & Arda, 2015). The findings of this study support the need for additional measures of patient experience. While this is likely the first time the veil of ignorance has been used to think about this specific way of measuring patient experience, the idea of using this frame of distributive justice to consider what is owed to groups of individuals is not new. The veil of ignorance has been used to determine how policies impact different groups and to evaluate the effects of those choices for issues like measuring population health (Pinto-Padres & Abellán-Perpiñán, 2005). Furthermore, this tool has long been understood as a way of considering policy related to poverty and structures that support oppression (Mason, 2014). Following these examples, it is difficult to imagine that rational actors would agree with this instrument in fairly determining the quality distribution of health care experience. Based on this research, this tool appears to offer the antithesis of benefits to the least advantaged subpopulation, instead completely ignoring their experiences of care to promote the experiences of the most advantaged as universally representative for all. Although the quantitative findings establish a lack of representation of racial and ethnic minorities in the response pool, the findings were unable to quantifiably establish a relationship between the race and ethnicity of respondents and how they rated their care experience. There were simply insufficient responses in minority subpopulations to establish a statistically meaningful relationship. This insufficiency helps to strengthen the choice of a mixed method study as the qualitative findings unequivocally show that racial and ethnic minorities are negatively impacted in how they experience health care.

Limitations of the Study

This study utilized data from a single health system with hospitals in a centralized geographic area. Therefore, the results may not represent other hospitals based on location or the myriad of characteristics that define them. The selection of calendar years 2018 and 2019 was intentional as compulsory collection of HCAHPS reporting was interrupted by the COVID-19 pandemic during the 2020–2021 calendar years, and the impact of the pandemic on the HCAHPS survey is still widely unknown. Research has established that Black and Latino patients were both hospitalized for and died of COVID-19 at higher rates than other populations (Bibbins-Domingo, 2020); hence, it has had a likely negative but as yet unknown effect on HCAHPS scores, subsequent hospital ratings, and experience quality.

Additionally, even with a sample size of over 100,000 admitted patients for the two calendar years, the less than 23,000 respondents to the survey represented such a small sample with such limited diversity that it was not possible to assess how or if race and ethnicity influence how patients rate their care experience. This aspect may not be true at every hospital or health system, and additional research is needed in this area. Much like how quantitative data may have limited transferability to other health systems, the qualitative data may also lack generalizability as it reflects the ideas and opinions of the 11 participants.

Participant bias may have also affected how participants responded to questions regarding the representativeness of the tool and the experiences of minority populations. These biases may have been present in promoting and silencing minority voices. Additionally, researcher bias may have factored into the findings; before the beginning of the research, the researcher believed that a lack of representation existed in the HCAHPS responses, based on tenure in the field of patient experience. This is consistent with what is known about bias influencing the ideas and contributions of research (Hill et al., 2005). Understanding the pervasiveness of concerns about representation and the challenges of diverse populations in health care settings could be an example of confirmation bias. Research has established that this bias can be particularly evident when examining other people and their impressions or behaviors (Peters, 2022). Further limitations may be related to the reflexivity of the principal researcher and the construction of the semi-structured interview protocol, verbal and non-verbal cues during the semi-structured interviews, and the prior relationship that existed with four of the 11 participants. Reflexivity refers to "how our own aspirations, characters, values, philosophies, experiences, belief systems, political commitments, and social identities have shaped the research" (Palaganas et al., 2017, p. 430).

Recommendations

This research was conceived based on the need for a tool that accurately and inclusively reflects the quality of experience for U.S. health care consumers. The topic and design evolved from a desire to understand the validity and reliability of the HCAHPS tool regarding racial and ethnic minorities, with an understanding that the scores and data derived from the tool were used pervasively within the health care industry. Recommendations are divided for applicability to future research, the HCAHPS tool, health care administrators, and policymakers at the health system leadership and federal rule-making levels.

Future Research

The findings of this research, specifically the quantitative findings, bear repetition more pervasively at the hospital and national levels. When tested based on race and ethnicity, the inconsistency of the data regarding race and ethnicity was concerning. Despite the inability to reject the null hypothesis, questions about the representativeness of the sample in the HCAHPS tool is disturbing, and additional confirmation at the hospital, regional, and national levels is required to confirm the tool's validity. Examination of the representativeness of HCAHPS is not new; it has been conducted, and adjustments have been applied for a wide variety of demographic factors and characteristics to prevent unfair evaluation across participating hospitals based on criteria beyond the hospitals' control, known as the patient-mix mode adjustment (Elliot et al., 2009), which has excluded race or ethnicity to date.

The HCAHPS Tool

Based on the qualitative findings, a re-examination of the HCAHPS tool itself is warranted. Participants specified that in identifying demographics of interest, sexual orientation and gender identity are neither assessed nor considered. Additionally, no questions related to experiences of bias are asked in the survey questions despite the stirring and distressing comments that participants described and shared from patients related to the topic. Precedent exists for revising what is asked on the survey; previous revisions to the HCAHPS tool have included questions regarding pain, which were revised in 2018 and ultimately removed in 2019 (CMS, 2021).

Recommendations for Health Systems and Health System Leaders

Although the administration of HCAHPS is a federally required condition of participation for U.S. hospitals wishing to participate in Medicare billing, the findings of this study suggest they are an incomplete data source to understand and, ultimately measure, patient experience quality. Unlike other quality measures, which are frequently tracked and monitored using process measures or measures that monitor the extent to which processes are followed to produce a desired outcome (Varkey et al., 2007), experience quality is most frequently tracked and monitored at a system or hospital executive level based on the HCAHPS scores. Moreover, these scores are an outcome measure, which is a consequence of health care reported in aggregate and influenced by outside factors (Varkey et al., 2007). Participants shared a plethora of process measures available for monitoring experience quality, and leaders should consider exploring more varied methods to improve this outcome.

Policy Makers

Based on the purported goals, a need exists to re-examine the HCAHPS survey. According to the HCAHPS website:

> Three broad goals have shaped the HCAHPS survey:
>
> 1. The survey is designed to produce comparable data on the patient's perspectives on care that allows objective and meaningful comparisons between hospitals in important domains to consumers.
> 2. Public reporting of the survey results is designed to incentivize hospitals to improve their quality of care.
> 3. Public reporting will enhance public accountability in health care by increasing the transparency of the quality of hospital care provided in return for public investment.
>
> With these goals in mind, the HCAHPS project has taken substantial steps to ensure that the survey is credible, functional, and practical. This methodology and the information it generates are available to the public. (HCAHPS Online, 2023)

The findings of this study do not support that the tool accurately reflects and provides incentives to improve or increase transparency regarding the experiences of bias in U.S.

hospitals. Despite organizations like the Centers for Disease Control and Prevention promulgating that they are tasked with leading the efforts to reduce health imbalances caused by racism in the United States, there has as yet been no call for CMS, which is the largest payer to health care systems in the United States and the entity that requires and monitors HCAHPS surveying, to adjust or even examine the survey and results for patient race and ethnicity. This demographic is a specific exclusion. Although patients are asked to self-identify race and ethnicity when they complete HCAHPS surveys and all HCAHPS data are publicly available on its website, no data regarding race are offered. An inquiry into the availability of this information in January 2024 resulted in a response from quality support that read in part:

> Thank you for your inquiry regarding HCAHPS data. HCAHPS survey is administered to a random sample of adult patients across medical conditions between 48 hours (about 2 days) and six weeks after discharge; the survey is not restricted to Medicare beneficiaries. CMS does not gather information by race. R. Silsdorf (personal communication, January 29, 2024)

The absolute and seeming indifference to the impact of race and ethnicity must be addressed, and policy should be enacted to require attention to this demographic. Moreover, the method and timing of data collection should be diversified to ensure that feedback is inclusive and representative of all racial and ethnic demographics. Technology now exists and should be implemented to allow patients to complete surveys before or at discharge. This tactic will allow the use of interpreters and other assistance that supports completion of the survey. Additionally, hospitals should be encouraged to provide technology to patients to complete the survey. Doing so will not only ensure that every patient has an equal opportunity to complete it but also allow conversations with staff regarding how feedback is used, which could encourage underrepresented groups to participate. Finally, including questions about experiences of bias is critical in forcing hospitals to confront behaviors and attitudes that perpetuate harm to minority patients in the hospital and negatively impact health care outcomes. Policy must be passed to require and publicly report racial and ethnic data. Further, funding appropriated for quality improvements must be predicated by the use of a representative sample; this must become a regulatory requirement. Failure to address these needed changes severely limits the utility of the published data for consumer decision-making, as it only reflects and applies to a limited group of consumers.

Conclusion

Examining the quantitative data within the context of the qualitative findings allowed for an alarming glimpse of the U.S. health care industry, which reveals that the move to patient-centered care is predicated on a nearly exclusive perspective of White/Caucasian patients despite a clear history of systemic discrimination committed against racially and ethnically diverse populations. This research has presented a first attempt at filling the existing gap in the literature regarding the impact of race and ethnicity on the HCAHPS tool used to measure patient experience in the United States. This mixed-method convergent parallel study provides evidence that the scores do not present a representative sample of the care experiences of the patient population of the selected health system. Moreover, the qualitative findings provide substantial and compelling evidence that the tool may be overvalued as a metric for experience quality and improvement while failing to encompass the needs and experiences of U.S. health care consumers. Ideally, these findings will support efforts to provide more equitable funding and process improvements and expand the base of patients whose perspectives are considered in the experience quality metric.

Ultimately, this study contributes to the knowledge of how experience quality is measured in the United States and should be of interest and value to the health care industry and the field of patient experience. This study has contributed to analyzing organizational health care problems and how hospitals measure impact; it also demonstrates ethical leadership and management theory in health care organizations. Most importantly, this study provides value to U.S. health care consumers and explicitly addresses the need to hear the voices of racial and ethnic minorities. To continue using the HCAHPS tool as the sole means of measuring experience quality with no adjustments or additions is a further example of bias at best or willful ignorance at worst. The time has come to step out from behind the veil of ignorance and attend to this inequity.

References

AbuDagga, A., & Weech-Maldonado, R. (2016). Do patient, hospital, and community characteristics predict variations in overall inpatient experience scores? A multilevel analysis of hospitals in California. *Health Services Management Research*, *29*(1/2), 25–34. https://doi.org/10.1177/0951484816632634

Agency for Health care Research and Quality. (2020, February). *Section 2: Why improve patient experience?* https://www.ahrq.gov/cahps/quality-improvement/improvement-guide/2-why-improve/index.html

American Hospital Association. (2024). *Patient and family advisory councils: Resources for the field.* https://www.aha.org/patient-and-family-advisory-councils-podcasts-and-blueprint

Baah, F. O., Teitelman, A. M., & Riegel, B. (2019). Marginalization: Conceptualizing patient vulnerabilities in the framework of social determinants of health—An integrative review. *Nursing Inquiry*, *26*(1), Article e12268. https://doi.org/10.1111/nin.12268

Ben, J., Cormack, D., Harris, R., & Paradies, Y. (2017). Racism and health service utilisation: A systematic review and meta-analysis. *PloS One*, *12*(12). https://doi.org/10.1371/journal.pone.0189900

Beckett, M. K., Hambarsoomian, K., Martino, S. C., Agniel, D., Hudson Scholle, S., Maksut, J. L., Mathews, M., Orr, N., & Elliott, M. N. (2023). Measuring equity in the hospital setting: An HCAHPS application of the Health Equity Summary Score. *Medical Care*, *61*(1), 3–9. https://doi.org/10.1097/MLR.0000000000001769

Benkert, R., Peters, R. M., Clark, R., & Keves-Foster, K. (2006). Effects of perceived racism, cultural mistrust and trust in providers on satisfaction with care. *Journal of the National Medical Association*, *98*(9), 1532–1540.

https://www.proquest.com/docview/214054119?pq-origsite=gscholar&fromopenview=true&sourcetype=Scholarly%20Journals

Bibbins-Domingo, K. (2020). This time must be different: Disparities during the COVID-19 pandemic. *Annals of Internal Medicine, 173*(3), 233–234. https://doi.org/10.7326/M20-2247

Birkelien, N. L. (2017). A strategic framework for improving the patient experience in hospitals. *Journal of Health care Management*, *62*(4), 250–259. https://doi.org/10.1097/JHM-D-17-00071

Boissey, A. (2020). Getting to patient-centered care in a post–Covid-19 digital world: A proposal for novel surveys, methodology, and patient experience maturity assessment. *NEJM Catalyst Innovations in Care Delivery*, *1*(4). https://doi.org/10.1056/CAT.19.1106

Brinkmann, S., & Kvale, S. (2018). *Doing interviews* (2nd ed.). SAGE Publications. https://doi.org/10.4135/9781529716665

Brown, A., & Patterson, D. A. (2001, July). *To err is human* [PowerPoint presentation]. First EASY Workshop on evaluating and architecting system dependability (EASY'01), University of California at Berkeley, CA, United States. http://roc.cs.berkeley.edu/talks/pdf/easy01.pdf

Browne, K., Roseman, D., Shaller, D., & Edgman-Levitan, S. (2010). Analysis & commentary measuring patient experience as a strategy for improving primary care. *Health Affairs, 29*(5), 921–925. https://doi.org/10.1377/hlthaff.2010.0238

Burns, L. & Pauly, M. (2018). Transformation of the health care industry: Curb your enthusiasm? *Milbank Quarterly*, *96*(1), 57–109. https://doi.org/10.1111/1468-0009.12312

Carter, J. C., & Silverman, F. N. (2016). Using HCAHPS data to improve hospital care quality. *The TQM Journal*, *28*(6), 974–990. https://doi.org/10.1108/TQM-09-2014-0072

Carter-Pokras, O., & Baquet, C. (2002) What is a "health disparity"? *Public Health Reports, 117*(5), 426–434. https://doi.org/10.1093/phr/117.5.426

Chakraborty, S., & Church, E. M. (2020). Social media hospital ratings and HCAHPS survey scores. *Journal of Health Organization and Management*, *34*(2), 162–172. https://doi.org/10.1108/JHOM-08-2019-0234

Chatterjee, P., Joynt, K. E., Orav, E. J., & Jha, A. K. (2012). Patient experience in safety-net hospitals: Implications for improving care and value-based purchasing. *Archives of Internal Medicine*, *172*(16), 1204–1210. https://doi.org/10.1001/archinternmed.2012.3158

Centers for Medicare and Medicaid Services. (2021, March). *HCAHPS fact sheet.* https://hcahpsonline.org/globalassets/hcahps/facts/hcahps_fact_sheet_march_2021.pdf

Center for Medicare and Medicaid Services (n.d.). *Home/hospitals-inpatient/hospital value-based purchasing (HVBP) program/participation*. https://qualitynet.cms.gov/inpatient/hvbp/participation

Cleary, P. D. (2016). Evolving concepts of patient-centered care and the assessment of patient care experiences: Optimism and opposition. *Journal of Health Politics, Policy & Law*, *41*(4), 675–696. https://doi.org/10.1215/03616878-3620881

Cohn, F. (1999). The ethics of end-of-life care for prison inmates. *Journal of Law, Medicine & Ethics*, *27*(3), 252-259. https://doi.org/10.1111/j.1748-720X.1999.tb01459.x

Cohen, J. B., Myckatyn, T. M., & Brandt, K. (2017). The importance of patient satisfaction: A blessing, a curse, or simply irrelevant? *Plastic and Reconstructive Surgery*, *139*(1), 257–261. https://doi.org/10.1097/PRS.0000000000002848

Cote, C. (2021, February 4). *What is data integrity and why does it matter?* https://online.hbs.edu/blog/post/what-is-data-integrity

Creswell, J. W., & Clark, V.L. P. (2017). *Designing and conducting mixed methods research* (3rd ed.). SAGE Publications. https://sagepub.vitalsource.com/books/9781506394671

DeCamp, M., Pomerantz, D., Cotts, K., Dzeng, E., Farber, N., Lehmann, L., Reynolds, P, Sulsmay, L., & Tilburt, J. (2018). Ethical issues in the design and implementation of population health programs. *Journal of General Internal Medicine*, *33*, 370–375. https://doi.org/10.1007/s11606-017-4234-4

Denscombe, M. (2017). *The good research guide: For small-scale social research projects*. McGraw-Hill Education (UK).

Donaldson, C. D., Bharadwaj, A., Giafaglione, B., Patton, P., Fortier, M. A., & Kain, Z. N. (2021). Ethnicity and language differences in patient experience: An analysis of the HCAHPS survey. *Journal of Racial and Ethnic Health Disparities*, 9, 899–908. https://doi.org/10.1007/s40615-021-01029-0

Douglas, D. M. (2015). Towards a just and fair Internet: Applying Rawls' principles of justice to Internet regulation. *Ethics and Information Technology, 17*(1), 57–64. https://doi.org/10.1007/s10676-015-9361-1

Dworkin, R. (1973). The original position. *The University of Chicago Law Review*, *40*(3), 500–533. https://doi.org/10.1515/9781503620919-005

Eklund, J. H., Holmström, I. K., Kumlin, T., Kaminsky, E., Skoglund, K., Höglander, J., Sundler, A. J., Condén, E., & Meranius, M. S. (2019). "Same same or different?" A review of reviews of person-centered and patient-centered care. *Patient Education and Counseling*, *102*(1), 3–11. https://doi.org/10.1016/j.pec.2018.08.029

Ekmekci, P. E., & Arda, B. (2015). Enhancing John Rawls's theory of justice to cover health and social determinants of health. *Acta Bioethica*, *21*(2), 227. https://doi.org/10.4067/S1726-569X2015000200009

Elliott, M. N., Beckett, M. K., Lehrman, W. G., Cleary, P., Cohea, C. W., Giordano, L. A., Goldstein, E. H., & Damberg, C. L. (2016). Understanding the role played by Medicare's patient experience points system in hospital reimbursement. *Health Affairs*, *35*(9), 1673–1680. https://doi.org/10.1111/j.1475-6773.2008.00914.x

Elliott, M. N., Lehrman, W. G., Goldstein, E., Hambarsoomian, K., Beckett, M. K., & Giordano, L. A. (2010). Do hospitals rank differently on HCAHPS for different patient subgroups? *Medical Care Research and Review*, *67*(1), 56–73. https://doi.org/10.1177/10775587093390

Elliott, M. N., Zaslavsky, A. M., Goldstein, E., Lehrman, W., Hambarsoomians, K., Beckett, M. K., & Giordano, L. (2009). Effects of survey mode, patient mix, and nonresponse on CAHPS® hospital survey scores. *Health Services Research*, *44*(2p1), 501–518. https://doi.org/10.1111/j.1475-6773.2008.00914.x

Epstein, R. M., & Street, R. L. (2011). The values and value of patient-centered care. *The Annals of Family Medicine*, *9*(2), 100–103. https://doi.org/10.1370/afm.1239

Feagin, J., & Bennefield, Z. (2014). Systemic racism and US health care. *Social Science & Medicine*, *103*, 7–14. https://doi.org/10.1016/j.socscimed.2013.09.006

Follesdal, A. (2014). John Rawls' theory of justice as fairness. In G. Fløistad (Ed.), *Philosophy of justice* (pp. 311–328). Springer Netherlands. https://doi.org/10.1007/978-94-017-9175-5_18

Fritz, Z., & Cox, C. (2019). Conflicting demands on a modern health care service: Can Rawlsian justice provide a guiding philosophy for the NHS and other socialized health services? *Bioethics*, *33*(5), 609–616. https://doi.org/10.1111/bioe.12568

Giordano, L. A., Elliott, M. N., Goldstein, E., Lehrman, W. G., & Spencer, P. A. (2010). Development, implementation, and public reporting of the HCAHPS survey. *Medical*

Care Research and Review: MCRR, *67*(1), 27–37. https://doi.org/10.1177/1077558709341065

Godden, E., Paseka, A., Gnida, J., & Inguanzo, J. (2019). The impact of response rate on Hospital Consumer Assessment of Health care Providers and System (HCAHPS) dimension scores. *Patient Experience Journal, 6*(1), 105–114. https://doi.org/10.35680/2372-0247.1357

Goldberg, A. E., & Allen, K. R. (2015). Communicating qualitative research: Some practical guideposts for scholars. *Journal of Marriage and Family*, *77*(1), 3–22. https://doi.org/10.1111/jomf.12153

Hill, C. E., Knox, S., Thompson, B. J., Williams, E. N., Hess, S. A., & Ladany, N. (2005). Consensual qualitative research: An update. *Journal of Counseling Psychology, 52*(2), 196–205. https://doi.org/10.1037/0022-0167.52.2.196

Hospital Consumer Assessment of Health care Providers and Systems. (2023, August 3). *HCAHPS summary analyses.* https://www.hcahpsonline.org/en/summary-analyses/previous-summary-analyses-documents/

HCAHPS Online. (2023, March). *Survey instruments*. https://hcahpsonline.org/globalassets/hcahps/quality-assurance/2023_survey-instruments_english_mail.pdf

Jaiswal, J., & Halkitis, P. N. (2019). Towards a more inclusive and dynamic understanding of medical mistrust informed by science. *Behavioral Medicine*, *45*(2), 79–85. https://doi.org/10.1080/08964289.2019.1619511

Kelley, B. (2015). *The patient experience as rated by consumers*. University of San Diego.

Kemp, E., Jillapalli, R., & Becerra, E. (2014). Health care branding: Developing emotionally based consumer brand relationships. *Journal of Services Marketing*, *28*(2), 126–137. https://doi.org/10.1108/JSM-08-2012-0157

Kumah, E. (2019). Patient experience and satisfaction with a health care system: Connecting the dots. *International Journal of Health care Management*, *12*(3), 173–179. https://doi.org/10.1080/20479700.2017.1353776st

Larson, E., Sharma, J., Bohren, M. A., & Tunçalp, Ö. (2019). When the patient is the expert: Measuring patient experience and satisfaction with care. *Bulletin of the World Health Organization*, *97*(8), 563–569. https://doi.org/10.2471/BLT.18.225201

Lee, D. (2019). A model for designing health care service based on the patient experience. *International Journal of Health care Management*, *12*(3), 180–188. https://doi.org/10.1080/20479700.2017.1359956

Lee, S. J., Venkataraman, S., Heim, G. R., Roth, A. V., & Chilingerian, J. (2020). Impact of the value-based purchasing program on hospital operations outcomes: An econometric analysis. *Journal of Operations Management*, 66(1/2), 151–175. https://doi.org/10.1002/joom.1057

Lujan, H. L., & DiCarlo, S. E. (2021). The racist "one drop rule" influencing science: It is time to stop teaching "race corrections" in medicine. *Advances in Physiology Education,* *45*(3), 644–650. https://doi.org/10.1152/advan.00063.2021%20

Majee, W., Anakwe, A., Onyeaka, K., & Harvey, I. S. (2023). The past is so present: Understanding COVID-19 vaccine hesitancy among African American adults using qualitative data. *Journal of Racial and Ethnic Health Disparities*, *10*(1), 462–474. https://doi.org/10.1007/s40615-022-01236-3

Malpani, R., Adrados, M., Mercier, M. R., McLynn, R. P., Galivanche, A. R., Pathak, N., & Grauer, J. N. (2020). Characteristics and predictors of HCAHPS nonresponse after spine surgery. *Spine, 45*(8), E448–56. https://doi.org/10.1097/BRS.0000000000003287

Manyazewal, T. (2017). Using the World Health Organization health system building blocks through survey of health care professionals to determine the performance of public health care facilities. *Archives of Public Health*, *75*, 1–8. https://doi.org/10.1186/s13690-017-0221-9

Manta, C., Patrick-Lake, B., & Goldsack, J. C. (2020). Digital measures that matter to patients: A framework to guide the selection and development of digital measures of health. *Digital Biomarkers*, *4*(3), 69–77. https://doi.org/10.1159/000509725

Mason, E. (2014, April 8). *Rawls in the real world.* https://www.huffpost.com/entry/rawls-in-the-real-world_b_5113792

Mazurenko, O., Collum, T., Ferdinand, A., & Menachemi, N. (2017). Predictors of hospital patient satisfaction as measured by HCAHPS: A systematic review. *Journal of Health care Management*, *62*(4), 272–283. https://doi.org/10.1097/JHM-D-15-00050

Morton, J. C., Brekhus, J., Reynolds, M., & Dykes, A. K. (2014). Improving the patient experience through nurse leader rounds. *Patient Experience Journal*, *1*(2), 53–61. https://doi.org/10.35680/2372-0247.1036

Navarro, V. (2009). What we mean by social determinants of health. *International Journal of Health Services*, *39*(3), 423–441. https://doi.org/10.1177/1757975908100746

National University. (2024, January 1). *Dependent samples t-test.* https://resources.nu.edu/statsresources/DependentSamples

Nuriddin, A., Mooney, G., & White, A. I. R. (2020). Reckoning with histories of medical racism and violence in the USA. *Lancet (London, England), 396*(10256), 949–951. https://doi.org/10.1016/S0140-6736(20)32032-8

Nussbaum, M. (2001, July 20). *The enduring significance of John Rawls.* https://www.chronicle.com/article/the-enduring-significance-of-john-rawls/

Organ Procurement & Transplantation Network. (2023, January 5). *OPTN Board approves waiting time adjustment for kidney transplant candidates affected by race-based calculation.* https://optn.transplant.hrsa.gov/news/optn-board-approves-waiting-time-adjustment-for-kidney-transplant-candidates-affected-by-race-based-calculation/

Padilla, T. (2017). Kindness: At the center of patient experience strategies. *Journal of Health care Management, 62*(4), 229–233. https://doi.org/10.1097/JHM-D-17-00083

Pajo, B. (2022). *Introduction to research methods: A hands-on approach*. Sage Publications.

Palaganas, E. C., Sanchez, M. C., Molintas, M. P., & Caricativo, R. D. (2017). Reflexivity in qualitative research: A journey of learning. *The Qualitative Report, 22*(2), 426–438. https://doi.org/10.46743/ 2160-3715/2017.2552

Papanicolas, I., Figueroa, J. F., Orav, E. J., & Jha, A. K. (2017). Patient hospital experience improved modestly, but no evidence Medicare incentives promoted meaningful gains. *Health Affairs (Project Hope)*, *36*(1), 133–140. https://doi.org/10.1377/hlthaff.2016.0808

Peters, U. (2022). What is the function of confirmation bias? *Erkenntnis, 87*(3), 1351–1376. https://doi.org/10.1007/s10670-020-00252-1

Pinto-Prades, J. L., & Abellán-Perpiñán, J. M. (2005). Measuring the health of populations: The veil of ignorance approach. *Health Economics, 14*(1), 69–82. https://doi.org/10.1002/hec.887%20

Poole, K. G., Jr. (2019). Patient-experience data and bias—what ratings don't tell us. *New England Journal of Medicine*, *380*(9), 801–803. https://doi.org/10.1056/NEJMp1813418

Powell, W., Richmond, J., Mohottige, D., Yen, I., Joslyn, A., & Corbie-Smith, G. (2019). Medical mistrust, racism, and delays in preventive health screening among African-American men. *Behavioral Medicine*, *45*(2), 102–117. https://doi.org/10.1080/08964289.2019.1585327

Pro, G., & Zaller, N. (2020). Interaction effects in the association between methadone maintenance therapy and experiences of racial discrimination in US health care settings. *PLoS One*, *15*(2), Article e0228755. https://doi.org/10.1371/journal.pone.0228755

Ramirez, A. G., McMurry, T., Turrentine, F. E., & Jones, R. S. (2018). Does the Medicare value-based purchasing program improve value of care among participating general and surgical hospitals? *Journal of the American College of Surgeons*, *227*(4), S144. https://doi.org/10.1016/j.jamcollsurg.2018.07.305

Ranard, B. L., Werner, R. M., Antanavicius, T., Schwartz, H. A., Smith, R. J., Meisel, Z. F., Asch, D. A., Ungar, L. H., & Merchant, R. M. (2016). Yelp reviews of hospital care can supplement and inform traditional surveys of the patient experience of care. *Health Affairs*, *35*(4), 697–705. http://dx.doi.org/10.1377/hlthaff.2015.1030

Rangnekar, A., Johnson, T., Garman, A., & O'Neil, P. (2015). The relationship between hospital value-based purchasing program scores and hospital bond ratings. *Journal of Health care Management, 60*(3), 220–231. https://doi.org/10.1097/00115514-201505000-00011

Rawls, J. (1971). *A theory of justice.* Belknap Press/Harvard University Press.

Ryan, A. M., Krinsky, S., Maurer, K. A., & Dimick, J. B. (2017). Changes in hospital quality associated with hospital value-based purchasing. *The New England Journal of Medicine*, *376*(24), 2358–2366. https://doi.org/10.1056/NEJMsa1613412

Schoonenboom, J., & Johnson, R. B. (2017). How to construct a mixed methods research design. *Kolner Zeitschrift fur Soziologie und Sozialpsychologie*, *69*(Suppl. 2), 107–131. https://doi.org/10.1007/s11577-017-0454-1

Sivo, S. A., Saunders, C., Chang, Q., & Jiang, J. J. (2006). How low should you go? Low response rates and the validity of inference in IS questionnaire research. *Journal of the Association for Information Systems, 7*(1), 17. https://business.ucf.edu/wp-content/uploads/2014/11/How-Low-Should-You-Go..Low-Response-Rates-and-the-Validity-of-Inference-in-IS-Questionnaire-Research.pdf

Stine, N. W., Chokshi, D. A., & Gourevitch, M. N. (2013). Improving population health in US cities. *JAMA*, *309*(5), 449–450. https://doi.org/10.1001/jama.2012.154302

Stone, M. (2020). Fossil fuels, takings, and Rawlsian justice. *Washington University Jurisprudence Review, 13*(1), 147. https://openscholarship.wustl.edu/law_jurisprudence/vol13/iss1/9

Tan, S. B., DeSouza, P., & Raifman, M. (2021). Structural racism and COVID-19 in the USA: A county-level empirical analysis. *Journal of Racial and Ethnic Health Disparities*, 1–11. https://doi.org/10.1007/s40615-020-00948-8

Tanenbaum, S. J. (2016). What is the value of value-based purchasing? *Journal of Health Politics, Policy, and Law*, *41*(5), 1033–1045. https://doi.org/10.1215/03616878-3632254

Varkey, P., Reller, M. K., & Resar, R. K. (2007, June). Basics of quality improvement in health care. *Mayo Clinic Proceedings, 82*(6), 735–739). https://doi.org/10.4065/82.6.735

Westbrook, K. W., Babakus, E., & Grant, C. C. (2014). Measuring patient-perceived hospital service quality: Validity and managerial usefulness of HCAHPS scales. *Health Marketing Quarterly*, *31*(2), 97–114. https://doi.org/10.1080/07359683.2014.907114

Wilson, M., Guta, A., Waddell, K., Lavis, J., Reid, R., & Evans, C. (2020). The impacts of accountable care organizations on patient experience, health outcomes and costs: A rapid review. *Journal of Health Services Research & Policy*, *25*(2), 130–138. https://doi.org/10.1177/1355819620913141

World Health Organization. (2023). *About WHO*. https://www.who.int/about

World Health Organization. (2010). *Monitoring the building blocks of health systems: A handbook of indicators and their measurement strategies.* https://www.who.int/workforcealliance/knowledge/toolkit/26.pdf

World Health Organization. (2024). *Social determinants of health*. https://www.who.int/health-topics/social-determinants-of-health#tab=tab_1

Yearby, R. (2020). Structural racism and health disparities: Reconfiguring the social determinants of health framework to include the root cause. *Journal of Law, Medicine & Ethics, 48*(3), 518–526. https://doi.org/10.1177/1073110520958876

Appendix A

HCAHPS Survey Tool

March 2023 1

HCAHPS Survey

SURVEY INSTRUCTIONS

♦You should only fill out this survey if you were the patient during the hospital stay named in the cover letter. Do not fill out this survey if you were not the patient.

♦Answer all the questions by checking the box to the left of your answer.

♦You are sometimes told to skip over some questions in this survey. When this happens, you will see an arrow with a note that tells you what question to answer next, like this:

☐Yes
☑No ➔ ***If No, Go to Question 1***

You may notice a number on the survey. This number is used to let us know if you returned your survey so we don't have to send you reminders.

Please note: Questions 1-29 in this survey are part of a national initiative to measure the quality of care in hospitals. OMB #0938-0981 (Expires September 30, 2024)

Please answer the questions in this survey about your stay at the hospital named on the cover letter. Do not include any other hospital stays in your answers.

YOUR CARE FROM NURSES

1.During this hospital stay, how often did nurses treat you with courtesy and respect?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

2.During this hospital stay, how often did nurses listen carefully to you?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

3.During this hospital stay, how often did nurses explain things in a way you could understand?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

4.During this hospital stay, after you pressed the call button, how often did you get help as soon as you wanted it?

1☐ Never

2☐ Sometimes

3☐ Usually

4☐ Always

9☐ I never pressed the call button

2 March 2023

YOUR CARE FROM DOCTORS

5.During this hospital stay, how often did doctors treat you with courtesy and respect?

1☐ Never

2☐ Sometimes

3☐ Usually

4☐ Always

6.During this hospital stay, how often did doctors listen carefully to you?

1☐ Never

2☐ Sometimes

3☐ Usually

4☐ Always

7.During this hospital stay, how often did doctors explain things in a way you could understand?

1☐ Never

2☐ Sometimes

3☐ Usually

4☐ Always

THE HOSPITAL ENVIRONMENT

8.During this hospital stay, how often were your room and bathroom kept clean?

1☐ Never

2☐ Sometimes

3☐ Usually

4☐ Always

9.During this hospital stay, how often was the area around your room quiet at night?

1☐ Never

2☐ Sometimes

3☐ Usually

4☐ Always

YOUR EXPERIENCES IN THIS HOSPITAL

10.During this hospital stay, did you need help from nurses or other hospital staff in getting to the bathroom or in using a bedpan?

1☐ Yes

2☐ No ➔ **If No, Go to Question 12**

11.How often did you get help in getting to the bathroom or in using a bed pan as soon as you wanted?

1☐ Never

2☐ Sometimes

3☐ Usually

4☐ Always

12.During this hospital stay, were you given any medicine that you had not taken before?

1☐ Yes

2☐ No ➔ **If No, Go to Question 15**

13.Before giving you any new medicine, how often did hospital staff tell you what the medicine was for?

1☐ Never

2☐ Sometimes

3☐ Usually

4☐ Always

14.Before giving you any new medicine, how often did hospital staff describe possible side effects in a way you could understand?

1☐ Never

2☐ Sometimes

3☐ Usually

4☐ Always

WHEN YOU LEFT THE HOSPITAL

15.After you left the hospital, did you go directly to your own home, to someone else's home, or to another health facility?

1☐ Own home

2☐ Someone else's home

3☐ Another health facility ➔ **If Another, Go to Question 18**

16.During this hospital stay, did doctors, nurses or other hospital staff talk with you about whether you would have the help you needed when you left the hospital?

1☐ Yes

2☐ No

17.During this hospital stay, did you get information in writing about what symptoms or health problems to lookout for after you left the hospital?

1☐ Yes

2☐ No

OVERALL RATING OF HOSPITAL

Please answer the following questions about your stay at the hospital named on the cover letter. Do not include any other hospital stays in your answers.

18.Using any number from 0 to 10, where 0 is the worst hospital possible and 10 is the best hospital possible, what number would you use to rate this hospital during your stay?

0☐ 0 Worst hospital possible

1☐ 1

2☐ 2

3☐ 3

4☐ 4

5☐ 5

6☐ 6

7☐ 7

8☐ 8

9☐ 9

10☐ 10 Best hospital possible

19.Would you recommend this hospital to your friends and family?

1☐ Definitely no

2☐ Probably no

3☐ Probably yes

4☐ Definitely yes

UNDERSTANDING YOUR CARE WHEN YOU LEFT THE HOSPITAL

20.During this hospital stay, staff took my preferences and those of my family or caregiver into account in deciding what my health care needs would be when I left.

1☐ Strongly disagree

2☐ Disagree

3☐ Agree

4☐ Strongly agree

21.When I left the hospital, I had a good understanding of the things I was responsible for in managing my health.

1☐ Strongly disagree
2☐ Disagree
3☐ Agree
4☐ Strongly agree

22.When I left the hospital, I clearly understood the purpose for taking each of my medications.

1☐ Strongly disagree
2☐ Disagree
3☐ Agree
4☐ Strongly agree
5☐ I was not given any medication when I left the hospital

ABOUT YOU

There are only a few remaining items left.

23.During this hospital stay, were you admitted to this hospital through the Emergency Room?

1☐ Yes
2☐ No

24.In general, how would you rate your overall health?

1☐ Excellent
2☐ Very good
3☐ Good
4☐ Fair
5☐ Poor

25.In general, how would you rate your overall mental or emotional health?

1☐ Excellent
2☐ Very good
3☐ Good
4☐ Fair
5☐ Poor

26.What is the highest grade or level of school that you have completed?

1☐ 8th grade or less
2☐ Some high school, but did not graduate

3☐ High school graduate or GED
4☐ Some college or 2-year degree
5☐ 4-year college graduate
6☐ More than 4-year college degree

27.Are you of Spanish, Hispanic or Latino origin or descent?

1☐ No, not Spanish/Hispanic/Latino
2☐ Yes, Puerto Rican
3☐ Yes, Mexican, Mexican American, Chicano
4☐ Yes, Cuban
5☐ Yes, other Spanish/Hispanic/Latino

28.What is your race? Please choose one or more.

1☐ White
2☐ Black or African American
3☐ Asian
4☐ Native Hawaiian or other Pacific Islander
5☐ American Indian or Alaska Native

29.What language do you mainly speak at home?

1☐ English
2☐ Spanish
3☐ Chinese
4☐ Russian
5☐ Vietnamese
6☐ Portuguese
7☐ German
8☐ Tagalog
9☐ Arabic
20☐ Some other language (please print):

NOTE: IF HOSPITAL-SPECIFIC SUPPLEMENTAL QUESTION(S) ARE ADDED, THE MANDATORY TRANSITION STATEMENT MUST BE PLACED IMMEDIATELY BEFORE THE SUPPLEMENTAL QUESTION(S).

THANK YOU

Please return the completed survey in the postage-paid envelope.

[NAME OF SURVEY VENDOR OR SELF-ADMINISTERING HOSPITAL]

[RETURN ADDRESS OF SURVEY VENDOR OR SELF-ADMINISTERING HOSPITAL]

Appendix B

Interview Protocol

Thank you for taking some time to speak with me today. I fully understand how valuable your time is and appreciate your sharing with me your thoughts regarding HCAHPS scores. Specifically, I am interested in understanding how well you believe the HCAHPS tool captures the full spectrum of patients in U.S. hospitals and the experiences of the patients cared for in the hospitals you have supported in your career. I also hope to understand any gaps you have identified between which type of consumers respond to surveys and the feedback received on the surveys. I hope to have a casual conversation and encourage you to express yourself candidly; although I will be recording our discussion and taking some notes, at no point will your identity be shared or associated with your comments. For your information, only I and the methodologist from my doctorial committee will have access to information about which professional offered which information; all information will be held confidential, and your responses will be shared as part of the general pool of information with no identifying data. Our conversation today is completely optional; if at any time you change your mind about sharing your thoughts, I will immediately stop the interview. It is my goal to learn as much about your perception of the completeness of the responses as possible and to understand how the scores may be important to your work and care sites as possible. It is my intention to conduct this research without inflicting any harm. I will stop the interview at any time at your request and will at your request decline to use any information you share as part of my data pool.

I expect to spend about a half hour to 45 minutes together but am available to listen as long as you would like to share.

1. How long have you worked in Patient Experience?

a. Tell me a little about hospitals you have supported?

2. Share with me some of the strategies you use to the hear the voices of your patients?

3. What are some of the challenges in understanding patients' perceptions of their hospital experience?

4. How important is it to hear from various subpopulations in gathering patient experience perspectives?

5. What are some of the ways that you have used HCAHPS scores in your work?

6. What if anything concerns you about using HCAHPS scores?

7. How important are HCAHPS to the hospitals you have supported and why?

8. How well do you think HCAHPS scores reflect the racial diversity that you serve?

9. What else if anything would you like to share about the completeness of the information you get from your HCAHPS surveys?

Thank you for speaking with me today. As I pool information in an attempt to understand the role that HCAHPS play in representing the care experience of health consumers I will not share any identifying information about you. I appreciate your time speaking with me and if after reflection you find you prefer that I exclude your comments from my research, I will do so upon your request.

Appendix C

IRB Approval Letter

FRANKLIN UNIVERSITY

Date: December 21, 2023

PI: Rachel Silsdorf

Department: Provost Admin, DHA

Re: Initial - IRB-2023-120

Examining Patients' Representativeness in Experience Surveying: A Mixed-Method Approach in Healthcare

The Franklin Institutional Review Board has rendered the decision below for *Examining Patients' Representativeness in Experience Surveying: A Mixed-Method Approach in Healthcare*.

Decision: Exempt

Category: Category 2.(ii). Research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording) if at least one of the following criteria is met:

Any disclosure of the human subjects' responses outside the research would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, educational advancement, or reputation; or

Findings: The PI is conducting interviews to explore how well HCAHPS scores represent the racial diversity of patients in United States hospitals and to understand how this data is used in these hospitals.

The IRB determination of exemption means:

- You must conduct the research as proposed in the Exempt application, including obtaining and documenting (signed) informed consent if stated in your application or if required by the IRB.

- Any modification of this research should be submitted to the IRB prior to implementation to determine if the study still meets federal exemption criteria.

- You are responsible for notifying the IRB Office with any problems or complaints about the research.

Students, please note the following:

- You must use only the approved consent and assent forms (as applicable).

- Prior to graduation, you will need to complete a Closure submission for the IRB Office to close the study. To do this, you will need to open your study in Cayuse and look for the blue '+ New Submission' tab on the righthand side of your screen. From there, click on 'Closure' and complete the submission.

Any modifications to the approved study or study closures must be submitted for review through Cayuse IRB. All approval letters and study documents are located within the Study Details in Cayuse IRB.

You may contact the IRB Office at 614-947-6037 or irb@franklin.edu with any questions.

Sincerely,

Franklin Institutional Review Board