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A Model for Improving Health Care Quality for Transgender and Gender Nonconforming Patients

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Abstract

Problem Definition: Transgender and gender nonconforming (TGNC) populations are disproportionately affected by limited health care access and poor health outcomes and commonly report discrimination and mistreatment in health care settings. Despite these disparities, comprehensive approaches to improve the quality of health care of TGNC patient populations are currently lacking.

Initial Approach: The Vanderbilt Program for LGBTQ Health has developed a multifaceted, community-engaged approach to improve the quality of health care of TGNC patients, which includes the creation of a transgender patient advocacy program, a community advisory board, and a transgender health clinic. To support the continuous quality improvement of transgender health care, the program is currently piloting a novel multilevel monitoring and evaluation (M&E) system to collect information at the individual patient visit and health systems levels.

Next Steps: The next steps for Vanderbilt's community-engaged M&E system are to identify the clinics and health services most used by TGNC patients and assess the level of patient satisfaction in each area. This process will support the identification of high- and low-performing clinics and

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health services and allow for targeted delivery of trainings to improve the quality of culturally competent health care TGNC patients receive systemwide.

Conclusion: In collaboration with TGNC patient populations and community stakeholders, Vanderbilt has created a model to improve the quality of both transition- and non-transition-related health care at the systems level that can be adopted by other health care systems nationally.

PROBLEM DEFINITION

An estimated 1.4 million adults, or 0.6% of the adult population of the United States, identify as transgender.¹ Current health care experiences of transgender and gender non-conforming (TGNC) patients, including both transition-(hormone replacement therapy, gender affirmation surgery, and so forth) and non-transition-related (care unrelated to a patient's TGNC identity), are often substandard and variable. Many TGNC patients choose not to seek medical help when necessary because they fear discrimination or mistreatment.²⁻⁸ According to a 2015 national study, 33% of transgender survey respondents who saw a health care provider in the previous year reported one or more negative experiences related to being transgender, including being refused treatment, being harassed or assaulted, or receiving incompetent care.² Transphobia is a major contributor to the barriers that inhibit TGNC patients' access to affirming care. In turn, these barriers contribute to disparate health outcomes observed among TGNC populations.⁹⁻¹² The Joint Commission has endorsed standards that have been used to improve health care quality and ameliorate health disparities among LGBT populations,¹³ including those related to nondiscrimination (Rights and Responsibilities of the Individual [RI] Standard RI.01.01.01, Element of Performance [EP] 29), privacy (EP 7), and dignified and respectful patient treatment (EP 4).¹⁴

To date, the predominant strategy to improve the health care of TGNC patients has centered on training individual providers to provide culturally competent care.^{13,15,16} These efforts are vital, as they ensure the availability of a limited number of providers who are well prepared to treat TGNC patients in a culturally competent, affirming manner. However, to ensure comprehensive and consistent high-quality TGNC health care, trainings and other provider-level interventions must be implemented at a health-systems level. The Joint Commission has published a guide to caring for LGBT patients¹³ that provides guidance for improving the cultural competence of individual providers and creating a welcoming environment for LGBT patients through the development of nondiscrimination policies and inclusion of information about the health of LGBT patients and families in clinical environments. However, most health care systems have focused their quality improvement efforts on clinical and policy environments rather than on care of TGNC patients. Care for TGNC patients is essentially a cottage industry—quality of care is highly variable among providers and systems. Few integrations of guidelines relating to TGNC health care go beyond transition-related care recommendations provided by the World Professional Association for Transgender Health, the Endocrine Society, and the Center of Excellence for Transgender Health at the University of California, San Francisco.¹⁷⁻²⁴ In addition, no consensus-based national quality metrics exist to improve the quality of health care TGNC patients receive, whether for transition-related or other health care needs. Consistent with best practices in research ethics and community-engaged research with vulnerable patient

populations,²⁵ the development of these metrics should reflect a patient-centered approach and accommodate the health care needs and preferences of TGNC patients.

INITIAL APPROACH

To improve the quality of health care for TGNC patients at both the patient-provider and health-systems levels, the Vanderbilt Program for LGBTQ Health has invested in the development of TGNC patient-specific initiatives since 2014. These include Trans Buddy, a transgender patient peer advocacy program (in which volunteers advocate and provide emotional/logistical support for trans patients during their health care visits), a community advisory board that includes both TGNC community members and parents of TGNC individuals, and two TGNC clinics created in partnership with hospital administration, program staff, affiliated program faculty, and Vanderbilt University Medical Center (VUMC) medical providers from a variety of specialties. The program has also continuously invested in the creation and expansion of a multicomponent monitoring and evaluation (M&E) infrastructure, which evaluates the success of VUMC initiatives to improve TGNC health care quality systemwide. These TGNC initiatives meet key recommendations outlined in The Joint Commission's LGBT Field Guide (Table 1),¹³ and are described in further detail below.

The Trans Buddy Program

The Trans Buddy Program is a transgender patient advocacy program created by and for transgender patients in April 2015. The program pairs trained volunteers with TGNC patients attending clinical appointments throughout VUMC. The program was created as a volunteer-led initiative, and a part-time, paid Trans Buddy Coordinator was added in 2016 due to patient and volunteer training demand. An annual summer intern was also hired to assist with Trans Buddy expansion.

To access Trans Buddy, TGNC patients contact a dedicated program staff member, who assigns them a Buddy to accompany them throughout their health care visit and in the appointment room, whether their appointment is outpatient, inpatient, or in the emergency room. Program staff members may also assign a Trans Buddy to a patient upon provider request and patient consent. By building strong relationships with key stakeholders in departments often visited by Trans Buddy patients (such as psychiatry, endocrinology, and adolescent medicine), provider request pathways are greatly eased and Buddy usage more accepted by providers.

Buddies are trained to provide emotional, logistical, and informational support for TGNC patients while facilitating communication between providers and patients and supporting continuity of care. Buddies serve on a volunteer basis and mostly consist of VUMC faculty/staff, Vanderbilt students, TGNC community members, and cisgender community members with an interest in supporting TGNC peers. Trans Buddies are selected via an application process, with consideration given to their background knowledge of basic trans issues and motivations for volunteering. Volunteers are trained in a single 16-hour weekend training session designed to provide an overview of trans health and teach volunteering logistics and empathetic skills. As of 2017, to accommodate increased patient demand, volunteer trainings

occur three times a year. This is in addition to refresher sessions for existing volunteers, which are designed to build volunteer community and maintain volunteer skills. In 2018 the Trans Buddy hotline was connected with VUMC's 24/7 provider call center, Synergy, to meet increased patient demand. Also in 2018 a case report system was implemented to track all patient experiences and satisfaction. The Trans Buddy Program directly supports TGNC patients by helping them seek care with reduced fear of discrimination, regardless of location within the VUMC system.

Community Advisory Board

As TGNC patient initiatives such as Trans Buddy and the Clinic for Transgender Health continued their development, in August 2018 the Vanderbilt Program for LGBTQ Health developed a community advisory board (CAB) to support the community-informed continuous quality improvement (CQI) of TGNC health at Vanderbilt. The CAB is composed of 15 patients and community members who serve on a volunteer basis. The CAB meets quarterly and provides nonbinding recommendations and guidance to Vanderbilt to improve the quality of TGNC health care, the operations of the Trans Buddy Program and Clinic for Transgender Health, and the community engagement strategy of the Vanderbilt Program for LGBTQ Health. CAB members are also invited to attend LGBTQ academic and community events sponsored by Vanderbilt, such as Nashville Pride and LGBTQ-related medical school lectures.

CAB members become eligible to join after applying and interviewing with the Vanderbilt Program for LGBTQ Health and are selected based on their investment in serving the LGBTQ patient community at Vanderbilt. The program pays particular attention to the demographics of the CAB; the board has TGNC-heavy representation to assist with the guidance of the multiple TGNC patient initiatives at VUMC, and members are selected who represent all sexual orientations and ages. CAB members can serve one-, two-, or three-year terms, and membership is capped at six years of service. By encouraging feedback from both TGNC patients and community stakeholders, the CAB identifies key areas of improvement for both transition- and non-transition-related TGNC health care and how to best engage with TGNC patient populations to accomplish this objective.

Clinic for Transgender Health

At the request of TGNC patient populations to streamline the provision of transition-related health care, including feedback from Trans Buddy volunteers and patients, the Program for LGBTQ Health worked with hospital administration to support the creation of two transgender health clinics (one adult, one pediatric) at VUMC in August 2018. These specialty referral clinics provide centralized access for TGNC patients to transition-related specialty care. Currently, clinic patients can receive services including hormone therapy, surgery consultation/follow-up, and primary care coordination on site and are referred to screened VUMC providers for a more comprehensive set of services, including gender-affirming surgery and mental health care. Staff from the Program for LGBTQ Health have ensured that all clinic health care providers have been trained to provide culturally competent care to both pediatric and adult TGNC patients. The adult clinic, housed at a VUMC ambulatory care site, provides services once a week, while the pediatric clinic,

housed in the children's hospital, has appointments once a month. Trans Buddy volunteers are embedded in the clinics and are available to provide support to all patients seen.

Key challenges in developing the clinics included identifying funding sources, space, and staffing. To overcome these hurdles, the program developed key working partnerships with various departments within VUMC, such as internal medicine, and physicians who were invested in the creation of the clinics and committed to providing trans-exemplary care. Because the clinics required larger institutional buy-in compared to other TGNC initiatives, having strong diversity advocates who recognized the importance of the clinics at high levels of administration made it easier to counter institutional pushback. Insurance navigation was another notable obstacle in clinic development, so it was crucial for the clinics to hire a social worker/insurance navigator to understand the nuances of billing transition-related care to best support our patients. Overall, combined with the Trans Buddy Program and the CAB, the Clinic for Transgender Health has created a centralization of transition-related care services that has helped VUMC develop a targeted M&E system for the evaluation of the quality of both transition- and non-transition-related health care experiences.

Monitoring and Evaluation System

To support an evidence-based, community-informed approach for the CQI of transition- and non-transition-related transgender health care, VUMC has developed and is currently piloting a multilevel M&E system to aid in the tracking of care utilization, quality of care, and health outcomes of transgender patients (Figure 1). The core components of the M&E system include assessment of activities at both the patient-provider and health-systems levels. In summer 2017, Trans Buddy Program volunteers began using a case report form to collect information about TGNC patient health care experiences. In November 2017 Vanderbilt transitioned electronic health record (EHR) systems from StarPanel, its homegrown EHR, to eStar, VUMC's customized installation of Epic (Epic Systems Corporation, Verona, Wisconsin). As part of this transition, VUMC began the structured collection of sexual orientation, preferred name, gender identity, and sex assigned at birth using the Epic Systems–developed Sexual Orientation and Gender Identification (SOGI) module. Select departments within VUMC immediately began training providers how to locate, administer, and document patient SOGI information via this module. An integrated Epic/VUMC–developed SOGI interface that centrally integrates SOGI information into the main patient dashboard is planned for launch in 2019 with input from the CAB. This custom-built module will be incorporated into care in all VUMC departments, and all providers will be trained in its use. Combining this module with preexisting approaches to identify TGNC patients using novel EHR algorithms and the monitoring of patient experiences at the Clinic for Transgender Health and Trans Buddy appointments, Vanderbilt is increasingly able to collect and evaluate data to ensure that the health care experiences, needs, and preferences of TGNC patient populations are used to improve the quality of TGNC health care. Each of these components is described in greater detail below.

Trans Buddy Case Report Form

In July 2017 the Trans Buddy Program launched a case report form system to capture Trans Buddy user demographics systematically. At every Trans Buddy appointment, TGNC

patients are asked to fill out a short demographic survey, which includes gender identity indicators and the patient's medical record number. The Trans Buddy volunteer then completes a report of the health care visit by recording the providers who treat the patient, reporting any incorrect use of pronouns or preferred name of the patient, and generally documenting both positive and negative experiences the patient identifies. All data in the case report form are collected via a HIPAA-compliant REDCap survey.^{25,26} By gathering data on patient interactions, the VUMC system is able to track the TGNC cultural competency of specific providers, as well as general departments and support staff (such as valets and receptionists), which will inform future directed staff training efforts and provide an avenue to recognize well-performing entities. In summary, the case report system gathers information about the health care experiences of TGNC patients across different areas of the health system, thereby providing a measure of VUMC's progress toward improving the overall quality of not only transition-related but also non-transition-related health care services received by TGNC patients.

Electronic Health Record Identification of TGNC Patients

Several initiatives have allowed VUMC to better identify TGNC patients served to improve future care. First, similar to other health systems, program staff have worked to develop novel algorithms that combine International Classification of Diseases (ICD) codes and natural language processing (NLP) of free text in EHR notes to identify TGNC patients.²⁶ Second, as part of the transition to eStar, program staff used the structured data capture elements, in combination with clinical informatics approaches, to extract and analyze data about the clinical and health services used by TGNC patients. Last, the launch of the Clinic for Transgender Health has resulted in the ability to identify TGNC populations receiving transition-related health services in its clinical locations. An internal Clinic for Transgender Health patient registry has been created for quality monitoring purposes: patients are flagged as clinic patients in their Epic chart, facilitating quick summarization of patient demographics, scope of services received, and patient satisfaction and experience scores. Taken together, these initiatives have enabled Vanderbilt to not only identify TGNC patients, but track the clinical utilization patterns of both transition- and non-transition-related health services at the health-systems level. Due to the patient registry, this information is most robust for patients engaged in care at the Clinic for Transgender Health. This has allowed VUMC to gain important insights about the quality of care provided to TGNC patient populations (Table 2).

NEXT STEPS

As the number of TGNC patients identified within the VUMC health system increases due to the rollout of the new SOGI interface and growth of the Clinic for Transgender Health, analyses of patient clinical utilization and health outcomes will support identification of both provider-level and systems-level quality challenges and successes of the health care received by TGNC patient populations at VUMC. A key future direction is the semiautomated development of individualized reports to be returned back to both clinical units and individual providers. These reports will synthesize information from both Trans Buddy case report forms and semiautomated clinical informatics reports to identify areas of current

success and areas where improvement is needed. This tailored feedback will support providing higher-quality, gender-affirming care to VUMC TGNC patients.

Collectively, both the community-engaged and clinical informatics initiatives employed by Vanderbilt describe a methodology to empower TGNC communities to continuously improve the quality of the health care environment encountered by TGNC patients. The combination of qualitative and quantitative feedback about the health care experiences and patient satisfaction of TGNC patients allows for a multilevel programmatic M&E approach. This enables TGNC patients, community members, and stakeholders to give input to generate new ideas to improve the quality of health care experiences of TGNC patient populations. These efforts also provide valuable information that could be used to help inform the development of future community-informed metrics and benchmarks to evaluate the quality of health care received. These findings, combined with the future collection of SOGI data within patient surveys that influence Medicare reimbursement rates (for example, the Hospital Consumer Assessment of Health Care Providers and Systems [HCAHPS]^{27–29}), could pave the way for developing a multilevel incentivized approach to ensure that the quality and value of health care for TGNC patients is transparent and nationally standardized (Sidebar 1).

CONCLUSION

Currently, TGNC health care quality is substandard and variable, resulting in higher instances of negative health care experiences and contributing to poor health outcomes for TGNC patients. To address the dearth of systems-level TGNC quality of health care initiatives, Vanderbilt has developed and piloted a multifaceted, health systems-level approach to improving TGNC quality of care, one rooted in transgender community feedback through community out-reach programs and clinical informatics research, including the Trans Buddy Program, CAB, Clinic for Transgender Health, and multilevel M&E system. By creating a structured health systems approach that incorporates TGNC patient needs into development of cultural competency trainings, tracking of transgender quality of care, and creation of CQI methods, Vanderbilt has created a model that has the potential to improve the quality of both transition- and non-transition patient-centered TGNC health care at the systems level.

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Sidebar 1.**Proposed Four-Step Framework for Health Systems to Improve the Quality of TGNC Health Care****TGNC Cultural Competency Training**

Health systems should offer high-quality transgender and gender non-conforming (TGNC) cultural competency trainings developed in consultation with TGNC community stakeholders and updated at least annually. Training modules should cover terminology and health disparities, build provider cultural competency skills, and provide additional learning resources. For maximal effectiveness and institutional cultural change, TGNC training should be mandatory, which is consistent with emerging regulations in state and local governments (California Business and Professions Code, Section 2190.1, 2014; California Health and Safety Code, Section 1257.5, 2008; LGBTQ Cultural Competency Continuing Education Amendment Act of 2015).

Monitor and Evaluate Patient Experiences

Health systems should add sex and gender identity questions to their patient satisfaction surveys, and such data should be routinely analyzed, with a comparison of the satisfaction of TGNC vs. non-TGNC patients. Additional methods of monitoring patient experiences include reports of TGNC patient care experiences from electronic health records, patient advocacy programs, and community advisory boards. Collectively, both qualitative and quantitative feedback about the care experienced by TGNC patients should be fed back not only to health systems staff, but also to TGNC community advisory board members of the health system.

Reward or Train Providers and Clinics Based on Patient Satisfaction Scores

Providers and clinics with high patient satisfaction scores for TGNC patients can be publicly rewarded for high-quality care with provider- and clinic-level awards. Providers and clinical units with poor scores can be selected for TGNC cultural competency refresher trainings. This two-pronged approach to training ensures efficient use of limited training resources. In addition to satisfaction scores, anonymized qualitative feedback from TGNC patient complaints can also be used to provide feedback to providers and clinics and select them for refresher training.

Build National Reporting Systems for TGNC Patient Quality Data

A national system of aggregating quality-of-care metrics including TGNC patient experiences, both positive and negative, can help identify gaps in care, geographic variation, disparities, and best performers. The Vanderbilt Patient Advocacy Reporting System (PARS) collects and analyzes patient complaints from more than 140 health care organizations.¹ Comparing local health system reports to a national data set of patient complaints, such as PARS, would allow for the identification of the importance of local vs. national trends in the number of complaints over time and in the types of negative experiences TGNC patients report. These trends could influence the content and targets of TGNC cultural competency trainings and help identify system-specific compliance issues of individual health systems within a broader national performance context. Future

efforts to integrate TGNC reporting into national systems could include advocating for the inclusion of sexual orientation and gender identity (SOGI) items into the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS).²

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A Health Systems Approach to Building a Community-Engaged Transgender Health Care Quality Improvement Program

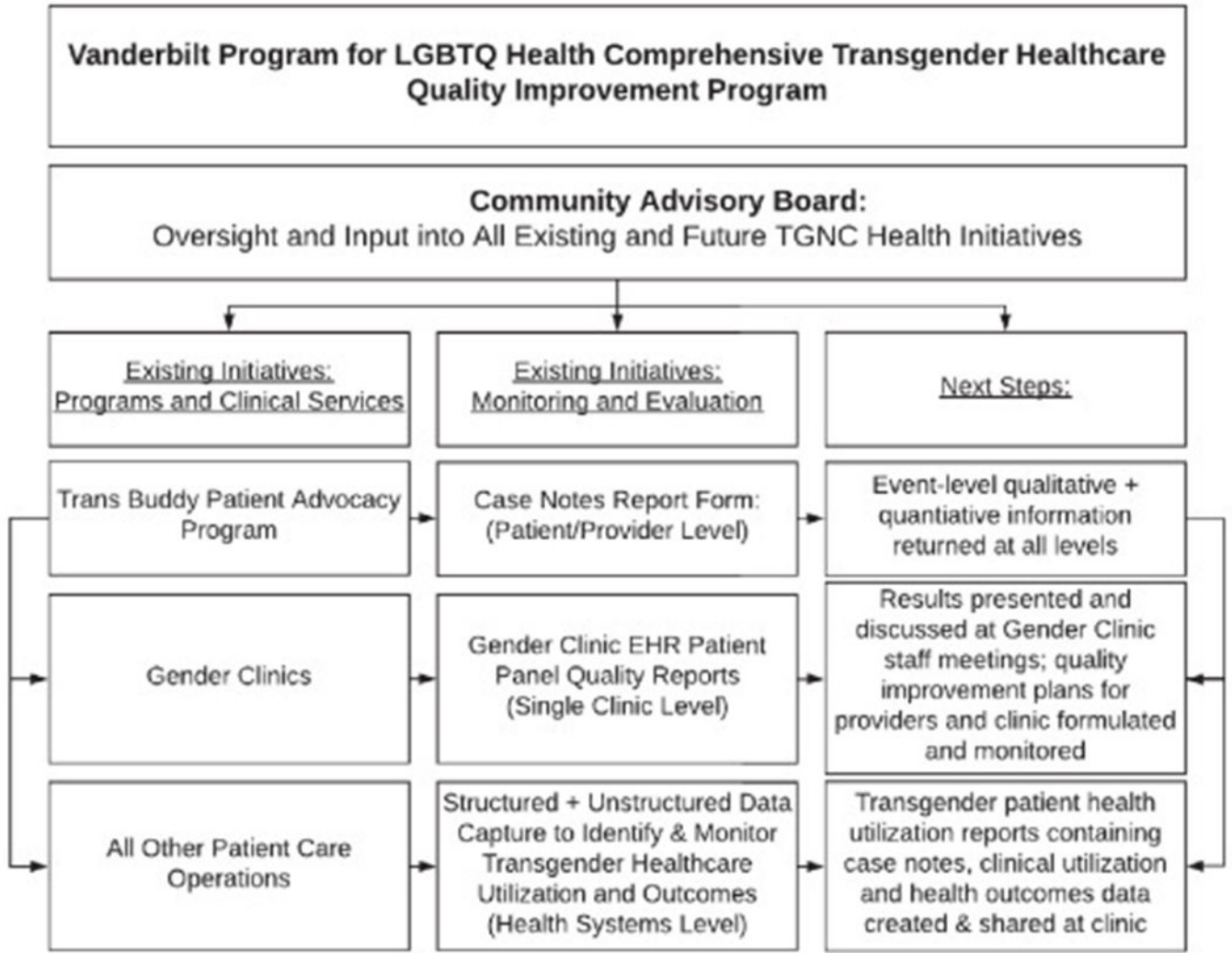


Figure 1:

This figure depicts Vanderbilt’s multilevel, community-engaged health systems model to improve the quality of care provided to transgender and gender nonconforming (TGNC) patient populations. All quality improvement activities center feedback from TGNC community stakeholders and patients via input from the community advisory board (CAB). Current programmatic initiatives to improve TGNC quality of care include the Trans Buddy patient advocacy program, the Clinic for Transgender Health, and trainings to improve the quality of health care provided generally to TGNC patients. The effectiveness of these programs is evaluated using a case-note report form that Trans Buddies and TGNC patients complete together and return to Program for LGBTQ Health staff, as well as ongoing clinical informatics approaches to identify TGNC patient population health outcomes across the institution. Vanderbilt is actively working on expanding the sophistication of its monitoring and evaluation systems to return results of quality studies to health care

providers, the CAB, and TGNC patients to continuously improve the quality of care offered to TGNC patients. EHR, electronic health record.

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Table 1. Examples of How the Vanderbilt Program for LGBTQ Health Met Joint Commission Recommendations

Initiatives		Recommendation Domains/Issues to Address		Recommendation Practice Examples	
<p>Clinic for Transgender Health</p>	<p>Monitoring and Evaluation System: Trans Buddy Case Reports and EHR Identification of TGNC Patients</p>	<p>Leadership: Demonstrate ongoing leadership commitment to inclusivity for LGBTQ patients and families.</p>	<p>Leadership: Demonstrate ongoing leadership commitment to inclusivity for LGBTQ patients and families.</p>	<ul style="list-style-type: none"> Identify and support staff or physician champions who have special expertise or experience with LGBTQ issues. Monitor organizational efforts to provide more culturally competent and patient- and family-centered care to LGBTQ patients, families, and communities. 	<ul style="list-style-type: none"> Identify and support staff or physician champions who have special expertise or experience with LGBTQ issues. Monitor organizational efforts to provide more culturally competent and patient- and family-centered care to LGBTQ patients, families, and communities.
<p>Monitoring and Evaluation System: Trans Buddy Case Reports and EHR Identification of TGNC Patients</p>	<p>Monitoring and Evaluation System: Trans Buddy Case Reports and EHR Identification of TGNC Patients</p>	<p>Data Collection and Use: Identify opportunities to collect LGBTQ-relevant data and information during the health care encounter.</p>	<p>Data Collection and Use: Identify opportunities to collect LGBTQ-relevant data and information during the health care encounter.</p>	<ul style="list-style-type: none"> Identify a process to document self-reported sexual orientation and gender identity information in the medical record. Train staff to collect sexual orientation and gender identity data. Ensure that strong privacy protections for all patient data are in place. Use aggregated patient-level sexual orientation and gender identity data to develop or modify services, programs, or initiatives to meet patient population needs. 	<ul style="list-style-type: none"> Identify a process to document self-reported sexual orientation and gender identity information in the medical record. Train staff to collect sexual orientation and gender identity data. Ensure that strong privacy protections for all patient data are in place. Use aggregated patient-level sexual orientation and gender identity data to develop or modify services, programs, or initiatives to meet patient population needs.
<p>Community Advisory Board</p>	<p>Community Advisory Board</p>	<p>Patient, Family, and Community Engagement: Collect feedback from LGBTQ patients and families and the surrounding LGBTQ community.</p>	<p>Patient, Family, and Community Engagement: Collect feedback from LGBTQ patients and families and the surrounding LGBTQ community.</p>	<ul style="list-style-type: none"> Encourage community input and collaboration by establishing a community advisory board. 	<ul style="list-style-type: none"> Encourage community input and collaboration by establishing a community advisory board.

LGBTQ, lesbian, gay, bisexual, transgender, and queer; EHR, electronic health record; TGNC, transgender and gender nonconforming.

Problems Identified with Quality of Care for TGNC Patients

Table 2.

Quality of care	Preventive screenings below quality targets due to inconsistent follow-up and communication challenges
Lack of awareness	Institutional failure to identify quality-of-care issues
Electronic health record	Default decision support configuration providing inaccurate recommendations due to gender transition
Patient experience	Patient kiosks and wrist bands displaying legal name, not preferred name; lack of provider cultural competency
Lack of cultural competency	Dearth of provider cultural competency and trainings
Policies and procedures	Gaps in multioccupancy room assignment policy (failure to automatically room trans patients with other same-gender patients and/or in a manner consistent with cisgender patients)
HIPAA	Unable to easily accommodate requests for medical record amendments (removal of former legal name) by TGNC patients after transition

TGNC, transgender and gender nonconforming.