1-1-2019

The Impact of a Revised Discharge Process from Acute Care to Home Care on Hospital Utilization in Children with Single Ventricle Heart Disease

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A Scholarly Project Presented to the Faculty of the School of Nursing

Boise State University

In partial fulfillment of the requirements

For the Degree of Doctor of Nursing Practice

By

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Table of Contents

Abstract

Problem Description: It is estimated that approximately ~0.5%, or ~400,000, of all U.S. children are identified as having complex chronic conditions (CCC) and account for as much as one-third, or ~$100 billion, of health care spending for all children. The goal of this quality improvement (QI) project was to identify the impact of a revised discharge process for children with Single Ventricle Heart Disease (SVHD) on hospital utilization rates and the parent's perception of discharge readiness during the interstage period. The QI project was conducted in a 44-bed cardiac care unit within a 336-bed freestanding pediatric, academic medical center in a large urban area. The participants of the project are the parents or guardians of the children with SVHD, not the children themselves.

Interventions: The outputs of the QI project included the development of a discharge bundle, which consisted of four specific aspects; 1. Assignment of a specific outpatient nurse coordinator; 2. Revised discharge education; 3. Utilization of remote home monitoring; and 4. Completion of a telemedicine encounter within 48 hours of discharge. Data reports were developed to measure hospital utilization rates and parent's perception of discharge readiness was measured utilizing two validated surveys, the Quality of Discharge Teaching Scale and the Patient Readiness for Hospital Discharge Study.

Results: This QI project was well received by all members of the clinical team as well as the parents. A total of five patients were enrolled with 100% compliance with all aspects of the discharge bundle. 36 telemedicine encounters were completed on the five patients enrolled in this project. A decrease in hospital encounters from an average of 3.75 encounters to 3.5 encounters within 30 days of discharge; a decrease of 7%. Patients in the pilot had an average direct cost per unique patient of $140,050 down from $164,088 in the pre-bundle discharge group, a decrease of

15%. There was no statistical difference in parent’s perception of discharge readiness, however, subjective data gathered from families was extremely positive.

Interpretation: Implementing new IT solutions at any organization is often time-consuming and challenging; this was no different for this QI project. Although the implementation of the home monitoring portion of this project took longer than expected, the outcome was a comprehensive, well-configured system that has provided a framework by which LCH could follow when future initiatives are identified

Conclusion: This project demonstrated the benefits and considerations that exist when implementing a revised discharge process for SVHD patients during the interstage period. Benefits came in the form of the telemedicine encounter and the ability for the nurse coordinator to address and visualize concerns related to feeding, breathing, and socialization. The acceptance of this QI project by all members of the clinical team and families suggest the need for a longitudinal review of the impact of this initiative.

Keywords: Complex chronic conditions, telemedicine, readmission rates, discharge bundle, hospital utilization, discharge, parental stress

The Impact of a Revised Discharge Process from Acute Care to Home Care on Hospital Utilization Rates in Children with Single Ventricle Defects

Problem Description

Introduction

Care of children with complex chronic conditions involves coordination and training for parents/caregivers to successfully manage in the home setting post-hospitalization (Russell & Simon, 2014). There remains a gap in the transition from the hospital setting to the home setting that leads to this population having higher rates of hospital readmission, emergency department utilization, and overall higher utilization of hospital services (Shermont, Pignataro, Humphrey, & Bukoye, 2016).

The primary goal of the DNP Scholarly Project was to implement a revised discharge bundle for pediatric patients with single ventricle heart disease (SVHD) at a large, free-standing pediatric academic medical center in the Midwest. The discharge bundle consisted of four specific aspects: assignment of a specific outpatient nurse coordinator, revised discharge education, utilization of remote home monitoring, and completion of a telemedicine encounter within 48 hours of discharge. The desired outcome was to measure the families’ attitudes and beliefs about improved preparedness for discharge and caring for their child at home and to measure the impact on the overall hospital utilization rates within the first 30 days post discharge.

Background

Children with complex chronic conditions (CCC) are defined as patients who have multiple specialty needs, have chronic conditions, often are technology dependent, and have high utilization of the health care system (Kuo, Melguizo-Castro, Goudie, Nick, Robbins, & Casey, 2015). It is estimated that approximately ~0.5%, or ~400,000, of all U.S. children are identified as having CCC (Kuo, Cohen, Agriwal, Berry, & Casey, 2011) and account for as much as one-third, or ~$100 billion, of health care spending for all children (Cohen, Berry, Camacho, Anderson, Wodchis, & Guttmann, 2012; Lassman, Hartman, Washington, Andrews, & Catlin, 2014). There have been several studies conducted to reduce hospital utilization rates in the adult setting, but there have been very few studies focused on children with complex chronic disease (Shermont et al., 2016). Studies have demonstrated success in reducing readmission rates and hospital utilization in the pediatric patient when interventions have included discharge bundles, improved discharge education, and improved care coordination (Jack, Chetty, Anthony, Greenwald, Sanchez, Forsythe, ... Culpepper, 2009; Kuo et al., 2015). In addition, emerging technology is enabling patients to be more active in their own care and leading to transformation in care delivery resulting in more engaged patients and improved patient outcomes (Clavelle, 2018).

Local Problem

Lurie Children’s Hospital (LCH) is one of the largest providers of pediatric care in the Midwest. Patients with SVHD are a group who were identified among children with CCC experiencing higher hospital utilization rates than other patient groups during the most recent triennial community health needs assessment at LCH (Lurie Children’s, 2016). LCH has one of the largest cardiology programs in the Midwest (Lurie Children’s, 2017) and expanded the size of the Regenstein Cardiac Care Unit at the hospital from 36 to 44 beds in spring 2018. The program admits more than 750 patients per year with the total patient days exceeding 8,500. On an annual basis, the number of new patients with single ventricle heart disease that are seen by specialists at LCH is 20-25. LCH has seen a rapid increase in the number of new patients diagnosed with SVHD since July 2017 because of the recruitment of a leading pediatric cardiovascular surgeon, pediatric cardiac anesthesiologist, and pediatric cardiac proceduralist. This increase in patient volumes has created an opportunity for the clinical team to identify ways to improve the care being delivered to improve outcomes and better managed hospital resources, including provider time, staff resources, and physical facilities.

Available Knowledge

According to the Center for Disease Control (2018), congenital heart defects affect nearly 1% or 1 out of every 40,000 live births. The occurrence of those with SVHD is about 1 in every 100,000 live births. Children with SVHD are born with one of the lower two ventricles of the heart undeveloped. This causes the mixture of unoxygenated blood with oxygenated blood causing decreased oxygenation to the body. To correct the problem, children will require a series of three complex cardiac surgical procedures within the first three years of life. This creates an increase in morbidity and mortality that results in higher hospital utilization rates and frequent admissions to the hospital. The outcomes of patients living with SVHD are improving resulting in better survival rates than were experienced in the past (CDC, 2018).

The issues and challenges facing parents/caregivers and providers of children with SVHD are immense. It is essential that pediatric cardiology programs identify interventions to assess clinical changes in the SVHD patient timelier and decrease overall hospital utilization through more appropriate clinical responses. In the past decade, nursing care has been transformed with the evolution of healthcare information technologies that have changed how nurses and families communicate and share information (Clavelle, 2018). LCH has recognized this opportunity and is focused on implementing innovative approaches to improving care for the patients with SVHD.

Literature Review

A literature search was conducted, which included utilization of several search engines including CINAHL, Pubmed, JSTOR, and ProQuest - Education Database. The search strategy focused on readmission rates, hospital utilization, patient hand-offs, and patients with complex chronic conditions. Keywords used included transfer, discharge, patient hand-off, readmission, patient readmission, hospital utilization, patient discharge, after care, and quality improvement. In addition, the search strategy also included keywords of child, pediatrics, medically fragile, medically complex, complex chronic illness, complex care, patient readmission, return visit, emergency room, and emergency department. For the purposes of this review, it was not required that the population being impacted during the intervention be children with CCC if the intervention was transferrable to pediatric populations. The literature search resulted in 12 research articles supporting the evidence-based research question. Research articles were divided into two main categories, with eight articles supporting the problem background and four articles supporting the problem intervention.

Studies were reviewed for study design and quality, and only studies with high or good quality as defined by the John's Hopkins Research Evidence Appraisal Tool and Non-Research Evidence Tool (Dearholt & Dang, 2012) were included. Research articles included one Level I randomized control trial, one Level II quasi-experimental study, three Level III studies with one of those a descriptive qualitative study and two retrospective cohort studies, and seven Level V studies. Level V studies included three literature review studies, one quality improvement and observational study, one retrospective cohort analysis, one cross-sectional study design, and one case report. Quality of all studies was either high or good as determined by well-executed study designs, well-structured studies, and evidence that is consistent with similar research studies. See Appendix A for the complete literature review table.

Synthesis of Evidence

A comprehensive review of the data identifies the background for the evidence-based quality improvement project and supports the need for a well-designed, family-focused intervention. According to Kuo et al. (2015), CCC children are less than 1% of all children but account for 11-33% of all health care spending. Jean-St-Michel, et. al. (2016) described the clinical course of patients with SVHD and identified a higher risk of death or cardiac transplantation prior to the stage II procedure. Patients with SVHD received more heart failure management and higher rates of hospital admission than other children with chronic illness (Jean-St-Michel, et al., 2016). The issues facing children with SVHD include developmental delay, feeding challenges, and growth delay, and contribute to their overall increase in hospital utilization rates. Health care professionals have identified the need to address unplanned readmission rates in CCC to manage spending, however, there remains opportunity to improve these rates and contribute to a decrease in overall hospital utilization rates. The literature suggests that the implementation of multifaceted discharge bundles that include improved education, specific home treatment plans, care coordination, and leverage technology, demonstrated improved patient outcomes and engagement.

Rationale

Theoretical Model

The chronic care model (CCM) was selected as a theoretical model because it uses a holistic approach to the management of chronic conditions using evidenced-based practice (Cupp Curley & Vitale, 2016). The CCM is focused on improving the care at the patient, community, organizational, and practice levels. There are six components of the CCM defined by Wagner (1998) which include the healthcare delivery system, the community, promoting self-care, decision support, delivery system design, and clinical information systems. The components of the CCM support the interventions that will be implemented for the SVHD patient population. The CCM was designed to provide focus and direction to clearly design, implement and evaluate strategies to decrease hospital utilization rates in the SVHD patients and improve perceptions of readiness for discharge in their parents or guardians. Considerations for the six components of the CCM and the connection with the QI project and a representation of Wagner's CCM can be found in Appendix B (Wagner, 1998).

Project Framework

The project framework for this quality improvement (QI) project was defined using the Kellogg Logic Model (Kellogg Foundation, 2004), (Appendix C). The purpose of the logic model is to align the resources, activities, outputs, and outcomes to allow for a clear, concise framework to be used as the project is planned and evaluated. The inputs in the logic model include the parents of patients with SVHD, providers, nursing staff, case management staff, and members of the clinical team. The logic model allows the proposed outcomes, such as reduction in hospital utilization rates, more timely hospital readmission rates, and increased parent or caregiver knowledge and perception of discharge preparedness, to be identified and aligned with the activities of the intervention.

Specific Aims

The QI project described in this article was conducted to implement a revised discharge bundle and measure the impact on perceptions of readiness for discharge in parents and legal guardians of patients with SVHD and determine the impact on hospital utilization rates for patients with SVHD. The fundamental impact of the project aim was to improve the knowledge and perceptions of parents/guardians at the time of discharge and to improve the care delivery model in the home setting resulting in improved value-based care as measured by a reduction in hospital utilization in the first 30 days post-discharge. The specific aims of the project were:

1. Identify the impact on the hospital utilization rates within 30 days of discharge for children with SVHD.
2. Identify if a focused intervention on improved identification of clinical changes at home impacted readmission timing in children with SVHD.
3. Measure the impact on the perceptions of discharge preparedness in the parents/guardians of children with SVHD to identify the impact of a revised discharge process.
4. Identify barriers to compliance with the discharge bundle that could be used to improve the process such that a standard process could be developed and used for patients with other disease processes.

Context

Population

LCH is one of the largest providers of pediatric care in the Midwest. LCH is a free-standing, pediatric tertiary-care hospital in a large urban city. The hospital has 336 licensed inpatient beds and is the largest provider for pediatric patients in the region. Lurie Children’s has more than 1,350 medical staff in more than 70 pediatric subspecialties and provides care for more than 200,000 unique patients on an annual basis (Lurie Children’s, 2017). The Heart Center at LCH is one of the largest in the country and provides care to thousands of children with cardiac disorders on an annual basis. According to the LCH website (2017), the Heart Center treats more than 10,000 pediatric patients in outpatient diagnostic visits, admits more than 300 inpatients, performs more than 550 cardiac catheterization procedures, and performs more than 450 heart surgeries each year. Along with high volumes of patients, the Heart Center at LCH has among the highest survival rates for children receiving complex cardiac surgery, with survival rates of those completing stage I procedures for SVHD greater than 80%, while the national average is 75% (Lurie Children's Hospital, 2017). The Heart Center at LCH has developed a center of excellence for single ventricle patients. This program brings together a multidisciplinary team aimed at providing comprehensive care to patients with single ventricle heart disease at all phases of their treatment, from infancy through adulthood.

Settings and Resources

The multidisciplinary clinical teams within the Heart Center at LCH represent a wide array of disciplines. These include pediatric cardiologists, cardiovascular surgeons, cardiac critical care intensivists, cardiac anesthesiologists, advanced practices nurses, registered nurses, child-life specialists, social workers, genetic counselors, and cardiac diagnostic technicians. The cardiac intensive care unit at LCH is a 44-bed, acuity adaptable unit in which patients remain for the entire length of stay. In this setting, patients do not move rooms, but rather the medical care adapts to the acuity of these patients. The care for these patients is optimized in this specially-dedicated unit, with clinical specialists and nurses specifically trained and experienced in the care of medically complex cardiac patients.

Leadership within the Heart Center at LCH has recently experienced change with a new division head and the addition of a fourth cardiovascular surgeon, a cardiac anesthesiologist, a cardiac proceduralist, and a medical director of clinical quality being named for the center. This has created an environment in which all aspects of the Heart Center, which includes the Division of Cardiology, the Division of Cardiovascular Surgery, and the Cardiac Intensive Care Unit, are working towards an aligned vision and set of goals. This leadership provides the ideal setting for improved care, as well as process and quality improvement initiatives. In addition, once patients have been discharged from the hospital, the Heart Center offers follow-up to providers at more than 10 locations throughout Chicagoland. This enables patients and families access to providers very close to the family's home, allowing for an impactful intervention related to the discharge process.

Congruence of Project with Organizational Mission and Values

Lurie Children's Hospital is a mission-based organization which is committed to the health and wellness of all children (Lurie Children's Hospital, 2017). Lurie Children's vision is guided by the belief that all children need to grow up in a nurturing and protective environment, so they can reach their fullest potential (Lurie Children's Hospital, 2017). The organization has developed Vision 2025, a strategic plan that guides the organization to become a top-tier pediatric hospital by 2025. One of the pillars of Vision 2025 is providing the best care and experience. This project aligns with this organizational imperative, which enabled the project team to receive support and resources from key departments at the hospital.

Evaluating Change and Readiness for Change

The Heart Center at LCH is led by a strong group of clinical and nursing leaders who are focused on excellence. This focus allows for a culture that is open to change and willing to promote changes in practice to improve care delivery. The key leaders within the Heart Center and LCH have agreed to focused interventions to improve the discharge process and measure the impact on hospital utilization rates for patients with SVHD. Team members were actively engaged in meetings and discussions focused on patients with SVHD and opportunities to improve the family/guardian’s perceptions of the discharge process impacting the hospital utilization rates of the SVHD patients.

Needs Assessment/Strengths and Weaknesses

Aligning the proposed intervention with the organization’s key strategies is essential to garnering the support and resources to make a project successful. Interviews with key leaders of the Heart Center at LCH assisted with identification of potential interventions. Although children who are described with complex chronic conditions such as SVHD account for only a small number of all children, they access a disproportionate amount of health care resources comparatively. Interventions to decrease this utilization must focus on improving access, coordination of care, and transitions of care across the continuum of care.

Completing a situational analysis of an organization is a baseline evaluation that describes the readiness of an organization for a project (White & Dudley-Brown, 2012). This process identified the strengths and weakness within the organization, the opportunities that position the project for success, and the threats that can prevent the success. A SWOT analysis for the implementation of the scholarly project can be found in Appendix D.

External Funding

There were no external funding sources utilized during the implementation of this scholarly project. All funding sources were from LCH operational funds or unrestricted philanthropic funds donated to the Heart Center.

Memorandum of Understanding

The memorandum of understanding (MOU) serves as an agreement between the DNP student and the organization. It outlines the terms and understanding between the student at

Boise State University and Lurie Children's Hospital. The MOU was reviewed, approved, and signed by the PI and LCH on January 29, 2018 (Appendix E).

Interventions

Logic Model

The project plan and evaluation plan were created utilizing a logic model described by the W.K. Kellogg Foundation (2004) (Appendix C). The focus of the logic model was to align the resources, activities, outputs, and outcomes of the initiative. Outcome goals (see Table 1 below) were developed to be specific, measurable, achievable, realistic, and timely (SMART). The outputs of the QI project included the development of a discharge bundle, which consists of four specific aspects:

1. Assignment of a specific outpatient nurse coordinator.
2. Utilization of revised discharge education.
3. Utilization of remote home monitoring.
4. Completion of a telemedicine encounter within 48 hours of discharge.

All four components of the discharge bundle had to be present for compliance to be counted. Additional outputs of the QI project included the development of marketing and awareness building for the project, revised educational tools that were provided to families, a survey that would be used to compare discharge readiness and quality of discharge education, and the specific educational plan that was used in the QI project.

Team members for the project included the cardiology physicians, cardiology nurses, discharge planner, social worker, the telemedicine coordinator, and the patient and families. A core leadership team was identified and included the Heart Center Quality Committee Physician, the Nursing Director, the Executive Director, the Advanced Practice Registered Nurse for SVHD patients, and the Project Coordinator. A series of core group meetings were conducted to determine the specific aims, context, interventions, timeline, and measures for the project. At multiple points in the process, key stakeholders from the Heart Center and LCH were engaged to provide input and confirm support of the project. Both short-term and long-term outcomes were developed, but only the short-term outcomes were addressed, measured, and evaluated in this DNP QI project.

Table 1. Short and Long-term Outcome Goals

Outcome 1 - Short-term	100% of families who have children with single ventricle heart disease admitted to the hospital were offered to participate in the discharge optimization program prior to discharge between the months of May and October 2018.
Outcome 2 - Short-term	100% of the discharge optimization bundle was completed within 48 hours of discharge for those children with SVHD discharged from the hospital between May and October 2018.
Outcome 3 - Short-term	A 20% improvement in family perception of transitions of care as measured by pre-survey and post-survey (QDTS) was demonstrated for those patients discharged between May and October 2018.
Outcome 4 - Short-term	A 10% decrease in hospital utilization as measured by total direct costs per unique patient for children with SVHD admitted to the hospital within 30 days of discharge by January 2019.
Outcome 5 - Short-term	A 20% improvement in quality of discharge education provided for the discharge needs of the patient with SVHD will be demonstrated by parents based on the QDTS survey and RHDS RN survey for those patients discharged between May and October 2018.
Outcome 6 - Long-term	The number of disease-specific populations participating in the discharge optimization program increased by 3 within 1 year of the initial intervention.
Outcome 7 - Long-term	Families utilizing the discharge optimization program was increased to 100% of eligible families by October 2020.
Outcome 8 - Long-term	A 50% improvement in family perception of transitions of care as measured by pre-survey and post-survey (QDTS) was demonstrated for those patients discharged with SVHD by October 2020.
Outcome 9 - Long-term	A 25% decrease in hospital utilization as measured by the average total direct costs per unique patient for children with SVHD admitted to the hospital within 30 days of discharge by October 2020.
Outcome 10 - Long-term	A 50% improvement in quality of discharge education provided for the discharge needs of the patient with SVHD will be demonstrated by parents based on the QDTS survey and RHDS RN survey for those patients discharged by October 2020.

Alignment of Interventions with the Theoretical Model elements/phases

The chronic care model is focused on improving the care at the patient, community, organizational, and practice levels. There are six components of the CCM which include the healthcare delivery system, the community, promoting self-care, decision support, delivery system design, and clinical information systems (Wagner, 1998). The interventions implemented in this QI project aligned well with all components of the CCM. Interventions were focused on improving the care coordination across the continuum of care for the patients with single ventricle heart defects. The ability for patients to provide self-care in the home setting and communicate the clinical condition effectively through remote home monitoring was the focus of the revised discharge educational plan while providing for decision support through the implementation of specific care coordinators and a telemedicine follow-up meeting within 48 hours of discharge. The QI project also leveraged technology as a component consistent with the CCM and aligned with the strategic goals of LCH.

Timeline

The course of the project consisted of planning, implementation, evaluation, and dissemination of clinical knowledge. During the planning phase, the clinical and administrative team members were identified, and the project charter was developed. Team members were selected from various areas within the organization, and included members of the Division of Cardiology, information technology, business analytics, nursing, information management, and social work. Ad hoc members identified during the planning phase and were engaged in the project. Other components of the planning period included development of a budget, resource requirements, marketing, educational planning, contract review, and development of remote home monitoring system. Once the planning phase was completed and the intervention was formulated and refined, implementation took place beginning spring of 2018. Duration of the implementation phase consisted of approximately 5 months. During this period, the outcome measures that had been established were collected. The implementation period was completed in the fall of 2018, at which time the data that had been collected was evaluated and analyzed. Findings will be shared and disseminated with team members and key stakeholders in the spring of 2019. A detailed timeline has been included (Appendix F).

Measures

The focus of the data measures used to evaluate the impact of the QI project were both quantitative and qualitative data. Specific quantitative data on readmission rates and utilization of inpatient hospital and emergency department services were gathered utilizing the SVHD Utilization Report (Appendix G), which was pulled from data in the LCH electronic health record (EHR), Epic. The SVHD Utilization Report was developed using a set of reports that existed previously and was used to measure Outcome 4. In the event that a report was not already developed, collaboration with the Data Analytics and Reporting team was done to create necessary reports or data elements. Descriptive statistics were utilized to describe the changes in the rates of readmission or IP hospital and emergency department visits after the QI project interventions were implemented. Readmission rates and hospital utilization data was described using a run chart to show how the process was running and identify trends. Information related to participation rates (Outcome 1) and bundle compliance (Outcome 2) was collected utilizing an Excel spreadsheet and chart audits completed within one week of the patient discharge. For the purposes of this project, the relatively small number of patients with SVHD allowed for this process to be maintained, but in the event of a larger initiative, a more sustainable process would need to be developed.

Quantitative data were gathered for parent/guardian's perceptions of readiness for discharge from the parents/guardians and the discharging nurse utilizing validated survey tools. Permission for organizational use of two validated survey tools was obtained for the following instruments:

I. Quality of Discharge teaching scale – to ask the parent; called 'QDTS' (Outcome 5) (see Appendix H). The QDTS was developed for the larger study and tested in a similar fashion to the RHDS, contained 6 paired items and used the same 0 to 10-point scaling format as the RHDS. Cronbach's alpha for the total scale was 0.89 and 0.80 for the Content Amount subscale in this study.

II. Parent readiness for hospital discharge study – for nurse to fill out; called 'RHDS RN' (Outcome 5) (see Appendix I). A Cronbach alpha score was not identified for the RHDS RN.

For comparison, the QDTS and RHDS RN survey tools were completed by the parents/guardians and the discharging nurse at time of discharge from the hospital stay, and then the QDTS was completed again by parents/guardians four-weeks post-discharge.

Qualitative data were gathered through Rounds Plus, an electronic survey application utilized at LCH for documentation of auditing and surveillance. This application allowed for the electronic collection of survey tools and provided data reports which were used to record and report data for outcomes evaluation. A complete Outcomes Evaluation Table can be found in Appendix J.

Project Budget Plan

The resources needed to support and maintain this QI project are essential and a 3-year budget was developed (Appendix K), along with a Project Expense Report (Appendix L) and a

Statement of Operations (Appendix M). The budget for the QI project considered organizational resources that were provided in-kind, as well as information technology that was purchased from an external vendor and used to support the remote home monitoring system. Project manager expenses for this project were provided in kind by the author as the DNP student. The expense for the remote home monitoring system includes a one-time system development fee and cost for 20 mini-iPads to be distributed to families for use during the QI project. These expenses were supported through an external donor to the Heart Center and did not require operational funding. In addition, there was a cost for the annual licensing fee of the remote home monitoring system, which was included in the budget, but will be waived if the tool is utilized for additional disease states. At this time, there is not a mechanism for generating revenue for the services rendered for home remote monitoring or a telemedicine visit in the State of Illinois. Future considerations for reimbursement of these services should be evaluated. Appendix N illustrates the budget items that were considered and the funding source.

Analysis

Qualitative Analysis

Qualitative data are beneficial because they can often provide a unique insight into how programs are working or not working and reasons for success or failures (Newcomer, Hatry, & Wholey, 2015). Qualitative analysis for this project included one question which was developed and supported by the Project Steering Committee asking, “If applicable, what prevented the bundle from being completed?” (Outcome 2). The answers to this question were tracked in an Excel document, and results were reported by the number of similar responses to revise and improve the discharge process for future phases of the project. Utilizing explanatory techniques enabled the ability to identify any trends in the reasons for noncompliance with the discharge bundle.

Quantitative Analysis

Quantitative analysis is used to describe the characteristics of a sample or population utilizing numbers (Newcomer et al., 2015). The use of a well-defined, balanced performance measurement system would enable the team to effectively track the progress of all components of the revised discharge process (Giuliano & Polanowicz, 2008). Data collected allowed the team to determine effectiveness of the intervention and identify opportunities for revisions of the process and improved outcomes. Completion rates of all components of the revised discharge bundle were tracked through chart audits and logged in Excel and shared with the clinical team monthly (Outcomes 1 and 2). In addition, survey results collected utilizing the QDTS and RHDS RN were collected utilizing Rounds Plus, an electronic survey application, and data was analyzed monthly (Outcomes 3 and 5). Descriptive Statistics were used to measure the mean, median, and standard deviations of the scores from the care transitions measure survey.

Data collected on the SVHD Utilization Report that provides hospital readmission and utilization data generated quantitative data that evaluated the impact of the SP initiative on hospital-specific metrics, including length of stay, costs, unplanned readmission rates, and reason/purpose for readmission (Outcome 4). The SVHD Utilization Report provided descriptive statistics that were used to describe the impact of the SP project on key hospital performance measures. Specific reports included:

- Volume and financial data by cardiac group - Patients were categorized using diagnosis codes and cardiac groups. Subsequently, a patient account could be presented in multiple cardiac groups. As a result, this report does not contain totals to prevent overstatement of financials.

- Volume and financial data by patient class - Unique patient accounts were reported. Year to year volume and financials were reported and reviewed for consistency
- Post 30-day activity - Using the original encounter specified, report activity post 30 days from discharge date was reviewed.

Data were collected monthly as aggregate data, reported as median, and shared with the core project team, consisting of nursing leadership, providers, the APRN coordinator, and Heart Center administrative leadership. The hospital utilization and readmission data for children with SVHD was collected during the pilot and subsequent phases. This pilot phase did not allow for direct comparison with previous discharge data because the project did not control for factors outside the control of the discharge process revisions.

Other Considerations

To maintain the integrity of the data that was collected, there was training with the PI and nurse coordinator on the project goals, data collection methods, and data review prior to data collection. In addition, the number of team members completing data collection was limited to the PI and nurse coordinator.

Ethical Considerations

Ethical Considerations and Protection of Participants

Ethical considerations were extremely important to this QI project, as the primary population that was being impacted were pediatric patients, often those without the ability to make decisions on their own. The participants of the project are the parents or guardians of the children with SVHD, not the children themselves. All patients and data were gathered within compliance with the Health Insurance Portability and Accountability Act (HIPAA). Patient privacy and confidentiality were maintained as no patient identifier information was collected.

CITI training on human subject's research was completed by the author and the project was approved through the Lurie Children's Institutional Review Board (IRB) and the Boise State University (BSU) IRB. The LCH IRB determined this project did not meet the criteria for a research study but was a QI project. A Letter of Determination indicating that this project met criteria for Quality Improvement was issued on February 26, 2018 (Appendix O) and submitted to the BSU IRB.

This QI project did not require an informed consent form for participation. The policy at Lurie Children's IRB is that for quality improvement initiatives, informed consent is not required. Parents/guardians of children with SVHD will be invited to participate in the QI project, and participation will be completely voluntary. There was no obligation for these parents/guardians to participate and if they chose not to participate, they would continue with the current discharge process, and the care they receive was not affected. The goal of the QI project is not to provide any direct patient care impact but to improve the discharge process.

Conflicts of Interest

The author has no conflicts of interest to disclose. There were no financial considerations for any of the initiatives selected and the author maintained no conflicts as it related to product utilization.

Biases

This QI project had the potential for several limitations and biases. The first limitation was that this was implemented in a single, academic, pediatric medical center. In addition, the single ventricle heart defect population is a small population of the overall complex chronic care patients at LCH. The results of the small population who meet eligibility criteria for the study may lead to nonresponse bias because of a potentially low number of respondents (Issel, 2014). This may result from attrition of participants in the QI project or participants who were difficult to reach for follow-up leading to incomplete data. In addition to nonresponse bias, another potential bias is response bias. Since a survey was utilized to measure the perception of readiness for discharge, there was the potential for participants to respond consistent with social desirability, or a way in which puts them in the most positive light (Issel, 2014). These biases were considered as data was evaluated and determined to not impact the current project.

Threats to Quality

Threats to the quality of the QI project that the author considered included missing data, reliability concerns, and validity of measures selected. As the data were collected and measured, the author reviewed and accounted for all missing data and the impact this had on the overall analysis of the SP's impact. It was essential that the data being collected was free of reliability concerns and free of errors. To address this, the author utilized currently available information technologies such as Epic or Rounds Plus. In the event data were collected manually, the author was the single source of collection for data as to maintain reliability of this data. Finally, validity of measures is the degree to which the tools being utilized captures what it is intended to capture (Issel, 2014). For the purposes of the SP, qualitative data was captured utilizing a validated tool. These surveys were collected utilizing interviews and entered into the Rounds Plus application to maintain freedom from any bias as well.

Results

Implementation of the QI project was completed during a 5-month period between June 2018 and October 2018. Over the course of the QI project, key improvement areas and specific interventions were measured for effectiveness (Appendix P). Key improvement steps focused on implementation of all four components of the revised discharge bundle (Appendix Q). A collaborative effort between physician, nursing, and Heart Center administrative leadership, along with the partnership of the clinical experts, allowed for robust discussion and thoughtful development of all bundle components. Any modifications that were made throughout the implementation period were discussed at the project core team meeting and implemented prior to enrollment of any patients into the process. This discussion was key to the success of the program.

Primary Nurse Coordinator

Assignment of the primary nurse coordinator for all new patients was completed at the point of initial diagnosis. For those patients identified with SVHD, the APRN coordinator was identified as the primary point of contact for all patients and followed the patients through all stages of treatment. The primary nurse coordinator remained an active member of the core team, served as the knowledge expert for SVHD workflows, and was instrumental in development, revisions, and implementation of this QI project. This role served as the liaison between the families, clinical team, and bedside nurses for all aspects of the QI project. Because of significant volume growth with this population, the need for an additional nurse coordinator position was requested and approved during this intervention. Onboarding of this new position occurred during the intervention period and specific education and training was completed during the orientation process.

Discharge Educational Materials

Discharge educational materials were an essential component of the QI project and revised discharge bundle. Historically, these materials were provided in paper and organized in a three-ring binder that the families were asked to carry with them to document patient progress. To implement a process that transformed the discharge process, the clinical team, which included physicians, nurses, and clinical nutritionists, took on the responsibility of reviewing and revising all aspects of the educational materials provided to families. Success of the educational material review was supported by this multidisciplinary, collaborative effort.

Discharge educational materials that were reviewed included the red flags and awareness of when to notify the clinical team, routine contact information, instructions for the emergency room, explanation of the interstage period, nutritional information, managing stress, importance of bonding and mealtime relationships, family support resources, and other key discharge information (Appendix Q). Once the discharge education materials were revised, they were built into the remote home monitoring system, Locus Health, and available for access by the patients at any point after discharge through a mobile device. In addition, the clinical team developed content for timed delivery which means at certain intervals within the patient’s episode of care the Locus Health program would push out education to ensure the family is receiving it. The team initially developed three education pushes for the QI project. The first is a welcome to the program information, second is cardiac catheterization information, and the third explained early intervention and what to expect.

Locus Health Remote Home Monitoring Application

The selection of a home remote monitoring system for this QI project was focused, comprehensive, and inclusive (Appendix R). This process included clinicians, nurses, administrative leaders, legal, compliance, the privacy officer, and information technology. A series of discussions were held between hospital leadership, legal, compliance, and the privacy officer to identify concerns related to data sharing, risk, and confidentiality prior to vendor selection. Concerns related to ownership of data, potential for a breach of data, and compliance with HIPAA were discussed. Once these concerns were appropriately addressed, a formal request for proposal (RFP) process was completed to select a vendor. The RFP included the review of three potential vendors, including a proposal to utilize the current LCH electronic health record. The RFP included company demographics, privacy statement, IT security plan, data ownership (vendor or LCH-owned), and benchmarking and cohort data.

Information gathered from the RFP was considered, and it was determined that Locus Health would be the vendor. Locus Health is a company that provides clinical support services that enable clinicians to leverage technology to support and enhance the care being provided. The Locus Health remote home monitoring program is utilized by other leading pediatric institutions and is configurable by program and population, including congenital heart disease, transplant, heart failure, NICU discharges, hematology & oncology, high risk pregnancy, and other medically complex populations. A vendor service contract and business associate agreement between LCH and Locus Health was initiated prior to initiation of the home remote monitoring.

This process of vendor selection took more than 12 months from initiation to completion. The process involved several levels of contract review and group meetings with the LCH IT and Telemedicine Departments and Locus Health to develop clear goals, expectations, and management of the process. This partnership between the clinical team, information technology, and the telemedicine staff was an unexpected consequence that led to a streamlined system that has allowed for consolidation of efforts and technologies. Initially, there was a perceived challenge with adding and accessing all applications on one iPad and families would need to access multiple applications from multiple devices. All teams worked diligently to negotiate a solution that would provide the best experience for the families. The solution developed a groundwork for future projects to utilize and has already been shown to benefit another group at LCH.

The challenges related to implementation of the remote home monitoring system delayed the start of the project by several weeks. The impact of that delay was minimal related to the timing of patient discharges. Patients who were identified to be included in the initiative were not clinically ready for hospital discharge until several weeks after the program was initiated. All patients who were identified during the initial weeks of the project were ultimately included in the project, but this is a consideration for future projects that involve relatively small sample sizes or rare disease populations.

Tele-Single Ventricle Program

Care for children with SVHD requires care that crosses acute and chronic care settings throughout the first year of life. It is a critical time of development that includes multiple surgeries and procedures which is stressful to the family system. The goal of the Tele-Single Ventricle program is to provide an option to in-person care to allow families to partner with treatment teams, to minimize additional trips to the main hospital and to maintain the family's resiliency. This program provides families access to a secure mobile video platform to engage with their child's care team in the comforts of their home environment. The program was structured to provide all patients who were enrolled in the project with a telemedicine encounter within two business days of discharge. Of the five patients enrolled in this project, 100% received a telemedicine encounter within the desired time frame.

Development of the Tele-Single Ventricle program utilized the current telemedicine platform at LCH. This enabled the team to quickly modify current telemedicine workflows to meet the needs of the SVHD patients (Appendix S). In addition to modification of the workflows, family educational tools (Appendix T) and documentation workflows (Appendix U) were also developed. Critical to the success of the Tele-Single Ventricle program was staff who trained, comfortable, and confident with navigating through the telemedicine visit. Formal training and education were completed by the Medical Director of Lurie Children’s Care Connect. This training consisted of a 30-minute, face-to-face session that covered the basics of telemedicine, troubleshooting, emergency response, and documentation. The telemedicine team remained a resource for staff and families throughout the project.

This support was essential to the ongoing learning of the project and the future practice of our providers. One of the biggest challenges facing the providers was to provide care via telemedicine in a consistent and efficient manner. As new staff, physicians, nurses, telemedicine coordinators, etc.) were onboarded, education and training were completed to ensure they were meeting the standards of care developed by our telemedicine team. In addition, the team quickly identified the challenges related to defining the expected amount of time for these calls. The team learned that these calls were taking longer than the typical telephone encounter and a process to shape the expectations of the parents was needed to limit the duration of these encounters.

Process Measures and Outcomes

The fundamental impact of the project aim was to improve the knowledge and perceptions of parents/guardians at the time of discharge and to improve the care delivery model in the home setting resulting in improved value-based care as measured by a reduction in hospital utilization in the first 30 days post-discharge. Process measures for this QI project included compliance with all four aspects of the discharge bundle. Chart audits were completed on all patients who participated in the project to determine if they received all components of the discharge bundle.

All eligible patients discharged between June and October 2018 were approached and enrolled in this project with 100% compliance (Outcome 1). A total of five patients were enrolled with 100% compliance with all aspects of the discharge bundle (Outcome 2). During the pilot, 36 telemedicine encounters, ranging from 1 encounter to 11 encounters (average encounters was 7), were completed on the five patients enrolled in this project (Outcome 2).

Parents were very willing to complete the surveys for this project. Table 2 demonstrates compliance with survey completion above 75% for all required surveys (Outcome 2). One patient was discharged on a Sunday without completing the QDTS survey at the time of discharge, since no coordinator was available, and one patient did not have the 30-day post discharge QDTS survey completed because the patient was readmitted to the hospital. Outcome 3 targeted a 20% improvement in family perception of transition in care. When answering the question, “Was information provided in a way you could understand” parents answered with an average score of 9.6 on the discharge survey compared to 10 on the 30-day post-discharge survey, a 4% increase. Although not statistically significant, this is a positive trend. When asked “Did the information provided decrease your anxiety” (Outcome 5) parents responded with an average score of 9.0 on the discharge survey compared to 9.2 on the follow-up survey, an increase of 2%. Again, not statistically significant, but still a positive trend. See Appendix V and W for complete survey results.

Table 2: *Survey compliance report*

Patient	Discharge Survey (y/n)	Telemedicine Call (y/n)	30-day post Survey (y/n)	RN Survey (y/n)
1	Y	Y	Y	Y
2	N	Y	Y	Y
3	Y	Y	Y	Y
4	Y	Y	Y	Y
5	Y	Y	N/A	Y
Completion Rate	80%	100%	100%	100%

To measure the impact of hospital utilization, the SVHD Utilization report (Table 3) was developed to track SVHD interstage patients who received treatment at LCH. The patients who were in this pilot showed a decrease in hospital encounters from an average of 3.75 encounters to 3.5 encounters within 30 days of discharge; a decrease of 7%. Patients in the pilot had an average direct cost per unique patient of $140,050 down from $164,088 in the pre-bundle discharge group, a decrease of 15% (Outcome 4). This report utilized the patient diagnosis and procedure codes defined in Appendix G and focused on patient encounters, which included inpatient, outpatient, radiology, lab, procedure, and emergency encounters, total patient length of stay (LOS), average LOS, total charges for all patients, and the average contribution margin for all patients. Data were compiled for the patients enrolled in this DNP Scholarly Project and for the patients undergoing the same surgery prior to the project between August 2017 and June 2018. The August 2017 start date for patients undergoing surgery was used because it marks the date a new cardiovascular surgeon performing these surgeries started at LCH, which would eliminate any variances related to surgical management of these patients. Table 3 provides pre-implementation data for patients treated between August 2017 and June 2018 (Pre-D/C Bundle Patients), and those having surgery during the Scholarly Project data collection period (Discharge Bundle Patients). A direct comparison cannot be made between the two groups because the project was not completed as a randomized-control trial.

Table 3: *SVHD Utilization Report (August 1, 2017- November 8, 2018)*

DISCHARGE BUNDLE PATIENTS	TYPE	NO. OF ENCOUNTERS	UNIQUE PATIENTS	ENCOUNTERS PER UNIQUE PATIENT	TOTAL LOS	AVERAGE LOS	DIRECT COSTS PER UNIQUE PATIENT
	ORIGINAL ENCOUNTER (OE)	4	4	1	379	95	140,050
	ENCOUNTERS POST30 DAYS OF OE DISCHAR	6	4	1.5	0	0	323
	Grand Total	**10**	**4**	**2.5**	**379**	**38**	**140,373**
PRE D/C BUNDLE PATIENTS	**TYPE**	**NO. OF ENCOUNTERS**	**UNIQUE PATIENTS**	**ENCOUNTERS PER UNIQUE PATIENT**	**TOTAL LOS**	**AVERAGE LOS**	**DIRECT COSTS PER UNIQUE PATIENT**
	ORIGINAL ENCOUNTER (OE)	14	14	1	787	56	164,088
	ENCOUNTERS POST30 DAYS OF OE DISCHAR	44	12	3.7	276	6	53,740
	Grand Total	**58**	**14**	**4.1**	**1063**	**18**	**210,151**

The data on the patients enrolled in the project only includes four patients, because one patient was admitted to the hospital within 30 days of discharge and information was not available at the time of this review. In phase 2 of this project, data will be collected and reviewed with the clinical team on a quarterly basis to identify trends in patient encounters, readmission rates, and direct costs of care.

Contextual Elements That Interacted with the Interventions

LCH is the largest provider of pediatric healthcare in the region and moved into a new hospital in June 9, 2012. LCH has experienced significant growth in their clinical programs since the move to the new hospital requiring expansion of the 288 licensed beds to 364 licensed beds in fall 2019. As part of this expansion, the Heart Center was relocated from a 36-bed unit on floor 15 to a 44-bed unit on floor 22 on June 9, 2018. The expansion project required the focus and attention of all members of the Heart Center team and limited the ability to focus on competing initiatives in the Heart Center during this period. This move occurred 6-weeks into the intervention period for this QI project. The core team continued efforts to monitor status of the patients and maintain education and training for staff participating in the QI project. During this expansion period, no patients were identified as meeting criteria for the QI project and, thus, no patients were enrolled during this time.

The growth in patient volumes was, in part, related to the recruitment of several new providers in 2017 and 2018. A new CV surgeon joined LCH in July 2017 and brought a new set of complex patients and procedures. This change had a direct impact on the severity level of the patients being seen in the Heart Center and the SVHD population. In addition, the CCU completed an expansion project that resulted in the addition of 8 new critical care beds along with a 20% increase in the nursing staff. The increase in staff, patient acuity, and volume may have contributed to an increase in patient days, charges, and encounters demonstrated on the SVHD utilization report.

Expansion and growth that was experienced at LCH also may have contributed to some of the delays related to implementation from an IT perspective. The support needed for all aspects of scoping, design, build, and implementation of the Locus Health Home Remote Monitoring system were required to be prioritized at a time when competing priorities of the organization were at a high. This prioritization was obtained, and the project moved was implemented but the target date was missed.

The overall complexity of the SVHD patients contributed to some of the challenges facing the entire clinical team as it relates to their management. Even though the Heart Center is an admit to discharge unit and they are an extremely collaborative team, there is still opportunity for improvement. There is the opportunity for improving communication and coordinating the discharge process better. The unit was operating at a capacity of 85% or higher for the duration of this project. This required management of patients and beds that may have resulted in patients being discharged prior to all aspects of the discharge process being completed in an optimal manner. For example, some patients were discharged when clinically stable but prior to having post-discharge follow-up appointments scheduled or prior to having final meeting with the clinical nutritionist to discuss additional feeding tips. Coordination between the Cardiology, Cardiovascular Surgery, and Cardiac Intensivists is done effectively but there are opportunities to improve the transition between these services.

Summary

There were several strengths and benefits identified because of this quality improvement project. Implementing new IT solutions at any organization is often time-consuming and challenging; this was no different for this QI project. Although the implementation of the home monitoring portion of this project took longer than expected, the outcome was a comprehensive, well-configured system that has provided a framework by which LCH could follow when future initiatives are identified. Once the project had been fully implemented, the focus of improving the perceptions of discharge readiness and improving outcomes post discharge were realized. When parents were asked on the QDTS survey “Did the information your child's nurses provided about your child's care at home decrease your anxiety about going home”, parents score this as 8.9 out of 10 demonstrating that families were receiving the appropriate information at discharge. The key to the successful implementation of all aspects of the revised discharge bundle was the diligence and focus of the clinical team partnering with all stakeholder departments.

Implementation of this QI project was embraced by all members of the clinical team and families were very willing to engage in the revised discharge bundle. There were no challenges with the transition from the previous paper form of patient monitoring to the new online version of remote home monitoring. At the time the first patient was enrolled in the project, the parent accidentally spilled coffee on the old education binder, offering some levity to the initiation of revised discharge bundle. The parents' comfort with technology allowed for a smooth transition to remote home monitoring and telemedicine. The strength of this project has come from the dedicated clinical staff who were motivated and fully supported all aspects of this project from the onset.

Interpretation

The ability for parents and families to effectively manage the comprehensive care of children with medical complexity is an extremely difficult proposition. A literature review completed at the onset of this QI project and studies consistently found that discharge planning, education, care coordination, clarity of treatment plans, and emerging technology is transforming care and improving outcomes as patients are transitioning from inpatient to outpatient settings (Kuo, Melguizo-Castro, Goudie, Nick, Robbins, & Casey, 2015; Jack, Chetty, Anthony, Greenwald, Sanchez, Forsythe, ... Culpepper, 2009; Kuo et al., 2015; Shermont, et.al., 2016; Clavelle, 2018). To address the challenges impacting patients with SVHD, this QI project was successfully implemented and included a combination of elements of successful discharge bundles described in the literature. A major focus of this QI project leveraged emerging technologies of telemedicine visits and a remote home monitoring application to document and share information between the parents and SVHD nurse coordinator.

The ability of families to be able to provide real-time data and connect with their clinical team through face-to-face telemedicine encounters improved the knowledge of the families and provided the clinical team with more complete health status information as demonstrated by

100% of families who participated in the home remote monitoring trial (Outcome 1). The ability to provide families with multimodal forms of information was essential to this pilot.

The project was implemented as planned and consisted of all four components of the discharge bundle. There were delays related to the implementation date that were largely attributed to the complex nature of implementing a new technology solution which required input from IT, legal, compliance, and the multidisciplinary clinical team. The cost of design and implementation consistent with the budget (Appendix K). During the pilot phase, efficiencies were demonstrated by utilization of one telemedicine device to support multiple applications, i.e. Locus Health and Lurie Children's Care Connect.

Policy Implications

Lurie Children's is the largest provider of pediatric clinical care in the State of Illinois. More than 50% of the patients served by Lurie Children's are covered by Illinois Medicaid and are not eligible for reimbursement for telemedicine services. In order to create, inform and shape policies to address this, the DNP nurse leader must be active in shaping evidence-informed policies (Mason, Gardner, Outlaw & O'Grady, 2016). Working with the External Affairs Department at Lurie Children's, the organization has identified the need to advocate for funding for reimbursement for telehealth programs, such as the efforts related to this SP, as these are ways in which access to care is increased while potentially lowering the cost of health care by limiting the need of the patient to come to the hospital for services. This advocacy strategy includes working with state legislatures to inform and address the following:

1. A shortage of pediatric specialists in Illinois and nationally leading to underserved populations. This creates barriers to pediatric health care related to the distance from appropriate providers which can be partially addressed via pediatric telehealth platforms

and technologies used by clinicians for consultations, case discussions, and ongoing clinical support.

2. Research on pediatric telehealth has been positive with respect to the patient and parent/caregiver satisfaction, provider satisfaction, and feasibility, citing telemedicine encounters as equivalent to in-person encounter (Clavelle, 2018; Wynter-Blyth & MacKinnon, 2017).
3. The State of Illinois does not have laws requiring reimbursement for telehealth services or mandating that governmental and commercial health care payors reimburse telehealth services at the same levels as if those services had been delivered face-to-face. Illinois is one of only 11 such remaining states that have not implemented policies to address telehealth reimbursement.
4. Lurie Children’s strongly encourages legislative and administrative efforts to promote the implementation of pediatric telehealth services in appropriate geographic areas, including passing legislation that provides reimbursement for underserved areas to create telehealth partnerships and mandates reimbursement by payors for telehealth services to the same extent as if those services had been delivered face-to-face.

Limitations

One of the limitations to this QI project was the small sample size of 5 patients. The project was limited to patients with the very rare condition of SVHD during their interstage period, which limited eligible patients. In addition, the small sample size can impact the utilization data collected during the project as one patient who had an adverse outcome could negatively skew the financial data as well as length of stay data. The short duration of the pilot also limited the true impact on morbidity and mortality of these patients. To address this, it is recommended that a longitudinal review be completed.

For this phase, patients who did not speak English were not eligible for the project. However, since the time of the pilot, the Locus Health application has been amended to include education in Spanish, as well as developing a process to have an interpreter present during the telemedicine call. The project was conducted on a single unit at one pediatric, academic medical center in the Midwest. As this was a QI project and not a research project, this was not a design flaw but served as a proof of concept that can be offered to additional program at Lurie Children's Hospital.

Conclusions

Healthcare is evolving at a rapid pace, and clinical teams are being charged with identifying ways to deliver high quality care, at a lower price, and in a manner that meets the needs of a diverse group of patients. Leveraging technology as a solution was a key component of this pilot quality initiative. This project demonstrated the benefits and considerations that exist when implementing a revised discharge process for SVHD patients during the interstage period.

One of the biggest fears a parent has is the death of a child. Parents of babies with SVHD must face this possibility daily. The implementation of the revised discharge process was a step that provided support to families by connecting families and healthcare providers in new ways. The pilot project demonstrated that parents were very willing and accommodating as the pilot was being implemented. Benefits came in the form of the telemedicine encounter and the ability for the nurse coordinator to address and visualize concerns related to feeding, breathing, and socialization. The aspect of socialization was an incredible benefit of the telemedicine encounter that enabled the parents to connect in a different way with their healthcare provider than over the phone. Visual cues enabled conversations and education on various topics from feeding, weight gain, and stress management. It is recommended that future projects focus on the impact of quality of life related to implementation of this initiative as the ability to reduce stress may not be realistic.

The greatest learnings were related to the IT implementation of this project. This project included two separate applications, Locus Health and Lurie Children's Care Connect, and required hardware and software implementations. It is recommended that IT is engaged early in the process and include plans for implementation and integration into the organizations EHR. Locus Health was implemented as a stand-alone application that did not interface into the LCH EHR, which has created challenges with availability of data in both systems. The additional work required because the systems were not interfaced is significant for the nurse coordinator's workflow. In addition, it is essential that all equipment and hardware that is being used is reviewed prior to implementation to ensure compatibility with the applications. The way local and public PCs in clinical areas are imaged is essential. For example, the version of Internet Explorer was several versions behind the requirements for running Locus Health in the outpatient clinics. This limited access to the data initially but was resolved quickly when it was identified. Finally, having a dedicated device for the telemedicine encounters with troubleshooting tips available eliminates delays during the telemedicine encounter. There were delays experienced during the pilot related to the telemedicine encounter room being a multi-purpose room, which led to individuals adjusting the equipment and creating issues when encounters were scheduled. A dedicated work space would be preferable, although the realization of space constraints may eliminate this as an option.

Sustainability is a critical part of implementing quality improvement projects in the healthcare setting, and without this, organizations and healthcare leaders will find themselves finding solutions to the same problems on multiple occasions (Minnier, 2014). Minnier (2014) described the essential elements that need to be present to build sustainability into the implementation phase of a QI project to ensure the project will achieve its goals over the long term. Factors that support long-term sustainability include engaged, educated staff and leadership; organizations with the culture and infrastructure for innovation and improvement; and a QI process that is adaptable, has developed a process for outcome measures, and when the value of the innovation or improvement is identified. Dissemination of results within the organization and at professional conferences should be considered as the relevance to practice settings is significant. Manuscript submission to professional journals including Journal of Nursing Administration and Journal of Pediatric Nursing should also be considered.

The leadership and staff of the Heart Center were fully engaged and active participants in this QI project. The providers, nurses, and administrative teams identified the value that would come from implementation of this QI project. Since the implementation of this pilot project, six additional patients have been enrolled into the program with additional patients continuing to be identified. At the center of that value was the impact to patients and the potential optimization of the care that was provided to an extremely fragile group of patients. In addition, LCH is a leading, pediatric hospital that is focused on improvement to care and contributions to pediatric medicine. This commitment and culture of excellence, along with the organizational infrastructure that was available from support departments such as IT and Data Analytics and Reporting, provided the ideal setting for sustainability and expansion of this QI project.

References

Berry, J. G., Hall, D. E., Kuo, D. Z., Cohen, E., Agrawal, R., Feudtner, C., ... Neff, J. (2011). Hospital utilization and characteristices of patients experience recurrent readmissions within children's hospitals. *Jama*, *305*(7), 682-690. http://dx.doi.org/10.1001/jama.2011.122

Burke, R. E., Guo, R., Prochazka, A. V., & Misky, G. J. (2014, September 23). Identifying keys to success in reducing readmissions using the ideal transitions in care framework. *BMC Health Services Research*, *14*. http://dx.doi.org/10.1186/1472-6963-14-423

Center for Disease control (2018). www.cdc.gov/ncbddd/heartdefects/data.html

Cohen E, Berry JG, Camacho X, Anderson G, Wodchis W, Guttmann A. (2012). Patterns and costs of health care use of children with medical complexity. *Pediatrics*, *130*(6):e1463–70.

Community Health Needs Assessment - 2016. (2016). Retrieved from Lurie Children's Hospital - Community: https://www.luriechildrens.org/en-us/community/community-health-needs-assessment/Pages/index.aspx

Clavelle, J. T. (2018). Leveraging technology to increase patient and family engagement and improve outcomes. *Nursing Administration Quarterly, 42 (3)*, 246-253.

Cupp Curley, A. L., & Vitale, P. A. (2016). *Population-based nursing: Concepts and competencies for advanced practice* (2nd ed.). New York: Springer Publishing Company.

Dearholt, S. L., & Dang, D. (2012). *Johns Hopkins nursing evidence-based practice: Model and guideline* (2nd ed.). Indianapolis, IN: Sigma Theta Tau International.

Giuliano, K. K., & Polanowicz, M. (2008). Interpretation and use of statistics in nursing research. *AACN Advanced Critical Care, 19*, 211-222. Retrieved from https://dpt-stats-in-pt.wiki.uml.edu/file/view/Giuliano+et+al+2008.pdf

Issel, L. M. (2014). *Health program planning and evaluation* (3rd ed.). Burlington, MA: Jones & Bartlett Learning.

Jack, B. W., Chetty, V., Anthony, D., Greenwald, J. L., Sanchez, G. M., Forsythe, S. R., ... Culpepper, L. (2009, February 3). A reengineerd hospital discharge program to decrease rehospitalization: a randomized trial. *Annals of Internal Medicine*, *150*(3), 178-187.

Jean-St-Michel, E., Chetan, D., Schwartz, S.M. et al. Pediatr Cardiol (2016) 37: 239. https://doi-org.libproxy.boisestate.edu/10.1007/s00246-015-1268-4

Kellogg Foundation, W. K. (2004). *Logic model development guide*. Battle Creek, MI: Author.

Kuo, D., Cohen, E., Agrawal, R., Berry, J.G., & Casey, P.H., (2011). A national profile of caregiver challenges among more medically complex children with special health care needs. *Archives of Pediatric Adolescent Medicine, 165*(11):1020–6.

Kuo, D. Z., Melguizo-Castro, M., Goudie, A., Nick, T. G., Robbins, J. M., & Casey, P. H. (2015). Variation in child health care utilization by medical complexity. *Maternal Child Health Journal*, *19*(1), 40-48. http://dx.doi.org/10.1007/s10995-014-1493-0

Lassman D, Hartman M, Washington B, Andrews K, Catlin A., (2014). US health spending trends by age and gender: selected years 2002–10. *Health Affairs 33*(5):815–22.

Lurie Children's Hospital. (2017). www.luriechildrens.org

Mason, D.J., Gardner, D.B., Hopkins Outlaw, F., & O'Grady, E.T. (2016). Policy and politics in nursing and healthcare (7th ed.). St. Louis, MO: Elsevier.

Minnier, T. E. (2014). How to build sustainability into the innovation process. Retrieved from https://innovations.ahrq.gov/perspectives/how-build-sustainability-innovation-process

Moy, N. Y., Sei, L. J., Chan, T., Grovey, B., Boscardin, W. J., Gonzales, R., & Pierluissi, E. (2014, May). Development and sustainability of an inpatient to outpatient discharge handoff tool: a quality improvement project. *Joint Commission Journal on Quality and Patient Safety, 40*(5), 219-227.

Nakamura, M. M., Toomey, S. L., Zaslavsky, A. M., Berry, J. G., Lorch, S. A., Jha, A. K., ... Schuster, M. A. (2014). Measuring pediatric hospital readmission rates to drive data quality improvement. *Academic Pediatrics*, S39-46.

Newcomer, K. E., Hatry, H. P., & Wholey, J. S. (2015). *Handbook of practical program evaluation* (4th ed.). New Jersey: John Wiley & Sons, Inc.

Peter, S., Chaney, G., Zappia, T., Van Veldhuisen, C., Pereira, S., & Santamaria, N. (2011). Care coordination for children with complex care needs significantly reduces hospital utilization. *Journal for Specialists in Pediatric Nursing*, *16*, 305-312. http://dx.doi.org/10.1111/j.1744-6155.2011.00303.x

Russell, C. J., & Simon, T. D. (2014, July). Care of childrens with medical complexity in the hospital setting. *Pediatric Annals*, *43*(7), 157-162. http://dx.doi.org/10.3928/00904481-20140619-09

Shermont, H., Pignataro, S., Humphrey, K., & Bukoye, B. (2016). Reducing pediatric readmissions: Using a discharge bundle combined with teach-back methodology. *Journal of Nursing Care Quality*, *31*, 224-232. http://dx.doi.org/10.1097/NQC.0000000000000176

Wagner, E. H. (1998, Aug-Sep). Chronic disease management: What will it take to improve care for chronic illness? *Effective Clinical Practice*, *1*(1), 2-4. Retrieved from ecp.acponline.org

Weiss, M.E., & Piacentine, I.B., (2006). Psychometric properties of the readiness for hospital discharge scale. *Journal of Nursing Measurement*, 14 (3), 163-80. https://doi-org.libproxy.boisestate.edu/10.1891/jnm-v14i3a002

White, K. M., & Dudley-Brown, S. (2012). *Translation of evidence into nursing and health care practice*. New York: Springer Publishing Company.

Wynter-Blyth, V., & MacKinnon, T. (2017, June). Streamlining perioperative care for oesophago-gastric cancer surgery patients using home remote monitoring. *Primary Health Care*, *27*(5), 27-31. http://dx.doi.org/10.7748/phc.2017.e1225

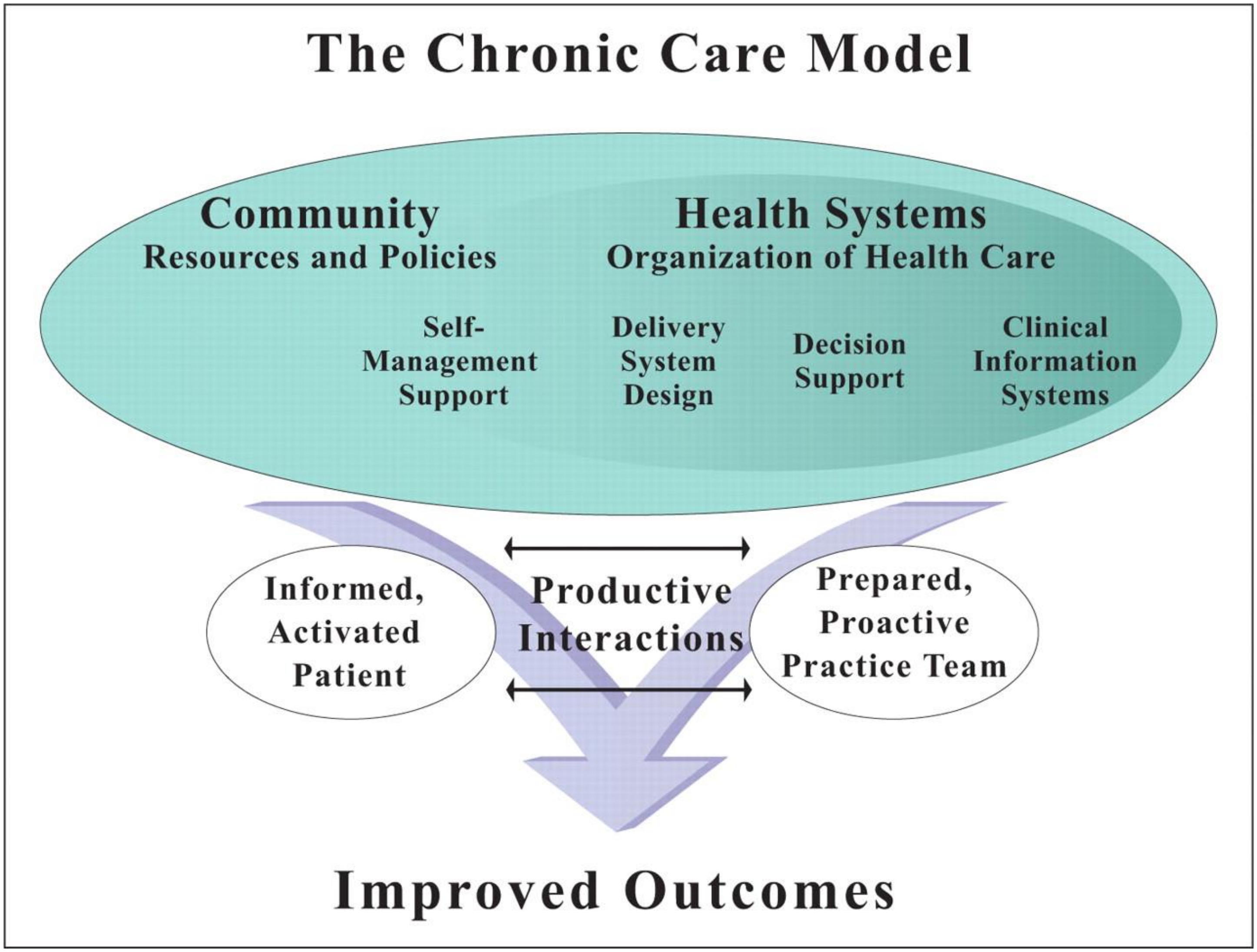
Appendix A: Literature Review Table

Category (Level Type)	Total Number of Sources/Level	Overall Quality Rating	Synthesis of Findings Evidence That Answers the EBP Question
Level I · Experimental study · Randomized Controlled Trial (RCT) · Systematic review of RCTs with or without meta-analysis	1	High	Demonstration that a formal d/c process including d/c RN advocate, after hospital care plan, & pharmacist call can improve readmission rates (9).
Level II · Quasi-experimental studies · Systematic review of a combination of RCTs and quasi-experimental studies, or quasi-experimental studies only, with or without meta-analysis	1	Good	Implementation of a nursing bundle, teach-back methodology, and structured handoff was effective in reducing unplanned readmissions (12).
Level III · Non-experimental study · Systematic review of a combination of RCTs, quasi-experimental, and non-experimental studies, or non-experimental studies only, with or without meta-analysis · Qualitative study or systematic review of qualitative studies with or without meta-synthesis	3	Good-High	Clear definition of CCC through creation of a classification system (7, 8). Utilizing this classification system, it is important to develop interventions which address the specific needs of these patients and families (10).

Category (Level Type)	Total Number of Sources/Level	Overall Quality Rating	Synthesis of Findings Evidence That Answers the EBP Question
Level IV · Opinion of respected authorities and/or reports of nationally recognized expert committees/consensus panels based on scientific evidence	None	N/A	N/A
Level V · Evidence obtained from literature reviews, quality improvement, program evaluation, financial evaluation, or case reports · Opinion of nationally recognized expert(s) based on experiential evidence	7	Good	Literature reviewed had strong quality overall and demonstrate well-supported and accepted databases Outcomes measures were complete and comprehensive. Background literature supports the need for the scholarly project (1, 2, 3, 4, 5, 6, 11)

Appendix B: Theoretical Model

CCM Component	Consideration for Children with CCC project
Healthcare delivery system	Improved care coordination and development of process for patients to receive return visits in multidisciplinary clinic on same day
Community	Community resources available to patients when out of the hospital, including the opportunity to connect with hospital resources through remote home monitoring and telemedicine visits
Promoting self-care	Development of education and training for parents and guardians
Decision support	Development of discharge bundle to guide and support clinical team in preparing family for discharge from hospital. Bundle may include follow-up visit coordination and medication training
Delivery system design	Identification of care coordinators or specific resource family can connect with when out of hospital and questions arise. Consider leveraging a remote home monitoring program and telemedicine.
Clinical information system	Lurie Children's utilizes Epic as the EHR. Encourage the use of MyChart for families caring for children with CCC for secure communications between family and healthcare providers


The Chronic Care Model
Community
Resources and Policies
Health Systems
Organization of Health Care
Self-Management Support
Delivery System Design
Decision Support
Clinical Information Systems
Informed, Activated Patient
Productive Interactions
Prepared, Proactive Practice Team
Improved Outcomes

Wagner (1998)

Appendix C: Logic Model

Resources/Inputs	**Activities**	**Outputs**	**Outcomes: Short term**	**Outcomes: Long term**	**Impact**
Includes the human, financial, organizational, and community resources a program has available to direct toward the work.	Includes the processes, tools, events, technology, and actions that are intended to bring changes or results.	Direct products of program activities and may include types, levels and targets of services to be delivered by the program.	Specific changes in program. SMART. Attainable during the DNP Scholarly Project timeline	Specific changes in program. SMART. Attainable 1-2 years after your DNP Project is completed.	Fundamental intended or unintended change occurring because of program activities within 3-5 years.
Children with single ventricle heart disease (SVHD); **Parents/guardians of patients with SVHD;** **Clinical team including nursing, providers, and case management;** **Telemedicine program coordinators**	Development of the need's assessment utilizing family advisory board as a stakeholder group; Education and training for clinical team; development of discharge optimization tools (educational and telemedicine); Secure final resources for tool development. Completion in March 2018 in advance of project initiation in May 2018.	Awareness building of the discharge optimization program to all key stakeholders (families, providers, staff); Marketing tools provided to units and staff/clinicians to inform and educate on process. This will prepare the team for implementation of the project.	100% of families who have children with single ventricle heart disease admitted to the hospital were offered to participate in the discharge optimization program prior to discharge between the months of May and October 2018 as evident by documentation audit.	The number of disease-specific populations participating in the discharge optimization program increased by 3 within 1 year of the initial intervention.	Value-based care was improved through the development and implementation of a patient-focused discharge initiative

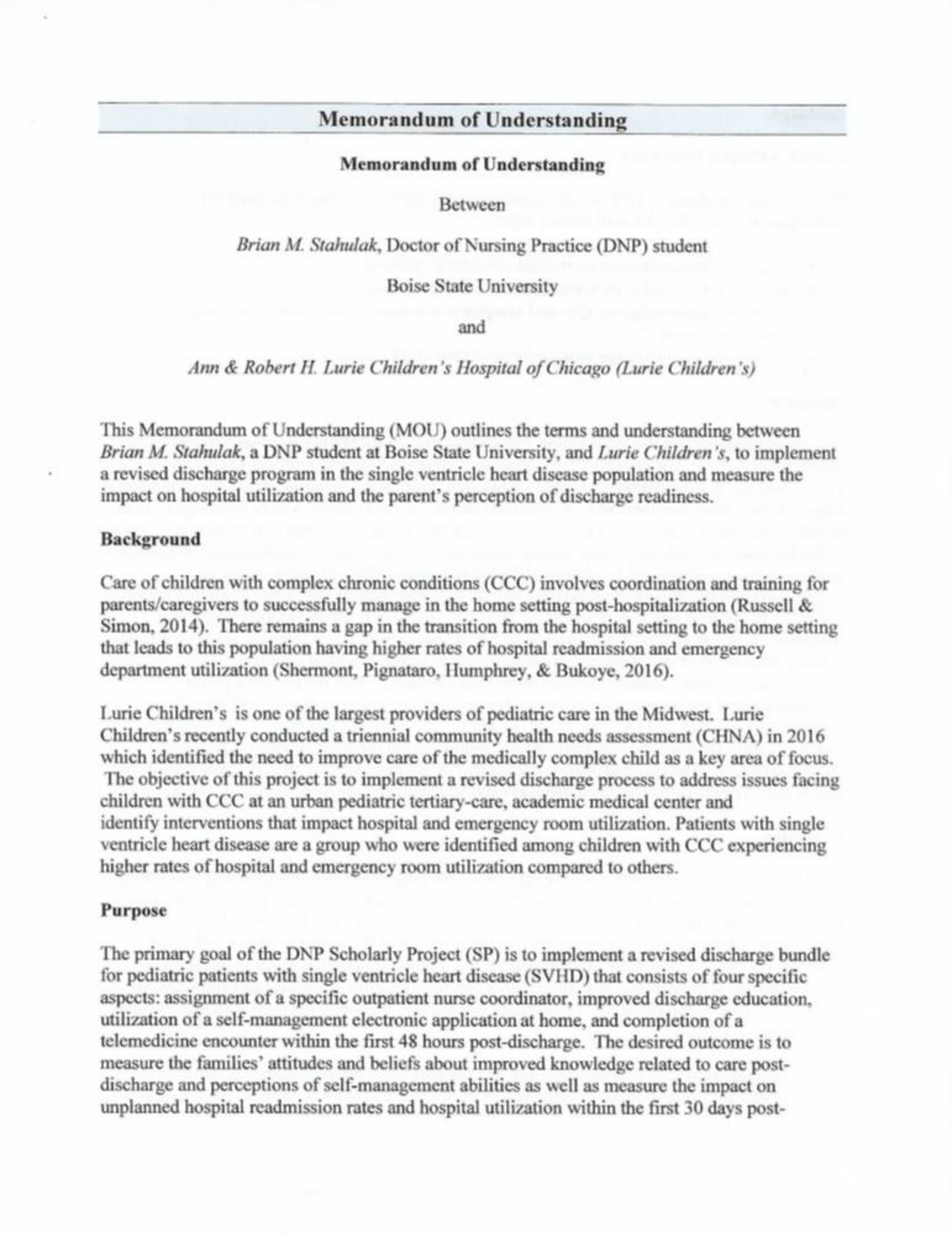
Parents/guardians of patients with SVHD; **Clinical team including nursing, providers, and case management;** **Telemedicine program coordinators;** **Community partners;** **Organizational leadership support**	Develop family education/training of new discharge bundle; establish roles and accountability of clinical team in the discharge process; Develop documentation templates for steps of discharge process; Develop marketing materials; Development of budget	Educational plan for patients and families; Program tools and information; Telemedicine program that connects patients post discharge with care coordinator; Dedicated clinical staff identified to complete revised discharge process	100% of the discharge optimization bundle was completed within 48 hours of discharge for those children with SVHD discharged from the hospital between May and October 2018. The bundle consists of four specific aspects: assignment of a specific outpatient nurse coordinator, improved discharge education, utilization of remote home monitoring, and completion of a telemedicine encounter within 48 hours of discharge.	Families utilizing the discharge optimization program was increased to 100% of eligible families by October 2020.	Unplanned readmissions to hospital and/or ER were decreased compared to pre-implementation data
Parents/guardians of patients with SVHD; **Clinical team including nursing, providers, and case management**	Secure person for use of a validated pre- and post- survey; development of database to track results of survey; approval of survey through IRB process; secure resources (human resources and	Survey training and education for clinical team; Staff identified to complete survey and enter survey results; Identify database to maintain data.	A 20% improvement in family perception of transitions of care as measured by pre-survey and post-survey (Ped RHDS parent form) was demonstrated for those patients	A 50% improvement in family perception of transitions of care as measured by pre-survey and post-survey (Ped RHDS parent form) was demonstrated for those patients discharged with	Improvement in discharge preparedness for patients resulting on improved clinical outcomes

	financial) for survey development		discharged between May and October 2018.	SVHD by October 2020.	
Children with single ventricle heart disease (SVHD); Parents/guardians of patients with SVHD; Clinical team including nursing, providers, and case management; Telemedicine program coordinators; ED providers/staff	Develop family education/training of new discharge bundle; establish roles and accountability of clinical team in the discharge process; Develop documentation templates for steps of discharge process; Develop marketing materials; Development of budget; Approval of budget	Educational plan for patients and families; Program tools and information; Telemedicine program that connects patients post discharge with care coordinator; Dedicated clinical staff identified to complete revised discharge process	A 10% decrease in hospital utilization as measured by total hospital charges for children with SVHD admitted to the hospital within 30 days of discharge by January 2019.	A 25% decrease in hospital utilization as measured by total hospital charges for children with SVHD admitted to the hospital within 30 days of discharge by October 2020.	Value-based care was improved through the development and implementation of a patient-focused discharge initiative
Parents/guardians of patients with SVHD; Clinical team including nursing, providers, and case management	Secure person for use of a validated pre- and post- survey; development of database to track results of survey; approval of survey through IRB process; secure resources (human resources and financial) for survey development	Survey training and education for clinical team; Staff identified to complete survey and enter survey results; Identify database to maintain data.	A 20% improvement in quality of discharge education provided for the discharge needs of the patient with SVHD will be demonstrated by parents based on the QDTS survey and RHDS RN survey for those patients discharged between May and October 2018	A 50% improvement in quality of discharge education provided for the d/c needs of the patient with SVHD will be demonstrated by parents based on the QDTS survey and RHDS RN survey for those patients d/c by October 2020.	Improvement in discharge preparedness for patients resulting on improved clinical outcomes

Appendix D: SWOT Analysis Table

Strengths	**Weaknesses**
1. Organizational/Leadership support 2. Experienced clinical leaders and staff 3. Heart Center is an identified growth area 4. One of the largest pediatric SVHD programs in Midwest; high volume CV surgical center	1. Current process is not leveraging technology 2. Complex, multidisciplinary clinical program
Opportunities	**Threats**
1. New CV surgeon has brought new patients to the system 2. Organizational strategies focused on developing innovative ways to address clinical needs 3. Family-centered organization that partners effectively with families 4. Technology solutions are available	1. Technology (IT) resources needed to implement this project 2. Several competing programs throughout the organization 3. Staff demands are high 4. Reliance on support from multiple departments (IT, Data Analytics & Reporting, Finance, Nursing, Providers)

Appendix E: Memorandum of Understanding



Memorandum of Understanding

Memorandum of Understanding

Between

Brian M. Stahulak, Doctor of Nursing Practice (DNP) student

Boise State University

and

Ann & Robert H. Lurie Children's Hospital of Chicago (Lurie Children's)

This Memorandum of Understanding (MOU) outlines the terms and understanding between *Brian M. Stahulak*, a DNP student at Boise State University, and *Lurie Children's*, to implement a revised discharge program in the single ventricle heart disease population and measure the impact on hospital utilization and the parent's perception of discharge readiness.

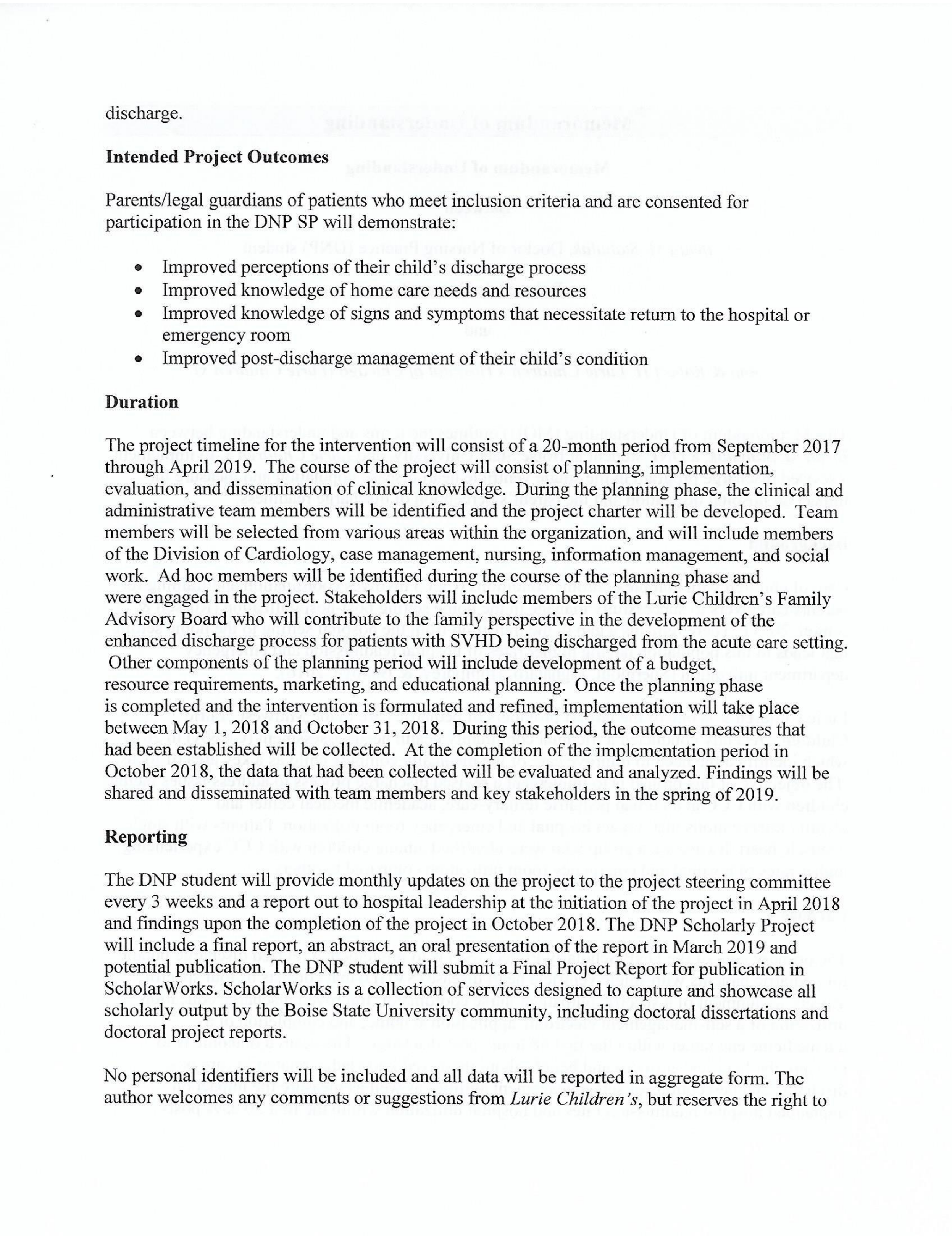
Background

Care of children with complex chronic conditions (CCC) involves coordination and training for parents/caregivers to successfully manage in the home setting post-hospitalization (Russell & Simon, 2014). There remains a gap in the transition from the hospital setting to the home setting that leads to this population having higher rates of hospital readmission and emergency department utilization (Shermont, Pignataro, Humphrey, & Bukoye, 2016).

Lurie Children's is one of the largest providers of pediatric care in the Midwest. Lurie Children's recently conducted a triennial community health needs assessment (CHNA) in 2016 which identified the need to improve care of the medically complex child as a key area of focus. The objective of this project is to implement a revised discharge process to address issues facing children with CCC at an urban pediatric tertiary-care, academic medical center and identify interventions that impact hospital and emergency room utilization. Patients with single ventricle heart disease are a group who were identified among children with CCC experiencing higher rates of hospital and emergency room utilization compared to others.

Purpose

The primary goal of the DNP Scholarly Project (SP) is to implement a revised discharge bundle for pediatric patients with single ventricle heart disease (SVHD) that consists of four specific aspects: assignment of a specific outpatient nurse coordinator, improved discharge education, utilization of a self-management electronic application at home, and completion of a telemedicine encounter within the first 48 hours post-discharge. The desired outcome is to measure the families' attitudes and beliefs about improved knowledge related to care post-discharge and perceptions of self-management abilities as well as measure the impact on unplanned hospital readmission rates and hospital utilization within the first 30 days post-



discharge.

Intended Project Outcomes

Parents/legal guardians of patients who meet inclusion criteria and are consented for participation in the DNP SP will demonstrate:

- Improved perceptions of their child's discharge process
- Improved knowledge of home care needs and resources
- Improved knowledge of signs and symptoms that necessitate return to the hospital or emergency room
- Improved post-discharge management of their child's condition

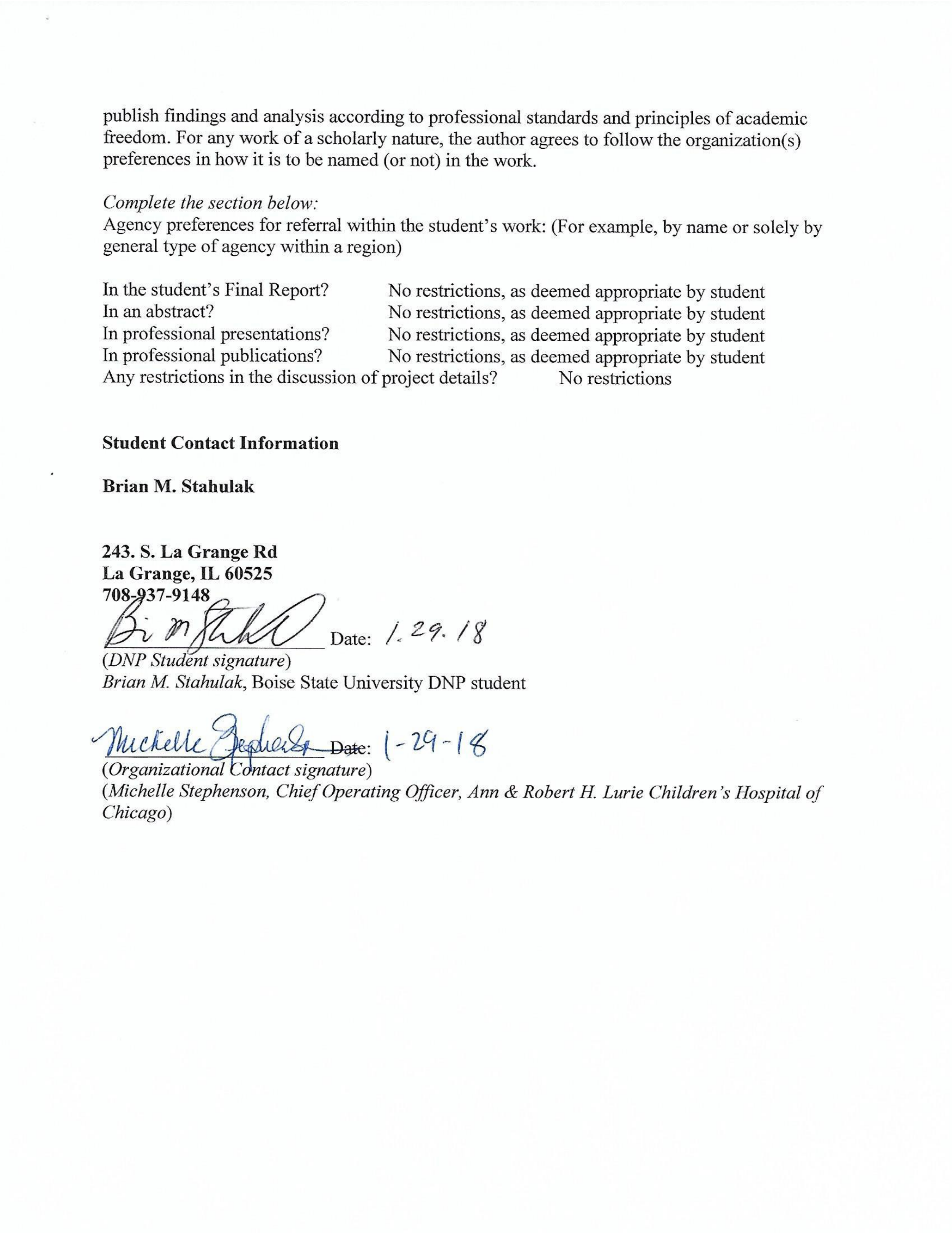
Duration

The project timeline for the intervention will consist of a 20-month period from September 2017 through April 2019. The course of the project will consist of planning, implementation, evaluation, and dissemination of clinical knowledge. During the planning phase, the clinical and administrative team members will be identified and the project charter will be developed. Team members will be selected from various areas within the organization, and will include members of the Division of Cardiology, case management, nursing, information management, and social work. Ad hoc members will be identified during the course of the planning phase and were engaged in the project. Stakeholders will include members of the Lurie Children's Family Advisory Board who will contribute to the family perspective in the development of the enhanced discharge process for patients with SVHD being discharged from the acute care setting. Other components of the planning period will include development of a budget, resource requirements, marketing, and educational planning. Once the planning phase is completed and the intervention is formulated and refined, implementation will take place between May 1, 2018 and October 31, 2018. During this period, the outcome measures that had been established will be collected. At the completion of the implementation period in October 2018, the data that had been collected will be evaluated and analyzed. Findings will be shared and disseminated with team members and key stakeholders in the spring of 2019.

Reporting

The DNP student will provide monthly updates on the project to the project steering committee every 3 weeks and a report out to hospital leadership at the initiation of the project in April 2018 and findings upon the completion of the project in October 2018. The DNP Scholarly Project will include a final report, an abstract, an oral presentation of the report in March 2019 and potential publication. The DNP student will submit a Final Project Report for publication in ScholarWorks. ScholarWorks is a collection of services designed to capture and showcase all scholarly output by the Boise State University community, including doctoral dissertations and doctoral project reports.

No personal identifiers will be included and all data will be reported in aggregate form. The author welcomes any comments or suggestions from *Lurie Children's*, but reserves the right to



publish findings and analysis according to professional standards and principles of academic freedom. For any work of a scholarly nature, the author agrees to follow the organization(s) preferences in how it is to be named (or not) in the work.

Complete the section below:
Agency preferences for referral within the student's work: (For example, by name or solely by general type of agency within a region)

In the student's Final Report?	No restrictions, as deemed appropriate by student
In an abstract?	No restrictions, as deemed appropriate by student
In professional presentations?	No restrictions, as deemed appropriate by student
In professional publications?	No restrictions, as deemed appropriate by student
Any restrictions in the discussion of project details?	No restrictions

Student Contact Information

Brian M. Stahulak

243. S. La Grange Rd
La Grange, IL 60525
708-937-9148

Date: 1.29.18
(*DNP Student signature*)
Brian M. Stahulak, Boise State University DNP student

Michelle Stephenson Date: 1-29-18
(*Organizational Contact signature*)
(*Michelle Stephenson, Chief Operating Officer, Ann & Robert H. Lurie Children's Hospital of Chicago*)

Appendix F: Timeline

Summer/ Fall 2017	Winter 2017	Spring 2018	Summer 2018	Fall 2018/Spring 2019
• Core group convened • Project reviewed • Literature review completed • Logic Model developed • Outcome plan confirmed • Bundle design completed • Patient education revised • RHM vendor selected	• IT scoping and design sessions • Parent & provider survey selected • Data reporting metrics built • Budget finalized • Vendor contracting begins	• Staff education plan completed • Telemedicine process confirmed • RHM build complete • External vendor contracting completed • Survey build • IRB approval • Project approval	• Project implemented • Monthly reporting • Core team meetings continue	• Project completed • Data gathering • Data review and evaluation • Core team meetings continued • Dissemination of data

Appendix G: SVHD Utilization Report

LOCUS DISCHARGED PATIENTS	FISCAL YEAR CARDIAC GROUP DESC	NO. OF ENCOUNTERS	UNIQUE PATIENTS	TOTAL LOS	AVERAGE LOS	TOTAL CHARGES	PAYMENTS	DIRECT COSTS	DIRECT COSTS per UNIQUE PATIENT	CONTRIB MARGIN	CONTRIB MARGIN per UNIQUE PATIENT	INDIRECT COSTS	NET INCOME
	2018												
	DILV	1	1	56	56	1,169,730	439,594	101,401	101,401	338,193	338,193	120,437	217,756
	HLHS	1	1	56	56	1,169,730	439,594	101,401	101,401	338,193	338,193	120,437	217,756
	2019												
	DILV	1	1	104	104	2,039,855	865,353	133,911	133,911	731,442	731,442	154,405	577,037
	HLHS	2	2	282	141	5,599,291	4,424,790	405,855	202,927	4,018,935	2,009,467	472,667	3,546,267
	TOTAL	**5**	**5**	**498**	**100**	**9,978,605**	**6,169,330**	**742,568**	**148,514**	**5,426,762**	**1,085,352**	**867,947**	**4,558,815**

PRE LOCUS PATIENTS	FISCAL YEAR CARDIAC GROUP DESC	NO. OF ENCOUNTERS	UNIQUE PATIENTS	TOTAL LOS	AVERAGE LOS	TOTAL CHARGES	PAYMENTS	DIRECT COSTS	DIRECT COSTS per UNIQUE PATIENT	CONTRIB MARGIN	CONTRIB MARGIN per UNIQUE PATIENT	INDIRECT COSTS	NET INCOME
	2018												
	DILV	4	4	330	83	8,739,294	2,631,405	950,516	237,629	1,680,889	420,222	1,080,300	600,589
	HLHS	9	9	650	72	17,895,293	5,189,833	1,896,665	210,741	3,293,169	365,908	2,141,792	1,151,377
	SV+DORV	2	2	264	132	6,317,186	1,745,285	700,190	350,095	1,045,095	522,548	794,422	250,673
	SV+MA	1	1	230	230	5,441,898	1,419,171	612,560	612,560	806,611	806,611	692,464	114,147
	TA	2	2	40	20	798,354	223,244	100,552	50,276	122,692	61,346	115,150	7,542
	TOTAL	**18**	**18**	**1514**	**84**	**39,192,025**	**11,208,939**	**4,260,483**	**236,693**	**6,948,456**	**386,025**	**4,824,129**	**2,124,328**

PATIENT POPULATION	PATIENT POPULATION GROUPER	PATIENT POPULATION Dx CRITERIA _melanieGEVITZ	COMMENTS-OTHER
1	HLHS	Q23.4	HYPOPLASTIC LEFT HEART SYNDROME
2	DILV	Q20.4	DOUBLE INLET VENTRICLE, Includes common ventricle, single ventricle
3	SV+MA	Q20.4 AND Q23.2 (not an OR statement)	Q23.2 covers mitral atresia AND mitral stenosis
4	SV+HETEROTAXY	Q20.4 AND (Q20.6 OR Q89.0 OR Q89.01 OR Q89.3 OR Q89.8)	Q20.4 covers single ventricle, heterotaxia itself is not in any one place – for example, atrial isomerism with asplenia or polysplenia is Q20.6 among the cardiac Q codes, but asplenia (congenital) is Q89.01 (or Q89.0 Congenital absence and malformations of spleen); also part of heterotaxy is transposition of abdominal viscera, which is covered by Q89.3 Situs inversus
5	SV+DORV	Q20.4 AND Q20.1 (assume you are looking at SV patients, DORV code alone gets you biventricular patients)	DOUBLE OUTLET RIGHT VENTRICLE, Includes Taussig-Bing syndrome (DORV-TGA type)
6	PA	Q22.0 (without Q21.0)	
7	TA	Q22.4	CONGENITAL TRICUSPID STENOSIS, Includes tricuspid atresia AND tricuspid stenosis
8	HRHS	Q22.6	HYPOPLASTIC RIGHT HEART SYNDROME, Correct, but you might also consider adding the pulmonary atresia code Q22.0 (which can be used with VSD close for PA-VSD patients)
For subset of SV with surgery(ies): Any of the above Dx combos AND Z98.890 OR Z95.818			
9	Norwood | Central Shunt | PAB	Z98.89	Other specified postprocedural states (Personal history of surgery, not elsewhere classif
9a	Norwood | Central Shunt | PAB	Z98.890	Other specified postprocedural states (Personal history of surgery, not elsewhere classif
10	BT Shunt	Z95.818	Presence of other cardiac implants and grafts [brackets mine – other specified items are given specific codes, e.g., defibrillators, pacemakers, heart valves, artificial heart, VADs, transplanted heart]
The Z87.74 implies correction, which might indicate Fontan patients			
11	Sano	Z87.74	Personal history of (corrected) congenital malformations of heart and circulatory system – not sure this applies since Sano isn't a corrective operation, but part of the Norwood – this code would apply to postop TGA or tet

Appendix H: QDTS Survey Tool

Study ID #_______________ **QUALITY OF DISCHARGE TEACHING SCALE -- PARENT FORM ©**

Please check or circle your answer. Most of the responses are on a 10 point scale from 0 to 10. The words below the number indicate what the 0 or the 10 means. Pick the number between 0 and 10 that best describes how you feel.
For example, circling number 7 means you feel more like the description of number 10 than number 0 but not completely.

1a. How much information <u>did you need</u> from your child's nurses about **taking care of your child** after you go home?	0 1 2 3 4 5 6 7 8 9 10 None A great deal
1b. How much information <u>did you receive</u> from your child's nurses about **taking care of your child** after you go home?	0 1 2 3 4 5 6 7 8 9 10 None A great deal
2a. How much information <u>did you need</u> from your child's nurses about **your emotions** after you go home?	0 1 2 3 4 5 6 7 8 9 10 None A great deal
2b. How much information <u>did you receive</u> from your child's nurses about **your emotions** after you go home?	0 1 2 3 4 5 6 7 8 9 10 None A great deal
3a. How much information <u>did you need</u> from your child's nurses about your child's **medical needs or treatments** (for example, caring for a wound, breathing treatments, using equipment, or taking your medications in the correct amounts and at the correct time) after you go home?	0 1 2 3 4 5 6 7 8 9 10 None A great deal
3b. How much information <u>did you receive</u> from your child's nurses about your child's **medical needs or treatments** after you go home?	0 1 2 3 4 5 6 7 8 9 10 None A great deal
4a. How much **practice** <u>did you need</u> with your child's **medical treatments or medications** before going home?	0 1 2 3 4 5 6 7 8 9 10 None A great deal
4b. How much **practice** <u>did you have</u> with your child's **medical treatments or**	0 1 2 3 4 5 6 7 8 9 10

medications before going home?	None A great deal
5a. How much information did you need from your child's nurses about **who and when to call** if your child has problems after you go home?	0 1 2 3 4 5 6 7 8 9 10 None A great deal
5b. How much information did you receive from your child's nurses about **who and when to call** if your child has problems after you go home?	0 1 2 3 4 5 6 7 8 9 10 None A great deal

6a. How much information did your family member(s) or others need about **your child's care** after you go home from the hospital?	0 1 2 3 4 5 6 7 8 9 10 None A great deal
6b. How much information did your family member(s) or others receive about **your child's care** after you go home from the hospital?	0 1 2 3 4 5 6 7 8 9 10 None A great deal
7. How much did the information provided by your child's nurses answer your **specific concerns and questions**?	0 1 2 3 4 5 6 7 8 9 10 Not at all A great deal
8. How much did your child's nurses **listen** to your concerns?	0 1 2 3 4 5 6 7 8 9 10 Not at all A great deal
9. Were your child's nurses **sensitive** to your personal beliefs and values?	0 1 2 3 4 5 6 7 8 9 10 Not at all A great deal
10. Did you like the way your child's nurses **taught** you about how to care for your child at home?	0 1 2 3 4 5 6 7 8 9 10 Not at all A great deal
11. Was the information your child's nurses provided about caring for your child	0 1 2 3 4 5 6 7 8 9 10

given to you in a way you could **understand**?	Not at all Always
12. Did your child's nurses **check** to make sure you understood the information and instructions?	0 1 2 3 4 5 6 7 8 9 10 Not at all A great deal
13. Did you receive **consistent** (the same) information from your child's nurses, doctors, and other health workers?	0 1 2 3 4 5 6 7 8 9 10 Not at all Always
14. Was the information about caring for your child given to you **at times that were good for you**?	0 1 2 3 4 5 6 7 8 9 10 Not at all Always
15. Was the information you received from your child's nurses given at **times when your family member**(s) **or others could attend?**	0 1 2 3 4 5 6 7 8 9 10 Not at all Always
16. Did your child's nurses help you to feel **confident** in your ability to care for your child at home?	0 1 2 3 4 5 6 7 8 9 10 Not at all A great deal
17. How confident do you feel that you would **know what to do in an emergency**?	0 1 2 3 4 5 6 7 8 9 10 Not at all Extremely
18. Did the information your child's nurses provided about your child's care at home **decrease your anxiety** about going home?	0 1 2 3 4 5 6 7 8 9 10 Not at all A great deal

Thank you for responding to our survey.

Appendix I: RHDS RN Survey Tool

Study ID #________________ READINESS FOR HOSPITAL DISCHARGE STUDY -- PARENT - NURSE FORM

You are being asked to assess the readiness for discharge of the parent of your hospitalized patient. Please complete the form within the 4 hours before the patient leaves your unit.

Please check or circle your answer. Most of the responses are on a 10 point scale from 0 to 10. The words below the number indicate what the 0 or the 10 means. Pick the number between 0 and 10 that best describes how you feel. For example, circling number 7 means you feel more like the description of number 10 than number 0 but not completely.

1a. As you think about this parent taking their child home from the hospital, do you feel the parent is **ready** to take the child home as planned?	[ ] No [ ] Yes
1b. Is the child **ready** to go home?	[ ] No [ ] Yes
2a. How physically **ready** is the parent to take their child home?	0 1 2 3 4 5 6 7 8 9 10 Not ready Totally ready
2b. How physically **ready** is the child to go home today?	0 1 2 3 4 5 6 7 8 9 10 Not ready Totally ready
3a. How would you describe the parent's **level of pain or discomfort** today?	0 1 2 3 4 5 6 7 8 9 10 No pain/ discomfort Severe pain/ discomfort
3b. How would you describe the child’s **level of pain or discomfort** today?	0 1 2 3 4 5 6 7 8 9 10 No pain/ discomfort Severe pain/ discomfort

4a. How would you describe the <u>parent's</u> **strength** today?	0 1 2 3 4 5 6 7 8 9 10 Weak Strong
4b. How would you describe the <u>child's</u> **strength** today?	0 1 2 3 4 5 6 7 8 9 10 Weak Strong
5a. How would you describe the <u>parent's</u> **energy** today?	0 1 2 3 4 5 6 7 8 9 10 Low energy High energy
5b. How would you describe the <u>child's</u> **energy** today	0 1 2 3 4 5 6 7 8 9 10 Low energy High energy
6a. How much **stress** does the <u>parent</u> feel today?	0 1 2 3 4 5 6 7 8 9 10 None A great deal
7a. How **emotionally** ready is the <u>parent</u> to take their child home today?	0 1 2 3 4 5 6 7 8 9 10 Not ready Totally ready
7b. How difficult will it be for the parent to manage the <u>child's</u> **emotions and/or behavior** at h	0 1 2 3 4 5 6 7 8 9 10 Not difficult Very difficult
8a. How would you describe the <u>parent's</u> **physical ability** to care for the child today (for example, hygiene, walking, toileting)?	0 1 2 3 4 5 6 7 8 9 10 Not able Totally Able
8b. How ready is the <u>child</u> to do the **usual activities** for his/her age (for example, eating, bathing, toileting, play)?	0 1 2 3 4 5 6 7 8 9 10 Not able Totally Able
9. How much does the parent **know about caring for the child** after they go home?	0 1 2 3 4 5 6 7 8 9 10 Know nothing at all Know all

10. How much does the parent **know about** taking care of the child's **personal needs** (for example, hygiene, bathing, toileting, feeding, play) after they go home?	0 1 2 3 4 5 6 7 8 9 10 Know nothing at all Know all
11. How much does the parent **know about** what the child needs for his/her **growth and development?**	0 1 2 3 4 5 6 7 8 9 10 Know nothing at all Know all
12. How much does the parent **know about** taking care of the child's **medical needs** (treatments, medications) after they go home?	0 1 2 3 4 5 6 7 8 9 10 Know nothing at all Know all
13. How much does the parent **know about problems to watch for** after they go home?	0 1 2 3 4 5 6 7 8 9 10 Know nothing at all Know all
14. How much does the parent **know about who and when to call** if the child has problems after they go home?	0 1 2 3 4 5 6 7 8 9 10 Know nothing at all Know all
15. How much does the parent **know about what the** child is **allowed and not allowed** to do after they go home?	0 1 2 3 4 5 6 7 8 9 10 Know nothing at all Know all
16. How much does the parent know **about what happens next** in the child's follow-up medical treatment plan after they go home?	0 1 2 3 4 5 6 7 8 9 10 Know nothing at all Know all
17. How much does the parent **know about services and information** available to the parent and child in their community after they go home?	0 1 2 3 4 5 6 7 8 9 10 Know nothing at all Know all
18. How well will the parent be able to **handle the demands** of life at home?	0 1 2 3 4 5 6 7 8 9 10 Not at all Extremely well
19. How well will the parent be able to **perform the** child's **personal care** (for example, hygiene, bathing, toileting, eating)?	0 1 2 3 4 5 6 7 8 9 10 Not at all Extremely well

20. How well will the parent be able to **perform the** child's **medical treatments** (for example, caring for a wound, breathing treatments, using equipment, or giving medications in the correct amounts and at the correct times)?	0 1 2 3 4 5 6 7 8 9 10 Not at all Extremely well
21. How much **emotional support** will the parent have after the child goes home?	0 1 2 3 4 5 6 7 8 9 10 None A great deal
22. How much **help** will the parent have with the child's **personal care** after they go home?	0 1 2 3 4 5 6 7 8 9 10 None A great deal
23. How much **help** will the parent have with **household activities** (for example, cooking, shopping, babysitting) after the child goes home?	0 1 2 3 4 5 6 7 8 9 10 None A great deal
24. How much **help** will the parent have with the child's **medical care** needs (treatments, medications)?	0 1 2 3 4 5 6 7 8 9 10 None A great deal

Thank you for responding to our survey.

Appendix J: Outcome Evaluation Table

Outcome	Data Collection Instrument / Data	Analysis Goal	Analytic Technique
100% of families who have children with single ventricle heart disease admitted to the hospital were offered to participate in the discharge optimization program prior to discharge between the months of May and October 2018.	**Instrument:** A recruitment report submitted to the QI Project Manager, which includes the following data elements: - Patient initials - Date of admission - Age - Race - Language preference - Comorbidities - Date of Discharge - Documentation by RN coordinator that information on revised discharge program was provided to legal guardian **Data:** The recruitment report will include HIPPA protected information, such as deidentified birthdate and randomized patient identifiers. It is expected that all new parents/guardians of patients who are less than 2 years of age, do not have other comorbidities, and do not have any significant language barriers (such that education would be impacted) will be educated on the revised discharge process.	1. To quantify the number of patients who are eligible to participate in the SP. 2. To quantify the number of patients who have been informed about the revised discharge process. 3. To understand the percentage of patients who are not informed about the revised discharge process to inform process steps to increase these rates.	Recruitment report provides descriptive statistics for determining nominal count and percentage of patients meeting inclusion criteria and percentage of patients offered participation in the revised discharge optimization program. Provides rates to be used by the PM to determine if interventions are needed if percentage of patients offered participation decreases.
100% of the discharge optimization bundle was	**Instrument:** This will be measured using both qualitative and quantitative data. For qualitative data,	**1.** To determine common clinician-reported	For qualitative data, utilizing

completed within 48 hours of discharge for those children with SVHD discharged from the hospital between May and October 2018, as evidenced by documentation of components in medical record.	a brief interview will be completed by the SP coordinator with discharge nurse and outpatient nurse inquiring reasons for all components of revised discharge bundle not being completed. Quantitative data will include the utilization of chart reviews to measure the compliance rates for cases in which all four components of the discharge bundle were documented. **Data:** The brief interview will include one question which has been developed and supported by the project steering committee, "What impacted the completion of each individual component not being completed?" This will be entered an electronic survey tool utilized by Lurie Children's Hospital, called Marbella and evaluated for themes. Completion rates of all components of the revised discharge bundle will be tracked through chart audits and logged in excel and shared with the clinical team on a regular basis.	factors for noncompliance of all components of revised discharge bundle. **2.** To quantify the bundle compliance rates. 1. To identify opportunities to improve compliance rates by addressing common reasons contributing to noncompliance.	explanatory techniques will enable the ability to identify any causal factors/relationships between the reasons for noncompliance with the discharge bundle. For quantitative data, descriptive statistics will be used to measure the rates of compliance, including the mean and median.
A 10% decrease in readmission rates and hospital utilization compared to the 12 months prior to the initiation of the project, for children with SVHD to hospital and emergency room was demonstrated within 30 days of discharge by January 2019.	**Instrument:** A SVHD Utilization Report was developed utilizing quantitative aggregated data to be extracted from the Lurie Children's Hospital EHR (Epic) and will include: - SVHD patient admission (reason, date of admission) and discharge (location, date of discharge) data - SVHD patient length of stay data - Cost per admission for patients with SVHD - Hospital unplanned readmission rates within 30 days of initial discharge o If readmission within 30 days, then additional data collected will include:	1. To generate quantitative data to evaluate the impact of the SP initiative on hospital-specific metrics, including length of stay, costs, unplanned readmission rates, and reason/purpose for readmission.	The ADT report will provide descriptive statistics that can be used to evaluate, measure, and analyze the impact of the SP project on key hospital performance measures. Data will be collected monthly as

	▪ Admission diagnosis and reason ▪ Length of stay ▪ Cost of readmission ▪ Discharge disposition - Emergency department visits within 30 days of initial discharge o If readmission within 30 days, then additional data collected will include: ▪ Admission diagnosis and reason ▪ Length of stay ▪ Cost of readmission ▪ Discharge disposition **Data:** A QI-specific data extract report will be created utilizing the Business Analytics Department and run on a monthly basis to monitor and report the quantitative metrics of the population who participated in the QI project. Patient data will remain compliant with HIPPA protections and be used to track the impact of the revised discharge optimization project on unplanned readmission rates and visits to the ED.	2. To provide a mechanism for sharing the outcomes and progress of the SP impact on care for patients with SVHD.	aggregate data, reported as median, and be prepared by the 15th of the month to be shared with the core project team. Data will be displayed in a matrix format for describing and displaying quantitative data. Data will be presented in the form of a table and line graph to display progress and potential trends over time.
A 20% improvement in family perception of transitions of care as measured by pre-survey and post-survey (Ped RHDS parent form) was demonstrated for those patients discharged	**Instrument:** Quality of discharge teaching scale (QDTS). Validity of this tool was confirmed utilizing confirmatory factor analysis, contrasted group comparisons, and predictive validity testing to support the 4-structure construct.	**1.** To calculate the families' perceptions of discharge readiness and self-management readiness prior to discharge from primary hospitalization.	Descriptive Statistics will be used to measure the mean, median, and standard deviations of the scores from the care transitions measure survey.

between May and October 2018.	**Data:** 18 question survey with 10-point Likert scale that is completed by the parents at the time of discharge and 30-days post discharge.	To identify opportunities for improvements and revisions to the discharge planning process based.	The use of a well-defined, balanced performance measurement system would enable the team to effectively track the progress of all components of the revised discharge process.
A 20% improvement in quality of discharge education provided for the discharge needs of the patient with SVHD will be demonstrated by parents based on the QDTS survey and RHDS RN survey for those patients discharged between May and October 2018	**Instrument:** Readiness for hospital discharge form (Peds RHDS). Validity of this tool was confirmed utilizing confirmatory factor analysis, contrasted group comparisons, and predictive validity testing to support the 4-structure construct. **Data:** 24 question survey with 10-point Likert scale that is completed by the RN at the time of discharge.	To measure the nurse's perceptions of the parent's readiness for discharge. To gauge anxiety and learning needs of parents.	Descriptive Statistics will be used to measure the mean, median, and standard deviations of the scores from the care transitions measure survey. The use of a well-defined, balanced performance measurement system would enable the team to effectively track the progress of all components of the revised discharge process.

Appendix K: Scholarly Project 3-Year Budget Plan

Revenues	**Year 1**	**Year 2**	**Year 3**	**Rationale**
Philanthropic support	$ 40,000.00	$ 12,000.00	$ 12,000.00	Ongoing support goal for philanthropic support of heart center
Total Operating Revenue	**$ 40,000.00**	**$ 12,000.00**	**$ 12,000.00**	
Expenses	**Year 1**	**Year 2**	**Year 3**	**Rationale**
Staffing	$ 8,463.80	$ 4,726.77	$ 4,868.58	1st year salary includes project team. Year 2 &3 salary includes project manager and RN with 3% annual increase in salary fro year 1.
Supplies and Support	$ 400.00	$ 420.00	$ 441.00	Assumes 5% annual increase
Remote Patient Monitoring Application Licensing Fee	$ 34,360.00	$ 9,000.00	$ 9,000.00	Annual licensing fee; fee waived if more than one specialty utilizes application
IT hardware	$ -	$ 2,000.00	$ 2,000.00	iPad replacement in Year 2 & 3; assumes purchase of 4 devices annually. Year 1 in Line 10
Education and Marketing	$ 250.00	$ 275.00	$ 302.50	Assumes 10% increase in marketing and education support annually

Reporting and Statistical Analysis	$ 550.00	$ 412.50	$ 412.50	Year 2 and 3 based on 75% of effort in year one as report modification require less support
Telemedicine	$ 100.00	$ 100.00	$ 100.00	Assume minimal ongoing support
Survey Development	$ 180.00	$ 180.00	$ 180.00	
Subtotal of Operating Expense	**$ 44,303.80**	**$ 17,114.27**	**$ 17,304.58**	
In-Kind	**$ (9,293.80)**	**$ (6,114.27)**	**$ (6,304.58)**	Excluded in-kind related to purchase of IT equipment - Remote patient monitoring application
Total Operating Expense	**$ 35,010.00**	**$ 11,000.00**	**$ 11,000.00**	
Net Operationg Income	**$ 4,990.00**	**$ 1,000.00**	**$ 1,000.00**	

Appendix L: Scholarly Project Expense Report

Source of Expense	Expense Description	Dollar Value	Type of Cost (Fixed or Variable)	Description of Cost	Estimated Volume	Expense per unit
Staffing - Core Steering Committee (In Kind)						
Project Manager	Salary offset for project management team	$ 90.00	Variable	salary support per hour	36	$ 3,240.00
Dvision Administrator		$ 56.25			30	$ 1,687.50
APN Manager		$ 61.24			30	$ 1,837.20
Telemedicine coordinator		$ 35.00			10	$ 350.00
RN coordinator		$ 44.97			30	$ 1,349.10
	TOTALS REQUESTED					**$ 8,463.80**
Administrative Supplies and Support						
Printer cartridges, paper, copying, handouts	Materials for meetings, education, and communication	$ 200.00	Variable	Supply costs - to be purchased through approved vendor	1	$ 200.00
Meeting Refreshments	Refreshments for kick-off meeting and educational sessions	$ 50.00	fixed	Food to be purchased through hospital cafeteria	4	$ 200.00
	TOTALS REQUESTED					**$ 400.00**
Remote Patient Monitoring Application						
One-time development	Development for Locus Health Application for Home monitoring of SVHD patients	$ 15,000.00	fixed	Cost for application development fee	1	$15,000.00
Annual Licensing Fee	Fee waived if project moves beyond pilot phase	$ 9,000.00	fixed	Annual licensing fee	1	$ 9,000.00
Apple mini iPad	iPad to be used for patient support	$ 500.00	fixed	one-time cost	20	$10,000.00

Intergration cost	Lurie IT cost to build VPN path to access platform	$ 45.00	variable	salary per hour	8	$ 360.00
	TOTALS REQUESTED					**$34,360.00**
Telemedicine Support (In Kind)						
Education and training - staff	Education materials for staff on how to utilize telemedicine equipment	$ 100.00	fixed	cost for tranining materials	1	$ 100.00
	TOTALS REQUESTED					**$ 100.00**
Survey Development (In Kind)						
Development of family perception survey in Marbella	Development of tool in Marbella Rounding App	$ 45.00	Variable	Salary per hour for education coordinator to build survey in Marbella	2	$ 90.00
Development of knowledge assessment survey in Marbella		$ 45.00			2	$ 90.00
	TOTALS REQUESTED					**$ 180.00**
Data Analytics and Reporting (In Kind)						
EPIC and ADT reporting builds	Build admission, discharge, length of stay, and readmission reports	$ 35.00	variable	Consultant salary for report build/hr	8	$ 280.00
Training	Training/education for staff on reviewing data	$ 35.00	variable	Consultant salary for report build/hr	2	$ 70.00
Statistical Analysis	Statistician support to assist with review of data	$ 40.00	fixed	salary support per hour	5	$ 200.00
	TOTALS REQUESTED					**$ 550.00**
Education and Marketing						
Training materials for families	Development of tools and resources for families related to th	$ 150.00	fixed	Cost for parent materials	1	$ 150.00

Marketing materials	Handouts and brochures to support marketing of discharge initiative to families and providers	$ 100.00	fixed	Cost for materials and development	1	$ 100.00
	TOTALS REQUESTED					**$ 250.00**
					Sub Total	**$44,303.80**
					In Kind support	**$(9,293.80)**
					TOTAL	**$35,010.00**

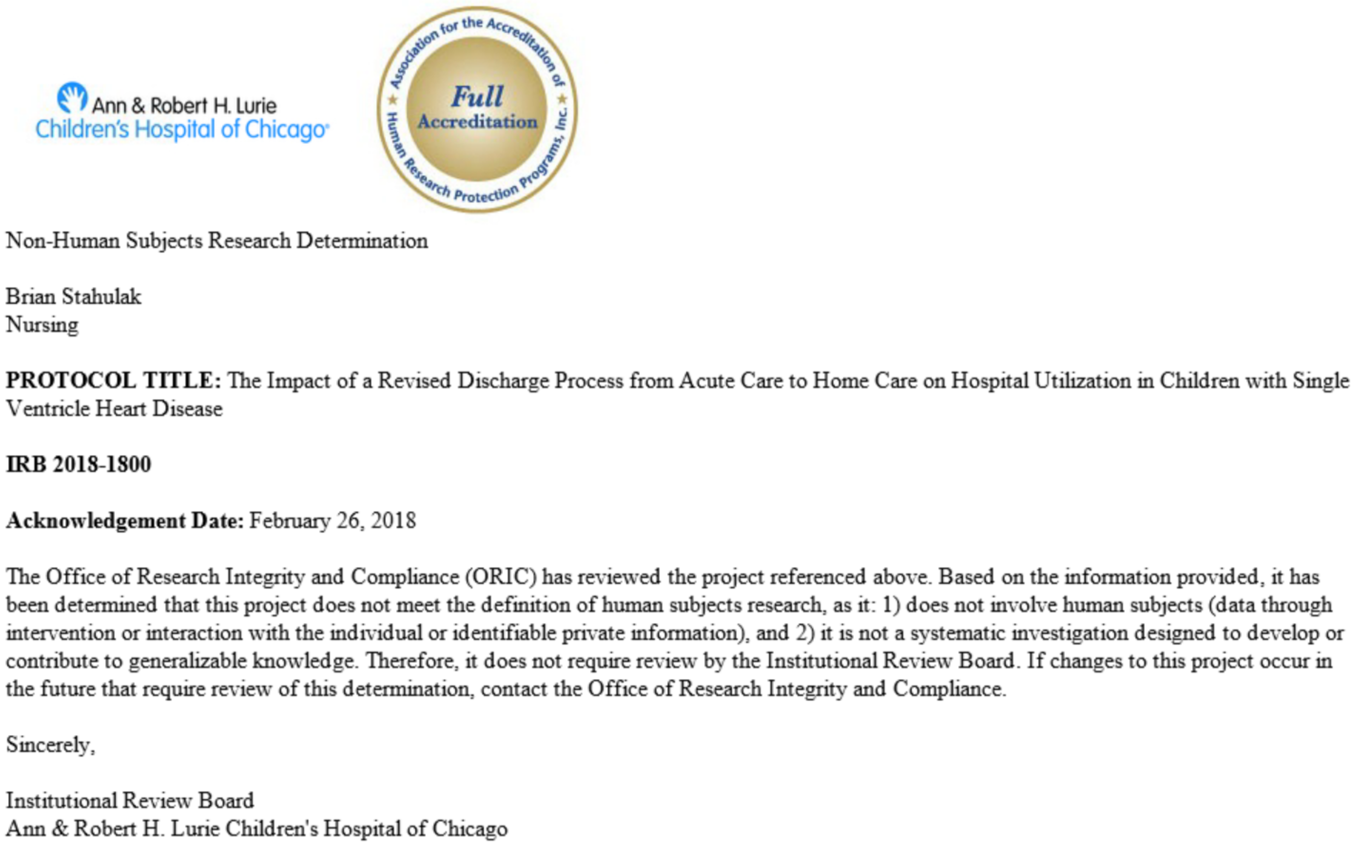
Appendix M: Scholarly Project Statement of Operations

Statement of Operations for year ending 2018		
Revenues	Year 1	**Comments**
Philantropic support	$ 40,000	
Salary (in-kind)	$ 8,464	
Program support (in-kind)	$ 830	includes IT, supplies, statistical, telemedicine, and educational support
Total	$ 49,294	
Expenses		
Salary	$ 8,464	
Supplies and Support	$ 400	
Remote Patient Monitoring Application Licensing Fee	$ 34,360	
IT hardware	$ -	
Education and Marketing	$ 250	
Reporting and Statistical Analysis	$ 550	
Telemedicine	$ 100	
Survey Development	$ 180	
Total	$ 44,304	
Operating Income		
Total	$ 4,990	

Appendix N: Funding Sources

Source of Expense	**Funding Source**
Staffing needed to support project design, planning, and implementation	In-kind
Administrative supplies/support	In-kind
Telemedicine support	In-kind
QI survey development	In-kind
Data analytics and reporting	In-kind
Educational materials	In-kind
Remote patient home monitoring application	
- Development fee	Externally funded philanthropic donation to Heart Center
- Annual licensing fee	Operational expense waived if application used beyond Heart Center
- Mini -Pad (20 iPads)	Externally funded philanthropic donation to Heart Center
- IT interface build	Included as part of the development fee

Appendix O: Scholarly Project IRB Approval Letter or Letter of Determination



Ann & Robert H. Lurie
Children's Hospital of Chicago

Association for the Accreditation of Human Research Protection Programs, Inc.
Full Accreditation

Non-Human Subjects Research Determination

Brian Stahulak
Nursing

PROTOCOL TITLE: The Impact of a Revised Discharge Process from Acute Care to Home Care on Hospital Utilization in Children with Single Ventricle Heart Disease

IRB 2018-1800

Acknowledgement Date: February 26, 2018

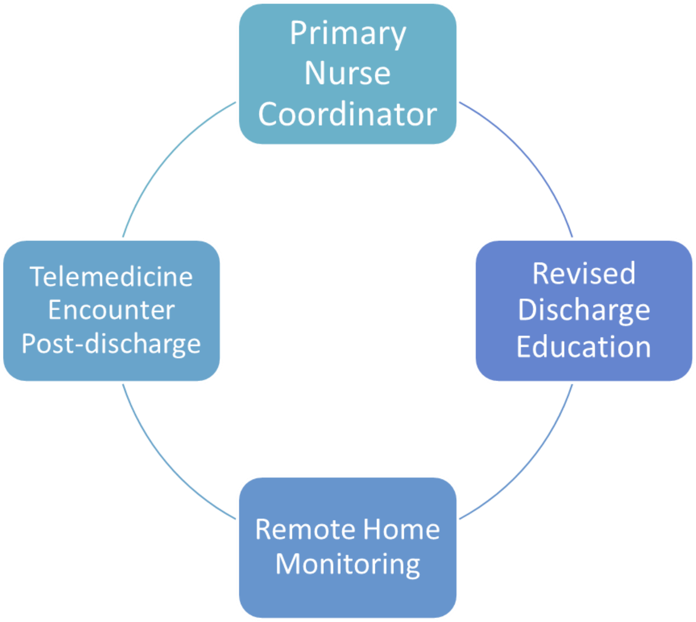
The Office of Research Integrity and Compliance (ORIC) has reviewed the project referenced above. Based on the information provided, it has been determined that this project does not meet the definition of human subjects research, as it: 1) does not involve human subjects (data through intervention or interaction with the individual or identifiable private information), and 2) it is not a systematic investigation designed to develop or contribute to generalizable knowledge. Therefore, it does not require review by the Institutional Review Board. If changes to this project occur in the future that require review of this determination, contact the Office of Research Integrity and Compliance.

Sincerely,

Institutional Review Board
Ann & Robert H. Lurie Children's Hospital of Chicago

Appendix P: Components and Steps of Revised Discharge Bundle

Components of Revised Discharge Bundle



Key Improvement Steps

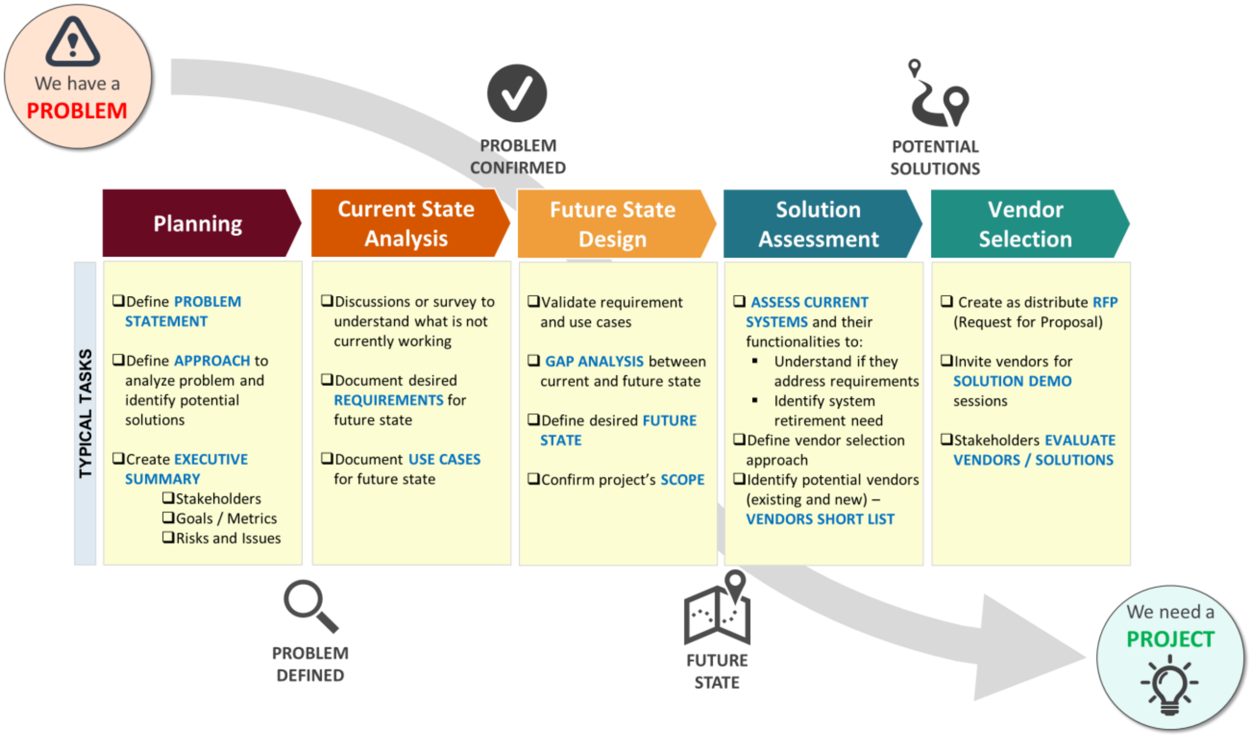
Bundle Component	**Key Improvement Steps**
Assignment of Nurse Coordinator	1. Assignment of primary APRN coordinator for all new patients 2. Increase in clinical nurse position to support growth in patient volumes for SVHD
Revision of Education Documents	1. Revision of clinical educational documents for discharge 2. Build these revised tools into Locus Health application
Locus Health Remote Home Monitoring	1. Design, build, and validation of application 2. Testing, training, and go-live
Tele-Single Ventricle Program	1. Development of educational tools for staff and families 2. Develop telemedicine encounter workflow 3. Develop documentation tools for telemedicine encounter 4. Complete training for staff related to telemedicine encounters

Appendix Q: SVHD Educational Content

Table of Contents: Specific education materials available upon request

1. Red Flags
   a. Emergencies and life-threatening concerns
   b. Information for Emergency Room
2. Routine Contact Information
   a. Weekday calls
   b. Weekday nights, weekends, and holidays
3. Importance of Home Monitoring
4. Managing care at home
   a. Nutrition and feeding
      1. Bonding and mealtime relationships
   b. Managing stress
   c. Parent support/community support
   d. Chest incision care
5. Medications and Vaccines
   a. How to give medications
   b. What to do if baby vomits after medications
   c. What can I give if baby not feeling well?
   d. Vaccines
6. Medication information
   a. Multivitamin with Iron (Poly-vi-sol)
   b. Vitamin D (cholecalciferol)
   c. Aspirin
   d. Captopril
   e. Digoxin
   f. Furosemide (Lasix)
   g. Sildenafil (Revatio)
   h. Spironolactone (Aldactone)
   i. Ranitidine (Zantac)
   j. Esomeprasole (Nexium)
   k. Lansoprazole (Prevacid)
7. Sick contacts and travel
8. Follow-up Appointments
9. Therapies, developmental follow-up and activities

Appendix R: Selection Process for Remote Home Monitoring System



Planning	Current State Analysis	Future State Design	Solution Assessment	Vendor Selection

❑Define PROBLEM STATEMENT
❑Define APPROACH to analyze problem and identify potential solutions
❑Create EXECUTIVE SUMMARY
  ❑Stakeholders
  ❑Goals / Metrics
  ❑Risks and Issues
	❑Discussions or survey to understand what is not currently working
	❑Document desired REQUIREMENTS for future state
	❑Document USE CASES for future state
		❑Validate requirement and use cases
		❑ GAP ANALYSIS between current and future state
		❑Define desired FUTURE STATE
		❑Confirm project's SCOPE
			❑ ASSESS CURRENT SYSTEMS and their functionalities to:
			▪ Understand if they address requirements
			▪ Identify system retirement need
			❑Define vendor selection approach
			❑Identify potential vendors (existing and new) – VENDORS SHORT LIST
				❑ Create as distribute RFP (Request for Proposal)
				❑Invite vendors for SOLUTION DEMO sessions
				❑Stakeholders EVALUATE VENDORS / SOLUTIONS

Appendix S: SVHD Telemedicine Workflows

Cardiology Telemedicine Workflow

Prior to discharge:

Patient identified by clinical team
Cardiology team introduces telemedicine program to family and determines best time for telemedicine coordinator to provide overview and assist family in setting system up
Cardiology clinical team contacts telemedicine coordinator (x73514 or LIgatekeepers@luriechildrens.org) to initiate program overview and setup
Telemedicine coordinator meets with family at appropriate time
Provides technology or shows family how to utilize their preferred device
Sets family up with system and technology, reviews instructions, provides reference kit, etc.
Cardiology clinical team confirms first scheduled telemedicine follow-up appt at/prior to discharge

Post-discharge:

Family and APN connects utilizing technology at scheduled time
APN documents in EMR

Post-discharge:

If family is requesting additional appointment/consult, family contacts either: APN or telemedicine coordinator to scheduled
If telemedicine coordinator, coordinator contacts APN to confirm time
Family and APN connects utilizing technology at scheduled time
APN documents in EMR

Appendix T: Tele-Single Ventricle Family Informational Tool

Lurie Children's Care Connect Tele-Single Ventricle Program

Why and what is Lurie Children's Care Connect Tele-Single Ventricle Program?

Your child's congenital heart disease (CHD) requires single ventricle care that crosses acute and chronic care settings throughout the first year of life. It is a critical time of development that includes multiple surgeries and procedures which can be stressful to your family system. The goal of this program is to provide an option to in-person care in order to allow you to partner with treatment teams, to minimize additional trips to the main hospital and to maintain your family resiliency.

Lurie Children's Care Connect Tele-Single Ventricle Program (a form of Telemedicine) gives your family access to a secure mobile video platform to engage with your child's care team in the comforts of your home environment. Tele-Single Ventricle Program care is currently available for families with children with single ventricle (and other complex CHD). This home program must be initiated in the 44-bed Regenstein Cardiac Care Unit on floor 22 and needs to be indicated by your child's care team for its use at home during the first year of life.

How does Tele-Single Ventricle Program work?

Step 1: Enroll in Tele-Single Ventricle Program (see details on next page on how to sign-up)

Step 2: Prior to discharge, your provider(s) with coordinate an appointment with you. This appointment will be done virtually using the secure mobile video platform and device provided by Lurie Children's.

Step 3: At the time of your scheduled appointment, you will login to the device and dial a 6- or 7-digit code that has been assigned to your child. This code will be unique and reserved specifically for your child's care.

When waiting for your virtual appointment with your child's care team, you should:

- Arrive to your virtual appointment early by logging into the device and dialing the assigned number 510 minutes prior to the scheduled appointment.

- Be in a secure, quiet location. As we will be discussing your children's medical condition, we ask that you are in a place that ensures privacy.
- Prepare questions, supplies, and/or resources needed for your virtual meeting. If a feeding is being observed, oral and other feeding supplies, formula, and an additional care provider may be helpful to have available.
- If you are unable to make the appointment, we understand. Please call the Single Ventricle Team at 312-227-XXXX to reschedule.

What do I need to use Tele-Single Ventricle Program?

You will need the following:

- The iPad and software/application that has been provided by Lurie Children's
  - Please note, the iPad will need to be added to a wifi network to work. Instructions for how to do this will be provided, but the iPad will need to be connected to a wifi network prior to the first appointment.
- Access to our system is limited to ONE device per family.

What if there are problems connecting?

- Ensure the iPad is connected to a wifi network
- Try restarting the iPad
- Ensure you are dialing the correct code for your child's appointment
- If you are unable to make your virtual appointment, please call the Single Ventricle Program at 312-227-XXXX.

How do I sign up for Tele-Single Ventricle Program?

One of our telemedicine coordinators will be checking in with you after your child's Tele-Single Ventricle Consult is placed. The coordinator will deliver the iPad and assist you in getting it set up. The telemedicine coordinator will also show you how to use it and what to do at the time of your child's appointment. Prior to discharge, your child's care team will set the time for your next Tele-Single Ventricle encounter.

How can I give feedback to improve Tele-Single Ventricle Program?

After your video conference, you will receive an email from Lurie Children's asking you about your experience with Tele-Single Ventricle Program. We are always looking to improve our interaction with our patients' families. Your input is greatly appreciated. Please take a few moments to complete the short survey.

Yes, we would like to participate in the Tele-Single Ventricle Program (please print):

Child’s name: ____

Parent’s/Guardian’s name: _________________________________

Serial number for iPad that will be provided: _______________________

E-mail:____

Polycom number (dedicated code assigned to your child for virtual appointments): _____

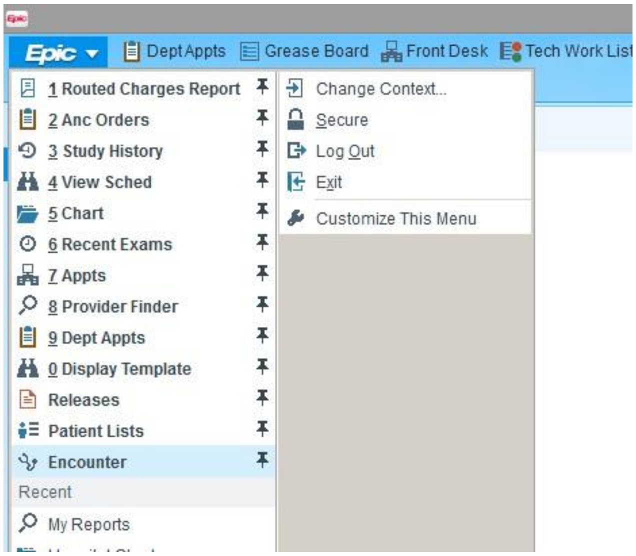
Please note: You will be provided with an iPad and dedicated software/application for use during this program. This iPad is to be used for education and medical care only and will need to be returned at a time determined by your child’s care team. If the iPad is lost or stolen, please contact Lurie Children’s Telemedicine Program immediately at 312-227-XXXX.

Appendix U: Tele-Single Ventricle Documentation Workflow

Telemedicine Encounter – How to Document (general consult)

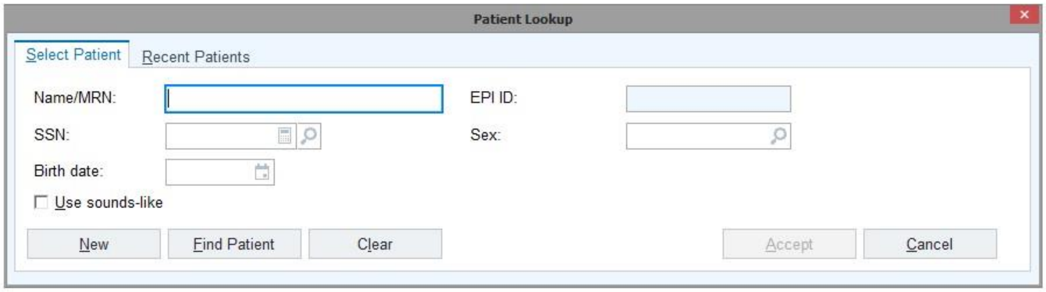
1. Sign in to normal department (or applicable department for telemedicine consult. Example: LC Neurology)
    a. Do not sign into LC Telemed

2. Select Encounter

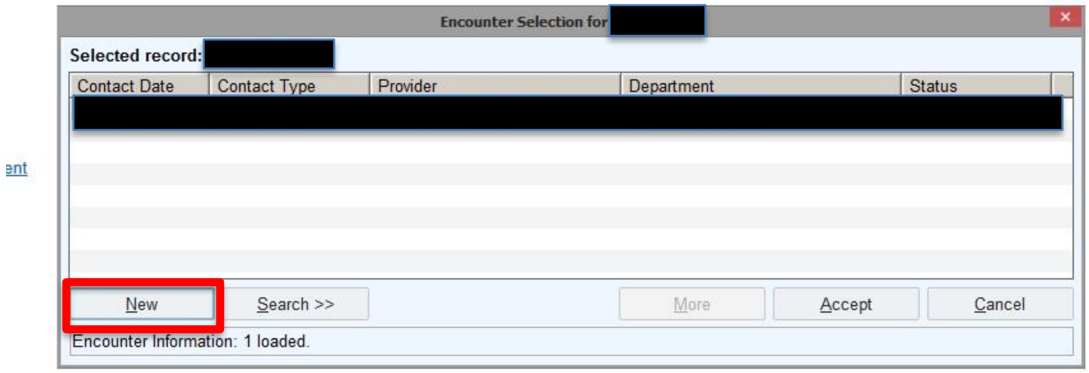


3. Enter appropriate patient/MRN

Ip Assignment



4. Select “New” on Encounter screen

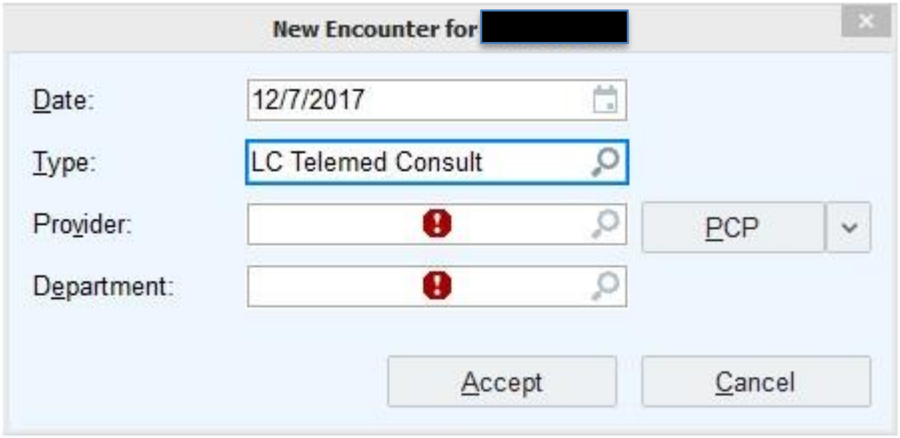


Selected record: [redacted]

Contact Date	Contact Type	Provider	Department	Status
[redacted]	[redacted]	[redacted]	[redacted]	[redacted]

Encounter Information: 1 loaded.

5. Select **LC Telemed Consult** under Type and enter provider and department (normal and/or applicable department. Example: Neurology)



Date: 12/7/2017

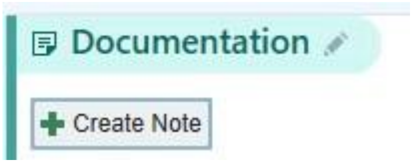
Type: LC Telemed Consult

Provider:

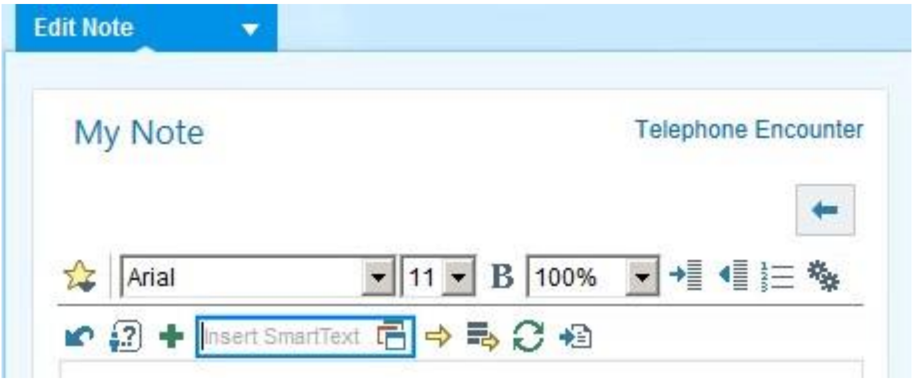
Department:

6. Complete documentation including **Place of Service** and **Documentation** sections a. Place of Service:
    i. If hospital, please select appropriate hospital
    ii. If International, please select
    iii. If other, please enter manually in location field (Example: Patient home, Advocate Christ Medical Center, etc.)

    b. Documentation:
        i. Within the LC Telemed Consult encounter, go to the Documentation section and click Create Note:



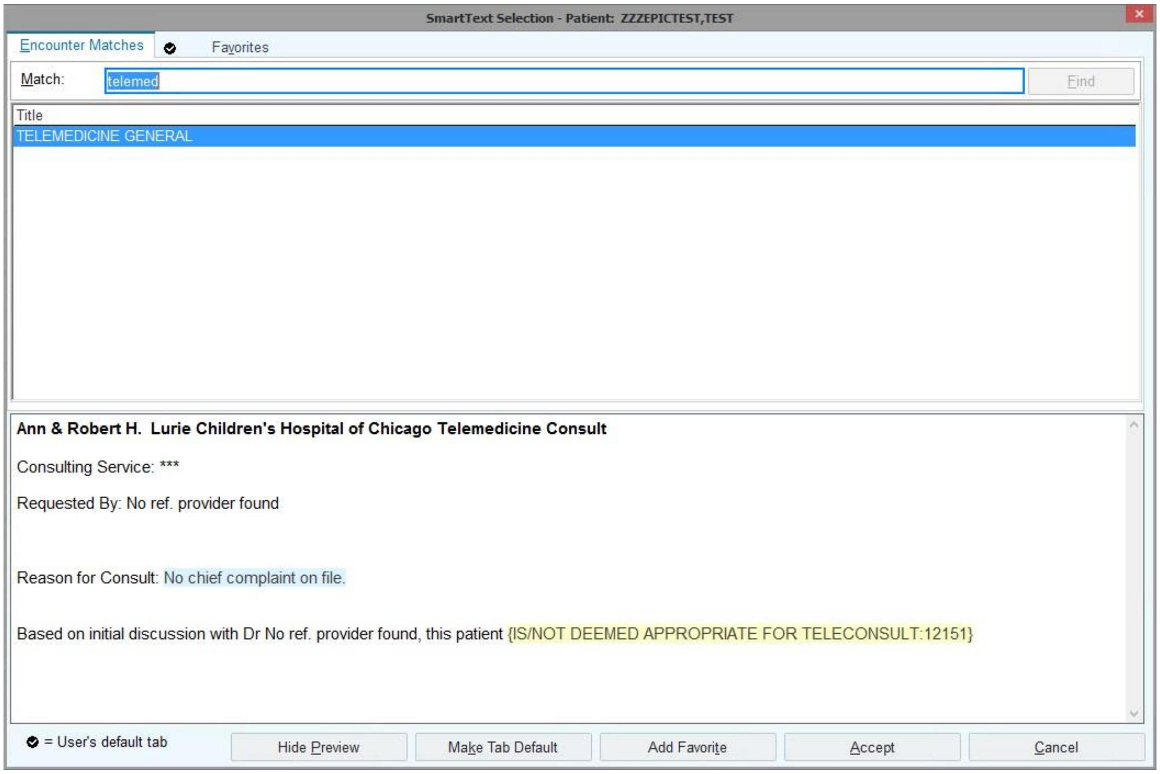
c. Click inside the “Insert SmartText” field:



d. Type “telemed” and press Enter on your keyboard

telemed

e. Find the “TELEMEDICINE GENERAL” SmartText, (optionally click Add Favorite) and click Accept:



Match: telemed

TELEMEDICINE GENERAL

Ann & Robert H. Lurie Children's Hospital of Chicago Telemedicine Consult

Consulting Service: ***

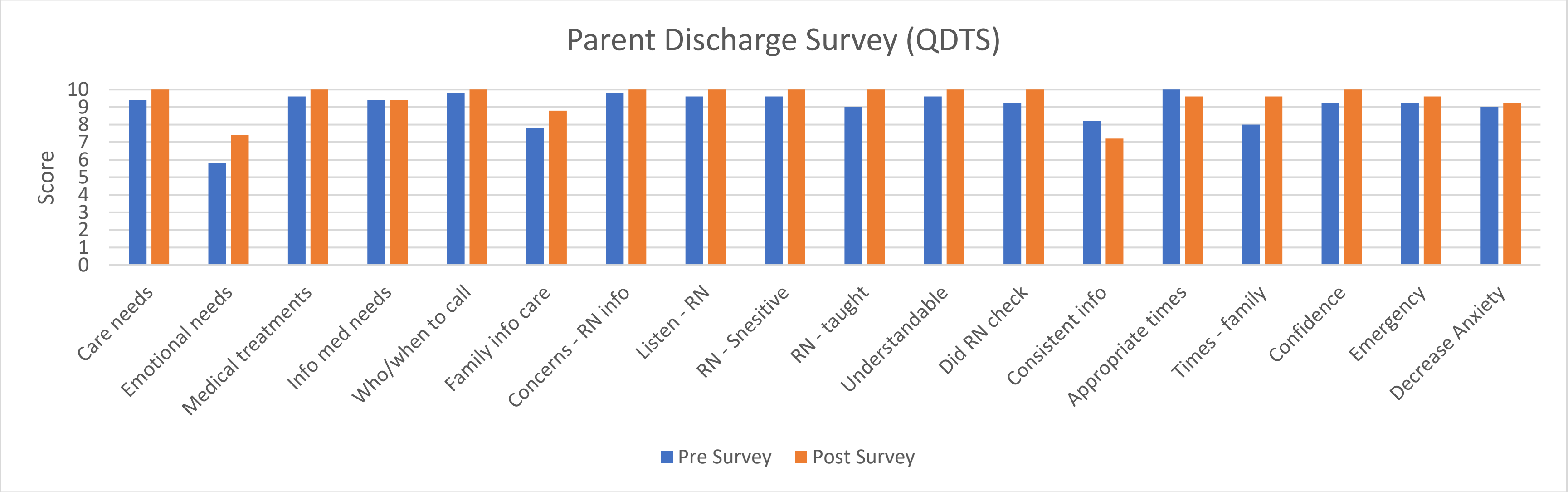
Requested By: No ref. provider found

Reason for Consult: No chief complaint on file.

Based on initial discussion with Dr No ref. provider found, this patient {IS/NOT DEEMED APPROPRIATE FOR TELECONSULT:12151}

Appendix V: Quality of Discharge Teaching Scale – Discharge/Post Discharge Survey

	Pre-Survey	Post Survey	Paired t-test
Care Needs	9.4	10	0.208
Emotional Needs	5.8	7.4	0.5352
Medical Treatments	9.6	10	0.1778
Info Med Needs	9.4	9.4	1.0
Who/When to Call	9.8	10	0.3739
Family Info Care	7.8	8.8	0.6993
Concerns - RN Info	9.8	10	0.3466
Listen - RN	9.6	10	0.3739
RN - Sensitive	9.6	10	0.3739
RN - Taught	9	10	0.189
Understandable	9.6	10	0.3739
Did RN Check	9.2	10	0.242
Consistent Info	8.2	7.2	0.3943
Appropriate Times	10	9.6	0.3739
Times - Family	8	9.6	0.4014
Confidence	9.2	10	0.242
Emergency	9.2	9.6	0.3739
Decrease Anxiety	9	9.2	0.778


Parent Discharge Survey (QDTS)
Score
10
9
8
7
6
5
4
3
2
1
0
Care needs
Emotional needs
Medical treatments
Info med needs
Who/when to call
Family info care
Concerns - RN info
Listen - RN
RN - Snesitive
RN - taught
Understandable
Did RN check
Consistent info
Appropriate times
Times - family
Confidence
Emergency
Decrease Anxiety
Pre Survey
Post Survey

Appendix W: Readiness for Hospital Discharge – RN Survey Mean Scores

How physically ready is the parent to take the...	8.6
How physically ready is the child to go home t...	8.2
How would you describe the parent's level of p...	6
How would you describe the child’s level of pa...	4.8
How would you describe the parent's strength t...	8.6
How would you describe the child’s strength to...	8.2
How would you describe the parent's energy tod...	8
How would you describe the child’s energy toda...	8
How much stress does the parent feel today?	8.6
How emotionally ready is the parent to take th...	8
How difficult will it be for the parent to man...	4.8
How would you describe the parent's physical a...	8.6
How ready is the child to do the usual activit...	8
How much does the parent know about caring for ...	8
How much does the parent know about taking car...	8.2
How much does the parent know about what the c...	8.2
How much does the parent know about who and wh...	8.6
How much does the parent know about what the c...	8.4
How much does the parent know about what happe...	8.4
How much does the parent know about services a...	7.8
How well will the parent be able to handle the...	8.4
How well will the parent be able to perform th...	8.4
How well will the parent be able to perform th...	8.4
How much emotional support will the parent hav...	7.6
How much help will the parent have with the ch...	8
How much help will the parent have with househ...	7.2
How much help will the parent have with the ch...	7.6