Everything Matters In

**Patient Care**

Clinical Research in Patient Care Services
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Editorial Staff:
As I am writing this, we are still facing pandemic challenges and awaiting a visit from The Joint Commission on Accreditation of Healthcare Organizations (JCAHO). We are in year three of the journey towards our fifth Magnet redesignation. Despite the lingering pandemic, unpredictable weather and staffing challenges, our staff remains resilient, courageous and committed to providing the highest quality nursing care to our patients and families. I am so proud of each of you as you have managed the stresses at work while balancing the needs of home, families and friends.

We are also developing our new Nursing Strategic Plan that will focus on Nursing Presence and Image, Infrastructure, Professional Practice and Development of our Talent. A key strategy under Professional Practice is the promotion of Evidenced-Based Practice and Clinical Inquiry. We want to dramatically increase our nursing research and publications, creating an entire team of nurse researchers, resulting in Nationwide Children’s Hospital leading the way in Pediatric Nursing.

I hope these articles help to highlight the extraordinary work our nurses have accomplished and inspire you to think about your role in creating best practice through nursing research at Nationwide Children’s.

**Improving Outcomes Through Innovation: A Multidisciplinary/Family-Centered Approach to Developing an mHealth App in the Hematopoietic Stem Cell Transplant Population**

Jessica Ralph, BA, Research Coordinator, Center for Biobehavioral Health
Micah Skeens, PhD, RN, CPNP, Principal Investigator/Nurse Scientist, Center for Biobehavioral Health
In the United States, poor adherence accounts for up to 70% of all medication-related hospital admissions, resulting in $100 billion in healthcare costs annually. An estimated 50-80% of pediatric patients are non-adherent. Reasons for non-adherence are multifactorial. The most important determinants of non-adherence are consistently documented as complexity and duration of treatment regimens, as well as forgetfulness. Extensive pediatric adherence research exists in many chronic illnesses such as solid organ transplant, cystic fibrosis and diabetes. However, there are limited studies in children receiving hematopoietic stem cell transplant (HSCT), and all report suboptimal adherence rates (52-78%) that worsen over time.

HSCT is the transplantation of hematopoietic stem cells derived from bone marrow (i.e. bone marrow transplant or peripheral blood stem cells). HSCT became the common treatment for life-threatening malignant (e.g., leukemia, lymphoma) and non-malignant (e.g., aplastic anemia, sickle cell disease, immune deficiencies) disorders in the mid-1980s. Recipients of bone marrow transplants must adhere to multifaceted outpatient regimens that require strict personal hygiene, environmental restrictions and complex medication regimens. Lack of adherence to any of these regimens can be life-threatening. Adherence to immunosuppressant medications during the acute phase (first 100 days) post-transplant is critical to prevent graft versus host disease (GVHD) and avoid graft failure. Non-adherence to oral medications has been associated with a greater incidence of infections in children during the outpatient HSCT treatment phase. However, no studies have examined adherence specifically to immunosuppressant medications, which are key to engraftment and ultimately survival. Children undergoing difficult HSCT that require medication indefinitely are at high risk for medication non-adherence.

In pediatrics, adherence relies largely on caregivers to fill prescriptions, retrieve medications and administer them correctly. Behavioral economics (BE) suggests that small reminders can produce and sustain behavior change. With mobile health (mHealth) access nearly ubiquitous and an estimated 3.7 billion mHealth app downloads in 2017 alone, technology has great potential to improve adherence. These types of universal interventions could be easily delivered by nurses as a frontline approach to family education and care.

With a strong clinical background and knowledge of the limited literature, our research team set out to develop and evaluate novel mHealth approaches to improve adherence and clinical outcomes among children receiving HSCT to prevent morbidity and mortality. We believed a mHealth app designed to send medication reminders to caregivers may increase adherence to immunosuppressants, thereby potentially reducing GVHD, readmissions and mortality. Knowing the importance of stakeholder (e.g. patient, parent/caregiver, provider, nurse) input the team used a mixed methods implementation approach to develop an mHealth virtual assistant “BMT4me” aimed at meeting the needs of caregivers post-HSCT. The development was funded by several sources including; the DAISY Foundation, the ONS Foundation and the National Institute of Nursing Research. (NINR)

“Medications don’t work in those that don’t take them.”
– Edward C. Koop
Clinical Collaborations: Multidisciplinary Clinical Research Fueling Best Outcomes

Jamie Boster, PhD, CCC-SLP, Clinical Researcher-Speech-Language Pathology, Speech Pathology
Ursula Findlen, PhD, Clinical Researcher-Audiology, Audiology

Clinical researchers in the Division of Clinical Therapies work collaboratively to conduct a range of research studies. The Research and Evidence-Based Practice Program within the division allows clinical researchers to play a unique role in the research activity. They are tasked with overseeing, their programmatic lines of research in addition to coordinating research projects with other departments, divisions and external partners. Clinical research is being conducted in the fields of audiology, speech pathology, occupational and physical therapies, sports and orthopedic physical therapy, therapeutic recreation, and massage therapy. Studies conducted by the clinical researchers strive to inform clinical practice and fuel best outcomes for children. Pragmatic research can occur in settings where it will be implemented, reducing the evidence-to-practice gap. The projects highlighted below demonstrate the multidisciplinary nature of the work being completed in the Division of Clinical Therapies.

In audiology, Ursula Findlen, PhD, has worked with a multidisciplinary team including audiology, speech pathology, plastic surgery, and Ear, Nose and Throat (ENT) to evaluate and improve evidence-based audiologic care for children with the Cleft Palate Program. Results of her work have led to improvements in care provision and optimized outcomes for children with cleft palate. In the speech pathology department, Jamie Boster, PhD, CCC-SLP, has focused her research on children with complex communication needs who also have visual impairments. Her work with a team of speech-language pathologists recently explored current interventions and accommodations for this population. Results of her work outlined considerations for researchers in the field of augmentative and alternative communication (AAC) to systematically investigate the design of communication devices and called for multidisciplinary research for children with cortical visual impairment. Kelly Tanner, PhD, OTR/L, BCP, from occupational therapy and Rachel Bican, PT, DPT, PhD, from physical therapy, recently collaborated to publish their process for implementing telehealth rapidly and shared data on patient satisfaction and numbers of visits over time. They specifically dove into patient diagnoses and therapist satisfaction. This unique collaboration has allowed Dr. Tanner and Dr. Bican to leverage clinical data and partnerships to learn from telehealth experiences and continue to inform practice. From sports and orthopedic physical therapy, Mitch Selhorst, PT, DPT, PhD, has also demonstrated how collaborative research activities can be beneficial for informing patient care. Recently, physical therapy collaborated with Nationwide Children’s Hospital psychologists to create a psychologically informed intervention that significantly improved negative thoughts and beliefs about knee pain. Their research suggests that this psychologically informed education helps improve pain and dysfunction in this population.

Clinical researchers in the Division of Clinical Therapies have pursued unique multidisciplinary collaborations, resulting in contributions to the literature and informed therapy practices for children both within Nationwide Childrens and elsewhere. The evidence-based approaches taken by this group have informed improvements in clinical care and have served as models for peer children’s hospitals. Clinical researchers in the Division of Clinical Therapies will continue their multidisciplinary approach in the pursuit of best outcomes for all our patients and families.
This is the story of a nurse-driven practice change implemented during a pandemic. “Small but mighty” was our group’s motto as Cathleen Opperman, RN, Nikki Hernandez, RN, and Caitlin McGee, RN, moved through the Evidence Based Practice (EBP) process. Follow our journey using the Melnyk & Fineout-Overholt seven steps as an exemplar for evidence-based practice change in your setting.

Clinical Inquiry: In late 2019, our organization was seeing lower scores in the patient/family satisfaction survey regarding “Quietness of the Hospital Environment.” A subgroup of our Night-Shift-Friendly committee accepted the challenge of determining best practices and improving these scores. Our compelling question was “How can we optimize patient rest and promote quietness of the hospital environment?”

According to Cook et al (2020) “Sleeplessness is exacerbated for pediatric patients, who can have difficulty returning to sleep and require more sleep than adults.”

PICO Question: In hospitalized children (P), how does a designated Quiet Time (I) compared to current practice (C), affect patient/family satisfaction? (O)

The group reviewed, organized and synthesized 169 articles eliminating non-interventional and sorting them into three global categories: 1) Processes for Quiet Times; 2) Environmental Modifications; and 3) Modifying Care Routines. The combination of strategies provided a menu as we facilitated the primary intervention of starting a designated Quiet Time.

Due to the pandemic, implementation was slow and methodical. Five units were targeted as having the most potential for improvement and unit leadership welcomed the initiative. Many stakeholders were approached in small groups providing a summary of the literature and asking for their contribution to the effort of minimizing disruptions to let the children sleep.

“Nocturnal rest leads to the tuning down of the nervous system and the regeneration of muscles, and results in physiological rest” (Ritmala-Castren, et al, 2015).

Outcomes: Our goal was to improve HCAHPS scores for “Quietness of Hospital Environment.” Data used to monitor success of the initiative was reduction of the number of labs drawn, B/P measured, baths given, weights taken and aerosols given from 1 to 5 a.m. This data was measured pre-intervention in Jan-March 2020, during implementation and post-intervention. The results of this effort, despite the pandemic, has been a sustained increase in HCAHPS scores and a reduction of sleep interruptions activities between 1 and 5 a.m.

While we disseminate our efforts through publishing and presenting at the national Society of Pediatric Nursing Conference in the spring, we want to challenge other nurses to explore “clinical inquiry” by asking questions about how the patient and staff experience could be better. You are the best change agent for the work that you do.

“Providing an environment without excessive noise and stimulation has been shown to decrease the duration of oxygen requirement, days on respiratory support, and the infant’s length of stay” 

Ahamed, Campbell, Horan and Ruen, 2018

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To facilitate success of designated Quiet Times, evidence-based interventions including environmental changes (lights, noise reduction, etc.), modifying care routines (cue-based feeding, clustering care, patient rounding, etc.) and interprofessional collaboration were part of the initiative.

“Poor sleep quality and negative mood decrease the parents’ ability to sustain attention and focus, and to care for their sick child” 

The Caring Nature of Clinical Trials

Chris and Shannon Ward, Parents

When Anderson was diagnosed with Hypoplastic Right Heart Syndrome, we knew our family’s journey would be filled with highs and lows. Through Anderson’s first few years of life, he underwent countless surgeries and procedures, and when you threw in a heavy struggle with eating, at times, it felt as though he couldn’t catch a break.

As planning began for Anderson’s last scheduled open-heart surgery, the Fontan Procedure, we were approached with a life-changing opportunity. Dr. Toshiharu Shinoka and Dr. Chris Breuer and their teams told us that Anderson was a candidate for the groundbreaking Tissue Engineering Vascular Graft (TEVG) clinical trial. After talking at length with Anderson’s Cardiothoracic surgeon, Dr. Patrick McConnell, we decided to enroll Anderson into the TEVG clinical trial, where he would become the first patient to receive a TEVG at Nationwide Children’s Hospital.

What stood out the most about the trial was the warm and caring nature of the entire team. They answered every question we had and Anderson’s heart and health were at the center of every aspect of the planning process. The team helped us understand that the procedure did not carry any more risk than the traditional Fontan, which made it the right choice for our family. Not only could Anderson potentially benefit from a vascular graft that would grow with him as he matured, but as the team followed him long-term, we knew that the research and data collected could positively impact generations to come.

As things progressed towards Anderson’s surgery date, we were nervous but confident when we learned the team’s planning was extremely detailed. Dr. Breuer and Julie Breuer, the lead nurse on the TEVG team, explained the procedure had been mapped out to the second, due to different aspects of the graft being built in the research facility across the street. Everything needed to be timed perfectly, as every second mattered.

“We were amazed when, after a week, they said that he was prepared to come home!”

Although stressful, the day of surgery went as well as expected and the team updated us throughout the entire procedure. Once he was out of surgery, the staff in the Cardiac ICU was prepared to receive Anderson, set with special instructions for the clinical trial. The TEVG team, including the founding doctors and surgeon, checked on Anderson at least twice a day. We were amazed when, after a week, they said that he was prepared to come home.

Over the past seven years, Anderson has been seen by the TEVG team frequently, and they have become like family to us. The team goes above and beyond to treat Anderson like royalty. We are forever grateful for the entire TEVG team, and the wonderful research that is happening at Nationwide Children’s as it truly changed our family’s future.
For decades, the United States has maintained the highest rate of incarceration as well as the largest correctional system in the world. Unfortunately, the majority of those behind bars are parents. Nearly 1 in every 14 youth, or about one or two students in every classroom, have had an incarcerated parent in jail or prison. The exposure to parental incarceration, once considered “rare,” is now common. Due to well-documented racial and ethnic disparities in who is arrested, sentenced and detained in the US, the effects of parental incarceration are not equally distributed. Youth who are Black, Hispanic/Latino, American Indian and youth in rural areas are much more likely to experience a parent’s incarceration. The separation of a child from their parent via incarceration can lead to several psychosocial stressors which include changes in living arrangements, changes in the custodial caregiver and economic disruptions upon the parent’s arrest as well as throughout incarceration. Upon release from incarceration, a record of the crime can restrict where a family can live and work, and in some states, can even restrict their eligibility for government aid. Studies have shown that youth exposed to parental incarceration are more likely to act out, have inattention, more likely to be in foster care (and for longer), more likely to engage in delinquent behaviors in adolescence and lastly, are more likely to rely on substance use for coping compared to those unexposed. Other studies have found these youth to be less prepared for kindergarten, more likely to drop out of high school, and more likely to have greater unmet health care service needs. Children who witness a violent arrest of their parent may especially need additional trauma screening and trauma-informed therapeutic interventions.

Using data from Nationwide Children’s Hospital electronic health record system from 2006-2020, roughly 2% (N = 51,855) of all youth had a correctional keyword in their medical chart (e.g. prison, parole, jail, probation) likely indicating a history of personal or family justice-involvement. This 2% made up 66% of all patients with cannabis-related diagnoses, 52% of all patients with trauma-related diagnoses, 48% of all stress-related diagnoses, 38% of all patients with psychotic disorder diagnoses and 33% of all suicidal-related disorders within this database. While this sample included children who had personal or other types of family justice involvement aside from parental incarceration, findings demonstrate we can do better in identifying, and supporting families affected by the correctional system.

Determining whether mass incarceration has had more negative net effects on children is a significant public health and justice issue. More importantly, if these findings are confirmed, the urgency of preventive interventions for children affected by the correctional system cannot be overstated, especially for their mental health.
Research Spark: Now What?

Cailin Coane, BA  Research Coordinator
Timothy Landers, PhD, RN, APRN-CNP, CIC, FAAN  Nurse Scientist

Every day at Nationwide Children’s Hospital, we have the opportunity to see children with unique health problems and find novel ways to help them. Many of the research ideas that begin as sparks continue to grow, like a song that gets stuck in your head. When you have such an idea, it can be difficult to know where to start, but there are practical steps to grow your idea into something more.

We like to think of these first steps as reading and talking.

Reading
During the initial stages of a research idea, it is helpful to understand what other people have written or how they have approached the problem. A first step is to look at existing papers. The Grant Morrow III Library staff at Nationwide Children’s can help identify a search strategy to find the most relevant articles.

At this stage, look for broad reviews of the topic — textbooks and review articles can be very helpful here. In addition, looking at specific papers on your topic using very specific search terms can be useful as well. Do not be discouraged if you do not find any articles that address the topic — it just reaffirms the importance of your research idea!

At this stage, it can be tempting to get buried in literature with too many papers. To combat this paralysis, try to limit your search to the most relevant articles.

Talking
Another step you can take is to talk through your idea. Formally and informally, talk with your clinical leader, nurse manager or physician colleagues. As you have these conversations, you will refine your idea and get insight on how you might approach the problem.

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Over 30 years ago, four American Academy of Nursing researchers studied characteristic behaviors in 41 hospitals that maintained nurse retention amid a national nurse shortage. One of the fundamental characteristics identified at these institutions was the nurses’ sense of empowerment to engage in quality improvement and research.

The finding that nurses remain in hospitals where nurse innovation is valued was developed as one of the Magnet Recognition Program® five Magnet Model® components titled New Knowledge, Innovations, & Improvements (NK). Stories submitted in this component require demonstration of hospital support for nurse influence over nursing practice, practice environment and patient care through nurse participation in design, implementation and dissemination of evidence-based practice and research.

As Nationwide Children’s Hospital works through a fifth Magnet® “designation,” it is evident that nurses are valued participants in the hospital’s ongoing innovation and research efforts. More than half of the NK stories are currently in the writing phase and demonstrate nurse engagement in areas such as infection prevention, nursing research, improved patient access to care, application of new technology, patient safety and redesign of the work environment.

One example of clinical nurses implementing evidence-based practice at Nationwide Children’s comes from the Neuroscience Unit where a clinical nurse questioned the practice of removing Mepilex® Ag dressings from patients prior to undergoing Magnetic Resonance Imaging (MRI). The nurse recognized that removal of the dressing could be painful and disrupt workflow.

After the nurse presented evidence from a robust literature review to the manufacturer and the Radiology team, multiple trials were conducted, and it was determined that there was no risk to patients when the dressings remained on during an MRI. This change in practice has resulted in improved patient experiences. Similarly, an example of nurses improving the practice environment included two clinical nurses who questioned if noise and interruptions for point of care tasks impacted patient healing. The nurses’ advocacy for a tool to measure noise levels in the practice environment revealed opportunities to bundle care and reduce noise levels. This initiative became known as Quiet Time and has resulted in improved interprofessional collaboration for clustering patient care, rounding and promoting an increase in restful periods that are shown to encourage patient healing.

Finally, an example of improved patient care involved nurses who advocated for Nationwide Children’s to provide hair care products for patients with textured hair. The nurses’ efforts to include patients and families, as well as incorporate hair care products into the hospitals’ supply chain influenced an organization-wide hair equity practice.

One of the best things about working for Nationwide Children’s is the overwhelming commitment to the 125-year vision that everything matters in the care of a child. The endless resources and welcoming culture for all employees, including nurses, to ask questions or raise concerns if they feel an opportunity for improvement exists encourages all to participate in ongoing innovation and makes seeking Magnet Recognition effortless.

The process of talking through your idea with others can help in narrowing down your topic area and clarifying its terms. Not only will this process help in focusing your topic, but talking with others across different backgrounds and experience with the subject matter can open your inquiry to new insights and perspectives.

Because we work with experienced colleagues, some people may not understand the importance of the problem or the value in a unique approach. In these situations, keep positive and use this information to deepen your understanding of the problem and other perspectives.

An important tool to remember when talking to others about your idea is your elevator pitch. This is a short, forty-five-second to one-minute pitch where you describe the inquiry you’re researching, why it’s important and what researching it will mean (as far as patient outcomes, cost, staffing levels, etc.). From managers to nursing staff to patients, if we’re not familiar with a topic, we may have short attention spans. The elevator pitch grabs the attention, gets to the point, and gets people on board who may help you with your research. Practice it beforehand, watch what words grab people’s attention, and refine it each time. If the topic is something you’re interested in researching, you could probably talk about it for hours — lone that passion down to a minute, and you will have an effective pitch.

Of course, there are more steps in getting a research project off the ground. There are many resources that can help you with these next steps. When you are ready — or even before you think you are ready — contact us at NursingResearch@NationwideChildrens.org.
Infection Prevention at Nationwide Children’s Hospital
Rachel Morrison, RN, BSN, Infection Preventionist, Epidemiology
Timothy Landers, PhD, RN, APIN-CNP, CIC, FAAN, Nurse Scientist

Infection prevention might be the least well-known hospital department yet the one that you rely on the most. Most of the advanced care we provide for patients at Nationwide Children’s Hospital relies on effective infection prevention measures. These measures help us keep our patients, families and staff free from infection and point us toward best outcomes. Not only during a pandemic but also throughout the year, across the nation and across Nationwide Children’s, infection prevention remains a cornerstone of modern health care. Infection Preventionists typically have a background in nursing, microbiology, medicine, public health or epidemiology. At Nationwide Children’s, the infection prevention team is comprised of eight infection preventionists (IPs) and an administrator. With a broad range of backgrounds, they are able to understand how different areas of the hospital function. “Our team is composed of both experienced IPs and those new to the field,” states Barb Roman, MT(ASCP), CIC, Director of Infection Prevention. “This enables us to have a very diverse approach as we work together.” IPs combined understanding of the clinical workflows and infection prevention training enable them to provide clear guidelines and policy standards that can be easily implemented. The goal of infection prevention is to improve patient outcomes and ultimately keep patients and staff safe.

Foundational infection prevention responsibilities include monitoring hand hygiene, performing education and surveillance for hospital-acquired infections (HAIs). HAIs are important indicators of health care quality and safety, and our IPs focus on catheter associated urinary tract infections, central line associated bloodstream infections and ventilator associated infections. These investigations involve reviewing lab results and medical records and then using standardized criteria to identify infections. When significant events do occur, infection prevention collaborates with stakeholders to ensure we are using best practices. Infection prevention strategies continually evolve and IPs work to ensure that our practices align with current research, best practices and national guidelines.

While much of our work includes computer-based surveillance, the IP team can often be seen circulating on units. These rounds are meant to increase awareness of the importance of infection prevention, observe how we are performing, provide a chance to talk with staff about infection control standards and ensure that appropriate protective equipment is being used. Unlike infection prevention in the adult settings, pediatric IP requires experience and knowledge of childhood health conditions, consideration for patients’ developmental stages and family-centered care as well as education for the caregivers about the importance of keeping their child safe from the unseen threats of opportunistic pathogens.

The infection prevention team has been very active during COVID-19. The challenges they faced have strengthened their ability to think critically, provide leadership and communicate across disciplines. IPs have worked closely with marketing to quickly communicate policy changes and with managers regarding prioritization of patients in negative airflow rooms. Working with laboratory services, IPs obtained and reported data on COVID-19 testing and positivity rates. In close collaboration with employee health, they were able to provide clear guidance for staff about quarantine and isolation. They partnered with outpatient clinics to provide guidance on how to proceed safely with visits and manage COVID-19 exposed or positive patients as quickly as possible while protecting staff and other patients. Lastly, collaborating with the behavioral health team to implement safe infection control practices while meeting the needs of the patient population.

During the pandemic, universal masking proved challenging due to supply chain shortages, visitors who had limited infection prevention knowledge and developmental and behavioral challenges. Despite the challenges, the organization saw nearly a 50% reduction in other hospital acquired respiratory infections as staff, patients and visitors paid increased attention to masking, hand hygiene and environmental cleaning.

Though sometimes seen as the “infection watchdogs,” the Nationwide Children’s infection prevention team is essential to maintaining a healthy and safe environment to ensure the best outcomes for children, families and staff.

Engaging Key Stakeholders to Improve Rehabilitation Care for Children with Traumatic Brain Injury
Jennifer Lundine, PhD, CCC-SLP, Clinical Researcher/Speech-Language Pathologist, Division of Clinical Therapies & Inpatient Rehabilitation Program
Christine Koterba, PhD, ABPP, Pediatric Neuropsychologist, Neuropsychology Department

Although comprehensive follow-up after TBI is critical, research suggests that most children with TBI do not receive adequate care over time, with low rates of service utilization and high rates of unmet needs. Thousands of children with traumatic brain injury (TBI) are treated in Ohio emergency departments every year. The chronic nature of a pediatric TBI and the potential negative impacts on long-term education, employment, health and quality of life pose a significant burden to public health and health care costs in the United States. Although comprehensive follow-up after TBI is critical, research suggests that most children with TBI do not receive adequate care over time, with low rates of service utilization and high rates of unmet needs. While emerging evidence identifies how gaps in care provision occur, little research focuses on stakeholder-driven methods to lessen these challenges. To address gaps in care provision and improve rehabilitation care for children with TBI, this project incorporated the perspectives of both caregivers and medical providers to develop recommendations for specific strategies that could target the needs of these stakeholders. The objective of this project was to engage key stakeholders in semi-structured interviews and focus groups to determine ways to improve the current standard of care to better meet the needs of parents of children with TBI.

Specifically, we aimed to (1) identify the long-term needs of children with TBI and the tools and strategies that can be used to improve service provision for children with TBI from the caregivers’ perspective and (2) identify the tools and strategies that can be used to improve service provision for children with TBI from the perspective of medical providers, based on themes identified during caregiver interviews. Semi-structured interviews and focus group transcripts were analyzed using qualitative data analysis methodology to identify themes across participants. The project included 20 caregivers and five focus groups (a total of 29 medical and educational professionals).

Themes identified from interviews with caregivers indicated that mental health support, limited transition support from hospital-to-home and later developing academic challenges are persistent barriers faced by families as they decide whether to seek long-term care for their children following TBI. Focus group participants identified possible targets to improve care including establishing support groups for caregivers and survivors, enhancing methods of education regarding injury and transition to home and funding a care coordinator to follow families long-term. Findings from this study have important and immediate implications for medical providers, researchers and policymakers. Information from this study will help us develop and research clinical tools with the potential to improve long-term outcomes for the thousands of children and families affected by TBI.
Genomic Medicine Translational Protocols - What Do They Mean for You and Patients Everywhere?  
Elizabeth Varga, MS, LGC, Director of Clinical Genomics Research and Development, Institute for Genomic Medicine

As part of the Journey to Best Outcomes, Nationwide Children’s Hospital has dedicated significant resources to genomic medicine, named as a key accelerator in the 2017-2021 strategic plan and as one of the three pillars that will be utilized to integrate research and clinical care over the next five years. In response, the Steve and Cindy Rasmussen Institute for Genomic Medicine has expanded resources devoted to genomic medicine translational protocols. Defined as projects that are meant to directly answer questions related to the diagnosis, prognosis and optimal treatment for patients evaluated across our hospital, translational protocols are vital to best outcomes.

These protocols help to identify the genomic approaches that are best suited to understand the pathogenesis of individual disease, predict the best course of treatment, and eventually validate the highest yield assays for clinical use.

As proof of concept of this N of one approach to improve patient care, the Comprehensive Genomic Profiling for Hematologic and Oncologic Disorders Study was launched in 2017. Since inception, this study has consented more than 370 unique patients with blood disorders and cancer to undergo comprehensive analysis, including sequencing of the protein-coding sequences of inherited DNA, as well as that in their tumor or affected tissue. The profiling has also included evaluation of the complete transcriptome allowing for better assessment of how genes are being expressed in the affected tissues. Further, in some cases, gene expression is turned off or on through a process referred to as methylation. This comprehensive profiling allows for comparison of methylation profiles between patients with different cancer types, as well as patients with similar tumors to obtain unique insights. In concert, the data gleaned has informed diagnosis, prognosis, and/or therapeutic choice in more than 90% of patients studied to date. Additionally, unique genomic alterations found through this approach have directly altered clinical decision making, as illustrated through patient stories shared publicly.

What makes the Genomic Medicine Translational Protocols unique is the intent to directly translate the findings from research to develop clinically available testing that can assist clinicians and patients at Nationwide Children’s and beyond. For example, the Institute for Genomic Medicine now offers three clinical tests that directly resulted from the experience with the cancer translational protocol, including a methylation array for central nervous system tumors, an RNA-fusion panel to identify rearrangements in chromosomes that could be targetable with a cancer therapy and a newly launched exome sequencing test to identify inherited and acquired genetic mutations that lead to cancer and other disorders. These tests are offered at very few children’s hospitals and are uniquely available in house to patients evaluated at our facility. This translational protocol has also allowed for five years of partnership between clinicians and the laboratory. With this partnership, education, collaboration and a shared language have developed, resulting in a streamlined clinical transition and opportunities for Nationwide Children’s to pave the way in innovation and adoption of personalized medicine.

Replicating the successes in cancer and blood disorders, the Institute for Genomic Medicine seeks to expand into other service lines to offer increased access to cutting-edge genomic technologies. With Nationwide Children’s commitment to fetal and neonatal services, a priority focus is providing rapid genomic diagnosis to critical newborns and children suspected of having a genetic disorder. With this in mind, a rapid genomic sequencing protocol was launched in 2020. This protocol has provided patients, families and care teams valuable information with results delivered in less than five days on average and a 35% diagnostic rate. By identifying an underlying genetic cause of the child’s condition quickly, the child may be started on a precision therapy and/or allow the family to make informed decisions regarding goals of care while avoiding futile treatments. In addition, challenges to implementation have been identified, such as consent and sample collection for parents, which is important to recognize prior to launching a clinical test. This has allowed the research team to work with hospital leadership and administration to devise ways to overcome barriers, including bedside phlebotomy and virtual consent options. It has also increased collaboration between teams in the Intensive Care Units and NICU/PICU to work with hospital leadership and administration to devise ways to overcome barriers, including bedside phlebotomy and virtual consent options.

The Division of Genetic and Genomic Medicine, leading to the creation of a full-time genetic counseling position within the Neonatal Intensive Care.

Over the next five years, we look forward to continued growth and demonstration of the value of genomic medicine to benefit patients everywhere. We will continue ongoing efforts in the areas of Rare Disease Diagnosis, Gene Discovery, Epilepsy and Disorders of Brain Development, as well as Behavioral Health. We look forward to expansion into new service lines including Immunology and Pathogen Detection, Digestive and Motility Disorders, and Fetal Therapy. We will double down on efforts to create a biorepository of specimens available for use by research investigators. Through these collaborative partnerships, we believe the promise of genomics will manifest through direct translation, such that all clinicians and patients will experience its impact for generations to come.

Nationwide Children’s Hospital’s Investments in genomics have yielded rapid growth in recent years

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<tr>
<th>Annual Enrollment of Targeted Populations on IGM Developed Translational Genomic Sequencing Protocols, #probands consented</th>
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<td>Cancer</td>
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The table above highlights the growth and demonstration of the value of genomic medicine over the past five years, with a focus on the rapid genomic sequencing protocol. This protocol has provided patients, families, and care teams valuable information, allowing for better assessment of how genes are being expressed in the affected tissues. Further, in some cases, gene expression is turned off or on through a process referred to as methylation. This comprehensive profiling allows for comparison of methylation profiles between patients with different cancer types, as well as patients with similar tumors to obtain unique insights. In concert, the data gleaned has informed diagnosis, prognosis, and/or therapeutic choice in more than 90% of patients studied to date. Additionally, unique genomic alterations found through this approach have directly altered clinical decision making, as illustrated through patient stories shared publicly.

What makes the Genomic Medicine Translational Protocols unique is the intent to directly translate the findings from research to develop clinically available testing that can assist clinicians and patients at Nationwide Children’s and beyond. For example, the Institute for Genomic Medicine now offers three clinical tests that directly resulted from the experience with the cancer translational protocol, including a methylation array for central nervous system tumors, an RNA-fusion panel to identify rearrangements in chromosomes that could be targetable with a cancer therapy and a newly launched exome sequencing test to identify inherited and acquired genetic mutations that lead to cancer and other disorders. These tests are offered at very few children’s hospitals and are uniquely available in house to patients evaluated at our facility. This translational protocol has also allowed for five years of partnership between clinicians and the laboratory. With this partnership, education, collaboration and a shared language have developed, resulting in a streamlined clinical transition and opportunities for Nationwide Children’s to pave the way in innovation and adoption of personalized medicine.

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Planning and conducting a research study can seem like a daunting task. To be successful, it takes a team of people who are interested in the topic and have the skills to bring a research project to fruition, but the titles used for people involved in research can be confusing. Regardless of the specific research question or clinical topic, there are standard ways to describe each role and what each team member contributes to a research study.

Each of us is critical to integrating clinical care and research on our journey to best outcomes. The most important person in any research project is you! Each of us has an opportunity every day to identify new and innovative approaches to the children and families who come through the doors of Nationwide Children’s Hospital.

Once a new idea is developed, team members come together to form a plan. At this stage, being clear about research roles and using descriptions of those roles can help everyone work together.

**Principal Investigator**

A Principal Investigator (PI) is a senior researcher who takes overall responsibility for the research project. Typically, PIs have doctoral preparation (such as a PhD, MD or DO) and are responsible for the design, conduct and reporting of a research project. As the team leader, the PI works with others to plan and carry out the specific steps in the study, analyze the results and report the findings. Depending on the type of project, the PI may also be called the Project Director (PD) or Project Lead.

Very large or complex research projects may designate Multiple Principal Investigators (sometimes called Co-PIs), who are each considered PIs. For example, some research projects are conducted at different sites across the country and each hospital or clinic may have a “Site PI” who oversees conduct of the study at that location.

**Consultants**

Consultants are people who assist with a specific area of expertise to add a technical skill or ability.

**Study Personnel**

Study personnel or study staff conduct the project – from recruiting patients to performing tests or procedures to collecting and aggregating data. They are the backbone of the work and clear communication with the PI and Co-Investigators is critical to ensure the rigor and strength of the results as well as the protection of patients participating in the research.

All people who participate in a research project are required to have completed study-specific training including human subjects protection, laboratory safety training and animal handling modules. Understanding who is involved in research and what they do is key to understanding how teams with research questions can work together.

As “One Team” members, we all have a role to play in keeping research integrated into patient care.
Daisy Award

Kimberly Stumpf, CRNA

The quarterly Nationwide Children's Hospital Daisy Award was presented to Kimberly Stumpf, CRNA. The Daisy Award is given in appreciation of the important difference our nurses make in the lives of our patients and families at Nationwide Children's.

Says Kimberly’s nominator: “There have been many times where I’ve personally witnessed her quick wit and cool composure called to action all the while maintaining her ability to teach in critical situations.

She comes to the OR joyous, bringing a refreshing energy and always keeping patient care at the forefront. As a younger colleague, I am truly inspired and she makes me feel good about the care our patients received and truly embodies the visions and missions this hospital set out for. I see no one more deserving than her.”

To learn more about our Daisy winners, and read their full nomination, visit NationwideChildrens.org/Daisy-Award