IROC
Improving Renal Outcomes Collaborative

IROC INTERVENTION PACKAGES

PARTNERING TO ACHIEVE HEALTH, LONGEVITY, AND QUALITY OF LIFE

Prepared for: IROC Centers
Prepared by: IROC Core Team
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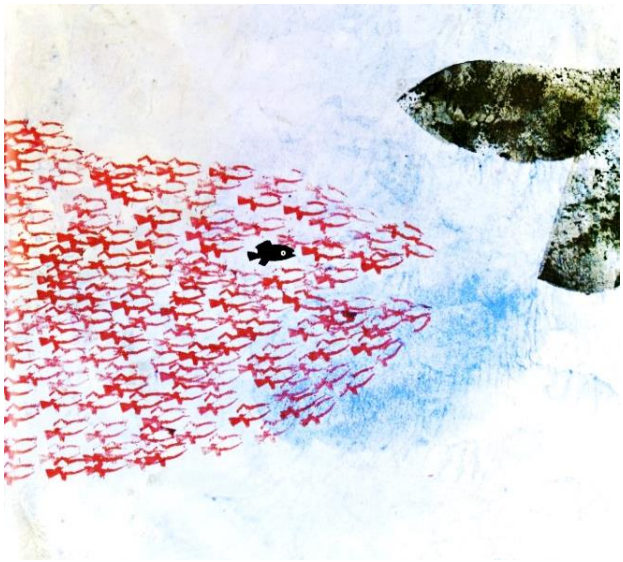
DESIGNED WITH OUTCOMES IN MIND

The IROC Intervention Package Design process is focused on IROC's mission to achieve health, longevity and quality of life equal to those of children without kidney failure or transplant. In order to do this, IROC's founding-year design sessions focused on three critical lead outcome measures for success:

1. Improving blood pressure control
2. Reducing acute allograft rejection
3. Improving quality of life for patients and families



Each intervention package is built to solve for one outcome measure in particular, though it may have an impact on the others.

COLLABORATIVE EXPERTISE

The IROC Intervention Package Design process was conducted by a multi-functional team of physicians, parents, transplant patients, designers, system experts and quality improvement specialists representing 16 US kidney transplant centers. The IROC design process was built to harness the inherent motivation of all stakeholders to improve care, spawn innovation and conduct research collaboratively to improve health and outcomes.

INTERVENTION PACKAGES

Each IROC Intervention Package is comprised of several interventions selected both for their individual impact & feasibility, and for the expected impact of their grouping, producing a whole greater than the sum of its parts. Interventions within a package are intended to be prototyped individually first, then in combination to demonstrate impact on the target outcome measure, and will have specific outcome goals associated with each package.

THREE KEY OUTCOME METRICS, ONE BIG GOAL

Managing a chronic disease like post-transplant care requires a truly systemic approach. As such, this constellation of interventions is designed to deliver targeted care and support for the three strategic outcome metrics that will work together to improve health, longevity and quality of life. No one package by itself will be the magic bullet; it is the network of care with all three sets of stakeholders that will create meaningful change.

INTERVENTIONS BY PACKAGE

REDUCE ACUTE ALLOGRAFT REJECTION	Kidney.Me	Pre-Visit Planning
		Customized Type & Group Visits
		Transition Support
		Caregiver's Virtual Roadmap
		Individualizable Adherence Evaluation & Treatment Toolfit
	Improving Adherence	Network-activated Peer Mentoring
		Total Adherence App
		Patient/Parent Exchange Platform
		Transplant Pharmacist on Call
		Individualizable Adherence Evaluation & Treatment Toolkit
		Pre-Visit Planning with Adherence Data
	Rejection Prevention Research	Central IRBs
		Explore Pediatrics vs Adult
		Enhanced Solution Shop
		IROC Exchange
		Mentorship for Research
IMPROVE BLOOD PRESSURE CONTROL	Home Monitoring & BP Follow-Up	Real-time education
		Kidney Transplant-Specific Activities & Exercise App
		Kidney Transplant- Self Care book for kids
		Mentoring program for patients and families
		Total Adherence App
	Patient-Oriented BP Management	Kid-Oriented BP Training Program
		Online BP Monitoring
		Total Adherence App
	Lowering BP Through Enhanced Registry	Pre-visit Planning
		Population Management
		BP Flowsheet
		Treatment Protocol
		QI Reports
IMPROVE QUALITY OF LIFE	Facilitating Connections	Customized Group Visits
		IROC Facebook Community
		Mentoring Program for patients and families
	Show Me The Way	Caregiver's Virtual Road Map
		Patient Report Card
		Medication Charts + Tracking
		Patient-Provider Communication System

KIDNEY.ME

PREVENTING ACUTE ALLOGRAFT REJECTION

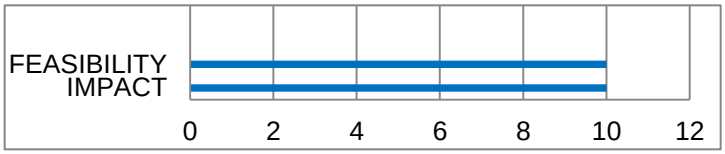
This package of interventions has the potential to provide tailored, comprehensive care using evidence and reliable systems that will lead to increased chance to save kidneys over time, reduce cost of hospitalizations, promote centers' ranking in the US and World reports, and more importantly deliver the ideal care to each patient seen in the network.

HOW IT WORKS

With this package of interventions, both clinicians and patients and their families are armed with the right tools and support systems to improve outcomes. It starts with the clinical teams pulling the Pre-Visit Planning reports ahead of the visits to ensure all critical elements are available. Those elements are collected from various systems, including Patient Reported Outcomes that patients share using a Total Adherence App. Themed group visits would allow patients and caregivers to be grouped based on common themes, such as transition to post transplant care where they could receive instruction and share learnings with one another. A comprehensive transition support tool, including a caregiver's roadmap, is provided to families so they understand the key milestones ahead of the journey. Patients and families are also assessed for specific barriers to treatment so they can be addressed and removed to minimize the risk of rejection.

INTERVENTIONS INCLUDED

- Pre-Visit Planning
- Total Adherence App
- Customized Themed & Group Visits
- Transition Support
- Caregiver's Virtual Roadmap



PRE-VISIT PLANNING

Create a system for comprehensive & precise pre-visit planning

- Pre-visit planning involves the multi-disciplinary team reviewing available patient data and goals and making a specific plan for each visit even before it happens. In this way, time during the visit can be maximized for the greatest benefit. Pre-visit planning can mean the difference between a clinic where

physiciasn and staff are floundering and frustrated and a clinic that runs smoothly with the capacity to handle any unanticipated issues that arise. System would include:

- Availability of a standardized template for performing pre-visit planning
- Adequate, timely and thorough preparation and documentation by care team before visit · Patient family engagement and input into pre-visit planning
- Application of appropriate protocols to lab monitoring and to recommendations / suggested actions
- Appropriate use of visuals and trends to facilitate decision making
- System for collecting feedback on pre-visit planning effectiveness and on execution of suggested actions
- Clinical team and patient initiated goals incorporated into process

TOTAL ADHERENCE APP

Create an app, driven from the clinic, to support all elements of adherence for patients and families.

- A collaborative effort between patients/families, clinicians and the informatics workgroup experts to create a comprehensive app.
- Offers pill/dosage reminders, clinic/lab visit prompts, information access and available on mobile devices all with the intent of enhancing patient engagement to improve adherence to treatment and positively influencing outcomes.
- Ability to interface with EHR systems
- Enable "between visit" communication between patient/family and care team

CUSTOMIZE THEMED & GROUP VISITS

Group visits set up by themes/focuses for specific populations or needs (e.g. – transition, teen clinic, weight concerns clinic, etc.)

- Dedicate clinic dates to a specific population to provide support/transition focus.
- Specific months may be dedicated to relevant topics (e.g. – blood pressure control, adherence, transition etc.)
- Sites could use educational quality metrics to assess which educational/social objectives were covered. · Physician and care team (including social worker, dietician, etc) could be scheduled for 1-on-1 time and then group time to address any questions.

TRANSITION SUPPORT

Build a support system that educates and provides social support through each transition of post-transplant care.

- Transition should include both transition to adult care and transition through the stages of the condition. In both cases, a clear roadmap for families would be very beneficial, as well as a support

network for patients and families to activate as a way to increase learning and bonding with peers. Such support group could be accessible virtually.

- IROC should learn from Iowa and its 5 stage approach to preparing children to adult care as early as 10 years old. Other similar programs should be tested at the network level to measure impact, particularly on medical adherence (a factor in assessing successful or failed transition to adult care)

CAREGIVER'S VIRTUAL ROADMAP

Create an online binder that serves as a "Road Map" to guide Caregivers through each stage of post-transplant care.

- Would be constantly available and continuously refreshed with new and relevant content, divided into stages.
- May even offer "push" email updates of stage-specific content based on time-since transplant, child's age, user-inputted conditions or vectors (similar to parents.com's "Your child at 4 years" style emails)

INDIVIDUALIZABLE ADHERENCE EVALUATION AND TREATMENT TOOLKIT.

System for identifying barriers to adherence and addressing those barriers with a set of shared-decision making tools and approaches that can be individualized to the patient. This would include a system for tracking medication adherence and providing feedback to patients and providers.

KEY DRIVERS

- Key Driver #1 : Identification of patient at risk
- Key Driver #2: Clearly defined treatment pathways
- Key Driver #3: Patient/family engagement (in own care and design of the system)

WHO DOES THIS PACKAGE IMPACT?

REDUCE ACUTE ALLOGRAFT REJECTION

KEY METRICS

- Acute Rejection Rate
- Days between acute rejection episodes
- Drug levels within range

TARGET

Ideally, one center should test the package and report out on progress and roadblocks. Likely all centers who would adopt the package would need to receive full leadership commitment.

PROTOTYPING CENTERS

CCHMC, Seattle, Colorado, Iowa, UAB, CHOP, Michigan, Nationwide, Riley, Emory

ENHANCEMENT IDEAS:

This package could be enhanced by adding other ideas that were generated during the design phase. For instance, group visits could enhance the package by creating a sense of accountability towards a larger group of peers, as well as promoting support mechanisms that are critical in treating a chronic condition. Cross-specialty teams could meet with the group of patients and offer a more holistic review of the patients' health. During these group visits, transition to post-transplant care could be addressed and motivational boards could be displayed to encourage peer to peer and parent mentoring. Pre-visit planning reports could also enhance this package if they were to target allograft and rejection.

IMPROVING ADHERENCE

MAKING PATIENTS AND PROVIDERS ADHERENCE PARTNERS

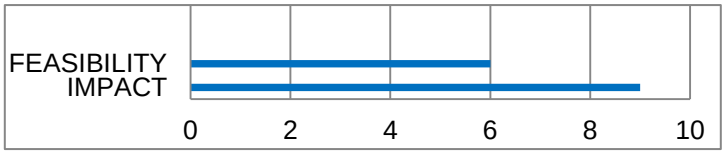
In order for patients to experience longevity and quality of life, they must prevent rejection of their kidney transplant by taking immunosuppressive medications. Too many adolescents and other patients end up disengaging with their providers and fail to maintain excellent adherence. This intervention package is designed to support patients and their families in engaging with their providers to develop life-long habits of taking appropriate immunosuppression.

HOW IT WORKS

This package supports patients and families in managing their immunosuppression medication by providing a comprehensive systematic approach that combines Network Activated Peer Mentoring and a Patient/parent Exchange Platform to provide social support, information sharing and mentoring, with practice level interventions that empower providers and patients with information about adherence behaviors and risk through the Individualized Adherence Evaluation and Treatment Toolkit and Pre-visit Planning and with interventions to improve adherence such as the Total Adherence App and Specified Transplant Pharmacist. The power of this package is that it has multiple assessments and interventions to cater to different personalities, barriers to adherence and other challenges. Successful development and implementation of this package has the potential to decrease allograft rejection and loss which will improve health, longevity and quality of life for patients, while also saving the healthcare system money.

INTERVENTIONS INCLUDED

- Network Activated Peer Mentoring
- Total Adherence App
- Patient/Parent Exchange Platform
- Transplant Pharmacist on Call
- Individualizable Adherence Evaluation & Treatment Toolkit
- Pre-Visit Planning with Adherence data



NETWORK-ACTIVATED PEER MENTORING

Peer Mentoring connect patients with a national group of transplant patients who have experienced similar stages/complexities/needs. The mentoring program is meant to be at a national scale and provide patients both the opportunity to mentor and to be mentored. It is thought that patients will be the best people to help other patients overcome barriers to taking their medications.

TOTAL ADHERENCE APP

A mobile application, driven from the clinic, to support all elements of Adherence/engagement for patients and families, including:

- A collaborative effort between patients/families, clinicians and the informatics workgroup experts to create a comprehensive app.
- Offers pill/dosage reminders, clinic/lab visit prompts, information access and available on mobile devices all with the intent of increasing convenience and enhancing adherence to treatment and positively influencing outcomes.
- Ability to interface with EHR systems
- Enable "between visit" communication between patient/family and care team
- May include gamification and other engagement strategies

PARENT/PATIENT EXCHANGE PLATFORM

- Create a national/international digital platform for parents/patients to meet and exchange ideas. This platform could be led and moderated by an expert "Parent Teacher Association" type of team of parents and providers, but could include clinician / IROC participation options:
- Used to create connections and peer mentorship relationships between patients/parents
- Could be used to gain insight in how to improve QOL standards and disease-specific PROs
- Used for resource-sharing and introducing parents/patients to new resources and test opportunities
- Offers story-sharing opportunities to build shared connection and camaraderie - "You are not alone"

TRANSPLANT PHARMACIST ON CALL

Given that the number of questions and concerns that patients/families have about medication and its administration, the current system of providers and nurses seems to be somewhat inadequate in terms of being able to dedicate enough time, effort and expertise to be able to do full justice to the need. This idea is about creating a system that would have a transplant specialized pharmacist available on call to field the medication related questions in a timely manner and influence patient/family knowledge and adherence to medications in a more direct manner.

- Offer a dedicated outpatient pharmacist who handles all facets of prescription pickup, including dosing review, fulfillment and prior authorization:
- Has all pharmaceutical needs taken care of and ready for clinic visits, and is available on clinic consult days for questions.
- The pharmacist delivers medications to inpatients and reviews dosing, etc.
- He/she can also serve as a resource to the transplant team.

Note: This model already exists at John Hopkins; we could learn from them.

INDIVIDUALIZABLE ADHERENCE EVALUATION AND TREATMENT TOOLKIT

System for identifying barriers to adherence and addressing those barriers with a set of shared-decision making tools and approaches that can be individualized to the patient. This would include a system for tracking medication adherence and providing feedback to patients and providers.

Note: this model already exists at Cincinnati Children's Hospital; may learn from them

PRE-VISIT PLANNING WITH ADHERENCE DATA

Create a system for comprehensive & precise pre-visit planning

- Pre-visit planning involves the multi-disciplinary team reviewing available patient data and goals and making a specific plan for each visit even before it happens. In this way, time during the visit can be maximized for the greatest benefit. Pre-visit planning can mean the difference between a clinic where physiciasn and staff are floundering and frustrated and a clinic that runs smoothly with the capacity to handle any unanticipated issues that arise. System would include:
  - Availability of a standardized template for performing pre-visit planning
  - Adequate, timely and thorough preparation and documentation by care team before visit · Patient family engagement and input into pre-visit planning
  - Application of appropriate protocols to lab monitoring and to recommendations / suggested actions
  - Appropriate use of visuals and trends to facilitate decision making
  - System for collecting feedback on pre-visit planning effectiveness and on execution of suggested actions
  - Clinical team and patient initiated goals incorporated into process

REDUCE ACUTE ALLOGRAFT REJECTION

WHO DOES THIS PACKAGE IMPACT?

KEY DRIVERS

- Key Driver #1: Identification of patient at risk
- Key Driver #2: Clearly defined treatment pathways
- Key Driver #3: Patient/family engagement (in own care and design of the system)
- Key Driver #4: Patient access to care and appropriate social support
- Key Driver #5: Effective self-management support and improved adherence

KEY METRICS

- Acute Rejection Rate
- Mediation possession ratio
- Drug levels within range

TARGET

Center with adolescents and transplant pharmacy support

PROTOTYPING CENTERS

CCHMC, Seattle, Colorado, Iowa, UAB, CHOP

ENHANCEMENT IDEAS:

This package could be enhanced by ensuring screenings of patients are done pre-transplant to assess the likelihood of adhering to treatment and address any barriers ahead of transplant. The pill box tool used at CCHMC could also enhance the package by allowing the monitoring of the adherence to treatment over time.

REJECTION PREVENTION RESEARCH

CONNECTING RESEARCH TO CLINICAL CARE

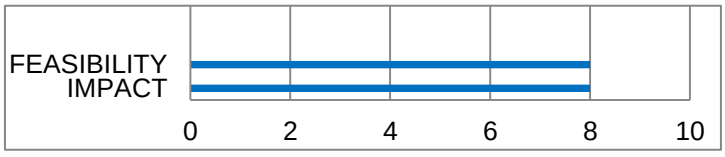
This package is intended to compliment the clinical care delivery arm of strategies and interventions related to acute rejection prevention. This research arm of rejection prevention aims to connect expertise from the basic scientists and practicing Nephrologists as well as patient and families through data that will help accelerate research in the field of rejection prevention.

HOW IT WORKS

This package consists of two sub-packages. The first sub-package consists of using IRB, data entry and exchange platform features and advantages. Sub-package 2 is based upon identifying the knowledge gap with mentoring, expert consultation and adult Vs peds differences. Using the approach of the package we expect to get increased power with decreased variability and increased sample size.

INTERVENTIONS INCLUDED

- Central IRB for IROC
- Reduced Multiple Data Entry
- Understand Differences in Peds vs Adult Standards of Care
- Enhanced Solution Shop
- IROC Exchange Platform



CENTRAL IRB FOR IROC

Use scale to drive consistency and efficiency by leveraging a central IRB and Master Reliance Agreements (MRA) when available (ex: PEDSNet)

REDUCE MULTIPLE DATA ENTRY

A means by which to reduce multiple registry entries and outputs. (NAPRTCS, Site QI data, UNOS, Investigator Collected Data)

UNDERSTAND DIFFERENCE IN PEDS VS ADULT STANDARDS OF CARE

Document and educate patients and families on pediatric standards of care vs. adult standards of care for transition, and incorporate into the transition program. There are differences between pediatric and adult standards of care. It is important to know these differences.

ENHANCED SOLUTION SHOP

Kidney Kombo Passionate Idea: Consultation team from across care centers to tap all experts to create an 'uber customized response'.

ONLINE IROC EXCHANGE PLATFORM

An all-sites IROC digital platform for exchanging information, data, research, prototypes, resources and breakthroughs (similar to Improve Care Now).

KEY DRIVERS

- Key Driver #1: Identify patients at risk for poor outcomes (biomarkers, adherence…)
- Key Driver #2: Clearly defined treatment and assessment pathways (includes: assessment of response and mitigation of side effects)
- Key Driver #3: Consistent implementation of treatment pathways

KEY METRICS

- Acute rejection rate (1)
- Risk based immunosuppression (1a)

WHO DOES THIS PACKAGE IMPACT?

REDUCE ACUTE ALLOGRAFT REJECTION

TARGET

Centers that are part of master reliance agreement

PROTOTYPING CENTERS

CCHMC, Colorado, Iowa, UAB, CHOP, Seattle

ENHANCEMENT IDEAS

This package could be enhanced by a data in once strategy, eliminating manual data entry into a registry that would follow patients post transition. Close collaboration with scientists and a staged implementation approach that would later include adult data and a biobank.

HOME MONITORING AND BP FOLLOW UP

SELF-MANAGEMENT AND BLOOD PRESSURE

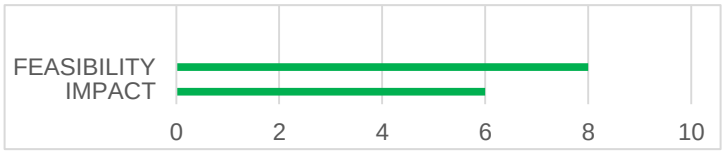
This package incorporates technology, intrinsic motivation of patient and measurable individualized monitoring. This intervention package is designed to empower self-management in kidney transplant patients and families relative to blood pressure measurement at home. The act of measurement, communication with providers, discussion of the results along with shared decision making between the patient family and the care team is what contributes to the overall objective of improved ling term cardiovascular outcomes for patients as well as favorably affect longevity of graft and of the patient.

HOW IT WORKS

This package consists of a combination of interventions related to education, use of apps and a self-care book. The power of this package as a combination comes from applying the knowledge from educational material and books related to self-management to a technological socially popular tool such as an “app”. The app would also open the door to additional potential interventions such as peer mentoring and medication adherence data. The package still needs details and specifics regarding the method and make of blood pressure measurement equipment that would be adopted.

INTERVENTIONS INCLUDED

- Real-time and Ongoing Education
- Kidney Transplant-Specific Activity & Exercise App
- Kidney Transplant Self-Care Book for Kids
- Mentoring program for patients and families
- Total Adherence App



REAL-TIME AND ONGOING EDUCATION

IMPROVE BLOOD PRESSURE CONTROL

This is an initiative to make ongoing post-transplant education available to all network members for access in real-time. Education tools may include: · Diagnosis search engine · Simulation experiences · Journal subscriptions with regular updates & call-out articles · Real-time news updates (via automatic hashtag searches & article keyword searches) · Quizzes & challenges · Patient story youtube videos

KT-SPECIFIC ACTIVITY & EXERCISE APP

Build a KT-specific app that uses existing activity/fitness trackers (e.g. - Fitbit, Apple Watch) to help patients manage and track exercise, fluids, etc. · Communicate results to the clinicians for recognition/rewards (ex: raffles etc.). · Use data to also educate patients and families on fitness and fluid benefits, cardiovascular risks associated with kidney transplants, etc. · Provide an opportunity for patients to indicate in-the-moment barriers to exercise and fluid intake.

KIDNEY TRANSPLANT SELF-CARE BOOK FOR KIDS

Support the creation and distribution of a children's book specifically written to train and empower children to take care of their transplanted kidney. · Could have multiple editions for age-appropriate communication and expectations for self-management (e.g. - elementary, pre-teen, teenager, etc.) · Could be told from first-person perspective of transplantee to help build identification & empathy · See: "Taking care of Kennedy"; "The Gutsy Girl" · Could include a kind of progression system that could be followed to encourage the skill development and life experiences necessary for a successful transition into adult care (something similar in form to the Boy Scout rank and merit badge requirements but all relating to kidney transplant)

MENTORING PROGRAM FOR PATIENTS & FAMILIES

Create a mentoring program that connects patients/families facing new or challenging medical experience with trained, veteran parents.

- Mentors are trained to provide support, modeling, suggestions and validation to families.
- Mentors share information and coping skills to help families reduce stress and manage their child’s healthcare in a positive way.
- Patient / family communication and information sharing forums enabled by intent, support and technology
- Appropriate support from hospital and community resources to encourage such mentoring and information sharing
- Building / enhancing trust and faith through encouragement, inspiration and support system created by patients/families
- local, in-person, and supported by centers. start family mentor program in addition to pre-existing peer mentors

TOTAL ADHERENCE APP

A mobile application, driven from the clinic, to support all elements of Adherence/engagement for patients and families, including:

- A collaborative effort between patients/families, clinicians and the informatics workgroup experts to create a comprehensive app.
- Offers pill/dosage reminders, clinic/lab visit prompts, information access and available on mobile devices all with the intent of increasing convenience and enhancing adherence to treatment and positively influencing outcomes.
- Ability to interface with EHR systems
- Enable "between visit" communication between patient/family and care team
- May include gamification and other engagement strategies

KEY DRIVERS

- Key Driver #1: Effective self-management practices amongst patients/families
- Key Driver #2: Timely assessment of response and appropriate adjustment to therapy

WHO DOES THIS PACKAGE IMPACT?

KEY METRICS

- Systolic blood pressure control (2)
- Appropriate follow up of uncontrolled SBP (3c)

TARGET

- Transplant clinic
- Group patients
- RN BP follow up visits

PROTOTYPING CENTERS:

- Stanford, Emory, Boston, Colorado, Seattle

ENHANCEMENT IDEAS

This package could be enhanced with the following elements:

- Actionable real time results to provider
- Network-Activated Peer Mentoring

IMPROVE BLOOD PRESSURE CONTROL

- Adherence monitoring – not shaming
- Medication adherence – electronic pill box
- Patient feedback loop – what is and is not working
- Can IROC develop health literacy sensitive educational tools for use by all centers?

PATIENT ORIENTED BP MANAGEMENT

EMPOWERING PATIENTS TO TAKE CONTYROL OF THEIR CARE

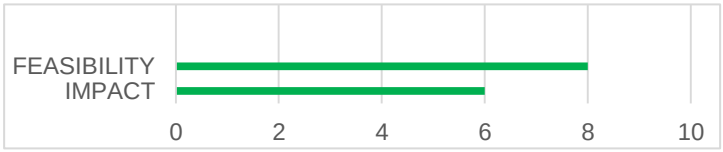
Patients need to learn how to take care of themselves. It starts with understanding how to properly measure their blood pressure. With today's technology we have an unlimited set of options to help us do just that. This package looks at technology driven interventions that have the potential to empower children and their families to care for their own health by correctly measuring their blood pressure and tracking the many moving parts of treating blood pressure.

HOW IT WORKS

This package includes technology driven interventions that combined have the potential to positively influence blood pressure control and ultimately adherence. It starts with training patients and families about the correct way to measure blood pressure. The training should be kid-friendly and incorporate technology already available such as Apple Care Kit. It would also include an app that would track all the elements that families need to remember such as visit appointments, lab results, medication regiment, and others.

INTERVENTIONS INCLUDED

- Kid-Oriented BP Training Program
- Online BP Monitoring
- Total Adherence App



KID ORIENTED TRAINING PROGRAM

Develop a kid-friendly training and support program to help kids manage their BP by doing the right thing each day with regard to food, exercise and other daily habits.

ONLINE BLOOD PRESSURE MONITORING

Give patients and families the tools and training to measure blood pressure at home; make data available at clinic and network levels.

- Train patients and families about the correct way to measure blood pressure and make sure the method used (either a BP machine or other modes) is reliable.
- Leverage the recent Apple Care Kit made available to all developers interested in using iphones to detect and track symptoms
- Make all these measurements available at the network level for IROC to be able to compare performance and make appropriate decisions for improvement and actions

TOTAL ADHERENCE APP

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- Offers pill/dosage reminders, clinic/lab visit prompts, information access and available on mobile devices all with the intent of increasing convenience and enhancing adherence to treatment and positively influencing outcomes.
- Ability to interface with EHR systems
- Enable "between visit" communication between patient/family and care team
- May include gamification and other engagement strategies

KEY DRIVERS

- Key Driver #1: Accurate Measurement
- Key Driver #2 : Timely assessment and Appropriate Adjustment to therapy
- Key Driver #3 : Effective Self-Management Practices among patients and families

WHO DOES THIS PACKAGE IMPACT?

IMPROVE BLOOD PRESSURE CONTROL

KEY METRICS

- Systolic Blood Pressure Control (2)
- Appropriate Blood Pressure documentation (2A)
- Appropriate follow up of uncontrolled SBP (3C)

TARGET

- Access to Online IT support to gather/review data
- Ancillary Staff to Educate

PROTOTYPING CENTERS

Stanford, Boston, Seattle, Emory, Colorado

ENHANCEMENT IDEAS

Below are suggestions for enhancing the package.

- One app for all purposes
- Small tips in app to see when uploading BP data into app
- Solution for those with and without access to home monitoring resources
- Complete family-centered training and equipment access during transplant admission
- use annual visit for time to retrospectively review SBP progress and reinforce key concepts
- Integration with pre-visit planning module
- Enrichment of cohort to only apply to those at higher risk for increased SPB initially to save resources

LOWERING BLOOD PRESSURE THROUGH ENHANCED REGISTRY

STRONG ANALYTICS FOR IMPROVED OUTCOMES

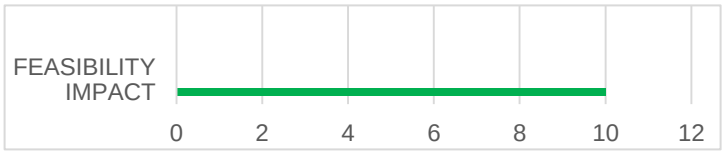
Clinicians need a coherent set of tools that seamlessly integrate a broad set of data collected through the EHR and external devices in order to provide the care their patients need. With this in mind, the Enhanced Registry is a data repository that houses data collected from various places in the system and is able to provide clinicians with a coherent view of their patient population. It allows practitioners to identify population at risks and find treatment protocols that are most efficient.

HOW IT WORKS

The Enhanced Registry is able to extract the relevant data point and automatically populate Population Management and Pre-Visit Planning Reports with the information needed for clinical support. It also provides the information needed to calculate the process and outcome measures the network has agreed to track over time. The QI reports include graphical representations of the performance of the network against these measures and identify for each center the data quality issues observed over time for the teams to correct on their own. This bundle of tools provide centers with a view of their performance at a system, network, clinical and patient level, allowing them to make informed decisions with positive impact at all levels of the system.

INTERVENTIONS INCLUDED

- Pre-Visit Planning
- Population Management
- BP Flowsheet
- Treatment Protocol
- QI reports



POPULATION MANAGEMENT

Create a Population Health Management system to aggregate patient data into a single patient record to drive action.

- Population Health Management is the aggregation of patient data through health information technology resources, the analysis of that data into a single, actionable patient record, and the actions through which care providers can improve both clinical, and functional outcomes.
- Review complete list of patients and whether they are achieving therapeutic goals and what therapy they are on.
- Systems to auto-generate / generate on demand population management reports.

PRE-VISIT PLANNING

Create a system for comprehensive & precise pre-visit planning

Pre-visit planning involves the multi-disciplinary team reviewing available patient data and goals and making a specific plan for each visit even before it happens. In this way, time during the visit can be maximized for the greatest benefit. Pre-visit planning can mean the difference between a clinic where physiciasn and staff are floundering and frustrated and a clinic that runs smoothly with the capacity to handle any unanticipated issues that arise. System would include:

- Availability of a standardized template for performing pre-visit planning
- Adequate, timely and thorough preparation and documentation by care team before visit · Patient family engagement and input into pre-visit planning
- Application of appropriate protocols to lab monitoring and to recommendations / suggested actions
- Appropriate use of visuals and trends to facilitate decision making
- System for collecting feedback on pre-visit planning effectiveness and on execution of suggested actions
- Clinical team and patient initiated goals incorporated into process

BP FLOWSHEETS

The Enhanced Registry can receive data from centers using flow sheets that are either built as Case Report Forms (CRFs) or integrated into an EMR through a smartform or equivalent.

QI REPORTS

IMPROVE BLOOD PRESSURE CONTROL

The Enhanced Registry issues QI reports on demand that show how a center performs against the network aggregate data on key outcome and process measures. The QI reports also include information on data quality issues pertaining to the centers, as a way to encourage staff to correct identified errors in the database.

KEY DRIVERS

- Key Driver #1: Accurate measurement and appropriate classification of measured SBP at clinic visit
- Key Driver #2 : Prescription of appropriate therapy for SBP control
- Key Driver #3 : Timely assessment of response and appropriate adjustment to therapy

WHO DOES THIS PACKAGE IMPACT?

KEY METRICS

- Systolic Blood Pressure Control (2)
- Data Quality Measure (TBD

TARGET

All Centers

PROTOTYPING CENTERS

Stanford, Emory, Boston, Colorado, Seattle, CCHMC, Michigan, Columbus, Riley

ENHANCEMENT IDEAS

In order to strengthen the intervention package, centers recommend including network driven data analytics around medications and blood pressure control. Finding ways to include patient reported blood pressure measurement before a visit and capture that information in the Pre-Visit report would be very helpful as well. All results, either from the patients themselves, or ancillary services (labs, pharmacy, etc.) should be captured by the EMR and available when the clinical team reports the encounter. The population management tool and pre-visit planning tool could also provide recommendations for medication treatment.

FACILITATING CONNECTIONS

CREATING AN IROC COMMUNITY

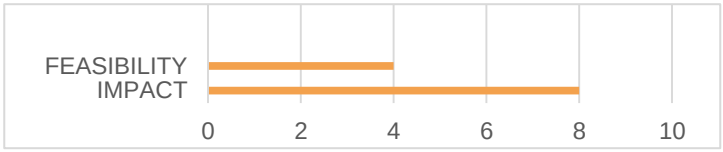
Evidence shows that the more connected to a community of patients are the better their clinical outcomes. Having a group of peers to rely on, either in person or virtually is key. This package includes interventions that aim to create the bonds that will help patients and their families become better educated and prepared to what lays ahead.

HOW IT WORKS

In today's world, virtual connections are taking a predominant role and young patients relate to peers over the internet, as well as if they were physically present. Therefore, building an IROC facebook community, and complementing this platform with a solid mentoring program can help make striking progress in the care of kidney transplant patients. Adding the possibility to attend group visits, can reinforce the notion of being part of a group of peers, and help forge the needed connections to support better outcomes.

INTERVENTIONS INCLUDED

- Customized/Themed Group Visits
- IROC Facebook Community
- Mentoring Program for Patients & Families



CUSTOMIZED/THEMED GROUP VISITS

Group visits set up by themes/focuses for specific populations or needs (e.g. - teen clinic, weight concerns clinic, etc.)

- Dedicate clinic dates to a specific population to provide support/transition focus.
- Specific months may be dedicated to relevant topics (e.g. - phosphorus in the diet, exit site care, etc.)
- Sites could use educational quality metrics to assess which educational/social objectives were covered. · Physician and care team (including social worker, dietician, etc) could be scheduled for 1-on-1 time and then group time to address any questions.

IROC FACEBOOK COMMUNITY

- Build a social network presence for IROC to offer support and share ideas.
- T1D's CGM in the Cloud Facebook Community for an example of success in action

MENTORING PROGRAM FOR PATIENTS & FAMILIES

Create a mentoring program that connects patients/families facing new or challenging medical experience with trained, veteran parents.

- Mentors are trained to provide support, modeling, suggestions and validation to families.
- Mentors share information and coping skills to help families reduce stress and manage their child's healthcare in a positive way.
- Patient / family communication and information sharing forums enabled by intent, support and technology
- Appropriate support from hospital and community resources to encourage such mentoring and information sharing
- Building / enhancing trust and faith through encouragement, inspiration and support system created by patients/families
- local, in-person, and supported by centers. start family mentor program in addition to pre-existing peer mentors

KEY DRIVERS

- Key Driver #1: Empowered and self-aware caregivers and patients
- Key Driver #2: Easy access to information, care and medications
- Key Driver #3 : Effective use of shared decision making/ co-production
- Key Drive #4: Adequate self-management levels per age?
- Key Drive #5: Robust psychosocial support
- Key Drive #6: Smooth transitions through life and care phases

WHO DOES THIS PACKAGE IMPACT?

IMPROVE QUALITY OF LIFE

KEY METRICS

- QOL metric to be determined

TARGET

centers with adequate space and support for scheduling, coordinating, and facilitating

PROTOTYPING CENTERS

CHOP, Boston, NKF, CCHMC, Iowa, Michigan, Riley, CMH

ENHANCEMENT IDEAS

This is a package that may require enough resources and space to accommodate large patient population outreach programs. Patient outreach also needs to include diverse groups of families and specific forum targeting minority groups might be required.

SHOW ME THE WAY

EMPOWERED COMMUNICATION TO CLARIFY THE PATH AHEAD

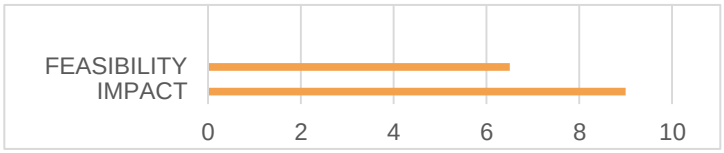
In order to see the path forward, patient families need to feel connected to their care system, aware of where they are on the journey, and keep apprised of what's to come. This intervention package is designed to help families and their care teams stay in touch with the post-transplant care process, and to manage the process of growth and change by staying ahead of the curve, providing a constant and reassuring voice of clarity in the fog of post-transplant care.

HOW IT WORKS

This package provides empowerment through *clarity*, *direction* and *connection* between stakeholders. By combining a cloud-accessible Road Map, an easy-to-understand Patient Report Card, a system for Medication Tracking and an advanced Patient/Provider Communication system, patient families and their care teams will have an always-on and accessible look at the state of the patient's journey and can look ahead and prepare for upcoming changes and potential roadblocks to patient success.

INTERVENTIONS INCLUDED

- Caregiver's Virtual Road Map
- Patient Report Card
- Medication Charts & Tracking
- Patient/Provider Communication System



CAREGIVER'S VIRTUAL ROAD MAP

Create an online binder that serves as a "Road Map" to guide Caregivers through each stage of post-transplant care.

- Would be constantly available and continuously refreshed with new and relevant content, divided into stages.
- May even offer "push" email updates of stage-specific content based on time-since transplant, child's age, user-inputted conditions or vectors (similar to parents.com's "Your child at 4 years" style emails)

PATIENT REPORT CARD

A Report Card that is given at each visit that can help caregivers and patients between visits.

- Based on what patients feel not just lab results
- Digital or hard copy
- Plain, clear language
- Compare results to other patients / larger population
- Sticker Charts
- Online reporting

FAMILY-FRIENDLY MEDICATION CHARTS & TRACKING

Create easy-to-follow medication charts designed for kids and parents and that can be used at each visit to ensure medications, doses and their purposes are clear for everybody.

- Chart templates could be designed by educational specialists with age-appropriate visuals/language
- Chart could be digital or physical or both and would be updated at clinic visits, then used at home.

PATIENT/PROVIDER COMMUNICATION SYSTEM

Develop a system to enhance the interactions between patients / families and providers / care team by using a questionnaire for patients/families to complete that would be an assessment of how well things were working or not relative to their post transplant status. The system would have several features which encourage productive interactions, including one where patients/families are empowered with a pause card / flag that they get to throw when they have questions.

KEY DRIVERS

- Key Driver #1: Empowered and self-aware caregivers and patients
- Key Driver #2: Easy access to information, care and medications
- Key Driver #3 : Effective use of shared decision making/ co-production

WHO DOES THIS PACKAGE IMPACT?

IMPROVE QUALITY OF LIFE

KEY METRICS

- QOL metric to be determined

TARGET

All pediatric transplant centers

PROTOTYPING CENTERS

CHOP, Seattle Children's, Boston

ENHANCEMENT IDEAS

This package could be improved if it includes a way for Patient family to provide feedback through the report card. The latter should be seen as a way to create a dialogue between families and clinicians. The roadmap should be customizable to highlight specific problems and remedies. Simple language should be used as much as possible.