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| **A. General Information** |  |  | | | | | | |  |  | | |  | |  | | | |  | |
| ***Project Title & Project #:*** | Improving Fontan Advanced Heart Failure Referral | | | | | | | | | | | | | | | | | | | |
| ***Department/Division/Team:*** | ***ACTION Network*** | | | | | | | | | | | | | | | | | | | |
| ***Population:*** | Fontan patients of any age receiving a consultation from the HF/VAD/HTx team (inpatient or outpatient) | | | | | | | | | | | | | | | | | | | |
| ***Brief Project Description (AIM):*** | The goal is to improve timely referral which may lead to better outcomes for both VAD therapy and before and after transplant. | | | | | | | | | | | | | | | | | | | |
| ***Measures:*** | To decrease the % of Fontan patients who need medical care escalation within 30 days of 1st consultation with HF/VAD/HTx service from 38% (12/2022) to 20% (by 10/2025, 2-year timeframe) | | | | | | | | | | | | | | | | | | | |
| ***Prepared By:*** | Kurt Schumacher, Sharon Chen & Project Leadership | | | | | | | | | | | | | | | | | | | |
| ***Date:*** | Began project design: 1/28/20  Project roll-out: 7/9/20  Project revision roll-out: 10/2/2023 | | | | | | | | | | | | | | | | | | | |
| **B. Project Background:** |  |  | | | | | | |  |  | | |  | |  | | | |  | |
| Individuals born with very complex congenital heart disease sometimes undergo a Fontan surgery to help them live. This surgery is excellent for allowing infants who otherwise might die early in childhood to live into adulthood. The Fontan surgery, however, has a unique set of complications and many individuals who have had a Fontan surgery end up requiring a heart transplant during childhood or as an adult. The current project aim is to assess when individuals with a Fontan heart are being referred to specialists in advanced heart failure cardiology and whether or not clearly defining patient issues or events that should prompt referral will improve patient experiences and outcomes after referral and after possibly VAD or transplant.  Fontan patients are expected to nearly universally require advanced heart failure care at some point during their lifetime, but exactly when that will occur varies greatly. There are no standardized guidelines dictating thresholds for referral for advanced HF care in this population. Outcomes after referral (anecdotally) and then VAD or transplant are worse among Fontan palliated patients than among two ventricle patients. Part of the reason for worse outcomes may be delay in referral, after irreversible damage has been done to end organ function or after patients have clinically deteriorated to such a degree that any intervention is high risk. A recent ACTION study demonstrated that a high proportion of patients require esacaltion to advanced therapies immediately upon referral to heart transplant, and nearly 10% were already deemed too ill to even be a candidate for advanced therapies. | | | | | | | | | | | | | | | | | | | | |
| **C. Project Scope (and exclusions)**: | | | | | | | | | | | | | | | | | | | | |
| The project seeks to decrease the proportion of Fontan patients who require immediate escalation to advanced therapies upon referral, as well as continue to define variables indicative of care escalation within 30 days of 1st consultation, and to define current practice in referral of Fontan patients for consultation with HF/VAD/HTx service.  **Inclusion:** Fontan patients of any age receiving a consultation from the HF/VAD/HTx team. May be inpatient or outpatient. Fontan patients have care escalated *at the same time/during same admission* as the initial HF/VAD/HTx consultation count as a “escalation event”.  **Exclusion:** Patients must have been discharged home from the hospital AFTER Fontan surgery PRIOR to the initial HF consultation to be eligible.  Population will be collected prospectively from ACTION centers. Data entry will begin right after the clinician sees a patient in clinic, on consultation, or as an inpatient. However, the clinician will not yet know the outcome at that time. The person entering the initial REDCap data will receive another short survey **30 days later** to complete the “outcome” data for each patient entered.  Two interventions are being developed to launch in October/November 2023.   1. **Grand Rounds** slide deck for provider education will be shared with the project cohort sites. Pre- and post- presentation surveys will be administered to measure cardiologists’ responses of feeling satisfied about the helpfulness/usefulness of slides and helpfulness/usefulness of the presentation content, as well as measure the likelihood the cardiologists will use the presentation. 2. **Fontan Surveillance Roadmap** that will help users know when a patient should be referred for advanced therapies, as well as recommendations for testing & surveillance. Use of the roadmap will be measured. (provider version & patient/family versions) | | | | | | | | | | | | | | | | | | | | |
| **D. High Level Timeline/Schedule (including Data Entry timepoints):** | | | |  |  | |  | | | |  | | |  | |  | | | |  |
| The baseline project rolled out to the network on July 9, 2020, after the *Advanced Heart Failure Consultation: When and Why Should We Refer Fontan Patients learning session webinar,* presented by Kurt Schumacher, MD.  The revised project will roll-out Fall 2023. The data colletion will resume in October 2023 to strengthen our basline data. The new interventions will begin October/November 2023.   * Baseline data collection (data entry): July 2020-July 2022 (2 years) * Design Phase: August 2022 – March 2023 * Development and implementation of interventions: March 2023-October 2023 * Follow-up data collection (data entry) and intervention roll-out: October 2023-October 2025 (2 years) | | | | | | | | | | | | | | | | | | | | |
| **E. Communication & Expectations:** | | | | |  | |  | | | |  | | |  | |  | | | |  |
| All ACTION sites with a completed IRB/DUA are welcome to be involved in this QI project (consent is not required for QI/non-human subjects research). Email [info@actionlearningnetwork.org](mailto:info@actionlearningnetwork.org) or complete the survey sign-up by **10/13/23** to inform us of your intent to participate. Please also inform us of any additional team members from your site that will need to be added to the project and ACHD/Fontan Committee.  Updates and learnings for this project will be discussed during the monthly ACTION ACHD/Fontan Committee, which meets the 3rd Tuesday of each month at 3pm ET. It’s OK if you are not ablet to attend this meeting, you can still participate in the project. Referral data will also be shared on these monthly meetings.  Link to baseline REDCap survey: <https://redcap.research.cchmc.org/surveys/?s=XMYPEAJLPR>  The baseline survey should be completed **within 5 days** of seeing the patient. The 30-day outcome follow-up survey should also be completed **within 5 days** to remain compliant with good standing data entry for the project. | | | | | | | | | | | | | | | | | | | | |
| **G. Project Risks & Mitigation**: | | | | | | | | | | | | | | | | | | | | |
| **Risk** | | | **Level (high/med/low)** | | | | | | **Mitigation and Escalation Strategy** | | | | | | | | | | | |
| Project is voluntary – we may miss some of the Fontan population in our network. | | | Low | | | | | | We will work to encourage all applicable ACTION sites to participate in this project. | | | | | | | | | | | |
| **F. Roles and Responsibilities** | |  | | | |  | | | | |  |  | | | | |  |  | | |
| **Sponsor/Champion:** Provides overall direction on the project. | | | | | | | | | | | | | | | | | | | | |
| **Name** | | | | | | | | **Title/Role** | | | | | | | | | | | | |
| Angie Lorts, MD, MBA | | | | | | | | ACTION Co-Executive Director | | | | | | | | | | | | |
| David Rosenthal, MD | | | | | | | | ACTION Co-Executive Director | | | | | | | | | | | | |
| **Team Leader:** Leads the team and provides guidance on scope of the project. | | | | | | | | | | | | | | | | | | | | |
| **Name** | | | | | | | | **Title/Role** | | | | | | | | | | | | |
| Kurt Schumacher, MD | | | | | | | | ACHD/Fontan Committee Leader | | | | | | | | | | | | |
| Kathleen Simpson, MD | | | | | | | | ACHD/Fontan Committee & Fontan Referral Project Leader | | | | | | | | | | | | |
| Ari Cedars, MD | | | | | | | | ACHD/Fontan Committee Leader | | | | | | | | | | | | |
| Shahnawaz Amdani, MD | | | | | | | | Fontan Referral Project Leader | | | | | | | | | | | | |
| Sharon Chen, MD | | | | | | | | Fontan Referral Project Leader | | | | | | | | | | | | |
| Thomas Glenn, MD | | | | | | | | Fontan Referral Project Leader | | | | | | | | | | | | |
| **Project Support** (**QIC/QOM/Data Analytics/Project Manager Support):** Leads in the planning & development of the project; manages the project to scope and/or provides data analysis and reporting expertise for the project. | | | | | | | | | | | | | | | | | | | | |
| **Name** | | | | | | | | **Title/Role** | | | | | | | | | | | | |
| Lauren Smyth | | | | | | | | Project Manager | | | | | | | | | | | | |
| Christy Larkins | | | | | | | | Sr. Specialist – Project Support | | | | | | | | | | | | |
| Toni Duganiero | | | | | | | | Sr. Specialsit - Data Management | | | | | | | | | | | | |
| Anaam Alzbui | | | | | | | | Sr. Data Analyst | | | | | | | | | | | | |
| Muhammad Farrukh | | | | | | | | Staff Scientist | | | | | | | | | | | | |
| **Team Members:** Works toward the deliverables of the project. | | | | | | | | | | | | | | | | | | | | |
| **Name** | | | | | | | | **Title/Role** | | | | | | | | | | | | |
| ACHD/Fontan Committee & Project Cohort Sites | | | | | | | |  | | | | | | | | | | | | |
| **Family/Patient Representative:** | | | | | | | | | | | | | | | | | | | | |
| **Name** | | | | | | | | **Title/Role** | | | | | | | | | | | | |
| Families in ACTION | | | | | | | |  | | | | | | | | | | | | |
| Enduring Hearts | | | | | | | |  | | | | | | | | | | | | |