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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 increase the % of Fontan patients who do not need medical care escalation within 30 days of 1st consultation with HF/VAD/HTx service from x to y by DATE (TBD) | | | | | | | | | | | | | | | | | | | | | |
| ***Prepared By:*** | Kurt Schumacher | | | | | | | | | | | | | | | | | | | | | |
| ***Date:*** | Began project design: 1/28/20  Project roll-out: 7/9/20 | | | | | | | | | | | | | | | | | | | | | |
| **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 advance 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 during their lifetime. There are no standardized guidelines dictating thresholds for referral for advanced HF care in this population. Outcomes after referral (anecdotally) and after 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 extremely high risk. | | | | | | | | | | | | | | | | | | | | | | |
| **C. Project Scope (and exclusions)**: | | | | | | | | | | | | | | | | | | | | | | |
| The project seeks 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. | | | | | | | | | | | | | | | | | | | | | | |
| **D. High Level Timeline/Schedule (including Data Entry timepoints):** | | | | |  |  | |  | | | | |  | | |  | |  | | | |  |
| This project is rolling out to the network on July 9, 2020, after the *Advanced Heart Failure Consultation: When and Why Should We Refer Fontan Patients learning serssion webinar,* presented by Kurt Schumacher, MD. We are starting this project to collect baseline data. We are not developing or testing any interventions at this time.  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. | | | | | | | | | | | | | | | | | | | | | | |
| **E. Communication & Expectations:** | | | | | |  | |  | | | | |  | | |  | |  | | | |  |
| All ACTION sites with a completed IRB/DUA are welcome to be involved in this project. Lauren Smyth will send a survey to invite centers to participate, and responses will be due by **7/16/20**. We will ask each participating center to identify 1 point person for the project, but anyone on the project team can enter data in REDCap.  The REDCap survey asks for an “ACTION ID.” Participating centers will need to create new ACTION ID’s for these patients and keep their own list of ID’s (since these patients will not be entered into the ACTION registry, unless they receive a VAD – please use the same ID for the ACTION Registry if the patient does receive a VAD). Centers will need this ID number to refer back to when they go to complete the 30-day outcome follow-up survey. We would suggest using an ACTION ID system that separates your Fontans from your VAD patients and your HF patients to avoid confusion.  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** | | | | | | | | | | | | |
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| **F. Roles and Responsibilities** | | | |  | | |  | | | | |  | |  | | | | |  |  | | | |
| **Sponsor/Champion:** Provides overall direction on the project. | | | | | | | | | | | | | | | | | | | | | | | |
| **Name** | | | | | | | | | **Title/Role** | | | | | | | | | | | | | | |
| Angie Lorts | | | | | | | | |  | | | | | | | | | | | | | | |
| David Rosenthal | | | | | | | | |  | | | | | | | | | | | | | | |
| **Team Leader:** Leads the team and provides guidance on scope of the project. | | | | | | | | | | | | | | | | | | | | | | | |
| **Name** | | | | | | | | | **Title/Role** | | | | | | | | | | | | | | |
| Kurt Schumacher | | | | | | | | |  | | | | | | | | | | | | | | |
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| **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 | | | | | | | | | | | | | | |
| Paige Krack | | | | | | | | | Quality Improvement Consultant | | | | | | | | | | | | | | |
| Tricia Heile | | | | | | | | | Data Analyst | | | | | | | | | | | | | | |
| Chloe Connelly | | | | | | | | | Data Analyst | | | | | | | | | | | | | | |
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| **Team Members:** Works toward the deliverables of the project. | | | | | | | | | | | | | | | | | | | | | | | |
| **Name** | | | | | | | | | **Title/Role** | | | | | | | | | | | | | | |
| Matthew O’Conner | | | | | | | | |  | | | | | | | | | | | | | | |
| Kathleen Simpson | | | | | | | | |  | | | | | | | | | | | | | | |
| Ari Cedars | | | | | | | | |  | | | | | | | | | | | | | | |
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| **Family/Patient Representative:** | | | | | | | | | | | | | | | | | | | | | | | |
| **Name** | | | | | | | | | **Title/Role** | | | | | | | | | | | | | | |
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| **H. Signatures** | | | | | | | | | | | | | | | | | | | | | | | |
| **Sponsor/Champion:** | | | | | | | | | | | | | | | | | | | | | | | |
| **Name** | | | | | | | | | **Signature** | | | | | | | | | | **Date** | | | | |
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| **Team Leader:** | | | | | | | | | | | | | | | | | | | | | | | |
| **Name** | | | | | | | | | **Signature** | | | | | | | | | | **Date** | | | | |
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