Learnings from our CoIIN project: Team Oregon

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March 24, 2020

INTRODUCTION

The Oregon team selected transition to adult healthcare from the six options presented in HRSA's 2017 CoIIN Notice of Funding Opportunity. We selected transition to align our CoIIN project with our Title V Block Grant NPM 12 work. We focused our work specifically on the transfer from pediatric to adult primary care based on the results of our environmental scan and the expectation that adult primary care could help facilitate transition between pediatric and adult specialists. The purpose of this brief is to summarize learning from implementation of our clinic-based quality improvement (QI) project, our team processes and the ways in which we have sought to disseminate our learnings.

Our current QI project is situated within OHSU Doernbecher General Pediatrics and Adolescent Health Clinic. Our team operationalizes "medical complexity" using the complex chronic disease category of the Pediatric Medical Complexity Algorithm (PMCA; Simon et al., 2014). Because our CoIIN problem statement focuses on the transfer of care, our implementation team identifies young adults with medical complexity (YAMC) who are aged 17 and older and seen in the General Pediatric clinic.

QUALITY IMPROVEMENT PROJECT LEARNING

After completion of our environmental scan, our Advisory Team prioritized root causes of our problem statement, explored three potential QI project options, and consulted with BU and our state coach to reach agreement on the nature of our clinical intervention. Our Implementation Team[1] envisioned a three-stage process for transferring a young adult with medical complexity (YAMC) from their pediatric primary care provider (PCP) to an adult PCP: (1) education about medical home, (2) development of health passport, and (3) preparation for identifying an adult PCP. We began recruitment and implementation in September 2019; Exhibit 1 summarizes our recruitment and implementation workflow. The exhibit also presents the number of patients in each step of the workflow as of December 2019. As of January 2020, we had not progressed beyond stage 1. Our learnings to date cluster into three levels: (a) pediatric provider, (b) patient / family, and (c) institutional.

Exhibit 1. Number of Young Adults By Stage 1 Workflow Action Step (Sept-Dec 2019)

Step	Action	Number
1	Clinical partners run report to identify YAMC ages 17 and older coming into the clinic in the coming 2 weeks who are eligible for the project	41
2	Clinic partners ask YAMC's PCP whether they can approach the YAMC/family about the project	
	Yes	15
	No or No Response	26
3	If yes, clinic team approaches YAMC/family after appointment and asks if they are interested	

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[1] Ana Valdez; BranDee Trejo; Marilyn Berardinelli, BS; Raúl Vega-Juarez, BS; Reem Hasan, MD, PhD; Reyna Lindert, PhD, RN; and our Core Team.

Step	Action	Number
	Yes	8
	No or No Response	2
	Did not attend appointment	4
	Already transferred care	1
4	If yes, clinic team introduces to project, consents YAMC/family into study, and	8
	Arranges a follow up contact	7
	Will contact family to arrange a follow up (family was unsure of next appointment)	1
5	Clinic team attempts to contact YAMC/family at agreed on date/time	
	Clinic team is able to reach YAMC/family	1
	Clinic team is not able to reach YAMC/family	1

Pediatric Provider

1. Pediatric PCPs showed reluctance to have their patients participate, which was unexpected. Providers prevented our clinic team from approaching most (63%) eligible patients.
2. Providers gave the following reasons for declining patient participation: (a) provider determination that the YAMC was not ready, (b) YAMC experiencing active health problems, or (c) provider desire to keep patient in their panel.

Patient

3. Of the 15 YAMC that PCPs identified as approachable for this project: 8 enrolled, 4 did not attend their appointment, and 2 declined to participate.
4. YAMC/family reasons for declining participation were: (a) lack of time to prioritize care transfer: families of medically complex children have competing medical priorities, transition may not be high-priority; (b) preference for staying with current provider (there are socio-emotional implications of leaving a familiar pediatric provider with whom the family and young adult has an established relationship); and (c) preference for obtaining a specific referral to adult provider in lieu of a multiple stage approach.
5. Our family representatives shared that families face numerous barriers to attending appointments in person with a medically complex child, which include in-clinic wait times and obtaining time away from work. They also explained that it may be difficult to prioritize transition, an event that will not immediately occur, given the daily needs of their child.
6. We expected that families would appreciate a phone option for transition preparation with nurses; however, nurses have not been successful reaching families by phone.

Institutional

7. The clinic lacks a policy identifying the age after which pediatric patients must transfer to adult care. Reasons for the lack of policy include: (a) pediatric residents care for many patients. Residencies last for three years, so the clinic would wait to transfer a 17 year or older patient until the provider finished their residency; (b) pediatric providers often transfer their patients to the adolescent health care providers, who keep their patients until they are 24 years old; and (c) a single policy for all providers not feasible because of different timelines for transition.

8. A particular EPIC text field is an important mechanism for clinic nurses to alert each other about a patient's enrollment and status in the intervention so that if the nurse who enrolled the YAMC/family is not in clinic, the next time the YAMC/family come in, another nurse can follow up with the YAMC/family.
9. We sought to expand our revised intervention to OHSU's Westside Clinic after one of their pediatric PCPs approached us about working with their clinic. Competing quality improvement projects coupled with limited nurse availability (maternity leave, open position) prevented their clinic from joining now.
10. Clinics are limited in the number of Medicaid-insured patients they can accept because of lower rates of service reimbursement compared to private insurers.

FAMILY INVOLVEMENT AND TEAM FUNCTIONING

A primary goal of our project's Core Team was to create a setting in which our external-to-OHSU Family Representatives (FR) could feel empowered. We have accomplished this goal as both FRs have shared (by their own volition) that they feel empowered. Exhibit 2 presents the activities that collectively we have identified as important for creating such a setting.

Exhibit 2. Activities to Promote Family Involvement

- Alert new partners that family involvement is a value of our project, and FRs are equal team members.
- Allocate budget to reimburse time, transportation, and provide supplies (e.g., pens, notepads, file folders, etc.).
- Create opportunity for FRs to present during project or professional meetings.
- Hold preparatory meetings in advance of team meetings to introduce new content or practice presentations.
- Invite FRs to represent CMC in Oregon's Title V needs assessment prioritization process.
- List meeting participants alphabetically in agendas and notes.
- Model asking for FR input during meetings and adding explicit agenda time for their input.
- Schedule meeting times and locations flexibly.
- Use consensus-based decision-making (everyone's vote is equal).
- Use first names instead of titles.
- Use participatory research approach for environmental scan.

Our team places strong value in building a culture of open communication and trust among our multidisciplinary team members. Our implementation team meeting discussions sometimes highlight the challenges that families and providers generally have when seeking/providing health care for a YAMC. Our PI and Project Coordinator acknowledge when one of our team members has bravely shared a challenging experience, celebrate accomplishments of all team members, and thank all of our team members for the way that collaborate for this project. Team members also thank each other for sharing their perspectives.

PAYMENT AND FINANCING

Our root cause analysis identified the lack of payment for transfer care and services as one of the roots of our problem statement. Payment also is essential for sustaining clinic-based transfer of care services. Peggy McManus and Annie Schmidt met with members of our implementation team in September 2019 to strategize about payment options and building a path for testing alternative payment methods. Following this meeting, our team began to gather information about the use of potential existing codes in Oregon (listed provided by Ms. McManus and Schmidt) and incorporate this work into our Title V Block Grant strategic planning. Currently, we are planning a payment code scenario to discuss with our Advisory Team members, clinical partners and Medicaid representatives.

KNOWLEDGE SPREAD

We have shared project learnings at multiple venues. In Oregon, we presented at the Oregon Pediatric Improvement Partnership (OPIP) partners' meeting in December 2019 and the OHSU Transition Taskforce in February 2020. These opportunities allowed to us explore project expansion and brainstorm about implementation challenges. Our poster proposal to the 2020 Pediatric Academic Society was accepted, which we planned to use as a preparatory step for writing a manuscript about our initial implementation experience. Additionally, our Family Representatives and PI presented at the 2019 AMCHP Conference. We are preparing two dissemination products about (1) the process for meaningfully engaging family representatives in quality improvement, and (2) the results of using a participatory approach to collecting data from YAMC families for our environmental scan. We are considering preparing a proposal in response to AAP's call for abstracts about children who experience complex medical conditions.

OUR QI PATH FORWARD

Our implementation team currently is unable to enroll patients into the project as OHSU has halted all non-essential clinical research due to the COVID-19 epidemic. Our implementation team, however, continues to plan for project improvement and expansion.

1. We shortened the intervention in January 2020 to reduce YAMC/family burden (see #4c above). The intervention now focuses on (1) preparing a Health Passport to hand over to adult provider (2) identifying an adult provider.
2. We are preparing to meet with Susan Labhard, MS, RN, Transition Coordinator, at Shriners Hospital in April 2020.
3. We have begun brainstorming the inclusion and identification of a clinical site in rural Oregon.

PRODUCTS

In addition to the documents previously linked in this summary, here are some additional products developed by our state CoIIN team