

Patient-Centered Care in Celiac Disease: A Collaborative Approach to Understanding Preferences for Timing, Type, and Providers of Care

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BACKGROUND

- Celiac disease (CD) is a common & serious autoimmune disorder¹.
 - Over 200 symptoms, such as poor growth, GI distress, brain fog, anxiety¹.
 - Only treatment: a strict gluten-free diet (GFD).
- Estimated that 40% of pediatric patients are non-adherent to the GFD^{2,3}.
 - Follow-up care is essential⁴⁻⁶.
- Leading celiac center in the US has a 91% follow-up rate⁷.
 - Colorado Center for Celiac Disease (CCCD)'s follow-up rate is 43%.
- Hypothesis: stakeholder-informed interventions will improve patient access to care, and ultimately a patient's adherence to a GFD and health outcomes.

METHODS

Phase one: define problem, investigate solutions

- 1. Enrollment in QI "Improvement Academy"
- 2. Using QI principles (DMAIC), identify barriers to follow-up & identify possible interventions.

Phase two: implementation of interventions

- 1. Universal EMR dotphrase
- 2. Patient newsletter

RESULTS

Main Barriers Identified

- 1. Inconsistent communication between clinicians & patients
- 2. Lack of easy patient tracking

Communication Intervention: Dotphrase Utilization By Medical Provider to **Patient** Open rate 36.0% .QICEL .CELNEXDX 382 opened Bounce rate 54% 79% 0.38%

Main Solutions Identified

- 1. Creation of dotphrase
- 2. CD-specific newsletter to foster sense of community

Communication Intervention: Newsletter

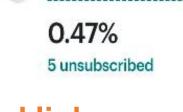
Total of 3 newsletters sent Most recent: 1,065 families











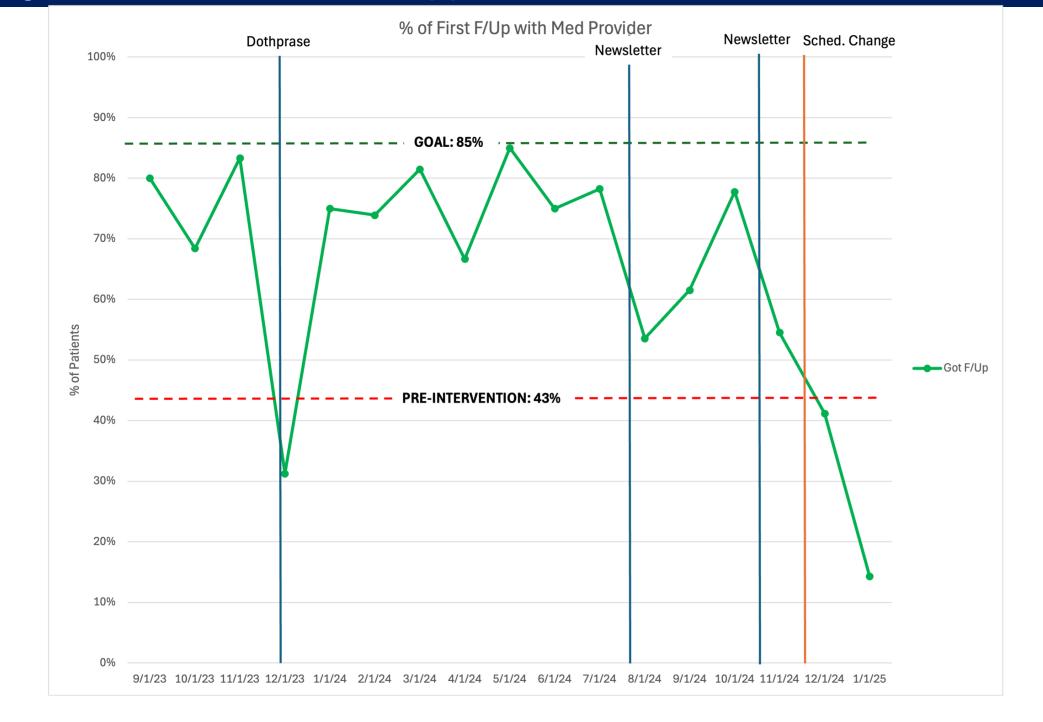
Most clicked links: community events (88% **Happy Spring!** Spring is a wonderful time to embrace

Quarterly Newsletter

Spring Edition | March 2025

Response to interventions

74% of all patients tracked during the time displayed returned for medical follow-up (though interventions do not appear to have direct correlation to results)



CONCLUSIONS

- **Barriers to Accessing Care:**
 - Communication & scheduling
- **Patients Requested:**
 - Newsletter to maintain engagement.
 - This has not impacted service utilization.
- **Prospective Data is needed:**
 - Patients are integral to identifying service utilization barriers & supports.
- **Limitation:** interventions are limited to this clinic & are unable to be generalized.

FUTURE DIRECTIONS

- Phase three:
 - Patient feedback surveys at multidisciplinary touchpoints in care.
 - Modify interventions based on feedback surveys.
 - Scheduling reminders to be sent to patients.

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