Assessing Health Literacy in Pediatric Type 2 Diabetes

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Team Members

- Site PI
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- QI Coordinator
  - Brooke Myers, MA

- Clinical Members:
  - Ingrid Libman De Gordon, MD PhD
  - Kathryn Williams, CRNP
  - Emir Tas, MD
  - Mary Ellen Vajravelu, MD

- CDCES
  - Brittaney Moore, DNP

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Background

- Health literacy (HL) defined as the degree to which an individual can understand medical terms about symptoms and illness, follow directions for procedures and therapies, and ask pertinent questions

- Current ADA and ISPAD guidelines emphasize the importance of HL in diabetes management

- ADA recommends using age-appropriate standardized and validated tools to screen for health literacy in youth with type 2 diabetes

Background

- Validated tools to assess HL in pediatrics are limited and not specific to diabetes
    - REALM-Teen(S): medical word recognition and reading level
    - HLSA: ability to understand and use health information effectively
    - PHLI: assesses understanding and application of health-related knowledge
- Adult HL tools specific to diabetes are more widely available
    - DKQ: assess understanding of key concepts of diabetes management
    - FCCHL scale, TOFHLA: HL in adults with diabetes
- **Currently no diabetes-specific health literacy instrument validated exclusively for pediatric type 2 diabetes**

Establishing Baseline

- Anecdotally, pediatric patients with type 2 diabetes appear to have poor outcomes, but it is unclear what the data show
  - *Data requested:*
    - *Average number of visits per year for Type 2 Diabetes patients, including no-show rate and average number of attended visits*
    - *Number of RD and CDCES visits per year*
    - *Average HbA1c levels for Type 2 Diabetes patients*
    - *Average duration of diabetes diagnosis within this age group (12-18 years)*
- Aim to assess baseline health literacy in our pediatric type 2 diabetes patients
  - Target interventions aimed at improving gaps in HL
  - Evaluate whether improved HL → decrease in comorbidities and contributes to better QOL
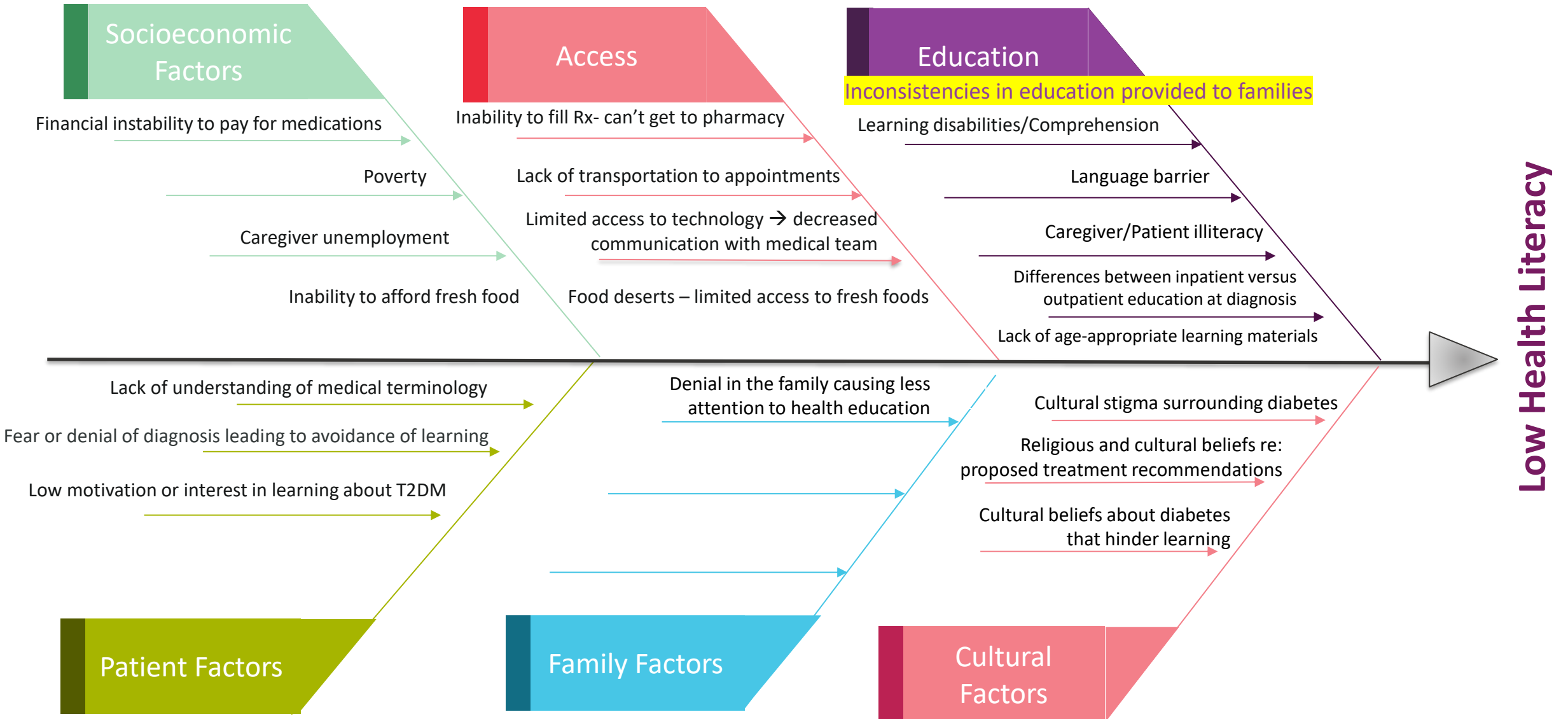
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Problem

- Less than 100% of patients ages 12-18 years with type 2 diabetes for at least 2 years have adequate health literacy about their disease, contributing to higher incidence of comorbidities and lower QOL

Fishbone Diagram

Socioeconomic Factors

Financial instability to pay for medications

Poverty

Caregiver unemployment

Inability to afford fresh food

Access

Inability to fill Rx- can't get to pharmacy

Lack of transportation to appointments

Limited access to technology → decreased communication with medical team

Food deserts – limited access to fresh foods

Education

Inconsistencies in education provided to families

Learning disabilities/Comprehension

Language barrier

Caregiver/Patient illiteracy

Differences between inpatient versus outpatient education at diagnosis

Lack of age-appropriate learning materials

Low Health Literacy

Patient Factors

Lack of understanding of medical terminology

Fear or denial of diagnosis leading to avoidance of learning

Low motivation or interest in learning about T2DM

Family Factors

Denial in the family causing less attention to health education

Cultural Factors

Cultural stigma surrounding diabetes

Religious and cultural beliefs re: proposed treatment recommendations

Cultural beliefs about diabetes that hinder learning

PRIORITIZE INTERVENTIONS

1. Provision of stipend/fresh food to those who screen positive for food insecurity
2. Provide consistent education to families (CHP team re-education)
3. Creation of age-appropriate learning materials on comorbidity risk
4. Increase technology use (CGM, Stello)
5. Optimize meter use (app)
6. Optimize treatment – educate providers
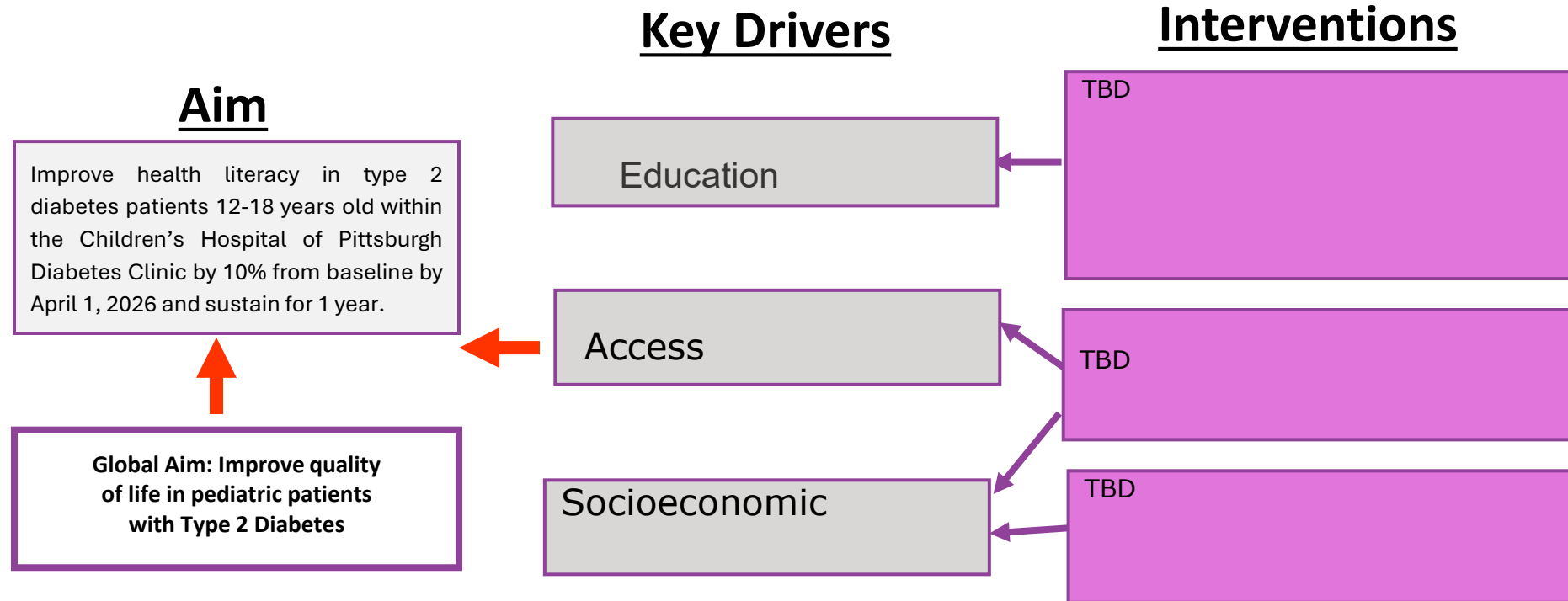7. Standardize education on comorbidity risk- Autotext for providers
8.
9.
10.

	Effort Impact Matrix	
	Low Effort	High Effort
High Impact	6 7 5	4 2 3
Low Impact		1

PDSA Cycles

#1 Administer HL survey to determine baseline gaps/opportunities

#2 Iteration of PDSA 1 - Expand to satellite clinics

#3 Meter use // Optimize treatment – educate providers

#4 Standardize education on comorbidity risk: Autotext for providers

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PDSA Cycle 1

- Determine baseline gaps/opportunities
  - **Plan:**
    - Create survey (Jan-April 2025)
      - Goal <10 questions
      - Multiple iterations with input from team (4 MD, 2 APP, 1 CDCES, 1 MA)
      - Inclusion criteria: Pediatric patients age 12–18 years with diagnosis of type 2 diabetes for at least 2 years [and their parents/guardians]
    - Administer survey to eligible patients/parents during T2DM clinics at main CHP over 4-week period
    - Goal 25 patients (18% of total population (137 patients))

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Question 1

DURATION OF DIAGNOSIS

Legend:
- 0-2 years
- 2-5 years
- >5 years
- I am not sure
- No Answer

Parents (outer ring): 42%, 15%, 9%, 9%, 9%, 40% (inner)
Inner ring values: 40%, 0%, 31%, 45%
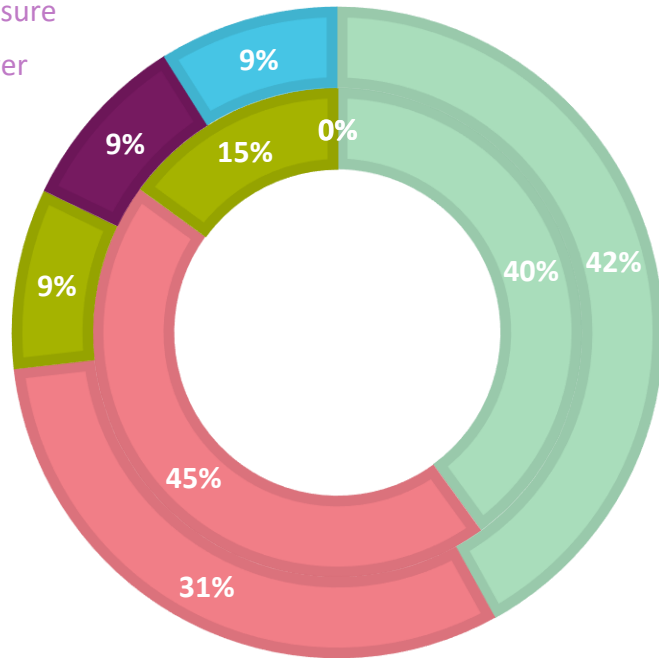
Question 2

UNDERSTANDING OF DIAGNOSIS

Legend:
- Very Well
- Some Understanding
- Little Understanding
- No Understanding

Outer ring: 0%, 30%, 50%, 70%
Inner ring: 5%, 0%, 45%, 70%
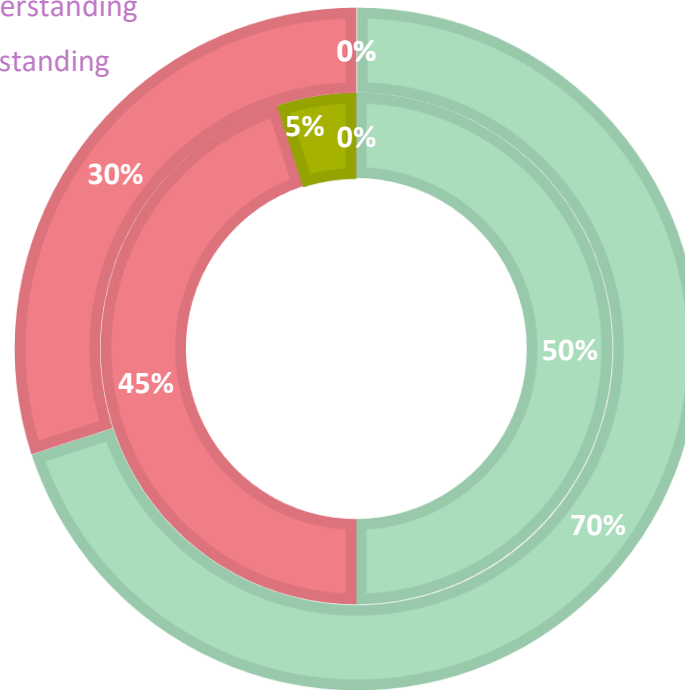
- >75% of patients/parents reported diagnosis within the last 5 years
- Half of patients and majority of parents reported very good understanding of their/their child's diagnosis
- Suggests regardless of recent diagnosis, patient/parent perception is that they have a good level of understanding of T2DM
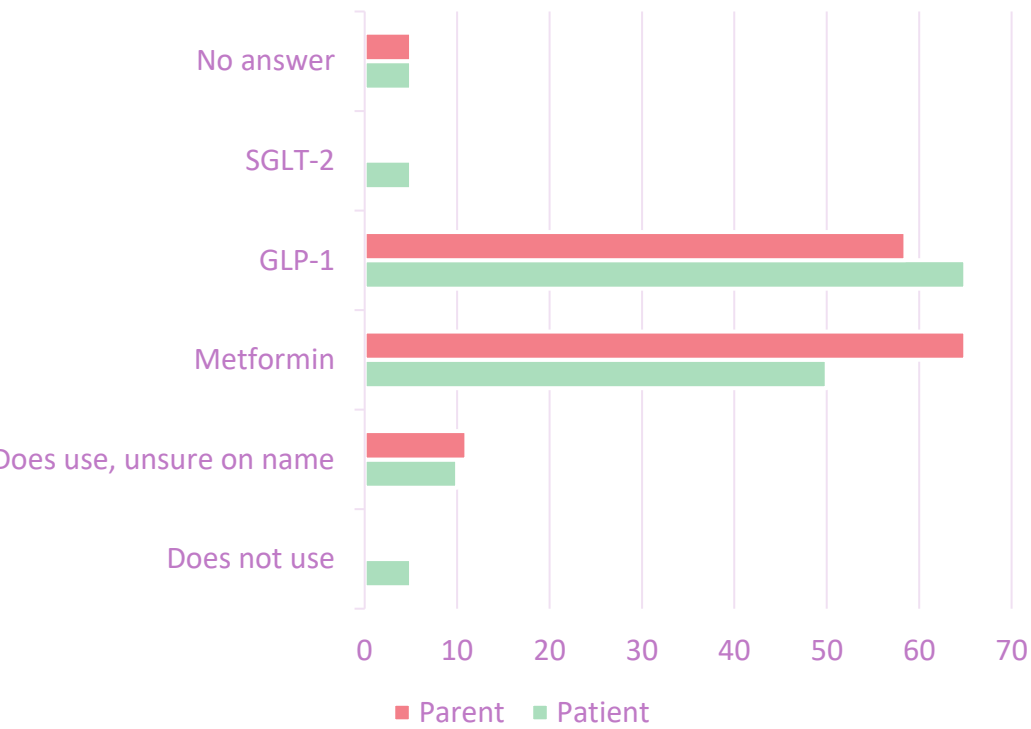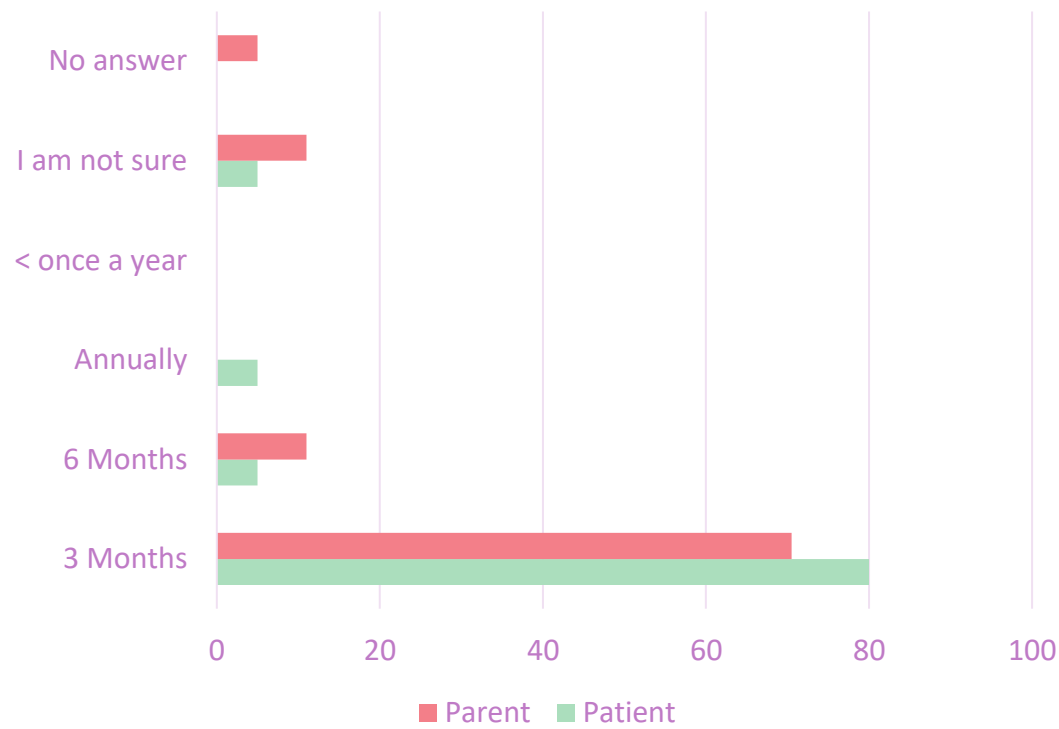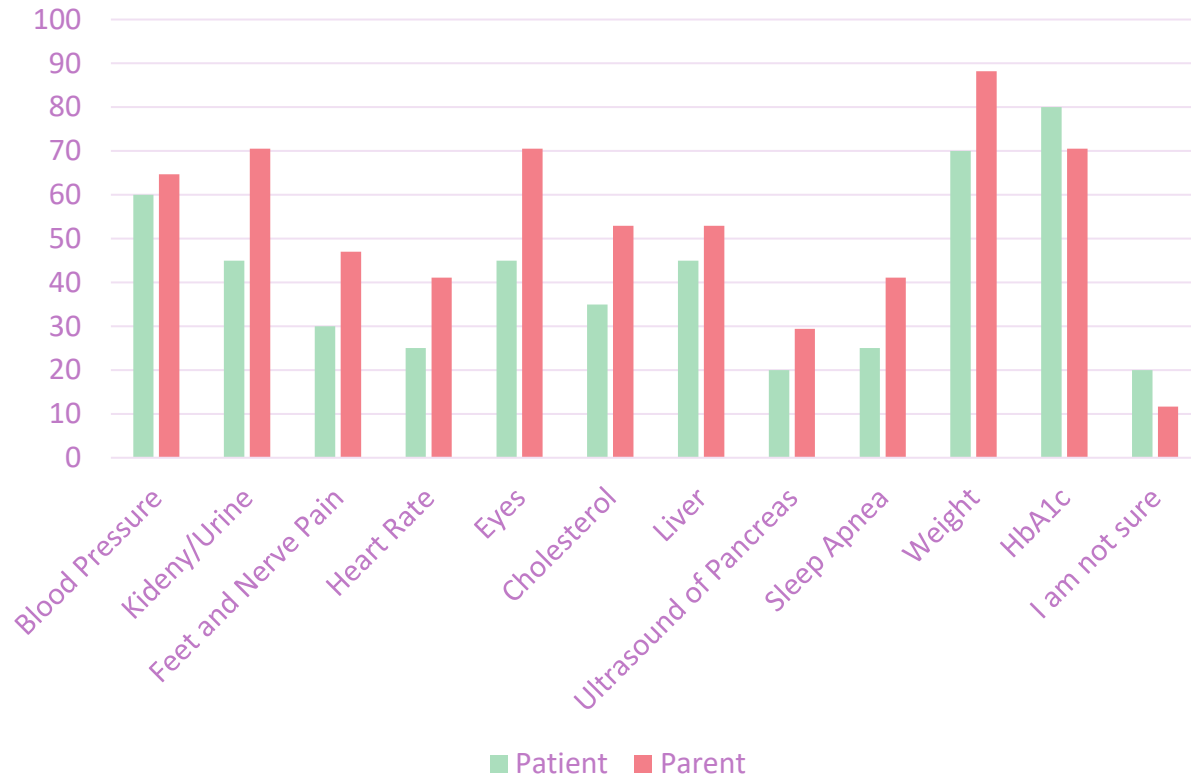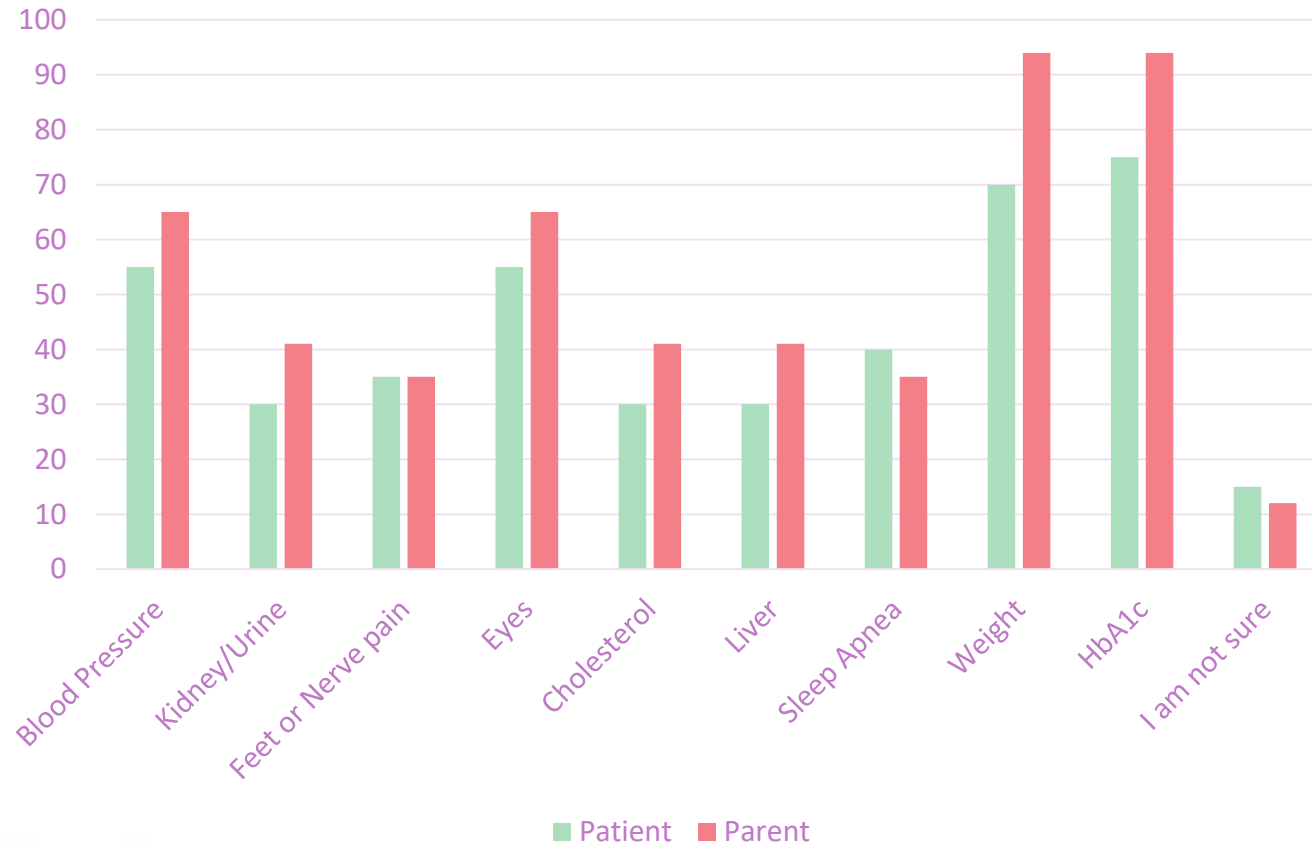
Question #5
Complications That Should Be Monitored

- HbA1c and weight were most frequently identified by both groups (patients: 80% and 70%; parents: 70.5% and 88.2%, respectively)
- Despite weight, HbA1c, and BP being routine measures at every visit, awareness was below 100% in both groups

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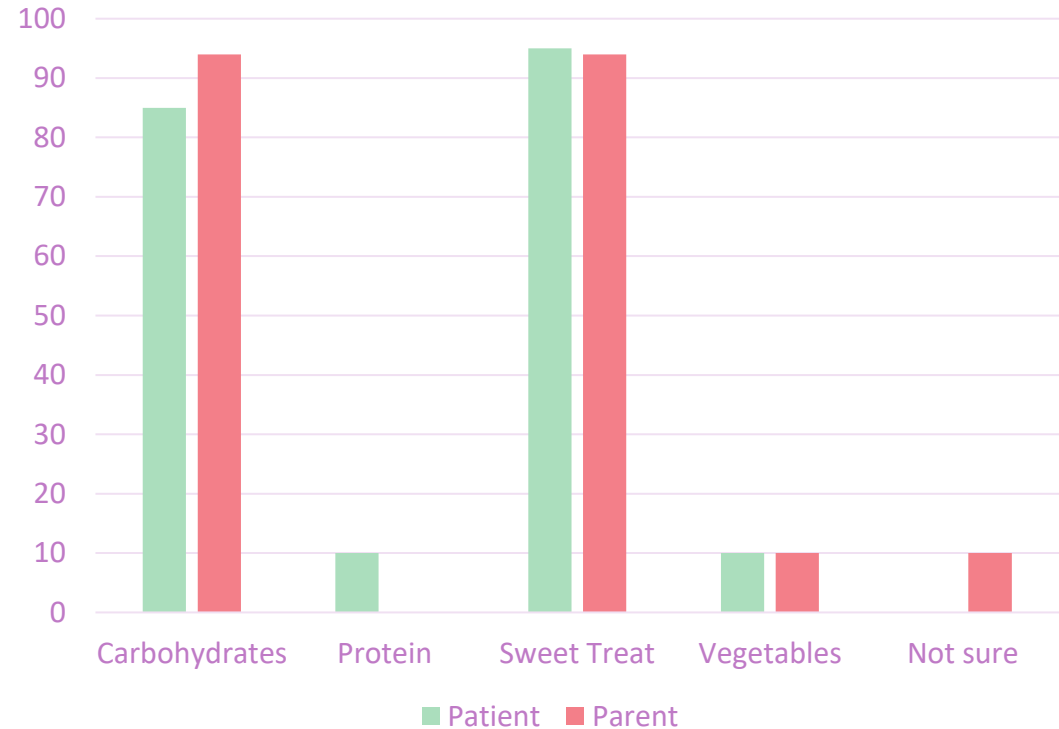
Question #6
Complications Discussed

- Weight and HbA1c are reported to be most frequently addressed (patients: 70% and 75% respectively; parents: 94% for both)
- Overall, parents reported higher discussion rates, reflecting greater engagement/understanding compared to patients

Question 7: What can help improve blood sugar levels?
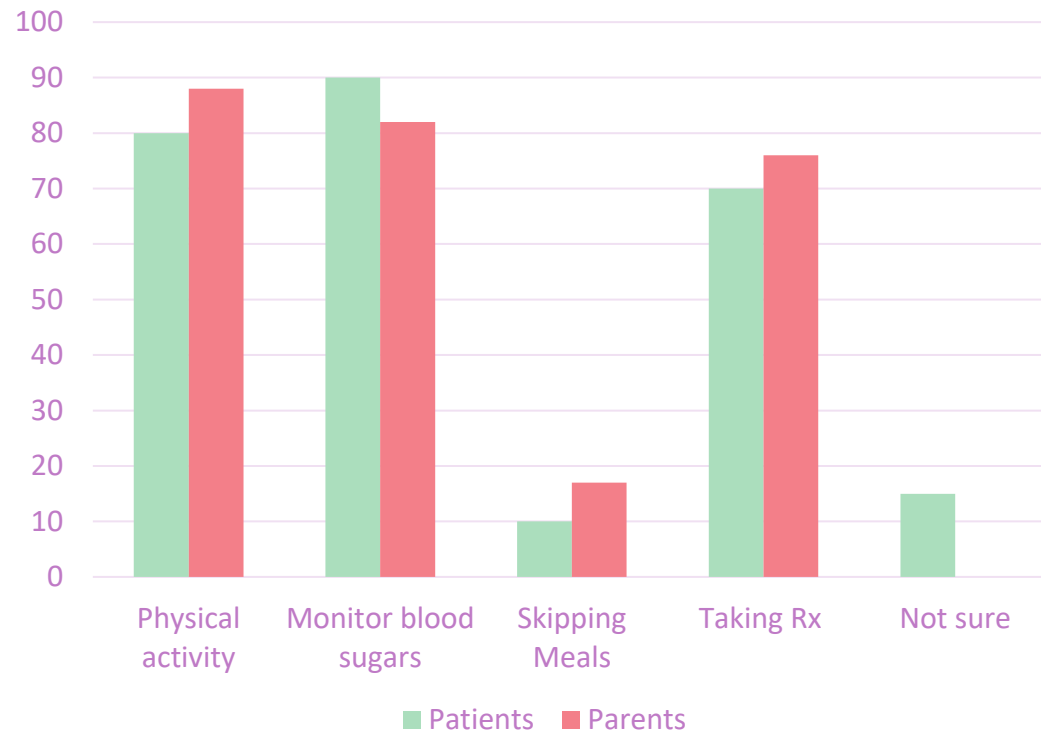
- 17% of parents and 5% of patients incorrectly identified skipping meals as a method to improve blood sugar
- 15% of patients expressed uncertainty

Question 8: Which foods can make your blood sugar high?

- Controversial question
- Highlights general awareness about carbohydrate-rich and sugary foods' effects on blood glucose
- Misconceptions regarding protein and vegetables impact persists

PDSA Cycle 1

Q1. How long have you had Type 2 Diabetes?
1. 0-2 years
2. 2-5 years
3. More than 5 years
4. I am not sure
5. No answer

Q2. How well do you understand your Type 2 Diabetes?
1. I understand it very well
2. I have some understanding
3. I have little understanding
4. I do not understand at all

Q3. Do you take any medication for your Type 2 Diabetes? (Select all that apply)
1. I do not use medication
2. I do take medication, but I do not know the name
3. Metformin (Glucophage, Riomet)
4. GLP-1 (Trulicity, Victoza, Saxenda, Wegovey, Ozempic)
5. SGLT-2 (Jardiance, Invokana, Farxiga)

Q4. How often should you visit your diabetes provider?
1. Every 3 months
2. Every 6 months
3. Annually
4. Less than once a year
5. I am not sure

Q5. Which complications of type 2 diabetes should your provider monitor? (Select all that apply)
1. Blood Pressure
2. Kidney/Urine
3. Feet and Nerve pain
4. Heart Rate
5. Eyes
6. Cholesterol
7. Liver
8. Ultrasound of the pancreas
9. Breathing/ Snoring during sleep (Sleep Apnea)
10. Weight
11. HbA1c (average blood sugar)
12. I am not sure

Q6. Has your diabetes provider ever discussed the following during your visit? (Select all that apply)
1. Blood Pressure
2. Kidney/Urine
3. Feet or Nerve pain
4. Eyes
5. Cholesterol
6. Liver
7. Breathing/ Snoring during sleep (sleep apnea)
8. Weight
9. HbA1c (average blood sugar)
10. I am not sure

Q7. What can help improve blood sugar levels? (Select all that apply)
1. Regular physical activity
2. Monitoring blood sugar regularly
3. Skipping meals
4. Taking prescribed medications
5. I am not sure

Q8. Which foods can make your blood sugar high? (Select all that apply)
1. Carbohydrates (bread, pasta, fruit)
2. Protein (chicken, red meat)
3. Sweet treat (Sugary drinks, cake/cookies)
4. Vegetables
5. I am not sure

Q9. What grade level are you in currently?
1. Elementary school
2. Junior High School
3. Senior High School
4. Some college/trade school

PDSA Cycle 1

- **Do:**
  - Survey administered during May 2025
- **Study:**
  - Obtained 17 patient surveys (12.4% of population)
    - 14 parent surveys
  - Did not meet goal (17/25 = 68% of goal)
  - Didn't track patient ID to confirm answers
  - High no-show rate
- **Act:**
  - Expand location to satellite clinics

PDSA Cycles

#1 — Administer Health Literacy survey to determine baseline gaps/opportunities

#2 — Iteration of PDSA 1 - Expand to satellite clinics

#3 — Meter use // Optimize treatment – educate providers

#4 — Standardize education on comorbidity risk: Autotext for providers

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PDSA Cycle 2

- **Plan:**
  - Expand location to satellite clinics
  - Administer survey during targeted T2DM clinics over 4-week period
  - Goal to reach a total of 25 patients/parents (18% of total population (137 patients))
- **Do:**
  - Survey administered June-July 2025 at main CHP + satellite clinics
  - QI Coordinator "scored" answers
  - Securely maintained patient ID
- **Study:**
  - Data analyzed
  - 20 patient surveys
  - 17 parent surveys

PDSA Cycles

#1   Administer Health Literacy survey to determine baseline gaps/opportunities

#2   Iteration of PDSA 1 - Expand to satellite clinics

#3   Optimize treatment – educate providers - TBD

#4   Standardize education on comorbidity risk: Autotext for providers

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PDSA Cycle 3 - TBD

- TBD
  - **Plan:**
  - **Do:**
  - **Study:**
  - **Act:**

Thank you!