# Summary of the American Diabetes Association's Type 1 Diabetes Screening Workflow Expert Roundtable

Following are the insights and recommendations from the virtual roundtable hosted by the American Diabetes Association® (ADA) on February 11—supported in part by Sanofi. This roundtable builds on previous efforts to generate awareness of type 1 diabetes screening among health care professionals (HCPs) and consumers. All information outlined below is based on expert opinion and does not necessarily represent the official position of the ADA's *Standards of Care in Diabetes—2025* (*Standards of Care*).

**The meeting objective** was to guide the creation of a clinical workflow resource that will assist HCPs in incorporating early detection screening for type 1 diabetes into their practices.

## Key Takeaways

- To be most effective, the clinical workflow should be **actionable and as simple as possible:**
  - Place a **minimal burden on primary care professionals (PCPs)**.
  - **Minimize unnecessary referrals** to specialty care.
- **Internal champions** are essential for facilitating adoption of type 1 diabetes screening within medical practices.
- The field must create a **clinical paradigm shift** where early-stage type 1 diabetes is understood to be diagnosed in presymptomatic stages by the presence of islet autoantibodies, not hyperglycemia. Emphasizing the rationale behind these initiatives can help **foster buy-in** among HCPs.
- This very new area of medicine and science will continue to evolve. Success will require a **two-pronged, ongoing educational approach:**
  - Generating awareness for the public.
    - General population
    - Pediatric population
    - Families with autoimmunity
    - Families already affected by type 1 diabetes
  - Supporting and educating HCPs about type 1 diabetes risk, early detection, and treatments that can delay clinical onset.
    - Implement **straightforward tips, guidelines, and protocols** to support HCPs in adopting the workflow.
- We must **empower patients** to initiate discussions on relevant topics, as this can significantly enhance engagement and awareness, particularly in busy primary care settings.

## Setting HCPs Up for Success

To implement the ideal clinical workflow, health care practices should:

- **Nominate an internal champion** who can:
  - Stay up to date on advances in type 1 diabetes screening.
  - Share information and resources with clinical staff.

  - Integrate policies and procedures into practice (with a specific focus on adapting to local infrastructure).
  - Coordinate with other members of the diabetes care team.
  - Serve as a point of contact or "navigator" for patients and families.
- **The champion need not be a physician**—in fact, other HCPs (medical assistants, nurses, front-desk staff, etc.) might be best suited, and the role could give them a chance to practice at the top of their license.
  - One roundtable participant said the champion in their practice is a phlebotomist. Another suggested it would be a good fit for a certified diabetes care and education specialist (CDCES).
- **Adopt clear guidelines and algorithms** for testing, following up with, and monitoring patients who have positive screening results.
- **Obtain educational materials** including patient-provider conversation guides, consumer handouts, and information about clinical trials.
- **Educate all patient-facing team members** on the type 1 diabetes screening program.
- **Identify the nearest labs** that can perform type 1 diabetes autoantibody testing.
- **Identify tools as order sets** on the local electronic health record (EHR).
- **Facilitate referrals** to endocrinology.

## Mechanisms to Identify Risk Factors

- **EHRs are an essential tool** for collecting risk factor information, linking family accounts, and automating steps of the screening workflow.
  - "It's really nice when structured data helps us guide our decision so that we're very consistent. …If you don't have that data, then it's going to rely on [HCPs] to remember it among the 5,000 other things that they're remembering to do."
  - HCPs should aim to **review and update patients' family history annually**.
    - "Of all the things that we do in the medical record, we probably are the poorest in [collecting and updating] family history."
  - EHRs could leverage decision support tools to help users know when to screen and how to **care for screen-positive patients at all points of care**. For example, if a patient with known early-stage type 1 diabetes comes to the ER with signs of illness, the EHR could suggest checking A1C and glucose. This could reduce the frequency of diabetic ketoacidosis (DKA) at diagnosis of stage 3 (clinical) type 1 diabetes.
- **Awareness materials in the waiting room** could prompt patients and family members to self-identify and ask their PCP about screening.
  - However, the experts cautioned against relying too heavily on this method, as it may not be sustainable long-term.
- The group agreed that a **new type 1 diabetes diagnosis provides a natural impetus** for family members to get screened.
  - As a new type 1 diabetes diagnosis can be an emotional time, HCPs can pose whether screening is right for the family, then put a note in the EHR to follow up at the next touchpoint.
- **Young children could be a screening priority** because they are at the highest risk for developing DKA at clinical type 1 diabetes onset.

- The Joslin Diabetes Center sends letters to patients at their diabetes and pregnancy clinic two years after they give birth. This reaches a high-risk pediatric population at the ideal time for initial screening.
- Young children who test negative for autoantibodies could be rescreened as they age, as autoantibodies may take years to develop.

- **WORKFLOW RECOMMENDATIONS →** The roundtable identified several entry points for screening people at risk for type 1 diabetes:
  - **Primary care/pediatrics:**
    - Family members of a child newly diagnosed with type 1 diabetes.
    - Children with a family history of type 1 diabetes (as documented in the EHR).
    - Adults who first receive an abnormal glucose result (fasting or A1C).
  - **Endocrinology:**
    - Adults with type 1 diabetes (to discuss risk and screening for family members, especially children).
      - "Focus on adult endocrine practices…because that's where most people with type 1 diabetes are being cared for. And they have family members and children."
    - People with other autoimmune diseases comorbid with type 1 diabetes (e.g., celiac disease).
    - The roundtable recommended **a structured approach to discussing family member screening** for ALL new type 1 diabetes diagnoses.
      - Standardized timing for the discussion should be soon after diagnosis, when families have the highest motivation to screen.
      - The discussion could be revisited yearly.
      - Practices without a TrialNet connection will need additional assistance.
  - **Other medical specialties where people with autoimmunity are concentrated:**
    - Rheumatology (lupus, rheumatoid arthritis)
    - Gastroenterology (celiac disease, inflammatory bowel disease)
    - Dermatology (vitiligo)
  - **Families affected by type 1 diabetes:**
    - Individual health care decisions are highly influenced by personal stories. People consider a story even more trustworthy when it comes from someone they have a relationship with.
      - "These patients and families [with type 1 diabetes] are untapped allies embedded in their communities."

## Initiating the Screening Process

- While **community-level screening** can increase awareness and catch people without a family history of type 1 diabetes (who make up about 90% of new cases of type 1 diabetes), it is not logistically feasible in most markets at this time. Meanwhile, an estimated 90% of first-degree relatives of someone with type 1 diabetes will test negative for autoantibodies.
  - "We should be focusing on **getting [primary care] to throw out the big net** and then anything that's even possible to catch with that is just referred over [to endocrinology]."

- **PCPs who order autoantibody testing need conversation scripts** to help explain how screening works and the sequence of events.
- **WORKFLOW RECOMMENDATIONS →** Once a patient is identified, engage in **shared decision-making** about the value of getting screened.
    - **Make it easy to follow through.** Screening should take place at the same practice or through a direct referral to another doctor's office, lab, or clinical trial.
    - **Autoantibody testing should be promoted as the best practice** for early-stage type 1 diabetes screening. This reflects the current understanding of how type 1 diabetes develops and helps streamline the workflow.
        - A1C testing alone would capture too many people. Said one endocrinologist: "We do not have capacity to do rule-out visits for all of the marginal A1C elevations. ...We have a lot of visits for patients that we don't need to be seeing."
    - **Inform the patient** of how the HCP/practice will follow up based on the test results.

## Test Results & Staging

- The roundtable group weighed the merits of funneling testing through **organizations with advanced type 1 diabetes screening experience** (e.g., TrialNet sites) versus the convenience of **local labs** (e.g., Quest, LabCorp).
    - **Research participation is optional** and cannot replace clinical care. Some patients may not wish to participate in research, so there needs to be another high-quality option.
    - Some autoantibody assays are more accurate than others. Laboratories should be encouraged to **group the four diabetes-related autoantibodies together** in one panel that is easy for HCPs to find and order.
- Most patients won't know how to **interpret their screening results**, which can cause unnecessary confusion and panic.
- **WORKFLOW RECOMMENDATIONS → Screening results should be reviewed and delivered by an HCP** who can explain what they mean and what to do next.
    - If possible, **avoid having test results sent straight to the EHR.** HCPs would benefit from accurate scripts for discussing the situations below.
    - **If the screening result is negative** and the patient has a known risk factor, recommend retesting in one to five years. Young children should be tested at least twice: around age 2 and then again at ages 5 to 7. (Source: PMID: 35803296)
    - **If the screening result is positive** for one or more autoantibodies:
        - Assess the patient for type 1 diabetes symptoms. Priority should be given to patients who are symptomatic or acutely hyperglycemic, which could indicate clinical diabetes.
        - Order a confirmatory test within three months plus an A1C test to help determine type 1 diabetes staging.
        - Refer the patient to endocrinology (if not already there).

## Monitoring Positive Results

- Endocrinologists, pediatric especially, may not be accessible in every geographic region. **Telehealth and e-consults** can help extend workforce capacity and suffice for monitoring patients with presymptomatic type 1 diabetes.

- Calling an early-stage type 1 diabetes diagnosis a “Pandora’s box,” the panelists emphasized the need for **continuing diabetes education**.
    - Most endocrine practices do not have structured approaches for early-stage type 1 diabetes care. This may lead people to believe that **“nothing can be done”** if they do not opt for or are not eligible for therapeutic interventions such as teplizumab.
    - Worse, unsupported **patients may make decisions that are not evidence-based** (e.g., adopting a very-low-carbohydrate diet, avoiding gluten or dairy) and that may lead to nutrient deficiencies.
    - **Nurse practitioners** could also fill gaps in the health care team where CDCESs are not available for diabetes education.
- Incorporating **behavioral health** can help families cope with the emotional toll of type 1 diabetes screening and diagnosis and stay engaged during what is often a years-long process.
    - “You have to support the person in the family at every step.”
- The roundtable weighed the pros and cons of different glucose testing methods.
    - **Oral glucose tolerance tests (OGTTs)** are often considered unpleasant and pediatric PCPs are unlikely to have much experience running them. But because OGTTs are more accurate at detecting stages 2 and 3, they can be useful for initial staging or monitoring, depending on the patient’s personal goals (preventing DKA at stage 3 transition versus identifying eligibility for disease-modifying therapies).
    - **Spot-checking blood glucose:** Fasting blood glucose is preserved in early-stage type 1 diabetes, so it is not helpful for asymptomatic patients.
    - **A1C tests** are more convenient but less sensitive than OGTT or CGM.
    - **Continuous glucose monitoring (CGM) was not routinely recommended** for people with early-stage type 1 diabetes. The devices are less likely to be covered by insurance and aberrations can cause undue anxiety in people who don’t already have hyperglycemia.
        - However, some families affected by type 1 diabetes may have access to a CGM and will be eager to use them, at least intermittently in pre-stage 3 diabetes. Whole-day blood glucose trends in early-stage type 1 diabetes should be interpreted by endocrinologists.
- **WORKFLOW RECOMMENDATIONS → The primary goal of monitoring is to prevent DKA and hospitalization.** Monitoring will differ based on how many autoantibodies the person has, their glycemia levels, and other factors such as age.
    - **Lowest risk (autoantibody negative):** If a patient has a positive family history of type 1 diabetes, they should be counseled that negative autoantibodies predict very low, but not zero, long-term risk of developing type 1 diabetes. Rescreening may be appropriate.
    - **Low risk (single autoantibody):** Periodic retesting is recommended. The patient may be able to be monitored by a PCP with appropriate guidance.
    - **Early-stage type 1 diabetes (two or more autoantibodies but presymptomatic):**
        - Conduct glucose and A1C surveillance according to the *Standards of Care*.
        - Educate on the symptoms of stage 3 type 1 diabetes.
        - Encourage healthy lifestyle habits including following a low-glycemic diet, staying physically active, and maintaining a healthy weight.
        - Offer therapeutic interventions to preserve beta cell function if eligible according to the *Standards of Care*.
        - Initiate insulin therapy once the patient advances to stage 3.
    - **All patients:**

- Provide ongoing diabetes education and behavioral health support.
- Encourage participation in research studies if interested.

## Ongoing HCP Education & Support

- The roundtable panelists agreed **PCPs need to understand the basics of type 1 diabetes screening** and prevention, and why it's important—but not so much information that it overwhelms them.
- **Desired knowledge:**
  - Risk factors for type 1 diabetes
  - Staging framework for type 1 diabetes
  - Diabetes screening strategies—a complete picture for asymptomatic people at risk for type 1 diabetes, type 2 diabetes, and rarer diabetes types
  - Autoantibody markers (moving away from glucose-centric definitions of type 1 diabetes)
  - Dispelling type 1 diabetes and type 2 diabetes misconceptions
    - Prototypical patient profiles have changed. For example, people with type 1 diabetes *can* present with overweight or obesity.
- **Desired skills:**
  - Interpreting autoantibody testing results
  - Basics of preventive therapy (for endocrinology to prescribe)
- The ADA's annual **Scientific Sessions** conference and the **Institute of Learning** are two high-impact avenues for educating HCPs about type 1 diabetes screening.

## Other Considerations

- The panel recommended making information about type 1 diabetes autoantibody screening **more prominent in the ADA's *Standards of Care*** section on diagnosing diabetes.
- To incentivize health systems, roundtable participants suggested that type 1 diabetes screening become a **quality metric** (i.e., something captured in health care rankings like the *U.S. News and World Report* for pediatric hospitals).
- **EHR software should be augmented** to complement the ideal clinical type 1 diabetes screening workflow and provide decision support and efficient pathways.
- **Future research** should explore the impact of the following interventions on health outcomes for people with early-stage type 1 diabetes:
  - **CDCES/diabetes education:** Does education help patients identify clinical symptoms sooner and improve their physical and mental wellbeing as they progress to clinical type 1 diabetes?
  - **CGM:** Does intermittent CGM wear in early-stage diabetes aid in proper timing of insulin initiation?
  - **Lifestyle modifications:** To what extent does lifestyle modification affect progression to stage 3 type 1 diabetes, and how should patients be counseled and supported in that process?

## Key Messages & Possible Additional Materials

- **Messaging for patients:**
  - For families with existing type 1 diabetes:
    - Knowing your family members' type 1 diabetes status can give you peace of mind and help you prepare for what's ahead.
    - This knowledge can also allow for a smoother transition to glucose monitoring and insulin therapy as part of a diabetes care plan.
    - Research participation helps the diabetes community move science forward.
  - For people who screen positive for type 1 diabetes autoantibodies:
    - You are going to be safe.
    - We can't predict if and when you will develop stage 3 type 1 diabetes, but we can be there to support you as soon as you need treatment.
    - You may be eligible for an FDA-approved medication to delay the onset of type 1 diabetes.
    - You may also be eligible for a clinical trial to test new preventive treatments and learn more about how type 1 diabetes develops.
- **Materials and resources:**
  - Conversation guides for HCPs at each step of the workflow.
  - One-pagers about type 1 diabetes screening and next steps (similar to what is typically provided during a vaccination).
  - Helpline/webpage for people to call/visit between type 1 diabetes screening and seeing their HCP.

## Next Steps

The ADA will produce a draft of the clinical workflow tool for the roundtable participants' feedback.

## Relevant Resources

- The ADA's *Standards of Care* Section 2: Diagnosis and Classification of Diabetes
- The ADA's *Standards of Care* Section 3: Prevention or Delay of Diabetes and Associated Comorbidities
- Consensus Guidance for Monitoring Individuals With Islet Autoantibody–Positive Pre-Stage 3 Type 1 Diabetes

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