ISPAD Clinical Practice Consensus Guidelines 2022 Compendium

The delivery of ambulatory diabetes care to children and adolescents with diabetes

1,2 Catarina Limbert, 3 Davide Tinti, 4 Faisal Malik, 5 Ioanna Kosteria, 6 Laurel Messer, 7 Yazid Muhammad Jalaludin, 8,9 Paul Benitez-Aguirre, 10 Sarah Biester, 11 Sarah Corathers, 12 Simone von Sengbusch, 13 M. Loredana Marcovecchio

Affiliations
1 Institution Hospital Dona Estefânia, Unit of Paediatric Endocrinology and Diabetes, Lisbon, Portugal
2 Nova Medical School, Universidade Nova de Lisboa, Lisbon, Portugal
3 Department of Pediatrics, University of Turin, Turin, Italy
4 University of Washington, Seattle, Washington, USA.
5 Aghia Sophia Children's Hospital, First Department of Pediatrics, National and Kapodistrian University of Athens, Athens, Greece.
6 University of Colorado School of Medicine, Barbara Davis Center, Aurora, CO, USA
7 Pusat Perubatan Universiti Malaya, Kuala Lumpur, Malaysia
8 Institute of Endocrinology and Diabetes, The Children's Hospital at Westmead, Sydney, NSW, Australia
9 Discipline of Paediatrics and Child Health, University of Sydney, Sydney, NSW, Australia.
10 Children's Hospital "Auf der Bult," Diabetes-Center for Children and Adolescents, Hannover, Germany.
11 Cincinnati Children's Hospital Medical Center, University of Cincinnati College of Medicine, Cincinnati, Ohio, USA.
12 Division of Pediatric Endocrinology and Diabetology, Campus Lübeck, University Medical Centre Schleswig-Holstein, Lübeck, Germany.
13 Department of Paediatrics, University of Cambridge and Cambridge University Hospitals NHS Foundation Trust, Cambridge, UK

Corresponding author:
Catarina Limbert
Unit for Pediatric Endocrinology and Diabetes
CHULC- Hospital Dona Estefânia
Rua Jacinta Marto, 1169-045
Lisbon, Portugal
email: climbert@gmail.com
1. WHAT IS NEW OR DIFFERENT?

- In this update, we have revised the general guidelines regarding the gold standard of care for children, adolescents and young adults with type 1 diabetes (T1D).
- We have expanded guidelines on current diabetes technology to include relevant information on telemedicine, data support, education and literacy in diabetes technology.
- We also provide guidance on type 2 diabetes (T2D) ambulatory care.

2. EXECUTIVE SUMMARY

Introduction:

- From diagnosis, the child or adolescent with diabetes and their careers must receive education and care from a multidisciplinary diabetes team comprised of specialists with training and expertise in both diabetes and pediatrics, including child and adolescent development. (B)
- The diabetes team should implement a person-centered care model, where the youths with diabetes and their family are the central members of the care team. (B)
- Clear and consistent communication around education and treatment plans is essential. (C)
- Current technologies commensurate with available resources and the individual child’s/family’s needs should integrate the treatment plan. (B)
- It is important to empower children and families with the awareness that diabetes is a treatable condition that can be managed and avoid the young person with diabetes being defined by the condition (“the diabetic child” or “the sick child”) and use language that
engages and motivates children and families towards a dynamic diabetes management. (C)

- If a multidisciplinary team is not locally available, the caring clinicians should have ready access to advice and expertise from the multidisciplinary diabetes care team in regional centers of excellence, and this could be facilitated using telemedicine. (C)

**Objectives of ambulatory care**

- The ultimate goal is to provide care that results in “on target” glucose profiles, good quality of life, normal growth and development, and lowest attainable risk of acute and long-term diabetes complications. (E)

**Key points in diabetes care delivery:**

- Specialized hospital medical care (E)
- Expert comprehensive ambulatory care for diabetes and associated conditions (E)
- Support available 24 hours a day for young people with diabetes and families (C)
- Comprehensive education for the young person and his/her caregivers on day-to-day management of diabetes including insulin therapies, glucose monitoring, nutrition (C)
- Ongoing diabetes education and self-management training on issues such as hypoglycemia, exercise, sick day management, travel, fasting, festivals and other special occasions (E)
- Integration of diabetes technology in pediatric diabetes care and appropriate education of young people with diabetes and their families in diabetes technology (C)
- Consistent and sensitive articulation of glycemic targets (C)
• Introduction of new therapies and technologies as diabetes management evolves (E)
• Screening for comorbidities and complications and related risk factors (B)
• Psychosocial support for all young people with diabetes and families (B)
• Advice for care at school, camps, and other venues where children with diabetes require care when away from home (E)
• Guidance on other age and developmentally appropriate goals and life events (including contraception, driving safety, use of alcohol, tobacco and other substances, and other risk-taking behaviors) (E)
• Extra attention, including psychosocial evaluation and support, for children who are at high-risk of acute and/or chronic complications due to suboptimal glycemic control, frequent health utilization of emergency departments/hospital, other social considerations and/or mental health needs (B)
• Recommendation on routine vaccinations to be provided for children with diabetes according to age-related and regional recommendations. Advice on annual vaccination against influenza for all individuals with diabetes above 6 months of age. Pneumococcal and meningococcal vaccines are also recommended (C)
• Enable telemedicine consultation for diabetes clinic visits and psychosocial counselling (C)
• Advice and support to physicians and health care professionals who provide diabetes care where immediate access to a specialized diabetes care team is not possible (B)
• Provision and updating the team (including the child with diabetes and the family) with current information on research in diabetes (E)
Key points in processes of diabetes care:

Following diabetes diagnosis and stabilization the child and caregivers should be provided with (C):

- Essential skills such as glucose monitoring and related technologies; administration of insulin including the concepts of dosing for meals; management of hypoglycemia and hyperglycemia
- Access to on-call team (24 hours a day)
- Instructions as to scheduled outpatient visits for follow-up.
- Routine visits, at least every 3 months should include:
  - ongoing evaluation of diabetes management with sharing of diabetes data, review of glucose profiles, data interpretation and decision-making empowerment based on standardized glucose reports
  - evaluation of growth, development, and general health (including concomitant medical conditions and medications)
  - physical examination with inspection of glucose monitoring sites and injection/insertion sites
  - nutrition consultation
  - options to communicate between visits, e.g., for insulin dose adjustments, should be provided, including text messages or virtual visits via video, telephone, or live chat.
- An annual review visit that in addition to the above routine care includes:
  - expanded physical assessments (such as pubertal staging, foot examination)
• additional self-management assessments, such as dietary knowledge (ability to estimate carbohydrate consumption and accurately determine insulin doses), glucose data interpretation, autonomy in diabetes management, sick-days rules knowledge
• Psychosocial assessment
• Screening for comorbidities, long-terms complications, and related risk factors

Other key aspects of ambulatory care:

• Identification of barriers to care (B)
• Considering specific needs of minority groups (C)
• A planned, structured transition approach to adult diabetes care to facilitate continuity of care during this critical time (B) The age of transition to an adult clinic varies according to individual maturity and local circumstances
• Contact with other families of children with diabetes (E)
• Promotion of diabetes camps (E)
• Interactions with school as part of day-to-day diabetes care (B)
• Facilitating access to care by in person visits and virtual diabetes visits through telemedicine or telehealth (B)

Quality of care

• Diabetes centers need methods to evaluate and enhance the quality and equity of the diabetes services they provide and the outcomes of their management (C)
• For this and given the complexity of T1D management, a multifaceted approach that integrates psychosocial supports, recognizes social determinants of health, leverages information science, and application of quality improvement (QI) (E)
methodology is required to complement emerging therapeutic modalities for T1D

- Diabetes registries can be an important tool for population management at individual centers, QI, and benchmarking across collaborative centers (B)
- Benchmark reporting that evaluates effectiveness of diabetes care measured against guidelines for standard practices can promote accountability and system-wide improvements in diabetes care (C)
- Involvement of governments and policy makers facilitates provision of adequate resources that are required for high quality diabetes care (E)

**Type 2 diabetes**

- The main goals of type 2 diabetes management include education for diabetes self-management, normalization of glycemia, weight loss, promotion of physical activity and control of comorbidities and complications, including hypertension, dyslipidemia, nephropathy, sleep disorders, and hepatic steatosis (B)
- Treatment challenges in T2D are different from T1D and should not be overlooked in the ambulatory care (E)
- The aims of therapy in youth-onset T2D are to improve glycemia, prevent acute and chronic complications, prevent metabolic decompensation, improve insulin sensitivity and provide exogenous insulin when necessary (C)
- Like T1D, the process of ambulatory care for children and youth with T2D includes an outpatient follow-up each 3 months and an annual review of care (C)
- Initial treatment of youth with T2D should include metformin and/or insulin alone or in combination (B)
• Blood glucose monitoring should be individualized, with a frequency based on specific
treatment, degree of glycemic control and available resources. Differently from T1D,
HbA1c concentration should be determined at least twice a year or quarterly (C).

Glucose monitoring technologies in the ambulatory care

• Continuous glucose monitoring (CGM) should be considered for all children with T1D
who are on intensive insulin therapy (B).

• Consistent use of CGM improves glycemic control in children, reduces incidence of
severe hypoglycemia and diabetic ketoacidosis and improves quality-of-life (B).

• Data from CGM systems can greatly enhance the effectiveness of the ambulatory care
visit. This facilitates the contact between the family and the diabetes care team, allowing
for an effective teleconsultation and promoting a “shared decision-making” approach. (C)

• Clinicians should review the Ambulatory Glucose Profile (AGP), available for most
CGM systems (C). The AGP is a standardized glucose report that allows for visualization
of daily curves of glucose, average blood glucose and percentage of time in range (TIR),
time below range (TBR) and time above range (TAR) of the reported period.

• Clinicians should focus on patterns of glucose levels, and less about single days. It is
recommended that clinicians review 14 days of data for adequate decision making. (C)

3. INTRODUCTION
This chapter of the ISPAD Consensus 2022 Guidelines outlines recommendations for ambulatory diabetes care, including routine clinical assessments according to best current practice. Specific recommendations for certain elements of ambulatory care, including insulin therapy, monitoring of glycemic control, nutritional management, diabetes education, screening for and management of comorbidities and vascular complications, T2D, age-group specifics, diabetes in schools, and use of diabetes technology are addressed in detail elsewhere in the ISPAD guidelines, which should be consulted in conjunction with this chapter.

Diabetes is primarily managed in the outpatient or ambulatory setting, where all children with diabetes should receive specialized person-centered care from a multidisciplinary team, qualified in providing up to date pediatric-specific education and support. The period following diabetes diagnosis and stabilization is a critical opportunity for commencement of education and preparation for outpatient care. Thereafter, regular, ongoing ambulatory diabetes care assessment should be provided throughout childhood and adolescence and be complemented with a well-supported program to facilitate transition to adult care in due course.

The overall goal of a well-structured and high-quality ambulatory diabetes care for young people with diabetes is to promote high quality of life, normal growth and development, and prevent risk of acute and chronic complications.

An investment in gold standard diabetes care, particularly during childhood and adolescence, should be advocated globally and is likely to be of significant economic benefit.

The components of clinical care include structure, processes, content and outcomes and they are extensively discussed in this chapter. Structure of care describes how delivery systems are organized and financed; processes of care describe how care is delivered; content of care describes what is being delivered, including treatment and education that affect outcomes.¹
Intermittent critical re-examination of these components provides an opportunity to continually improve the quality of care delivered using available tools and resources. Because diabetes is a chronic disorder, approaches to all aspects of clinical care will undoubtedly change over time. This chapter aims to establish ideal guidelines for a comprehensive diabetes service. A dedicated ISPAD 2022 Consensus Guidelines Chapter 25 on Management of Diabetes in Limited Resource Settings is available separately to complement this guidance.

4. STRUCTURE OF CARE

The structure of diabetes care delivery should support accomplishment of the following:

- **Overall Goals**: to promote a high quality of life, normal growth and development, a balanced approach to the psychological handling of a demanding chronic condition, early detection of co-morbidities and avoidance of severe short- and long-term complications.

- **Individualized Treatment Plan**: offering glucose monitoring and insulin regimen that should, ideally, mimic physiologic insulin secretion to maintain healthy metabolism, and is in accordance with child with diabetes and family treatment preferences, which may change over time.

- **Access to multidisciplinary diabetes expertise**: medical providers, educators, mental and behavioral health resources that are available both during episodic visits and between encounters, when most of the diabetes management is performed by individuals and caregivers.

4.1. Person-centered diabetes care
Diabetes care is complex and is best delivered by a multidisciplinary team of specialists with training and expertise in both diabetes and pediatrics, and knowledgeable of child and adolescent development. Diabetes requires extensive skilled self-management. Therefore, from diagnosis, it should be emphasized that the child and immediate family are the central members of the care team.\(^2\) (Figure 1) The diabetes care team should have the resources to develop strong links, effective communication, and shared practices with extended family members or other care providers, school nurses, day-care staff, teachers, and others who care for children, who often play an important role in the child’s diabetes care and may serve as a liaison between the child and the medical team. Teams should be sensitive to language and numeracy barriers and information delivered with language appropriate resources and pitched at relevant levels for understanding.\(^3\) Review of such knowledge and understanding on a regular basis at clinic visits is paramount.

Engaging directly with the young person with diabetes and their caregivers to gauge understanding regarding diabetes knowledge, health behaviors, goals, perceived benefits, and risks should be built into standard structures of care delivery. It is imperative to promote the understanding that the child retains his/her full prior potential to achieve goals physically and intellectually. Over time, continued engagement by the diabetes team with children as they mature, using developmentally appropriate educational tools, while recognizing that the child must be treated in the context of their existing psychosocial environment is essential. Effective and clear communication at all levels, between team and families and within the family structure are crucial predictors of early glycemic control and future psychosocial functioning.\(^4,5\)

It is important to empower children and families that diabetes is a treatable condition that can be managed, rather than being defined by the condition (“the diabetic child” or “the sick child”),
and to use language that engages and motivates children and families. This requires the multidisciplinary team to have a high level of cultural competence, avoiding blaming and stigma (#Language Matters campaign). Substitution of judgmental words (such as “uncontrolled”, “non-compliant”, “non-adherent”) with neutral ones (like “time in target/range”, “higher HbA1c”, “difficulties in”, “troubles in”) can lower anxiety, build confidence, and promote positive therapeutic relationships. Since people encounter various difficulties while managing their diabetes, the team should use language that supports a pathway to navigate challenges rather than underline mistakes. Labeling persons with diabetes with their condition (“the diabetic”) increases stigma and may lead to unconscious discriminatory behaviors from the clinician. All these efforts are needed to increase treatment satisfaction and engagement, which are recognized factors impacting health outcomes.

4.2. Individualized diabetes care

The general aims of the diabetes care team should be to provide individualized diabetes care that best meets the needs of the child and family. This requires care delivery structured for:

- **Aims of the diabetes care team:**
  - Ongoing diabetes education and self-management training
  - Up-to-date advice on insulin management, glucose and ketone monitoring techniques
  - Monitoring for comorbidities, complications, and risk factors for complications
  - Consistent and sensitive articulation of individualized goals, such as HbA1c or glucose metrics from CGM
  - Contact with other children and families with diabetes and support groups
  - Psychosocial screening and referrals to social worker or psychology as indicated
• Providing families an opportunity to raise questions about information they may have obtained from the internet or other sources, given the ease of obtaining information from multiple sources 12
• Current information on research in diabetes for people with diabetes and regional physicians
• Ongoing training for the diabetes care team on technology and communication skills.
• Ongoing commitment to advancing clinical practice through the optimal application of existing and new technologies and the development and evaluation of new technologies.

4.3. Diabetes team organization

The exact organization of the diabetes care team, its size, and composition will depend on geographical and demographic characteristics; indeed, there is significant variation worldwide 13. In general, for members of the pediatric diabetes team to obtain sufficient experience, the number of children and youth with diabetes in the center should be at least 150. The number of practitioners depends on local circumstances; a suggested guide to optimal resource allocation per 100 patients is: 1.0 - 1.25 diabetes nurse, 0.75 – 1.0 pediatric diabetologist, 0.5 dietitian, 0.3 social worker/psychologist 14, which is similar to expert consensus recommendations provided through the international diabetes consortium SWEET peer recognition program. While not all clinics will be resourced in this manner, this staffing should be sufficient to meet standards of care. Clinics should be outfitted with digital diabetes data platforms capable of interfacing with cloud-based systems for blood glucose (BG) meters, continuous glucose monitors, insulin pumps, and insulin pens to enable glucose pattern review for decision making at and between visits.
A multidisciplinary team is unlikely to be available in areas of low population density and where childhood diabetes rarely occurs. In these circumstances, care usually is provided by a local pediatrician or general (family) practitioner, who should have ready access, via electronic means of communication, to the diabetes care team at a regional center of excellence. Alternatively, teams from district or regional centers often organize outreach clinics to accommodate children and families living in remote areas. Adequate resources are needed to sustain such services. In some areas, two-way telecommunication utilizing video – computer technology or platforms for Voice over Internet Protocol (VoIP) and local medical staff to facilitate the telemedicine visit allows for more efficient and effective distant care. COVID-19 dramatically impacted care delivery, with widespread use of telemedicine becoming more prevalent, enabling more efficient and effective distance care. Regarding telemedicine and data sharing from devices, awareness of current data protection rights and regulations is important. For example, the European Union’s General Data Protection Regulation (https://gdpr.eu/article-9-processing-special-categories-of-personal-data-prohibited/) introduced in spring 2018 may impact remote monitoring of people with diabetes devices and telehealth; regulations vary between regions. In all cases, appropriate reimbursement must be available to support these essential non-face-to-face services in order to ensure that diabetes care team can afford to sustain provision of input to individuals with diabetes using these technologies.

5. PROCESSES AND CONTENT OF CARE

It is important to maintain a framework which reassures the child and family that the child is able to live a normal and healthy life (although a few restrictions remain regarding safety-sensitive
The importance of providing a good start with clear, positive messages, support, and advice, cannot be overemphasized. Setting appropriate expectations and empowering people with diabetes and parents with relevant and developmentally appropriate information is paramount. Generally accepted good clinical practices for the successful management of children and adolescents with diabetes need to be practiced through the lifespan.

5.1. Process of Care Following diagnosis:

a) Education and practical care guidance

- Depending on the severity of the symptoms and center organization, education should be started immediately after stabilization in either an in- or out-patient setting.
- Soon after diagnosis the child with T1D and caregivers should be provided with an age-appropriate and comprehensive diabetes education module that allows the self-management of diabetes in an outpatient setting (Box 1).
- The management of children who are metabolically stable following diagnosis (not requiring admission), requires members of the diabetes care team to be experienced in the outpatient initiation of insulin therapy, management, and education.
- It is important to create a partnership between the care providers and the child and family allowing for shared decision-making and a long-term relationship based on trust.
Box 1: Modular age-appropriate education should include

- Insulin as a life-saving therapy
- In due course insulin adjustment, carbohydrate counting, and bolus advisors should be introduced
- Blood glucose monitoring and glycemic control
- Role of technology in diabetes management
- Nutrition and healthy eating
- School and diabetes care
- Management of hypoglycemia and hyperglycaemia
- Managing exercise and sports
- Sick day management
- Psychosocial support and adapting to living with diabetes

b) Setting expectations

It is important to explain to the child and family the natural course of T1D from diagnosis. This includes the expected changes from a ‘catch up nutrition phase’ with escalating insulin requirements and increased appetite, to the development of a ‘honeymoon phenomenon’ when insulin requirements can significantly decrease. The latter is important to highlight as it can frequently bring into question the diagnosis and need for insulin therapy. Revision of the diagnosis and differences between T1D and T2D is often helpful at this stage. It also allows for an ongoing conversation about the need for ongoing insulin therapy, regular home glucose monitoring, growth and development of the children with diabetes.

c) Psychosocial support for the child and family

This includes identifying the significant members of the family who will provide care (e.g. one or both parents, a grandparent or another relative, or others) and ensure they receive the necessary education in the clinic and/or hospital.

It is important to identify and addressing detrimental health beliefs (e.g. that diabetes is not contagious, and the child does not need to be segregated from other children). Written and/or
pictorial age-appropriate materials should be provided in a format (e.g. paper pamphlets, booklets, soft copies on their mobiles) and language the family understands. Such materials are readily available on several excellent websites of associations involved with pediatric diabetes care, including the ISPAD website (www.ispad.org), Life for a Child (https://lifeforachild.org), and Changing Diabetes in Children (https://www.ispad.org/page/changing).

5.2. Outpatient care after diagnosis

After stabilization and provision of the education module, outpatient care should be well planned and expectations of contact and support managed. The following approach is suggested (Box 2):

<table>
<thead>
<tr>
<th>Box 2: Outpatient Care after Diagnosis of T1D</th>
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<tbody>
<tr>
<td>Approach after diagnosis for youth and families:</td>
</tr>
<tr>
<td>• Introduction to the diabetes team members and a clearly laid out plan for review upon discharge should be provided and explained</td>
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<tr>
<td>• Regular review and access to on-call team (24 hours a day)</td>
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<tr>
<td>Outpatient follow-up:</td>
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<tr>
<td>• Every three months a regular outpatient clinic review should be programmed</td>
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<tr>
<td>• An annual review is recommended, which in addition to routine care, should include screening for other relevant comorbidities*</td>
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<tr>
<td>• Complications screening should be scheduled and occur in accordance to the recommended guidelines#</td>
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</tbody>
</table>

*(see ISPAD 2022 Consensus Guidelines Chapter 19 on ‘Other complications and associated conditions in children and adolescents with type 1 diabetes’)
#(see ISPAD 2022 Consensus Guidelines Chapter 18 on Microvascular and macrovascular complications in children and adolescents)
5.3. Outpatient care follow-up

a) The honeymoon phase

In the first months to year after diagnosis, many children experience a partial, temporary remission (the “honeymoon” period) and insulin requirements may decrease dramatically. Frequent contact with the diabetes care team is necessary to help manage the changing insulin requirements typical of the early phases of diabetes. Contact may occur through frequent clinic visits, telemedicine, telephone, text messaging, home visits or other methods of communication. Depending on local circumstances, contact often occurs through a combination of these methods. Insulin treatment should not be discontinued even if the insulin requirement is very low, and people with diabetes should be encouraged to continue regular glucose monitoring. It should be emphasized to the family that it is a temporary phase, and not a “cure”, and that insulin needs will gradually increase over time.

A prolonged “honeymoon” period lasting more than one year during which insulin requirement remains $\leq 0.5 \text{unit/kg/day}$ should raise consideration of a form of monogenic diabetes, such as Maturity Onset Diabetes in the Young (MODY) in the person and the family. In this case, genetic testing should be considered if pancreatic antibodies are negative \(^{27}\).

b) Mental and psychosocial health

Screening for a cognitive or mental health disorder soon after diagnosis will identify individuals (either child or caregiver) who may require greater support to adhere to treatment and self-care. Five to ten percent of all children suffer from a neurocognitive disorder and at least 2% from a psychiatric disorder. The combination of a cognitive or mental health disorder with diabetes or
the presence of a psychiatric disorder in a parent/caregiver increases the likelihood of inadequate or incorrect self-care \(^{28}\). These individuals need special attention and treatment.

### 5.4. The outpatient visit

It is standard practice for the diabetes care of children and adolescents to be reviewed in an outpatient clinic (face-to-face or remotely) every 3 months, and more often if difficulties in managing diabetes are recognized, or the child is very young (Please refer ISPAD 2022 Consensus Guidelines Chapter 23 Managing diabetes in preschool children). Multidisciplinary team consultation should be made available at each visit if required (e.g. nutrition or psychology consultation).

Outpatient and/or telehealth visits with members of the diabetes care team should include interval history and assessment of the following:

- **Diabetes management review:**
  - Self-management skills
  - Assess hypoglycemia history including determination of hypoglycemia awareness, method of treating hypoglycemia and access to glucagon.
  - Engagement and management of glucose data: enabling the young person and their carer(s) to use and upload data from the available technologies including BGM and CGM to cloud systems. Promoting and enabling them to understand and synthesize the information to alter and improve their diabetes management behaviors. Required skills for this to occur include:
    - Understanding of relevant targets including time in range and HbA1c.
    - Ability to connect and upload device data to cloud systems at home.
- Analysis of home glucose monitoring data (BGM from glucose meter readings, real time CGM, “intermittent” glucose monitoring (isCGM), urine glucose/ketone monitoring, symptoms of nocturia and hypoglycemia).

- When using BGM and no cloud system available, checking glucose values stored in the glucose meter memory for accuracy of information reported by parents/child.

- Having open, non-judgmental dialogue as to concerns about accuracy of data provided if inconsistent with overall glycemic control measured with a reference method of HbA1c. Exclude technical reasons for inconsistencies including glucometer/CGM malfunction (e.g. expired or improperly stored test strips, poor testing technique, wrong code).

- **Intensive Insulin Therapy:**

  Intensive insulin therapy consists of multiple daily injections (MDI) and insulin pump therapy (continuous subcutaneous insulin infusion – CSII). Young people with diabetes and their families need to be familiar with and able to manage the insulin therapy they receive. Insulin types, doses, and injection/insulin delivery devices, adequacy of storage and transport of insulin, injection technique should be reviewed regularly. Insulin adjustments for glucose values, food, and exercise are an essential part of the discussion with families. (Figure 2)

- **MDI:** familiarity with the concepts of carbohydrate counting, insulin to carbohydrate ratio and insulin sensitivity factors (correction) need to be reinforced and reviewed at every visit. More recently, the use of Application (Apps) based bolus calculators has proliferated and is widely and freely available. Adoption of a consistent system by the diabetes team helps in rationalizing implementation and education of such systems.
• **Pump therapy: CSII, sensor augmented CSII and hybrid closed loop systems.** Several Insulin pump (CSII) delivery system platforms are commercially available. Recently the use of hybrid closed loop systems has become more widespread (*see ISPAD 2022 Consensus Guidelines Chapter 16 ‘Technology: Glucose monitoring’; and Chapter 17 ‘Technology: Insulin Delivery’*).

Regardless of the pump system, review of “back up” basal rates should occur regularly, particularly in adolescents during rapid growth pubertal phases. Optimization of insulin to carbohydrate ratios, insulin sensitivity factors (correction) and blood glucose targets should also occur at each visit in order to optimize algorithm adjustments (Figure *Disconnection doses*) and management of pump failure should be reviewed at each visit to ensure safety and clear procedures are in place in the event of device failure.

• **General health and well-being:**

  • History of intercurrent health problems such as infections, enuresis/nocturia, diabetes-related emergency and hospital/emergency visits, and other pediatric and developmental problems).

  • Review of all current medications and supplements including medications from alternative medicine streams, and herbal preparations.

  • Systems review with particular attention to symptoms relevant to associated comorbid conditions. In the presence of symptoms or signs, given the predisposition to autoimmune conditions, additional evaluation may be indicated (coeliac disease, autoimmune thyroiditis, adrenal insufficiency).
• New health conditions, including disordered eating behaviors and/or changes in dietary preferences (e.g., adopting a vegan or ketogenic diet).

• Changes in developmental performance, education (particularly school absences or behavioral problems), leisure and sport activities, and psychosocial status.

• **Physical examination:**
  
  • Height, weight, body mass index (BMI) and pubertal status (data recorded and tracked on appropriate growth charts, on which mid-parental height is marked). Weight status can give a general indication of glycemic control, with weight loss and/or delayed puberty suggesting poor glycemic control.

  • Blood pressure with reference to age-appropriate normal levels.

  • Oral mucosa and dentition (for dental caries, gingivitis)

  • Thyroid gland, cardiac, and abdominal (for hepatomegaly) examinations, feet (for corns, ingrown toenails and other lesions as well as neurological function, e.g. light touch, vibration sense.

  • Skin, particularly at the injection, catheter insertion, and self-monitoring sites, for evidence of lipo-hypertrophy, lipoatrophy, infection or skin reactions to sensors. Providers should reinforce the need for rotation of sites for injection, catheter or sensor. Also note presence of acanthosis, suggestive of insulin resistance, and in girls, of acne or hirsutism, which may be indicative of polycystic ovarian syndrome.

• **Laboratory assessment**, particularly HbA1c every 3 months
5.5. Annual review visits

It is good practice to provide an annual review, which includes the above-described routine outpatient assessment and screening for complications as per guidelines in *ISPAD 2022 Consensus Guidelines Chapter 18 on Microvascular and macrovascular complications in children and adolescents*’ and summarized in Table 1. The main components of the annual review visit are:

- Expanded physical development and well-being with particular emphasis on growth and pubertal development.
- Additional diabetes self-management assessment (e.g. exercise, nutrition and sick-day rules)
- Additional new pertinent family history (e.g., new diabetes or other endocrine diagnoses, cardiovascular events/diagnosis).
- Discuss new aspects of diabetes management including diabetes technology
- Consider expanded review by a dietitian of the nutritional plan and dietary management. Parents may be encouraged to bring a food diary recording the last few days’ diet to inform the consultation about individualized dietary advice.
- Consider expanded review of physical activity and insulin dose adjustments made in management for activity.
- Psychosocial assessment that includes screening for depression and disordered eating, household structure (e.g., single vs two-parent, joint families, sibling issues, household stability, marital stress, parental support), bullying or discrimination at the home, school or workplace.
• Assessment of the family’s and child’s adjustment to diabetes and age-appropriate transfer of responsibility for self-care to the older child/adolescent, by a psychologist or social worker.

• Determination of barriers to successful diabetes management including needle fears, fear of hypoglycemia (parent and child), and financial challenges (see section below).

• Education concerning the need for routine dental care. Poor glycemic control in children and adolescents has been associated with higher salivary glucose levels and more dental caries.

• For adolescents, guidance around safe driving, impact of tobacco, alcohol, marijuana and other substances on glucose values and long-term health, sex, contraception and preconception counseling. It is appropriate to request parents/caregivers wait in another room so that these topics can be discussed privately and candidly with the adolescent and to allow the adolescent an opportunity to practice speaking directly to their provider.

• For adolescents and youth, preparation for transition.

• Assessment of understanding of risks for complications and care plans to minimize these risks.

• Screening for co-morbidities and complications (see Table 1). This includes screening for thyroid dysfunction and celiac disease in asymptomatic children at regular intervals. In some settings, consider obtaining a hemoglobin or hematocrit, as anemia is common and could be nutritional, pernicious anemia, associated with hypothyroidism or celiac disease, or due to menorrhagia. In the presence of additional risk factors, such as family history of dyslipidemia, additional testing and/or intervention may be indicated. (Please see ISPAD
The most common autoimmune comorbidities include:

- **Autoimmune thyroiditis.** Ask regarding fatigue, constipation and/or poor linear growth). Monitor thyroid function tests every 2 years (more frequently, if antibodies are positive or if symptomatic). Less commonly hyperthyroidism may occur as a form of Hashimoto’s thyroiditis or Grave’s disease.

- **Coeliac disease.** Consider testing for possible malabsorption secondary to celiac disease by screening autoantibodies to tissue transglutaminase (TTG) and/or endomysium, every 2-5 yearly (or sooner if symptomatic or presence of first degree relative with celiac disease).

- **Adrenal insufficiency.** This is less common but significantly important and may present with unexplained hypoglycemia or decreasing insulin requirements, weight loss and anorexia. Examine for hyperpigmentation and evaluate the child or adolescent for possible primary adrenocortical insufficiency (cortisol, electrolytes, ACTH and perhaps 21-hydroxylase antibodies) as and when indicated.

### 6. OUTCOMES OF OUTPATIENT CARE

The outcome of each visit should include:

- An individualized plan of diabetes care that includes:
  - updated specific calculations for carbohydrate counting, insulin sensitivity and BGM targets
particular needs of each child/adolescent and family to optimize the child’s diabetes outcomes (e.g. exercise, nutrition, sick days management)

- A written copy of the plan is provided to the family at the conclusion of the visit and including results of HbA1c measurement (including individual HbA1c target) and screening tests for comorbidities/complications.

- Identification of behavioral goals for the upcoming interval. Motivational discussion including the family’s and child’s understanding of general treatment goals and an understanding of the medical rationale behind these, e.g. good glycemic control is associated with better quality of life and lower risk of microvascular and macrovascular complications. Because children and adolescents may find problems occurring in the distant future difficult less compelling, emphasis on immediate benefits of good control (feeling better, better academic and physical performance) may more effectively drive behavioral change.

7. TYPE 2 DIABETES

7.1. Structure of care

Management goals include education for diabetes self-management, normalization of glycemia while minimizing hypoglycemia, weight management, dietary changes, increase in physical activity and exercise capacity and control of comorbidities and complications, including hypertension, dyslipidemia, nephropathy, sleep disorders, and hepatic steatosis.

Education should be delivered by team members with expertise and knowledge of the unique dietary, exercise, and psychological needs of youth with T2D. The education and treatment team
for T2D ideally should include a pediatric diabetologist, nutritionist, psychologist and/or social worker, and exercise physiologist. Education in T2D places greater emphasis on healthy lifestyle habits including behavioral, dietary and physical activity changes than is generally required for T1D, and should be provided in a culturally sensitive and age-appropriate manner. Lifestyle change is the cornerstone of treatment of T2D and clinicians should initiate a lifestyle modification program for children and adolescents at the time of diagnosis of T2D. The interventions include promoting a healthy lifestyle through behavior change, including nutrition, exercise training, weight management, and smoking cessation.

The entire family will need education to understand the principles of T2D management and the critical importance of lifestyle changes for the entire family to successfully manage a youth with T2D.

Differences in treatment challenges between T2D and T1D that should not be overlooked in the ambulatory care are:

- Economic status: in developed countries, T2D disproportionately affects those with fewer resources, for example, lower income levels, less educated parents, and less well insured, whereas in Asia and in other emerging economies, it primarily affects affluent individuals.
- Age at onset: T2D typically occurs during adolescence.
- Family history: most adolescents with T2D have a family member with the same disease.
- Gestational factors: more children with T2D have a history of either low or high birth weights and were exposed to gestational diabetes compared with those with T1D.
• Associated comorbidities and complications, such as fatty liver, sleep apnea, dyslipidemia, and hypertension are present already at the time of diagnosis and microvascular and macrovascular complications occur at an accelerated rate. Therefore, screening for these abnormalities is recommended at the time of diagnosis and treatment may be required at the time of initiation of therapy for dysglycemia (see ISPAD 2022 Consensus Guidelines Chapter 3 on ‘Type 2 diabetes’).

• Lifestyle education: intensive lifestyle intervention is a dominant feature of therapy in youth with T2D \(^{33,34}\). However, treatment adherence is a great challenge when implementing lifestyle interventions in obese adolescents \(^{33}\).

7.2. Processes and Content of care of T2D

The aims of therapy in youth-onset T2D are to improve glycemia, prevent acute and chronic complications, improve insulin sensitivity and endogenous insulin secretion if possible, restore glucagon and incretin physiology, and provide exogenous insulin when necessary. The choice of therapeutic approach should also consider the effect on comorbidities and cardiovascular risk.

At onset

• The importance of providing a good start with clear, positive messages, support, and advice, cannot be overemphasized. As for T1D, easy access (24 hours a day) for rapid diagnosis and initiation of treatment with availability of written protocols, provision of practical care guidance at diagnosis, and creating a partnership between the care providers and the child and family allowing for shared decision-making should be upheld.
• Providing psychosocial support for the child and family, assessing resources and potential barriers to adjustment to the diabetes diagnosis are some of the measures that the diabetes team should also initiate.

• Written and/or pictorial age-appropriate materials should be provided in a format (e.g. paper pamphlets, booklets, soft copies on their mobiles) and language the family understands. Unfortunately, such material is not readily available for children with T2D compared to T1D. Some of the materials are available at TODAY public website (portal.bsc.gwu.edu/web/today) and as an ADA program called Be Healthy TODAY; Be Healthy for Life (http://www.diabetes.org/living-with-diabetes/parents-and-kids/childrenand-type-2/)

• Initial treatment of youth with T2D should include metformin and/or insulin alone or in combination. The specifics of the initial treatment modality are determined by symptoms, severity of hyperglycemia, and presence or absence of ketosis/ketoacidosis (see ISPAD 2022 Consensus Guidelines Chapter 3 on Type 2 Diabetes).

Subsequent management of T2D

• The goal of initial treatment should be to attain an HbA1c of less than 7.0% (53 mmol/mol) and in some situations <6.5% (48 mmol/mol) 35. This can usually be accomplished with metformin and basal insulin, alone or in combination. Use of other oral or injected agents known to be effective in adults with T2D for youth with T2D may be beneficial in addition to, or instead of, metformin and insulin. Liraglutide has been shown to be effective and safe for use in adolescents with T2D aged 10-17 years and has been approved for use since June 2019 36. (Please refer ISPAD 2022 Consensus Guidelines Chapter 3 on Type 2 Diabetes)

• Blood glucose monitoring
Blood glucose monitoring (BGM) should be individualized, with a frequency based on specific treatment, degree of glycemic control and available resources. More frequent monitoring is required during acute illness or when symptoms of hyper- or hypoglycemia occur. Differently from T1D, HbA1c concentration should be determined at least twice a year and quarterly, if possible.

Literature to support the use of CGM in youth-onset T2D is limited. A cross-sectional study using CGM to measure free-living glucoses in 98 obese youth, including individuals with prediabetes and early T2D, found that even those with normal HbA1c, fasting plasma glucose, and 2 h OGTT, had higher free-living glucose concentrations than historically reported normal weight controls. CGM has also been used as a tool for studying potential differences in the causes of insulin resistance in T2D youth, with CGM-detected hyperglycemia being correlated with increased insulin resistance.

Given the greater burden of disease in youth with T2D, further studies are required to identify whether intermittent use of CGM may lead to glycemic improvements and how best to use the device (who may benefit, how often to prescribe and when) to inform therapeutic recommendations in this age group.

Ongoing diabetes care

- Similar to T1D, the process of ambulatory care for children and youth with T2D includes an outpatient follow-up each 3 months and an annual review of care (C) (Table 1). (see ISPAD 2022 Consensus Guidelines Chapter 3 on Type 2 Diabetes)

8. GLUCOSE MONITORING TECHNOLOGIES IN THE AMBULATORY CARE
8.1. **Indications for the use of Continuous Blood Glucose meters (CGM)**

CGM should be considered for all children with T1D who are on intensive insulin therapy – that is, three or more injections a day or using a pump. Real-time CGM and intermittently scanned CGM devices (isCGM, e.g. Freestyle Libre) offer significant advantages over blood glucose monitoring (BGM) for the child. Real time- CGM should be worn near continuously, and isCGM should be scanned at least once every 8 hours, and more frequently for T1D in order to use the information well. All CGMs can provide auditory and vibratory alerts when glucose levels exceed or are predicted to exceed high or low preset thresholds, or for rapid rises and falls in glucose level. These alert settings should be discussed, as unnecessarily tight settings may lead to excessive alarms, leading to alarm fatigue and/or anxiety for children or their caregivers.

Hypoglycemia alerts should most often be used, with hyperglycemia alerts used to improve overall glycemic variability. Additional alerts may be considered (rapid rise, rapid fall, predicted hyper- and hypoglycemia), but should be weighted if they are clinically useful to the family.

CGM systems also display trend arrows in addition to glucose numbers. Insulin dosing can be anticipatorily adjusted based on the direction and angle of the arrow. Earlier approaches to this included increasing or decreasing insulin doses by 10% to 20% based on how quickly glucose levels were changing. Newer guidance suggests a set number of units increase or decrease based on correction factor. While these algorithms may be helpful for some children and families, it is unknown how much this improves glycemic control in children.

Consistent use of CGM improves glycemic control in children and can also reduce incidence of severe hypoglycemia and diabetic ketoacidosis. CGM must be worn consistently to improve glucose control, and two recent randomized control trials in adolescents and young children
indicated much higher use of CGM than previous trials, with 68% of adolescents/young adults and >90% of young children (ages 2-7 years) wearing the sensor ≥ 5 days/week. International registry data indicate high usage of CGM in children and youth as well. While there is some benefit to using either real-time CGM or intermittently scanned CGMs, the real-time CGMs more consistently demonstrate improved glycemic control over intermittently scanned systems. Further, there are still significant burdens to CGM use that can impact the amount of wear. Factors impacting adherence include cost/insurance coverage, wear-related issues (pain, skin irritation, not liking how the device looks on body), hassle, disruptive alerts, and difficulty trusting device. An adequate time investment in education and interpretation of data is necessary to assist youth in optimizing use of these technologies.

Other potential benefits, in addition to improved glycemic control, may be improved quality-of-life by reducing the burden of the number/intensity of fingerstick blood glucose tests, reducing fear of hypoglycemia in children and parents, and decreasing parental worry and improved sleep better detection of nighttime hypoglycemia. These systems also provide alternatives for young persons involved in jobs/trades where BGM is impractical. However, limitations of measurements in both hyper- and hypo-glycemic extremes must be acknowledged with CGM and clinical context should always be considered; when in doubt, BGM should be used to confirm or refute the reported CGM glucose concentration. This is especially pertinent with hypoglycemia, as CGM can lag behind blood glucose concentrations by up to 15 minutes. A confirmatory BGM can confirm glucose levels are rising before the CGM may indicate this, reducing the risk of overtreatment with carbohydrates.

8.2. CGM and pump therapy
CGM is also used in conjunction with pump therapy. This can be configured as a sensor augmented pump (SAP system), where CGM data displays on an insulin pump, or in some cases a “closed-loop system”, where a computer algorithm uses CGM data to partially automate insulin doses administered by the insulin pump also known as automated insulin delivery (AID) systems. Integration of CGM to diabetes care requires an additional level of education, as well as time and effort from the child/adolescent, families, and the diabetes care team.

8.3. How to utilize glucose monitoring data

Glucose monitoring device data (either from blood glucose meters or continuous glucose monitors, CGMs) can be downloaded onto the family’s home computer or the manufacturer’s platform for family review and for transmission electronically to the diabetes care team before routine care visits or when families require advice on management. This facilitates the contact between the family and the diabetes care team, allowing for an effective teleconsultation and promoting a “shared decision-making” approach.

Electronic data became essential during the COVID-19 pandemic where the bulk of ambulatory diabetes care reverted to telehealth paradigms, making sharable data paramount to sufficient clinical care 51. While digitally-based data have enormous advantages for sharing of data to healthcare teams, it can increase burden on clinicians time to review data. While some healthcare systems have designed reimbursement paradigms for analysis of CGM data, diabetes teams should determine whether adjustments in staffing requirements are needed to accommodate the time-intensive downloading and interpreting of data.

Because real-time CGM systems can remotely share data to parents or other caregivers via internet connectivity, many children using CGM now carry mobile smartphones (phones with a
mobile computing platform). Further, mobile phone usage among adolescents is becoming nearly ubiquitous, and a high proportion of adolescents owns smartphones. This lends the importance advance of allowing parents to remotely monitor glucose levels for children using CGMs, leading to a reduction in anxiety related to diabetes. It is suggested that families discuss who should be included for remote monitoring of CGM data, from a safety and privacy level. For young children, safety of the child with diabetes is paramount. For adolescents who may desire some separation from their parents and other caregivers, negotiations should occur to assure that the adolescent feels comfortable with caregivers following their glucose data and agreeing on when caregivers should intervene.

8.4. Practical approach to CGM users and diabetes teams

Data from CGM systems can greatly enhance the usefulness of the ambulatory care visit. Most CGM systems have similar versions of the Ambulatory Glucose Profile (AGP), which is a standardized glucose report that allows for visualization of daily curves of glucose, median (50%) glucose values and percentage of time in range (TIR), time below range (TBR) and time above range (TAR) of the reported period (Figure 3). Clinicians should focus on patterns of glycemia, and less about single days. It is recommended that diabetes clinicians review 14 days of data for adequate decision making, which can either be done ahead of time if the persons with diabetes downloads their device at home, or can be done at the time of the clinical visit. The CGM data should be reviewed in consultation with the family in order to promote a shared decision-making approach, and a learning opportunity for the family on how to interpret data themselves. Typically, patterns for hypoglycemia should be the most urgent concern to mitigate with insulin dosing adjustments or behavioral instruction (counting carbohydrates, timing of
insulin doses). After that, patterns of hyperglycemia should be evaluated, and causes assessed. In general, clinicians should consider making 1 or 2 dosing or behavioral changes at a time, as too many changes may confuse the family or lead to new unintentional glucose concerns.

9. TELEMEDICINE AND TELEHEALTH

Telemedicine and telehealth can be described as the use of telecommunications to deliver health services, including interactive, consultative, and diagnostic services. The most used approaches are virtual visits via video, telephone, or live chat. Telehealth also includes chat-based interactions to transmit health data to healthcare providers to review and deliver a consultation, diagnosis, or treatment plan. Other approaches are remote monitoring and technology-enabled modalities, e.g. physician-to-physician consultation and diabetes education to the families.

9.1. Evidence for feasibility and positive results

Diabetes is a chronic medical condition, well-suited for telemedicine given that the individual’s treatment data can be recorded and shared electronically. In recent years, but especially during the COVID-19 pandemic, video consultations have become enormously important because it has often not been possible to care for children, adolescents, and adults with diabetes in any other way. Evidence that video consultation is feasible for diabetes clinic visits and psychosocial counselling in young adults with diabetes has been provided by recent studies. The care concept of the Diabeter clinics in the Netherlands, for example, has shown for many years how in-person care for children supplemented by multiple contacts via video, telephone, and email can improve the outcome of children with diabetes. Some
qualitative studies^60,61^ have reported high satisfaction with telemedicine use among study participants and diabetes care team members, as telemedicine visits can help to overcome barriers related to time and travel distance and offer increased flexibility, feeling of security and higher frequency of appointments for families. Nevertheless, it is highly dependent on either the level of infrastructure available or affordability of smartphone/internet technology as to what level of telemedicine can be achieved.

Historically, ambulatory diabetes care has taken place primarily as face-to-face consultations in a diabetes outpatient clinic. However, the organizational design of ambulatory care for children and adolescents with diabetes depends on many factors, including the ratio of diabetes providers for the number of children requiring care in a region and the size of the catchment area.

Depending on a clinic’s resources and person’s needs, it may not always be possible for each individual with diabetes to achieve the minimum of one in-person visit with the diabetes care team on a quarterly basis.

Telemedicine may be an avenue to explore the promotion of equitable care, though limited access to hardware and software required for video consultations may conversely exacerbate inequities. Taking into account available staff and time resources, it may also be important to consider whether more frequent but shorter and scheduled video consultations may allow for better use of existing resources.

**9.2. Two models of telemedicine and telehealth**

A typical synchronous (live and interactive) video consultation can offer a virtual environment that is comparable to the outpatient clinic setting through image and audio transmission. The prerequisite for effective video consultation is the transmission and joint viewing of therapy data
that ideally includes BGM or CGM, as well as information about insulin administration and meals. The storage and graphical presentation of CGM, insulin pump, insulin pen and other therapy data in cloud-based software has made virtual review of therapy data feasible before, during, and after a video consultation. In comparison, asynchronous telemedicine is a time-delayed communication often via email between health care providers and persons with diabetes. Persons with diabetes and their families can contact their care team between clinic visits and then receive feedback in a defined time window.

9.3. Requirements for implementation of telemedicine

Appropriate staffing models to support video consultations and processes of care to support billing and prescription issues for telemedicine visits need to be clarified and established. This could involve both IT support as part of the team and/or team training in technology literacy. Interventions and challenges for restructuring of a diabetes outpatient clinic to successfully include telemedicine and video consultation were assessed especially during the COVID-19 pandemic\textsuperscript{23,62,63}. A first important step is to ensure that individuals with diabetes can actively upload their data to a diabetes software and receive technical help, if necessary. Passive data upload and sharing may be available once an app has been linked to the software account. It will be necessary to revise the outpatient care workflows, provide video contacts, and redistribute roles and responsibilities (Figure 4b). To enhance the efficiency of telemedicine, it will be important to overcome the issue of interoperability of the different software solutions, which often do not allow data from different medical devices to be merged.

Telemedicine has shown to have great potential to provide regular and extra synchronous real-time video contacts to families without the burden of travelling to the diabetes clinic, as well as
asynchronous communication with the diabetes care team. An advantage of telemedicine is the use of mobile health products (e.g. apps), emails or short text messages to allow extra contacts with families. In the last years, telemedicine has proven to be feasible in diabetic retinopathy screening using digital photographs of the fundus, which are forwarded and analyzed by a distant eye-care specialist/ophthalmologist. In a meta-analysis, the accuracy of telemedicine retinopathy screening was found to be overall high. In a recent study, the use of a non-mydriatic camera directly in the diabetes outpatient clinic has been found to be a suitable option to implement retinopathy screening recommendations directly at the pediatric outpatient appointment. Telemedicine services can be an excellent addition to the ongoing outpatient care of children and adolescents with T1D, by providing an increased frequency of counselling contacts and additional and various modes of contact or access to online diabetes education or expert advice, when needed (Supplementary Figure 1).

As a result, telemedicine can play an important role in improving access to health care, if a family is equipped with internet access and diabetes technology, which allows data recording and software data sharing. The experience with telemedicine during the COVID-19 pandemic should be used to expand the existing care system to include appropriate use of telemedicine.

10. TRANSITION TO ADULT CARE

T1D is a common chronic condition diagnosed in childhood that will require lifelong medical care involving both pediatric and adult healthcare systems. Planned transition between pediatric and adult health care is a purposeful process over time distinguished from transfer of care, which is a discrete point at which the provider or care setting changes. Both transition preparation and transfer between health systems occur in parallel with the broader developmental
task of moving from adolescence to adulthood. Emerging adulthood (late teens through mid-twenties) is recognized as an interval marked by increasing independence and exploration of educational, vocational, social, and financial challenges and opportunities. For emerging adults with diabetes, this developmental stage is often also associated with increasing responsibility for self-management as parental involvement in diabetes care and oversight decreases. Paradoxically, emerging adults may also have a developmentally normative sense of invulnerability, where one discounts risk to future health. Therefore, even though transition is an expected process as adolescents age out of pediatric care, the challenge of integrating increased responsibility of diabetes management occurs in the broader context of competing life priorities, which may contribute to lapses in care and deterioration of glycemic control often observed in this population.

Globally, reports from centers in different countries, including those with universal health insurance systems, demonstrate that between 25% and 65% of young adults experience gaps between pediatric and adult diabetes care for significant periods of time and express dissatisfaction with the transition experience. Adverse diabetes-related outcomes, including poor glycemic control, increased diabetes-related hospitalizations post-transfer, emergence of chronic diabetes complications and premature mortality are widely reported.

In response, clinical guidelines and a growing body of literature recognize the significance of planned transition from pediatric settings to adult receivership models for emerging adults with diabetes to mitigate the risk of adverse outcomes. Anticipatory guidance and identification of modifiable factors, such as transition readiness, self-management skills and psychosocial supports, can promote higher levels of success as indicated by individual-reported satisfaction with care, effective self-management post transfer, and decreased gaps in care.
Discussion about transition to another care team or diabetes care provider at multiple visits before transfer occurs helps young people prepare for transition. In addition, providing counseling on how care and practices may differ in adult clinics may be helpful to teens. Peer mentoring can be effective to share experiences and organize ways to overcome social barriers to diabetes care that may not be addressed in a medical context.

A 2011 joint consensus statement, along with related resources from Got Transition/Center for Health Care Transition Improvement (www.gotttransition.org), set forth specific health care system recommendations and guidelines for planning the transition from pediatric to adult care that include establishing: 1) clinic transition policy; 2) mechanism for tracking persons with diabetes; 3) readiness assessment to identify individual-specific health care needs; 4) longitudinal transition planning; 5) facilitated transfer of care process; and 6) successful transfer completion confirmation. In parallel, recommendations for successful adult receivership include communication between providers, reassessment of knowledge and skills after transfer to adult care, establishing new trusting relationships, addressing psychosocial needs, and a team-based approach.

A joint effort sponsored by several organizations including ISPAD provides a tool kit of ready to use resources for transition preparation and successful transfer of care available online: (https://www.endocrine.org/improving-practice/transitions#tId).

There are methodological challenges to systematically evaluate impact of transition interventions and compare outcomes, based on heterogenous models of pediatric and adult care (Figure 5a). The age and process of transfer to an adult clinic varies by location and health care delivery system, and is influenced by local practices and resources, young people with diabetes and family preferences, and national policies. Descriptive reports of transition programs, systematic reviews of the literature, and clinical trials provide insights into
existing models and evidence. While results are variable in degrees of successful outcomes, the general absence of deterioration indicates an advantage over trends of observational studies of existing care.

There are several reported processes for transition between pediatric and adult care, outlined in Figure 5b.

- Structured transition programs that include developmentally tailored diabetes education, case management, and clinical care have demonstrated proof of concept in improving glycemic control and health care utilization amongst young adults previously with history or risk for lapses in care. 98-102

- Programs featuring transition coordinators, or “patient navigators” decrease post-transition gaps and improve post-transition clinic attendance and have been noted to reduce DKA rates. The role of navigator may be a community health coach, social worker, or diabetes nurse, who is able to play a coordinating role setting up appointments, addressing transportation or financial barriers, and making phone calls to confirm successful transfer. 103-106

- There are models that are established to provide case management for adolescent during an at least one year transition process, that are established for many chronic diseases (www.btp-ev.de). 107

- Physician continuity between pediatric and adult health care systems can provide a level of familiarity to ease changes in health care settings. Joint attendance of pediatric and adult diabetes care providers at the last pediatric clinic visit and first adult clinic appointment may be beneficial, although is not always feasible. Alternatively, a combined adolescent/young adult clinic with both pediatric and adult diabetes specialists has been proposed as an
optimal model of transition to adult care.\textsuperscript{108-110}

- Innovative uses of technology including telemedicine and shared medical appointments can simultaneously reduce barriers to in person visits and provide peer support.\textsuperscript{111-113} Web-based and text messaging interventions have also been used to engage adolescents with chronic conditions between visits \textsuperscript{114,115}. As COVID 19 has become a catalyzing factor of telemedicine, uptake of video telehealth visits has been increasingly pragmatically tested in the setting of adolescent care.

- Adult providers play an essential role in caring for emerging adults with diabetes by receiving them from pediatric care and maintaining health throughout the lifespan. Adult receivership practices should be in place to facilitate ongoing education, clinical support, and promotion of self-management initiated in pediatric care \textsuperscript{94,95}.

In summary, emerging adults with diabetes have many demands for balancing self-management with competing life priorities when moving between pediatric and adult health systems that contribute to risk for deterioration of glycemic control with associated increased mortality and morbidity. Based on available evidence and clinical recommendations, a planned, structured transition approach is multi-faceted with elements of longitudinal preparation in pediatric care, active engagement by persons with diabetes and their families’ in readiness assessments, psychosocial evaluation and interventions, peer support, health navigation guidance, communication between providers, and adult receivership clinics. There is an ongoing need for consensus on meaningful outcome measures to support further rigorous evaluation of intervention studies. In the interim, clinics are encouraged to utilize available free resources to promote an organized approach to transition within the structure of local health systems.

11. BARRIERS TO OPTIMAL CARE
There are many potential barriers to delivering optimal ambulatory diabetes care, which can be broadly categorized as those related to (Supplementary Table 1):

(i) **the organization and infrastructure of health care services**, including the accessibility, availability and affordability of care. Barriers related to infrastructure of care include the distance a individuals with diabetes must travel to a diabetes center, inconvenient clinic appointment times, restricted reimbursement, and the shortage and time restraints of trained physicians in diabetes management \(^{116,117}\). Potential solutions for accessibility/availability barriers are to offer local diabetes clinic options, or in cases where organizing smaller diabetes centers or regular outreach clinics is not feasible, training local primary care physicians, implementing a shared electronic medical record to track the child’s care and identify “red flags” that might impact adherence and clinic visit attendance. Virtual hub-and-spoke networks can be organized in order to disseminate knowledge in underserved areas and support primary care physicians \(^{118,119}\).

The extensive use of telemedicine during the COVID pandemic has provided a potential practical solution to overcome the barriers related to travel and the absence of local expertise in diabetes management \(^{23,120}\). The use of telemedicine has been greatly supported by the new technologies used in diabetes management regarding data integration, sharing, visualization, analysis and decision support systems \(^{121}\). Where affordability of care is the main barrier, efforts should focus on advocacy for reimbursement, as well as promoting collaborations between local/national government agencies and diabetes advocacy groups.

(ii) **social determinants of health**, including a) socioeconomic status and related housing and food insecurity, as well as limited access to social security, b) educational status and literacy, c) neighborhood and built environment that can provide access to healthy eating and space for
exercise, and d) determinants of social context and cohesion, such as incarceration, domestic violence, substance abuse, as well as discrimination and stigma. Minority status, a crucial social determinant of health that encompasses most of these factors, is discussed separately 122,123. These factors have been consistently correlated with poor glycemic control and clinic attendance, highlighting the importance of focusing on these factors 124,125.

Screening for social determinants of health could help identify issues affecting diabetes management and overcome communication gaps between diabetes care providers and young people with diabetes and their families 126,127. Stigma is perceived in 36-78% of people with diabetes even in socially sensitive societies 128. Integration and acceptance should begin in the school setting and supported at the community level through educational campaigns, as well by advocating for equal opportunities and school and workplace accommodations (e.g., access to a safe, clean place to test glucose and administer insulin).

Diabetes care teams should have a high level of awareness for social needs within the health care setting, as well as have an ability to assist families to use community services if social needs are identified. Health Care Professionals (HCPs) should regularly consult resources on social determinants of health that are currently available from various organizations 123.

(iii) **Psychological factors/Individual perceptions and needs that pertain to the acceptability of care.** The perception of the child and their family regarding the burden of diabetes management in their everyday life should be acknowledged. Some families may underestimate the usefulness of structured educational programs, regular clinic attendance or even the benefits of efficient self-management and good glycemic control, and they might feel already self-confident and empowered, even if diabetes is not optimally managed 129. It is crucial that the diabetes team identify and address these issues (i.e. exercise, university life) 130,131, by providing
a problem-oriented interactive education that may include integrating technology, revisiting daily routines and treatment options, ensuring mental health support, and restoring communication and balance within the family 132-135. Language used by HCPs is crucial for building a strong relationship that is required to overcome the barriers to effective diabetes care. Therefore the language should be kept accessible and simple, motivating, compassionate, yet realistic, not judging or shaming and adjusted to the personal preferences of the child with diabetes 136.

The presence of mental health comorbidities, including depression, diabetes distress, generalized anxiety, and disordered eating behaviors in older youth, should also not be overlooked. Diabetes-related family conflict can influence diabetes management as well 137,138. At the diabetes clinic level, reliable tools that may be used to screen for and identify mental health comorbidities and barriers to diabetes self-care 139-147.

While the aforementioned barriers of care are relevant when analyzing the reluctance of many young persons with type 1 diabetes and their families to incorporate the use of technology in their daily care 148-150, other factors should be considered including concerns about (i) the increased burden on diabetes management (overwhelming data, difficulties in downloading and data interpretation, alarms, faulty devices); (ii) the therapeutic effectiveness of the devices (mistrust of automated decision making technology, inaccuracy of measurements); (iii) the physical interference of the devices (adhesion and insertion issues, multiple devices, body image, “public display” of diabetes, interference with daily activities and exercise) 43,151,152. In some cases, even HCPs are often reluctant to actively introduce technology, being themselves overwhelmed by the extra burden related to its implementation 153,154. The sustained benefit of the use of technology on metabolic control and quality of life of children, adolescents and young adults with T1D is by itself the most rewarding motivation.
Globalization and migration are great challenges to the health care systems. The recent fluxes of immigrants and refugees have changed the characteristics of the populations accessing the healthcare services in the host countries, requiring changes of the local HCPs to address the needs of these people.

Data demonstrates that children with diabetes from migrant/minority families have poorer glycemic control, higher body mass index, less physical activity, lower utilization of technologies and higher frequency of diabetes-related hospitalization than the general endemic population\textsuperscript{155,156}.

Recent immigrants and refugees are usually not aware of the health insurance policies and organization of the health system of their host countries. In collaboration with social services or non-governmental organizations (NGO), it must be ensured that children with diabetes have unrestricted access to a safe location to store insulin, glucagon, diabetes management-related consumables and devices and that instructions are well understood and followed.

Key points to the ambulatory diabetes care of children from minority groups and immigrant populations

- Define structured pathways of care for the initial visits.
- Assign a regular provider for each child
- Provide home and school visits, when possible.
• When available, dedicated staff members known as ‘patient navigators’ may help families with T1D through the healthcare system (e.g. set up appointments for doctor visits and medical tests, get financial, legal, and social support if needed)\textsuperscript{157,158}.

• Licensed interpreters must be used to support the diabetes team in understanding some of the cultural norms. If a licensed interpreter is not available, a non-family member may serve as an interpreter. The child or other family members should only be used as an interpreter if no other option is available.

• Translation of educational material, diabetes management plans, instructions for emergencies, as well as important administrative forms (i.e., informed consent for the use of personal data) in the most common preferred language. If possible, medical certificates that accompany the child should also be translated\textsuperscript{159-161}.

• The diabetes team should be aware and familiar with cultural differences that may have an impact on diabetes management. The use of culturally sensitive toolboxes such as EthnoMed (\texttt{www.ethnomed.org}) can aid in communication, diet advice, and encouraging empowerment and altering preconceptions or negative and unhealthful beliefs about diabetes. Specific guidelines for the management of diabetes during fasting during Ramadan or other religious observance are available and should be discussed with specific families (See related ISPAD 2022 Consensus Guidelines Chapter 24 on \textit{Ramadan and other religions fasting by young people with diabetes}). Where available, cultural and language specific materials should be used (i.e Translation and Cultural Adaptation of the “Barriers to Diabetes Adherence” into Arabic Context, picture-based carbohydrate-counting resource for Somalis etc.)\textsuperscript{162}. 
Structured efforts have been made to approach and meet the needs of minority children with T1D, including the Shared Meeting Appointment program for Latino T1D that have been successful in improving glycemic control especially in younger children and, most importantly, in disseminating the use of technology \textsuperscript{163}. Similar efforts include a promising home telehealth group appointment model (CoYoT1 clinic) that have been adapted to address the needs of a racially/ethnically diverse population of young adults with T1D \textsuperscript{55}.

12.1 Racial disparities

It is important to recognize the presence of racial disparities in the provision of ambulatory diabetes care. Studies have shown differences in the receipt of recommended screening for diabetes-related complications and comorbidities, based on race/ethnicity \textsuperscript{164,165}. Racial disparities are particularly evident in the use of diabetes technology. These differences cannot be solely attributed to lower socio-economic status, educational level or health insurance status, but may reflect a possible lack of a culturally sensitive approach and systemic structural racism \textsuperscript{166-168}. To overcome these barriers, efforts should be made to actively support the use of technology in a trackable and standardized way to all.

13. EDUCATION AND LITERACY IN DIABETES TECHNOLOGY
Diabetes technology has evolved rapidly and the number of youth using advanced diabetes technologies has increased substantially in the past decade. Youth with diabetes are routinely using CGM, smart insulin pens, CSII using insulin pumps, and AID to support glucose monitoring and insulin delivery for their day-to-day management. Despite the rapid integration of diabetes technology into pediatric diabetes care, there continue to be multiple barriers to the uptake, use, and accessibility of diabetes technologies for youth with diabetes. Thus, robust diabetes education, device training, and follow-up of children and families are essential to minimize device discontinuation and maximize proper device use to help achieve target glycemic outcomes.

Health care teams play an important role in setting realistic expectations for the youth and family when starting on any new diabetes technology and ensuring an understanding of what devices can and cannot do to support diabetes management. Technology selection must be appropriate for the youth with diabetes. While device companies offer online tutorials and training videos, as well as written materials on their use, structured education delivered by the care team can

<table>
<thead>
<tr>
<th>Technology</th>
<th>Topics to cover</th>
</tr>
</thead>
<tbody>
<tr>
<td>CGM</td>
<td>Type of continuous glucose monitoring, physical placement, site issues, calibration, alerts/alarms, sensor lag, trend arrows, glucose reports, data transmission and sharing data</td>
</tr>
<tr>
<td>Insulin pump</td>
<td>Types of insulin pumps, transition from multiple daily injections, physical placement, pump operation, site issues and potential infusion set failure, carbohydrate ratios and correction factors, advanced pump settings (e.g., temporary basal rates, extended/square/dual wave bolus), data transmission and sharing data</td>
</tr>
<tr>
<td>AID</td>
<td>CGM and insulin pump topics + algorithm fundamentals, adjustable and fixed parameters, impact of missed boluses and overtreatment of hypoglycemia, automation activation and optimization</td>
</tr>
</tbody>
</table>
provide youth and families with practical guidance to support the successful adoption and use of technologies (Box 3).

Historically, structured, person-centered, and empowerment-based education programs for diabetes technology use have been delivered mostly in-person by a certified diabetes specialist. With the expansion of telehealth services during the COVID-19 pandemic, virtual training sessions to start diabetes technology have been shown to be feasible since CGM and insulin pump data can be uploaded from home and accessed remotely by care teams. The benefits of virtual training can include scheduling flexibility, access to individuals who live in more remote locations, and reaching individuals who experience challenges traveling to appointments. Depending on the availability of videoconferencing equipment and internet access, virtual training sessions may allow for the broadest possible inclusion of youth to use diabetes technology in their diabetes care.

Since multiple caregivers are generally involved in a child’s care (e.g., babysitters, daycare providers, school nurses, teachers), education and support must extend beyond the youth and family in pediatric diabetes care. In addition, routine clinic visits should be used to re-evaluate the benefit being achieved by and the adequacy of use of the diabetes technology by the medical provider. If there is a lack of measurable benefit, or a concern about safe use of the technology, ongoing training and education in the use of diabetes technologies for youth and their families should be provided, especially given that the technologies are constantly being improved and updated. Studies examining re-education of more experienced insulin pump users, for example, showed reduced frequency of hypoglycemic events and slightly improved HbA1c levels. Ongoing education and support can occur at times of routine follow-up care for youth with diabetes or as separate visits with multidisciplinary team care members.
Deficiencies in literacy and numeracy can make diabetes education and the use of diabetes technology very difficult. Low numeracy skills have been adversely associated with glycemic control in certain studies. Pictorial materials can be developed to assist with these situations. Innovative measures can be used, such as teaching the mother or child to draw the numbers because they cannot write them, providing pre-marked syringes (wrapped with colored tape to mark the dose), and using color coding to designate doses of insulin based on proximity of glucose reading to target range. Somewhat similar is the problem of multiple languages or dialects as educational and instructional materials may not be available in the local language. Finally, education should be provided in a developmentally appropriate format that meets the behavioral and emotional needs of a growing child and family. To support the incorporation of child-centered language, the act of play can be used to introduce information about diabetes technology in an age-appropriate manner. Given the potential of play-based strategies providing the child with positive experiences related to their ongoing diabetes care and their interactions with the diabetes team, certified child life specialists can be incorporated as members of the multidisciplinary care team.

Health care team members training and supporting the youth and family on the use of diabetes technology must be proficient with all glucose monitoring and insulin delivery technologies available to prescribe to their persons with diabetes. Teams should develop formal standards, which set out the core competencies expected of staff delivering diabetes technology education and care. In addition, to support requisite expertise on the multidisciplinary care team, teams should consider:

- Having at least one staff member with formal training in the use of each diabetes technology device approved for use for their young children with diabetes.
• Providing guidance to entire care team on available systems and their suitability for different types of users
• Offering relevant continued professional development, if available, to entire care team and encouraging the use of demonstration systems to support understanding of the functionality of advanced diabetes technologies

Applications (apps) for smartphones designed to support diabetes self-management offer an additional tool for supporting diabetes education and self-management. These include apps for tracking data (e.g., blood glucose values, insulin doses, and carbohydrate counting), apps for teaching and training, and food reference databases. While the growth of digital health apps has the potential to offer benefit to youth with diabetes, the available evidence on the safety and effectiveness of mobile health apps for diabetes remains limited. Regardless, given the growing use of diabetes apps, health team members should be knowledgeable of commonly used apps and their strengths and weaknesses. Further, care team members should be comfortable on how to support youth and their families on the use of digital health apps to augment diabetes management, as well as inform them the privacy risks and steps that can be taken to keep data confidential and secure.

14. CHILDREN WITH DIABETES AT SCHOOL: HOW TO INTEGRATE DIABETES MANAGEMENT IN A SCHOOL SETTING. (For additional information see ISPAD 2022 Consensus Guidelines, Chapter 22 ‘Management and support of children and adolescents with T1D in school’)

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Children with diabetes have the same right to participate in education as their peers without diabetes. However, data show they are at higher risk from being excluded from school. Normalization of day to day living and functioning in the school settings for children should be a primary goal of diabetes care. Children spend 40–50% of their waking hours in school, and much of their socialization is learned there. Diabetes care in school is an important part of their diabetes management plan. Schools need to be engaged as part of the team caring for the child, empowered through education; and supported through provision of relevant and adequate information. Recent data shows a lack of knowledge by teachers in some countries, which may be improved by a structured education provided to teachers. However, the volume of information to be provided should be adapted according to local possibilities and can be considered as:

- Minimal information level - Emergency awareness: allows teachers to react in case of emergency (Box 4)

**Box 4: Minimal information level Emergency awareness for school-setting caretakers**

- Child has diabetes
- Care in case of hypoglycemia
  a. Symptoms
  b. Oral intake of carbohydrates
  c. BLS (Basic Life Support) in case of seizure and/or unconsciousness and application of glucagon if available
- Care in case of hyperglycemia
  a. Symptoms
  b. Consultation with parents
  c. Emergency call in case of vomiting

- Basic information level: allows for prevention of emergency provided by teacher, educator, kindergarten teacher that support children with diabetes (Box 5)
• Ideal information level for care support provided by school nurses, school assistance.

This information should be given to school nurses or school assistance by diabetes team.

Preferably, the information is individualized to the child or adolescents’ treatment. (Box 6)

**Box 5: Basic information level for school-setting caretakers**

1. Knowledge about diabetes
2. Information about Insulin treatment
3. Explanation about BGM/CGM
   a. Normal, low and high values
4. Hypoglycemia
   a. Symptoms, b. Treatment, c. Causes, d. Prevention
5. Hyperglycemia
   a. Symptoms, b. Treatment, c. Causes, d. Prevention
6. Nutrition
   a. Basic information about carbs, fat, protein
   b. What kind of food affects blood sugar

**Box 6: Ideal information level for school-setting caretakers**

<table>
<thead>
<tr>
<th></th>
<th>Information about diabetes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>- Chronic disease</td>
</tr>
<tr>
<td></td>
<td>- Not contagious for other children</td>
</tr>
<tr>
<td></td>
<td>- Children can do same everyday school life than other children</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Insulin and Glucose targets</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>- Why do we need insulin?</td>
</tr>
<tr>
<td></td>
<td>- How is it working?</td>
</tr>
<tr>
<td></td>
<td>- Glucose target: mg/dl or mmol/l</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Individualized information about treatment of the child</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>- MDI: Pen or syringe demonstration</td>
</tr>
<tr>
<td></td>
<td>- CSII: Demo pump to train bolus delivery, glucose values on pump</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Individualized information about the system of glucose monitoring:</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>- BGM: demonstration and training of a BG measurement</td>
</tr>
<tr>
<td></td>
<td>- CGM: demo device to demonstrate glucose values and trends</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Hypoglycemia</th>
</tr>
</thead>
</table>
School personnel must be supportive of providing diabetes care and encouraging diabetes management during school hours in particular:

1. Monitoring of blood glucose in young children and older newly diagnosed children and adolescents until they can perform the task independently. The use of CGM at school is recommended and school personnel should receive adequate training and specific instructions through a clear school plan about how to respond to sensor data and when it is necessary to perform a blood glucose measurement.
2. Identification and treatment for all degrees of hypoglycemia. Although most teens are independent with diabetes management at school, nonetheless, they may require assistance with management of moderate to severe hypoglycemia. Therefore, all school personnel should be trained to recognize hypoglycemia symptoms, initiate treatment, and know when to call for assistance or how to treat severe hypoglycemia. Newer, easier-to-use formulations of glucagon, such as intranasal glucagon is available in some countries. The single-dose nasal glucagon is indicated in adults, adolescents and children over 4 y of age. Study results on intra-nasal formulation have shown improved glucagon delivery, effective correction of hypoglycemia and reduced stress in the management of hypoglycemia for people with diabetes and their families \(^{182-184}\). Anyhow, parents should make sure glucagon is available at home, in school and during travel for emergencies.\(^{182,185}\)

Schools should be able to make provisions for the child to keep/ carry glucose monitor and insulin and a place where BGM and insulin administration can be done safely (e.g.in the classroom, medical room, etc.). Where age appropriate, the school should support a child’s prescribed medical treatment, and changes in activity patterns should be incorporated into the medical plan (e.g. extra snacks for extra activity).

The child with diabetes should have the security of knowing that all relevant persons in the system are aware of his/ her diabetes and would be able to help in case of need.

School staff should watch out for any bullying that may occur on account of diabetes. The child with diabetes has the ability and should be given the confidence to participate equally in all school activities, including outdoor activities and sponsored events away from school, and to receive adult support and supervision for diabetes care during school hours. At the same time,
school staff should be aware that on occasion, children or families will try to use diabetes as an excuse to manipulate situations; this should be discouraged.

Internationally available guidelines provide sound information on which to base local care plans for children with T1D. In a limited number of countries, national diabetes associations and organizations provide published guidelines for school care and recommendations and programs to assist school personnel and families in coordinating diabetes care in schools. Recently, information in specialized journals or brochures about children with diabetes in school may be of help.

However, while school personnel can become knowledgeable about the complex medical care requirements of children with diabetes, many remain apprehensive about taking on the responsibility of providing diabetes care. Furthermore, ongoing investment in capacity building of staff is required as persons with knowledge of T1D management move on to different roles or institutions.

15.CHILDREN WITH DIABETES IN ORGANIZED CAMPS

Diabetes camp (or diabetes school camp) is an educational activity developed for children, adolescents and young adults with diabetes, in a setting located outside the hospital. Diabetes camps have been organized since the first half of 20th century, soon after insulin introduction in people with diabetes. These camps, likewise a normal camping experience, may include various activities with different durations, and are suitable for different purposes related to diabetes care.
Many local and national diabetes organizations manage residential and day camps for children and adolescents with diabetes. It is estimated that worldwide 15,000 – 20,000 young people attend diabetes camps annually. Diabetes camps are usually staffed by professionals and volunteers trained in the management of children with diabetes. Please see Box 7 for details of requirements of Diabetes Camps.

**Box 7: Camps specializing in children with diabetes should have:**

- Adequately trained staff
- Presence of a complete diabetes team, including
  - At least 1 physician serving as camp coordinator
  - At least 1 pediatrician/pediatric resident every 10 campers
  - At least 1 nurse every 5 campers
  - At least 1 dietitian and 1 psychologist
  - An adequate number of educators/entertainers for the regular execution of the camp
- Available insulin and consumables to meet children’s needs
- Knowledge of insulin dose adjustments (considering an increased level of activity)
- An understanding of how to manage different glucose sensors, pumps and algorithms
- A staff trained to recognize and treat hypoglycemia and ketosis (and decide when referral to a medical facility)
- A member with knowledge of nutrition, carbohydrate content of meals, and the principles of insulin doses adjusting for variable carbohydrate content of meals
- A plan to maintain a log of each camper’s glucose levels and insulin doses

Diabetes camps offer children and adolescents the opportunity to enjoy a camping experience in a safe environment and to experience a setting where caring for diabetes is a shared experience with other campers who also have diabetes. For many children, this is an opportunity to meet other peers with diabetes and learn healthy ways to manage diabetes. During their diabetes camp experience, many children learn more about how to care for their diabetes and may subsequently be able to safely attend any camp of their choosing with friends and family. However, camp staff should understand that the primary goal of camp is to provide an enjoyable experience for each child and to interact with other children with diabetes in a safe environment.
Most camps provide some education on diabetes management, either in planned formal sessions or, more commonly, by taking advantage of helping campers ‘learn by doing’ and of ‘teachable moments’ to discuss one-on-one or in a group related to diabetes care and outcomes.

While school camps are a moment of learning and usually glucose control is not the main focus, in a recent meta-analysis on thirty-three studies, organized camps have been described to improve glycemic control (mean HbA1c -0.59%, -0.95;-0.23) as well as diabetes knowledge (mean standardized score 1.99, 1.28;2.70) in the short term. Children and adolescents with diabetes highly benefit in terms of distress and independence in self-care, while parents can live the experience with a certain level of concern. Nevertheless, despite these advantages, vulnerable people with diabetes (such as children from racial/ethnical minorities) are less likely to attend a diabetes school camp.

Camps can also be a valuable moment to test a new technology (CGM, pump, algorithm, drug) in children and adolescents with diabetes in a real-life setting. Furthermore, camps can be used to conduct studies in a small group of people, to evaluate different aspects of the disease (such as physical or psychological) or to evaluate a clinical algorithm.

Certified camps specializing in the care of children with diabetes can be found on the Internet. Many national organizations have position statements or guidelines for the care of children with diabetes in a camp setting. These are valuable references and should be reviewed by camp medical directors to ensure adherence to national standards.

Other out of the clinic activities in which the diabetes team may be involved include the following:

- Local (and national) support groups
- Advanced education sessions (e.g., advanced insulin pump classes, use of CGM)
• Resources (information leaflets/books, equipment, informational websites, etc.)
• Nutrition, games, experiments and innovations
• Discussion groups, activity days, visits, lectures, holiday events, family camps, etc.

**16. QUALITY OF CARE, STRUCTURE OF CARE, PROCESSES OF CARE AND OUTCOMES**

Despite remarkable advances in pharmacology and diabetes device technology, many people with T1D continue to experience sub-optimal health outcomes \(^{41,204}\) that confer an unacceptable burden of short term and long-term complications. Diabetes centers need methods to evaluate and enhance the quality and equity of the diabetes services they provide and the outcomes of their management \(^{205}\). Given the complexity of T1D management, a multifaceted approach that integrates psychosocial supports \(^{11}\), recognizes contributions of social determinants of health \(^{206}\), leverages information science \(^{207}\), and application of quality improvement (QI) methodology \(^{208}\) is needed to complement emerging therapeutic modalities for T1D.

Quality improvement methods describe a systematic and continuous approach to accomplish measurable change in a process or outcome of care \(^{209,210}\). Reliable implementation of evidence-based care processes, such as uptake of diabetes technology and rates of preventative screening labs and services, predictably precede improvements in clinical outcome measures such as HbA1c, TIR, severe hypoglycemia, quality of life, and reduced long-term complications of retinopathy or nephropathy. Structure of care refers to how care delivery systems are organized and financed. The impact of features such as composition of diabetes care team, access to care and costs, frequency of visits, type of encounter via telehealth or in-person, community and peer supports on clinical outcomes remains an important topic for health services research in in
pediatric diabetes and is an emerging area for further quality improvement efforts. Across categories of structure, process, and outcomes, selection of meaningful measures is essential to the practice of quality improvement to monitor progress and direct interventions. Increasingly, there is recognition of the importance of metrics beyond HbA1c alone to describe salient elements of care delivery, diabetes management, and lived experience. Efforts towards inclusion of individual-reported outcomes, partnering with people with diabetes and families in QI initiatives, addressing social determinants of health, and screening for common co-morbidities associated with T1D offer further opportunities for an even more comprehensive understanding of quality assessment of pediatric diabetes services.

Diabetes registries can be an important tool for population management at individual centers, quality improvement, and benchmarking across collaborative centers. Benchmark reporting that evaluates effectiveness of diabetes care measured against guidelines for standard practices can promote accountability and system wide improvements in diabetes care. When data transparency through benchmarking is combined with quality improvement methods and open sharing of best practices, it is possible accelerate and sustain process improvements and measurable changes in outcomes. The international SWEET registry showed worldwide improvement of HbA1C and increase of diabetes technology associated with twice yearly benchmarking. The Swedish National Pediatric Registry (SWEDIABKIDS) is an example of a national quality improvement collaborative that observed sustained decrease in mean HbA1c level for children 0-18 years from baseline of 62.6 mmol/mol (7.9%) in 2010 to 56.9 mmol/mol (7.4%) in 2014 and continues to be a leader in pediatric diabetes outcomes.

Involvement of governments and policy makers facilitates provision of adequate resources that are required for high quality diabetes care. It is a priority collecting and providing information on
cost of care and long-term cost effectiveness data of optimal care of children with diabetes to governments and health care agencies.

17. BALANCING COSTS AND BENEFITS IN DIABETES CARE

Diabetes imposes a large economic burden on the individual, their families, national health systems, and countries. Existing burden of T1D in low-income and middle-income countries (LMICs) most likely underestimate the true burden owing to the scarcity of representative population-based information and potential premature deaths before diagnosis. In other areas of the world, these numbers are, however, gross underestimates of true costs as they do not account for loss of quality of life, loss of productivity as well as burden of care on the families.

There is vast disparity in health spending between regions and countries. In 2019, only 14.8% of global diabetes health expenditure was spent in LMICs, where 41.8% of people with diabetes live. A study in LMICs reported that annual inpatient and medication costs were the most expensive aspects of diabetes care, with a high degree of cost variability; some studies reported annual inpatient costs lower than US$20, whereas others reported costs higher than $1000, and medications alone ranged from less than $20 per year to more than $500. Studies by the International Insulin Foundation found suboptimal access to insulin in seven LMICs, with availability in only 20% of public sector outlets in Mali and Mozambique. In LMIC countries access to insulin is limited as well as the use of new technology due to costs.

Analysis of costs of care is important in helping to determine appropriate recommendations for care and in health policy decision making. The total health care expenditure for diabetes was
estimated to be greater than USD$ 760 billion dollars and equivalent to ~12% of all global health expenditure. It is of great concern that ~80% of all expenditure is associated with treatment of complications, suggesting that prevention of complications could significantly reduce health costs globally.

Despite promising downward trends in mortality and disability-adjusted life years (DALY) rates observed over the past three decades, there remains a substantial gap in life expectancy between people with T1D and the general population, even within HICs. In Sweden, Scotland, and Taiwan, T1D resulted in 10.2–17.7 lost life years; this life-expectancy gap is more pronounced among low-income settings with poor access to insulin. A Swedish study showed that the variation in life expectancy was negatively correlated with HbA1c and positively correlated with estimated glomerular filtration rate.

The proportion of children with optimized glycemic control (HbA1c <7.5%) was estimated to be 32.4% in high income countries (HICs), 27.5% in upper-middle-income countries (UMICs), 21.7% in LMICs, and 12.7% in low-income countries (LICs). Notably over the past 15 years, on average about 76.4% children with T1D globally were unable to achieve optimized glycemic control. Hence, an investment in gold standard care particularly during childhood and adolescence should be advocated globally and it is likely to lead to significant economic benefits. Improved glycemic control through adequate education and regular glucose monitoring can decrease the risk of complications. It is obvious that regular home glucose monitoring is cost effective, decreasing costs of diabetes care by decreasing emergencies. Moreover, safe intensive diabetes management aimed at near-normal glycemia is impossible without frequent and consistent glucose monitoring.
Both rapid- and long-acting analogs have been shown to reduce the frequency of mild and moderate hypoglycemia. Given the reduced incidence of hypoglycemia, newer analogs may be even more cost-effective. However, affordability for individuals remains a challenge in many settings with cumulative markups ranging from 8.7% to 565.8% and the magnitude of markups being country specific and variable within and across sectors and regions. In many LMICs, the price of insulin is paid for in full by an individual or, in some contexts, subsidies are in place. By contrast, in most HICs, various government-funded or health insurance schemes provide some form of financial protection, either ensuring that insulin is provided for free to the individual or, at least, that the person does not bear the full cost.

The most notable change in diabetes management over the past 5–7 years was the substantial increase in use of CGM which led to a reduction in HbA1c. This increase has been most prominent among young children, giving parents the ability to monitor the glucose data remotely. The early adoption of insulin pumps and CGM are associated with less frequent hospital admissions because of diabetes ketoacidosis compared with injection users. Among individuals with diabetes using CGM, HbA1c concentrations were similar among MDI users or insulin pump users. On the basis of such promising results, efforts must be made to research and find ways to improve glycemic control and overcome disparities in diabetes management in individuals from LMICs.

Studies on CSII versus MDI suggest that CSII modestly lowers HbA1c compared with MDI, but there is insufficient data on other glycemic outcomes. Dos Santos and colleagues reviewed the evidence for CSII versus MDI among disadvantaged young people living in HICs, such as immigrants, ethnic minority groups, non-recipients of state assistance, and children whose parents have a lower education level. Despite the overall suboptimal glycemic control, the
socially disadvantaged groups did achieve some improvement in the glycemic outcomes when on CSII therapy\textsuperscript{240}. A large non-randomized prospective follow-up study supports the idea of an early pump initiation following T1D diagnosis\textsuperscript{241}. However, Blair and colleagues who compared clinical outcomes and costs associated with CSII with MDI concluded that CSII was not clinically superior to MDI when started at diagnosis and was associated with significantly higher costs\textsuperscript{242}.

AID with predictive low-glucose suspend was superior to SAP at decreasing daytime and nocturnal hypoglycemia without increasing the risk of diabetic ketoacidosis or hyperglycemia\textsuperscript{243}. There have also been recent advances in diabetes care with the use of SAP therapy with automatic insulin suspension, hybrid and full closed-loop systems, and CGM, all showing improved glycemic control\textsuperscript{239,244}.

Closed-loop systems with artificial pancreas might offer even better futures for children and young adults living with T1D, and could one day be made available in LMICs\textsuperscript{245}. Both inpatient and outpatient trials have indicated that closed-loop systems are more effective than conventional therapy at maintaining optimal mean glucose concentration, a higher percentage of time in range, and reduced time in hypoglycemia and hyperglycemia\textsuperscript{246}. There are still no data comparing the costs using the different insulin delivery systems.

In 2017, the SWEET Working Group compared children's access to CGM systems and insulin pumps in 29 European countries, and access was not awarded everywhere\textsuperscript{149}. On one hand we all know the clinical advances of insulin analogs, rtCGM systems or the higher AID systems, but on the other hand it depends on the health care system if it can provide such high-priced health care advances.
Personal expenses for diabetes care vary widely around the world, with costs being prohibitive in some countries and completely paid for by the state or private health insurance in others. With the increased cost of diabetes care, some countries or health insurance systems are considering or have already restricted use of newer insulin analogs and newer technologies, requiring those choosing these technologies to bear up to 100% of the cost.

Regardless of the source of payment for care, information about cost-effectiveness is required to inform health care decisions. It is important to continually reassess cost-effectiveness of insulin therapies and technologies as advances are made and as outcomes data are collected over longer periods of time. Advocacy for broad access and affordability of optimal therapies is needed, for most equitable delivery of care.
<table>
<thead>
<tr>
<th>Evaluation</th>
<th>Type 1 Diabetes</th>
<th>Type 2 Diabetes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Glycemic Management</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hemoglobin A1c</td>
<td>Quarterly at each visit</td>
<td>At each visit and in between visits as needed for insulin dose adjustments</td>
</tr>
<tr>
<td>Glucose values from meter, log, or CGM AGP report for TIR, TBR, TAR</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Cardiovascular risk factors</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blood pressure</td>
<td>Every visit</td>
<td>Every Visit</td>
</tr>
<tr>
<td>Smoking status</td>
<td>Discourage smoking in youth who do not smoke and encourage smoking cessation in those who do</td>
<td></td>
</tr>
<tr>
<td>Lipids</td>
<td>Begin ≥ 11 years; if normal results are obtained, this should be repeated every 3 years.</td>
<td>Begin after glycemia control or after 3 months of diagnosis; repeat annually</td>
</tr>
<tr>
<td><strong>Microvascular complications</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kidney disease: Urinary albumin:creatinine ratio</td>
<td>Start at puberty or from age 11 years, whichever is earlier, with 2-5 years diabetes duration; repeat annually</td>
<td>Begin at diagnosis; repeat annually</td>
</tr>
<tr>
<td>Retinopathy: Dilated Eye Exam</td>
<td></td>
<td></td>
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<tr>
<td>Neuropathy: Comprehensive foot exam</td>
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<td></td>
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<tr>
<td><strong>Autoimmune screening</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thyroid function: TSH, total or free T4 and thyroid antibodies</td>
<td>At or near diagnosis; Every 2 years: TSH (sooner if positive thyroid antibodies at diagnosis or with symptoms)</td>
<td>N/A</td>
</tr>
<tr>
<td>Celiac screening (TTG-IgA, if IgA sufficient)</td>
<td>At or near diagnosis; Repeat at 2-5 years intervals (sooner if symptomatic or first degree relative with celiac disease)</td>
<td>N/A</td>
</tr>
<tr>
<td>Addison’s disease (primary adrenal insufficiency), autoimmune hepatitis, autoimmune gastritis, dermatomyositis, and myasthenia gravis</td>
<td>As clinically indicated</td>
<td>N/A</td>
</tr>
<tr>
<td><strong>Psychosocial screening</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes distress, depression, disordered eating</td>
<td>Begin shortly after diagnosis; Routinely (at least annually)</td>
<td></td>
</tr>
<tr>
<td><strong>Anticipatory guidance</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pre-conception counseling, risk-taking behaviors, transition to adult care</td>
<td>Pre-conception counseling for girls of childbearing potential. Discussion about risk-taking behaviors and preparation for transition to</td>
<td></td>
</tr>
</tbody>
</table>
adult care can begin in early adolescence and be revisited at least annually.

References


UK and Wales National Paediatric Diabetes Audit 2020-2021. [https://www.rcpch.ac.uk/resources/npda-annual-reports](https://www.rcpch.ac.uk/resources/npda-annual-reports). Accessed 02/05/2022,


Diabetes care is best delivered by a multidisciplinary team with youth with T1D and family at the center. The team should consist of: pediatrician specializing in diabetes or endocrinology (preferred), or physician/advanced nurse practitioner with a special interest (and training) in childhood and adolescent diabetes, diabetes nurse specialist or diabetes nurse educator, dietitian trained in pediatrics with knowledge of childhood diabetes and normal growth, psychologist trained in pediatrics and with knowledge of childhood diabetes and chronic illness, pediatric social worker with training in childhood diabetes and chronic illness. The team should get training and education on technology regularly and have the resources to develop strong links, effective communication, and shared practices with primary healthcare providers, schools, and other essential caregivers.
**Figure 2: Insulin Carb Ratio (ICR) and Insulin Sensitivity Factor (ISF)**

### How to calculate insulin sensitivity factor (ISF):

1800/TDD (for BG in mg/dl) or 100/TDD (for BG in mmol/l)

For example, if the TDD is 20 units:

ISF is 1800/20 = 90 (mg/dl) or 100/20 = 5 (mmol/l)

- So, 1 unit of insulin lowers blood glucose by 90mg/dl or 5mmol/L

### How to calculate approximate insulin/carbohydrate ratio:

500/TDD or 300/TDD (often used instead for young children) rule

For example, if the TDD is 20, the ratio is 500/20 = 25.

- That is, 1 unit insulin should be given with 25 g carbohydrates

---

**EXAMPLE ON HOW TO CALCULATE PRE-MEAL INSULIN DOSE**

Assuming that: ICR= 1 unit to 25 gr CHO;
ISF= 90  and Target BG= 100 mg/dl

**CALCULATE BOLUS INSULIN DOSE FOR A MEAL**

gr CHO divided by ICR

| Carbs meal content= 75 gr | 75/25 (ICR)= 3 units |

**CALCULATE CORRECTION DOSE IF BLOOD GLUCOSE IS ABOVE TARGET**

(BG- Target BG) divided by ISF

| Preprandial BG= 200 mg/dl (11.1 mmol/l) | (200-100)/90 = 1 units or (11.1 - 5.6)/5= 1 units |

**CALCULATE TOTAL DOSE OF BOLUS INSULIN =**

Bolus insulin dose for meal + correction dose

3 + 1= 4 units

---

TDD= total daily insulin dose; BG= blood glucose
Figure 3: Ambulatory Glucose Profile (AGP)

**Example of an Ambulatory Glucose profile (AGP)**

**GLUCOSE STATISTICS AND TARGETS**
- **8 April 2022 - 21 April 2022**
- **14 Days**
- **% Time Sensor is Active**: 92%

**Ranges and Targets For**
- Type 1 or Type 2 Diabetes

<table>
<thead>
<tr>
<th>Glucose Range</th>
<th>Target (for readings - MiniMed)</th>
<th>Greater than 70% (125-160mg/L)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Below 3.9 mmol/L</td>
<td>Low</td>
<td>Less than 4% (8mmol/L)</td>
</tr>
<tr>
<td>Below 3.5 mmol/L</td>
<td>High</td>
<td>Less than 1% (10mmol/L)</td>
</tr>
<tr>
<td>Above 10.0 mmol/L</td>
<td>Low</td>
<td>Less than 0% (9mmol/L)</td>
</tr>
<tr>
<td>Above 13.3 mmol/L</td>
<td>High</td>
<td>(10.5-13.9 mmol/L)</td>
</tr>
</tbody>
</table>

**Time in Ranges**
- **Very High**: >13.9 mmol/L (105-139 mg/dL) 1%
- **High**: 10.5 - 13.9 mmol/L (180-250 mg/dL) 13%
- **Target Range**: 3.9 - 10.0 mmol/L (70-180 mg/dL) 83%
- **Low**: <3.9 mmol/L (<70 mg/dL) 3%
- **Very Low**: <3.9 mmol/L (<70 mg/dL) 0%

**Average Glucose**: 7.4 mmol/L
**Glucose Management Indicator (SMI)**: 6.5% or 48 mmol/L
**Glucose Variability**: 33.4%
**Defined as percent coefficient of variation (%)C; target ≤ 44%

**AMBULATORY GLUCOSE PROFILE (AGP)**

AGP is a summary of glucose values from the report period, with median (50%) and other percentiles shown as if occurring in a single day.

![Ambulatory Glucose Profile Graph](image)

**Time in Range Recommendations**
- > 70% of readings between 3.9-10.0 mmol/L (70-180 mg/dL)
- < 4% of readings < 3.9mmol/L (<70mg/dL)
- < 1% of readings < 3.0mmol/L (<54mg/dL)
- < 25% of readings > 10.0 mmol/L (>180mg/dL)
- < 5% of readings > 13.9 mmol/L (>250 mg/dL)

- **Blue line**: is the median the median glucose of that particular hour of the day
- **Dark blue area**: indicates the interquartile range or 50% of all values (area between the 25th and 75th percentiles)
- **Lighter blue area**: (between the 10th and 90th percentile lines) indicate that only 10% of glucose reading are above or below that values
Figure 4a: Video visits in detail

Video visits for children with diabetes

Upload by the family of CGM, insulin and therapy data to cloud-based software
- Virtually any software, whether installed locally on the PC or cloud-based, can save the data as a pdf.
- Families can either send the data directly to the diabetes team or give the team access to their data in the cloud-based software.
- Many insulin pumps and CGM systems transfer the data from their corresponding user app directly to the software.

Download of CGM, insulin and other therapy data
Data analysis and commentar
- Positive, motivational commentary on the data and why adjustments to the therapy are being recommended. Use of comment function and highlighter in pdfs.
- Option 1: Send the data pdf to the family in an encrypted email so that they can actively prepare.
- Option 2: Share the screen and discuss the data during the video consultation.

Video consultation and/or additional contact via phone or e-mail
- Discuss trends, TIR, TBR, changes in insulin and other settings
- If possible: HbA1c Home-Test as a supplement to Software-GM
- Give technical advice e.g. trend arrows, temporal basal rate
- Provide advice on psycho-social and legal issues
- Favour empowerment-based counselling and shared decision-making

Child with diabetes and caregiver
Diabetes team member
**Figure 4b: Video-consultation step by step**

**Step by step tutorial: incorporating video consultation into long-term outpatient care**

<table>
<thead>
<tr>
<th>Step</th>
<th>Description</th>
</tr>
</thead>
</table>
| **1. Preparation** | 1. Ensure that families have the required equipment (smartphone, or computer with camera and microphone) and diabetes software. Install professional video chat software for the team.  
2. Discuss appropriate data protection measures  
3. Test of hardware and software  
4. Provide information for families on how to upload diabetes data and how to use the video chat program  
5. Clarify financing of video consultations as a supplement or replacement for outpatient consultations |
| **2. Integration** | 1. Define type of integration into previous outpatient care: Video consultation can be offered as an occasional replacement, as a regular replacement with higher frequency of appointments in the Virtual Clinic, or as an Add-on to supplement regular outpatient consultations  
2. Define target groups e.g. younger children for Add-on or children with AID systems, children with good or suboptimal metabolic control, or children living far away from the diabetes team, for preferable treatment in a Virtual Clinic  
3. Explain to families the new mix of in-person and virtual appointments and its advantages, but also the tasks for parents (uploading data, keeping appointments, switching to phone call in case of technical problems) |
| **3. Process** | 1. How can patients register for video consultation?  
2. Which team members will perform video consultation?  
3. What will be the duration/timing of the appointments? If the objective is to make small adjustments to the therapy, then more frequent, but shorter, sessions are a good option.  
4. Should families view the data pdfs before the video appointment? Preliminary work on CGM data by parents and young adults is desirable, but it takes time for healthcare professionals to pre-send the data pdf with comments |
| **4. The video consultation** | 1. Prepare the data PDF (if not already done): Highlight GMI, TIR, Td/TiR and improvements (e.g. infusion set changes, number of injections) and identify the „best days“ when metabolic control was very good  
2. Check camera position (should be at eye level) and background  
3. Explain curves, trends and statistical measures, mention successful days and actions and discuss issues needing attention  
4. Discuss the insulin setting  
5. Schedule a new appointment  

Postponed and missed appointments: call the family and investigate the reasons for not responding
**Figure 5a: Transition Models to Adult Care**: Transition models vary in physical proximity, sharing of medical records, and care providers (as indicated by distance and solid or dotted lines in model). Strategies for building connections between pediatric and adult diabetes providers need to be tailored to local contexts.
Structured Transition Programs: developmentally tailored diabetes education, case management, and clinical care

Transition coordinators or “patient navigators”: coordinating role setting up appointments, addressing transportation or financial barriers, and making phone calls to confirm successful transfer

Provider continuity or handoff: Joint attendance of pediatric and adult providers, combined adolescent and young adult clinic

Pediatric clinic preparation for transition

Adult clinic receivership for successful transfer of care

Use of technology for telemedicine, shared medical visits, peer support, messaging between visits.
Supplementary Figure 1: Long term outpatient care: New models.

## Models for integrating video consultation into long-term outpatient care

### Occasional replacement
Replacement of one quarterly contact with one or two video consultations

<table>
<thead>
<tr>
<th>1. Quarter</th>
<th>2.</th>
<th>3.</th>
<th>4.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>![Person]</td>
<td>![Computer]</td>
<td>![Person]</td>
</tr>
</tbody>
</table>

### Add-On
Extra video consultations at times of high need for counselling, e.g. after onset, or when switching to an insulin pump

<table>
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<tr>
<th>1. Quarter</th>
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### Virtual clinic
Primarily virtual support with at least one face-to-face contact per year for physical examination, lab-test and psycho-social counselling

<table>
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<th>1. Quarter</th>
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### Very limited access to medical care
If only one in-person contact per year is manageable, all available contact methods, such as phone calls, e-mails or text messages, should be used to advice the family throughout the rest of the year

<table>
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