


**ISPAD CLINICAL PRACTICE CONSENSUS GUIDELINES**

# ISPAD Clinical Practice Consensus Guidelines 2018: The delivery of ambulatory diabetes care to children and adolescents with diabetes

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## 1 | WHAT'S NEW?

In this update, we have expanded general guidelines on current diabetes technologies, transition from pediatric to adult care, anticipatory guidance, and barriers to care.

## 2 | EXECUTIVE SUMMARY

From the outset, the child or adolescent with diabetes and relevant family members should receive care from a multidisciplinary diabetes team comprised of specialists with training and expertise in both diabetes and pediatrics, and knowledgeable of child and adolescent development (E). The diabetes care team should emphasize that the family and child are the central members of the care team (E). Clear and consistent communication around education and the treatment plan is essential. The treatment plan should integrate current technologies commensurate with available resources and the individual child's/family's needs. (E) A multidisciplinary team is unlikely to be available in areas of low population density and where childhood diabetes rarely occurs. In these circumstances, care is likely to be provided by a locally based pediatrician or general (family) physician, who

should have ready access to advice and expertise of the diabetes care team in regional centers of excellence<sup>1-3</sup> (C). The family can be encouraged to travel to see the diabetes specialty team recommended by their doctor, if feasible.

The diabetes care team should provide

- Specialized hospital medical care. (E)
- Expert comprehensive ambulatory care for diabetes and associated conditions. (E)
- Comprehensive education for the young person and his/her caregivers on day-to-day management of diabetes including insulin therapies, nutrition, and psychosocial support. (C)
- Expert advice for the child and the family on issues related to daily diabetes management including hypoglycemia, exercise, sick day management (infectious disease such as gastroenteritis), travel, fasting, festivals, and other special occasions. (E)
- Anticipatory 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).<sup>4,5</sup>
- Introduction of new therapies and technologies as diabetes management evolves. (E)

- Advice for care at school, camps, and other venues where children with diabetes require care when away from home. (E)
- Screening for comorbid conditions, complications, and risk for complications. (B)
- Emergency telephone or other support 24 hours a day to patients and families. (C)
- Psychosocial support for all patients and families. (B)
- 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)
- Advice and support to physicians and health care professionals who provide diabetes care where immediate access to a diabetes care team is not possible. (B)
- Routine vaccinations should be provided for children with diabetes according to age-related and regional recommendations. While specific recommendations vary by region, annual vaccination against influenza is also generally recommended for all individuals with diabetes above 6 months of age; pneumococcal and meningococcal vaccines are also recommended. (C)

Processes of diabetes care should include

- Routine visits, at least every 3 months for ongoing evaluation of diabetes management and review of home management records, as well as evaluation of growth, development, and general health. Physical examination with inspection glucose monitoring sites and injection/insertion sites should occur at each visit. Options to communicate between visits, for example, for insulin dose adjustments, should be provided, including text, phone call. (C)
- An annual visit that includes,
  - expanded physical assessments (such as pubertal staging, foot exam),
  - additional self-management assessments, including dietary knowledge (ability to estimate carbohydrate consumption and accurately determine insulin doses), self-management skills and behaviors, psychosocial needs,
  - screening for comorbidities and risk factors for long-term complications (B),
- Identification of barriers to care. (B)
- A planned, purposeful transition to adult diabetes care, to facilitate continuity of care during this critical time<sup>6,7</sup> (B). The age of transfer to an adult clinic varies according to individual maturity and local circumstances.
- Culturally sensitive communication, counseling, and encouragement for altering preconceptions or negative and unhealthful beliefs about diabetes.<sup>8</sup> (E)
- Contact with other families of children with diabetes. (E)
- Assistance to access care. This includes assuring that patients and families can have in person visits as well as communication with the care team through telehealth, telephone, or other communication modalities (see ISPAD Clinical Practice Consensus Guidelines 2018: Diabetes technologies DOI: 10.1111/pedi.12731) (E)

Outcomes of care

The ultimate goal is to provide care that results in high quality of life, normal growth and development, and lowest attainable risk of acute and long-term diabetes complications. This is best accomplished by helping children and families become proficient in self-management, remain motivated throughout childhood and adolescence, and allow for children to develop into independent, healthy adults (E).

Individual care is provided by documenting progress over time, on paper or electronic medical record (EMR); whereas clinic registries can facilitate population management; lastly, sharing/comparison of data across institutions is useful for benchmarking to identify structures of care that promote improved outcomes (B).

Based on the success of such benchmarking efforts, diabetes programs should be encouraged to enroll in benchmarking activities, or at least work on quality improvement programs as resources allow (E).<sup>9-11</sup>

Involvement of governments and policy makers facilitates provision of adequate resources are provided for high-quality diabetes care. A high priority should be given to 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. Continuous support is essential for uninterrupted care of children in developing countries. Advocacy efforts and community education can promote awareness and understanding of diabetes, improving the safety and well-being of children with diabetes (E).

### 3 | INTRODUCTION

This section of the ISPAD Consensus 2018 Guidelines outlines recommendations for ambulatory diabetes care, including periodic assessments of clinical outcomes, as well as best and emerging practices. Resources and costs are important considerations in processes of care. The availability of resources varies widely among countries, within countries, and among patient populations. Some children have access to new technologies, whereas others have limited access even to insulin and other basic diabetes supplies. Comparisons of ambulatory diabetes care practices and cost effectiveness of care are important areas for which there are limited data. Specific recommendations for certain elements of ambulatory care, including insulin therapy, assessment and monitoring of glycemic control, nutritional management, diabetes education, screening for and management of microvascular and macrovascular complications, type 2 diabetes, age-group specifics, diabetes in schools and camps, telehealth, and use of diabetes technology are addressed in detail elsewhere in the ISPAD guidelines, which should be consulted in conjunction with this chapter.

After initial stabilization at diagnosis, diabetes is primarily managed in the outpatient or ambulatory setting. Regular, ongoing ambulatory diabetes care assessment for youth with diabetes is essential to achieve and maintain optimal glucose control and to monitor for risk factors that predispose to acute and chronic complications. The components of medical care include structure, processes, content, and outcomes. *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.<sup>12</sup> Intermittent critical reexamination 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 medical care will undoubtedly change over time. It may also be helpful to review guidelines from other organizations, both national and international.<sup>13</sup>

#### 4 | STRUCTURE OF CARE

The goal of treatment is 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 comorbidities and avoidance of severe short- and long-term complications. The insulin regimen should, ideally, mimic physiologic insulin secretion and aim to restore normal metabolism. Insulin affects the metabolism of carbohydrate, protein, and fat, and is necessary for normal growth. The main aim of insulin treatment is to achieve optimal glycemic control, meeting the HbA1c target with minimal hypoglycemia, and striving for maximal “time in range” (ie, percent of values in the range of 70–180 mg/dL per unit of time), while optimizing the psychological health of the patient and family.<sup>14</sup>

Acute complications of diabetes include hypoglycemia and diabetic ketoacidosis (DKA). Hypoglycemia can cause seizures or loss of consciousness, thus fear of hypoglycemia can be present for children and their caretakers.<sup>15</sup> DKA can be associated with r seizures and thus can be distressing to caregivers and patients. Hyperglycemia, although it may cause less pronounced acute symptoms, predictably increases long-term sequelae. Inadequate control of diabetes over time may result in severe complications that can gravely impair quality and length of life.<sup>16</sup> Complications can already be observed within the first decade after diagnosis, as observed in approximately one in three youth or young adults with type 1 diabetes and two in three youth or young adults with type 2 diabetes.<sup>17</sup> These complications of diabetes also lead to substantial societal costs. Given the relatively high prevalence of diabetes (there are over 1 million children under that age of 20 years living with type 1 diabetes, and both type 1 diabetes and type 2 diabetes are increasing in children), this represents an urgent public health challenge globally.<sup>18</sup> Both the medical and economic consequences are further aggravated by the fact that type 1 diabetes mellitus (T1DM) generally appears at an early age. It is a challenging task to educate and support effective self-care among children and adolescents with diabetes and their caregivers, not least those with low economic and educational resources. Disparities in care and outcomes exist—less intensive treatments, poorer glucose control, and increased rates of DKA are reported in children from less advantaged homes as well as from countries with fewer resources.<sup>19–24</sup>

Health care staff should strive to determine each young person's and their caregiver's status regarding knowledge, perceived glycemic control, and risk perception, as well as perceived benefits and costs of health behaviors. The diabetes team is encouraged to engage 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. This requires the multidisciplinary team to have a high level of cultural competence.

Diabetes care is best delivered by a multidisciplinary team. The team should consist of:

- Pediatrician specializing in diabetes or endocrinology (preferred), or physician 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.

From the day of diagnosis, it should be emphasized that the child and immediate family are the central members of the care team. Extended family members or other care providers, school nurses, day-care staff, teachers, and others who care for children often play an important role in the child's diabetes care and may serve as a liaison between the child and the medical team. It is imperative to promote the understanding that the child retains his/her full prior potential to achieve goals physically and intellectually. It is also essential to empower the child and his/her family that he/she has 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.<sup>25</sup>

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 is accomplished through:

- Ongoing diabetes education and self-management training.
- Up-to-date advice on insulin management, glucose and ketone monitoring techniques, and monitoring for comorbidities, risk factors for complications, and complications.
- Consistent and sensitive articulation of individualized biochemical goals (glucose values from glucose meter as well as continuous glucose monitors or “intermittent” glucose monitors [CGM/iCGM], glucose variability, and HbA1c targets).<sup>26</sup>
- Contact with other children and families with diabetes and support groups.
- Provide 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.<sup>27</sup>
- Current information on research in diabetes for patients and regional physicians.
- Ongoing contributions to advancing clinical practice through the optimal application of existing and new technologies and the development and evaluation of new technologies.

Diabetes requires skilled self-management in the home and local environment. The diabetes care team should have the resources to develop strong links, effective communication, and shared practices with:

- The child and family at home, and extended family members or guardian.
- The young person at day care, school, or college/university.
- Primary health care providers.
- Pediatricians and other health care providers in areas of low population density/low diabetes prevalence.

The organization of the diabetes care team, its size, and its location will depend on geographical and demographic characteristics. In general, for members of the pediatric diabetes team to obtain sufficient experience, the number of patients in the practice should be at least 150. The number of practitioners depends on local circumstances; a suggested guide to optimal resource allocation per 100 patients: 1.0 to 1.25 diabetes nurse, 0.75 to 1.0 pediatric diabetologist, 0.5 dietitian, and 0.3 social worker/psychologist.<sup>28</sup> While not all clinics will be resourced in this manner, this staffing should be sufficient to meet standards of care.

- 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.<sup>29</sup>
- In some areas, two-way telecommunication utilizing video-computer technology or platforms such as Viber or Skype and local medical staff to facilitate the telemedicine visit allows for more efficient and effective distant care.<sup>30-33</sup>
- Computer interfacing with blood glucose (BG) meters, continuous glucose monitors, insulin pumps, and insulin pens allows patients to interact directly with the diabetes care team between visits, which may improve diabetes management.
- 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 introduced in spring 2018 may impact remote patient monitoring with diabetes devices and telehealth; regulations vary between regions.
- 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.
- Appropriate reimbursement must be available to support these essential non-face-to-face services in order to insure that diabetes care team can afford to sustain provision of input to patients using these technologies.<sup>34,35</sup>

## 5 | PROCESSES OF CARE

Generally accepted good clinical practice for the successful management of children and adolescents with diabetes includes the following:

### 5.1 | At onset

- Easy access (24 hours a day) for rapid diagnosis and initiation of treatment with availability of written protocols for management of DKA and other presentations of childhood diabetes (see ISPAD Clinical Practice Consensus Guidelines 2018: Diabetic ketoacidosis and hyperglycemic hyperosmolar state: A consensus statement from the International Society for Pediatric and Adolescent Diabetes DOI: 10.1111/pedi.12701)
- Provision of practical care guidance at diagnosis includes the education required to enable the family to feel confident to provide diabetes care at home and have a basic understanding of the pathophysiology of diabetes and its treatment. 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.
- Psychosocial support for the child and family, assessing resources and potential barriers to adjustment to the diabetes diagnosis. This includes identifying and addressing detrimental health beliefs. For example, the team may need to provide reassurance that diabetes is not contagious, and the child does not need to be segregated from other children, or provided special foods. It is important to identify the significant members of the family who will provide care (eg, one or both parents, a grandparent or another relative, or other) and ensure that they can receive the necessary education in the clinic and/or hospital. Written and/or pictorial age-appropriate materials should be provided in a format (eg, paper pamphlets, booklets, soft copies on their mobiles) and language the family understands. Such material is readily available on several excellent websites of associations involved with pediatric diabetes care, including on the ISPAD website, Life for a Child, and Changing Diabetes in Children.

Ambulatory management of children who are metabolically stable at the time of diagnosis is possible in some centers with appropriate resources, but can only be recommended when members of the diabetes care team are experienced in the outpatient initiation of insulin therapy, management, and education, and adequate reimbursement for ambulatory diabetes team care is available. Hospital facilities must also be available in case of metabolic deterioration.

The importance of providing a good start with clear, positive messages, support, and advice, cannot be overemphasized. It is important to maintain a framework which reassures the child and family that the child is normal and can live a healthy life (although a few restrictions remain regarding safety-sensitive careers).<sup>36</sup> Education and proactive discussion around common problems that can occur, such as insulin omission, may help decrease the risk of such problems arising later. In the first weeks, it is important to explain to the family that the honeymoon phenomenon may occur; otherwise they may get confused and experience doubt when insulin needs drop. Because type 2 diabetes mellitus (T2DM) is much more common than T1DM in the general population, families must understand how their child's diabetes is different from T2DM in adults, with which they may be more familiar; for example, oral medications do not work, lifelong multidose daily insulin is needed, more stringent home monitoring of glucose is

needed, weight loss is usually not needed, management must take into account growth and development of the patient.

### 5.1.1 | Practical issues around diabetes management

Diabetes is an expensive condition to manage for families, particularly in countries where a socialized health system does not provide coverage for medications, supplies, and/or clinical care services. The treatment regimen prescribed from the onset should bear in mind the family's economic, social and educational situations. Patient preference and cost may impact individualized insulin regimens; however, the following general tenets of therapy will be consistent across modes of administration:

- Basal insulin
- Bolus insulin coverage for carbohydrate intake, and to a lesser extent fat and protein
- Correction for hyperglycemia (sensitivity factor, ie, one unit of insulin is expected to bring about a reduction in glucose of xx mg/dl or mmol/L) and target glucose (see Figure 1)
- Prevention and treatment of hypoglycemia
- Pictorial educational materials and simple instructions are essential for families with no or limited numeracy and/or literacy.

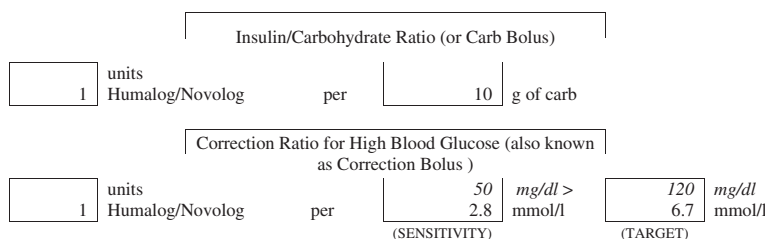
Access to insulin types may be limited in different settings due to cost constraints. For example, human regular insulin and isophane/protamine insulin (NPH) are far less costly than insulin analogs<sup>37</sup>; insulin vials cost less than cartridges for use in pens, and glucose meters

that use less expensive strips can be as accurate as those with advanced features. Insulin syringes and testing lancets can be reused, in resource challenged situations, for the same person with reasonable care. In relevant settings, families with limited means should be advised of such cost saving methods.<sup>1,2</sup>

At the other end of the diabetes care spectrum, diabetes technologies such as insulin pumps and continuous glucose monitors and their integration into closed-loop insulin (and multihormonal) delivery systems are now available in some diabetes centers, but costs must be affordable in order to reach/achieve their potential to improve diabetes care worldwide (see ISPAD Clinical Practice Consensus Guidelines 2018: Diabetes technologies DOI: 10.1111/pedi.12731).

Several insulins are now commercially available in multiple concentrations, for example, U-40, U-100 (100 units/mL), U-200 and U-500. For almost all children, U-100 is the most appropriate insulin. For very young children, diluted insulin (eg, U-10) may be appropriate. It is important to instruct families to check the insulin concentration when in receipt of insulin, and to understand the importance of using the child's insulin and not that of other family members. If using insulin syringes for administration, they must make sure the correct syringe is used, that is, U-100 syringe with U-100 insulin, and U-40 syringe with U-40 insulin.

Insulin cannot be exposed to extreme temperatures. After purchasing the insulin, the family must be taught how to transport and store it. Insulin inadvertently frozen must be discarded. At the other extreme, insulin becomes less potent after exposure to warm temperatures: at temperatures of 32°C to 37°C, loss of potency starts after 3 weeks, while at 25°C to 26°C, potency is retained by the end of



Use for: Breakfast/Lunch/Dinner/ALL MEALS

Grams of Carb	Blood Glucose Value in mg/dl or mmol/l								
	< 170 <9.4	170 – 219 9.4 - 12.1	220 – 269 12.2-15.7	270 – 319 15.8-17.7	320 – 369 17.8-20.5	370 – 419 20.6-23.2	420 – 469 23.3-26.0	470 – 519 26.1-28.9	
0	0	1	2	3	4	5	6	7	
10	1	2	3	4	5	6	7	8	
20	2	3	4	5	6	7	8	9	
30	3	4	5	6	7	8	9	10	
40	4	5	6	7	8	9	10	11	
50	5	6	7	8	9	10	11	12	
60	6	7	8	9	10	11	12	13	
70	7	8	9	10	11	12	13	14	
80	8	9	10	11	12	13	14	15	
90	9	10	11	12	13	14	15	16	
100	10	11	12	13	14	15	16	17	
110	11	12	13	14	15	16	17	18	
120	12	13	14	15	16	17	18	19	
130	13	14	15	16	17	18	19	20	
140	14	15	16	17	18	19	20	21	
150	15	16	17	18	19	20	21	22	
160	16	17	18	19	20	21	22	23	

**\*\*Disclaimer\*\*** - Dose may be less than (by 0.5 units) or the same when compared to a dose calculation using a calculator. The table is meant to be used at home or while at school, as a quick reference.

**FIGURE 1** Sample of a quick reference table (home or school use) for calculating rapid-acting insulin doses based on glucose values and carbohydrates to be ingested. Dose may be less than (by 0.5 units) or the same when compared to a dose calculation using a calculator



4 weeks. Insulin pump users should be taught to change the insulin in the reservoir more frequently, for example, on a daily basis, when the temperature is above 30°C. In areas where ambient temperatures may be as high as 45°C to 48°C, and where refrigeration is not available, insulin can safely be stored in local cooling devices with which temperatures of about 25°C to 26°C can be achieved.<sup>38,39</sup> Poor glycemic control may be due to using insulin that has lost its potency, but this is often overlooked.

A person testing BG and injecting insulin several times a day would inevitably generate vast numbers of “sharps” (needles and lancets) on a regular basis. Families must be taught and frequently reminded to safely dispose of these sharps. This can be done in a variety of ways, appropriate to the local conditions. If nothing else is available, families can be asked to collect all sharps in a thick-walled metal or plastic container (eg, shampoo bottle) and bring them on each visit to the clinic for safe disposal.<sup>3</sup>

## 5.2 | The first 6 to 12 months

- 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, home visits, and telephone, messaging, 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 patients should be encouraged to continue regular daily glucose monitoring. It should be emphasized to the family that is a temporary phase, and not a “cure,” and that insulin needs will shortly start increasing. A prolonged “honeymoon” period lasting more than 1 year during which insulin requirement remains  $\leq 0.5$  unit/kg/day should raise consideration of a form of monogenic diabetes such as Maturity Onset Diabetes of the Young (MODY) in the patient and the family.
- Screening for a cognitive or mental health disorder soon after diagnosis will identify individuals (either child or caregiver) at higher risk of being non-adherent to self-care. Five to ten percentage 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.<sup>40</sup> These patients need special attention and treatment.

## 6 | ONGOING DIABETES CARE

It is standard practice for the diabetes care of children and adolescents to be reviewed in an outpatient clinic or setting every 3 months, more often if difficulties in managing diabetes are recognized, or the child is very young (see Managing diabetes in preschool children DOI: 10.1111/pedi.12554). Outpatient visits with

members of the diabetes care team should include interval history and assessment of the following:

- General health and well-being:
  - Assess hypoglycemia history, including determination of hypoglycemia awareness, method of treating hypoglycemia and access to glucagon. Intercurrent health problems (infections, enuresis/nocturia, diabetes-related emergency and hospital/emergency visits, and other pediatric and developmental problems).
  - Comprehensive review of systems 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. For example, with fatigue, constipation and/or poor linear growth, assess for thyroid dysfunction; with weight loss, anorexia, unexplained hypoglycemia or decreasing insulin requirements, look for hyperpigmentation and evaluate the patient for possible primary adrenocortical insufficiency (cortisol, electrolytes, Adrenocorticotropic Hormone (ACTH), and perhaps 21-hydroxylase antibodies); and consider testing for possible malabsorption secondary to celiac disease by screening autoantibodies to tissue transglutaminase (TTG).
  - New health conditions, including disordered eating behaviors and/or changes in dietary preferences (eg, adopting a vegan or ketogenic diet).
  - Changes in developmental performance, education (particularly school absences or behavioral problems), leisure and sport activities, and psychosocial status.
- Self-management skills
- Glucose data:
  - Analysis of home glucose monitoring data (glucose meter readings, continuous glucose monitoring [CGM], “intermittent” glucose monitoring (iCGM), urine glucose/ketone monitoring, symptoms of nocturia and hypoglycemia),
  - Check glucose values stored in the glucose meter memory for accuracy of information reported by parents/child if computer based uploading system is not available
  - HbA1c and home monitoring should be used in a complementary fashion to assess glycemic control: a lower HbA1c which is due to recurrent hypoglycemia does not mean better glycemic control
  - Regularly check home glucose meters for accuracy with a reference method of plasma glucose measurement at the clinic, particularly if glucose meter values are not consistent with HbA1c. Home-based meters can differ by 10% to 15% or more from a laboratory measurement. In case of greater differences, look for reasons for meter malfunction (eg, expired or improperly stored test strips, poor testing technique, wrong code).
  - In patients who cannot afford regular CGM/iCGM, use of these devices for a few days preceding the clinic visit can be suggested.
- Insulin regimen
  - Insulin types, doses, and injection/insulin delivery devices, adequacy of storage and transport of insulin, injection technique and, if insulins are being mixed, mixing technique.

- Insulin adjustments for glucose values, food, and exercise.
- Physical exam
  - 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, eg, light touch, vibration sense).
  - Skin, especially injection, catheter insertion, and self-monitoring sites, for evidence of lipo-hypertrophy, lipoatrophy, or infection. Providers should reinforce the need for rotation of injection or catheter insertion sites. 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
- Review of all current medications and supplements including medications from alternative medicine streams, and herbal preparations.

The outcome of each visit should include:

- An individualized plan of diabetes care incorporating the particular needs of each child/adolescent and family designed to optimize the child's diabetes outcomes. This plan may include updated specific calculations for carbohydrate counting, insulin sensitivity, and BG targets (see Figure 1).
  - A written copy of the plan is provided to the family at the conclusion of the visit outlining any changes made to the child's diabetes management, 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, for example, 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.
- It is good practice to provide an annual review of care that includes, in addition to routine care:
- Physical development and well-being with particular emphasis on growth and pubertal development.
  - Additional new pertinent family history (eg, new diabetes or other endocrine diagnoses, cardiovascular events/diagnosis).
  - Assessment of diabetes-specific knowledge appropriate to the age of the patient, and the family's diabetes knowledge.
  - Assessment as to whether the diabetes care plan is optimally intensified, taking the above into consideration.
  - 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.
  - Review of physical activity and insulin dose adjustments made in management for activity.
  - Psychosocial assessment
    - 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.
    - Household structure (eg, single vs two-parent, joint families, sibling issues, household stability, marital stress, parental support).
    - Bullying or discrimination at the home, school or work place.
    - Determination of barriers to successful diabetes management including needle fears, fear of hypoglycemia (parent and child), and financial challenges (see section later) financial status
    - Screening for depression and disordered eating
  - Education concerning the need for routine dental care. Adults with diabetes have a higher incidence of gingivitis and periodontitis compared to the general population.<sup>41</sup> Poor glycemic control in children and adolescents has been associated with higher salivary glucose levels and more dental caries.<sup>42,43</sup>
  - For adolescents, anticipatory 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.
  - Review of all current medicines and supplements, including complementary and alternative therapies.
  - Assessment of understanding of risks for complications and care plans to minimize these risks.
  - Screening for comorbidities and complications (see Table 1). This includes screening for thyroid dysfunction and celiac disease in asymptomatic children. 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 Clinical Practice Consensus Guidelines 2018: Other complications and associated conditions in children and adolescents with type 1 diabetes. DOI: 10.1111/pedi.12740 and ISPAD Clinical Practice Consensus Guidelines 2018: Microvascular and macrovascular complications in children and adolescents. DOI: 10.1111/pedi.12742 for additional information on comorbidities and complications.

**TABLE 1** Screening and prevention guidelines for routine pediatric and adolescent diabetes visits<sup>44</sup>

	Evaluation	Type 1 diabetes	Type 2 diabetes
Glycemic management	Hemoglobin A1c	Quarterly at each visit	
	Glucose values from meter, log, or continuous glucose monitor	At each visit and in between visits as needed for insulin dose adjustments	
Cardiovascular risk factors	Blood pressure	Every visit	
	Smoking status	Every visit Discourage smoking in youth who do not smoke and encourage smoking cessation in those who do	
	Lipids	Begin $\geq 10$ years; if abnormal repeat annually, if LDL $< 100$ repeat every 5 years	Begin at diagnosis; repeat 1-2 years
Microvascular complications	Kidney disease: urinary albumin:creatinine ratio	After diagnosis $> 5$ years, begin at puberty or age $\geq 10$ years; repeat 1-2 years	Begin at diagnosis; repeat annually
	Retinopathy: dilated eye exam		
	Neuropathy: comprehensive foot exam		
Autoimmune screening	Thyroid function: TSH, total or free T4 (thyroid antibodies are optional, may predict thyroid dysfunction)	At or near diagnosis; annually or if symptoms arise	N/A
	Celiac screening (TTG IgA if IgA sufficient)	At or near diagnosis; repeat within 2 years and thereafter every 5 years or as symptoms arise	N/A
	Addison disease (primary adrenal insufficiency), autoimmune hepatitis, autoimmune gastritis, dermatomyositis, and myasthenia gravis	As clinically indicated	N/A
Psychosocial screening	Diabetes distress, depression, disordered eating	Begin shortly after diagnosis; Routinely (at least annually)	
Anticipatory guidance	Preconception counseling, risk-taking behaviors, transition to adult care	Preconception counseling for girls of childbearing potential. Discussion about risk-taking behaviors and preparation for transition to adult care can begin in early adolescence and be revisited at least annually	

Abbreviation: TTG, tissue transglutaminase; LDL, low-density lipoprotein; TSH, thyroid stimulating hormone; N/A, not applicable.

## 6.1 | Interim communication and management

There are many models of care that aim to improve communication of home glucose monitoring data, insulin dosing, dietary, and exercise information between the child/adolescent, family and the diabetes team. Because children are generally on a flexible insulin dosing regimen, the home records should be used to discuss with the caregivers and the child how to make decisions regarding insulin doses and timing, food and activity, to ensure glucose levels remain as close to normal as possible. The family should be encouraged to review and attempt to analyze the data before contacting the diabetes team for advice.<sup>45</sup> The diabetes care team can then confirm that the caregivers' plan was correct, or it can be used as a teaching point. The well-educated family can be encouraged to make dose adjustments on their own, contacting the diabetes team for advice as needed. Examples of useful clinical management tools include:

- Personal handwritten records, monitoring diaries or logbooks, including glucose values, insulin doses and any remarks related to diet or exercise.
- Electronic personal health data. Several apps are now available (see later),
- BG meters with memory capacity ( $\pm$ computer/(smart)phone links)
- Continuous glucose sensors with memory capacity ( $\pm$ computer/phone links)

The ability to download data from glucose meters, insulin pens, pumps, and continuous glucose monitors provides valuable insight into home management between clinical visits. These data often allow the diabetes team to identify areas where adjustments need to be made in diabetes care plans and, more importantly, to identify areas where the young patient needs additional help or supervision from the family or a supportive adult, and/or a better understanding is needed of self-management.

In many countries, all or a portion of health care expenditures remain out of pocket for the family. Therefore, many families try to save money by not testing glucose on a regular basis. It is useful to explain to parents that regular testing and adjusting insulin doses accordingly can help prevent hospital visits for hypoglycemia and ketosis, and thereby save money in the long run. Not infrequently children and adolescents or their families may fabricate glucose data or deny/minimize dietary indiscretions, as they do not want to disappoint parents or health professionals. Giving patients and their family's permission to have "imperfect" high and low glucose readings or occasionally eat the "wrong" foods is essential in establishing honesty and clarity. The glucose meter or CGM downloads/memory may be used to confirm accuracy of reported data. Such events present an opportunity to engage patients and their families in a constructive dialog regarding the benefits of real glucose measures. Unrealistic expectations of perfect behaviors or near normal glucose levels need to be dispelled. An open disclosure approach minimizing guilt can result in



improved engagement. The role of the health professional as a support for the child/adolescent rather than an authority to judge results also needs to be underscored. Such events may also indicate the need for additional psychological evaluation and counseling. It should be emphasized that glucose meter memories and clinic downloads are not substitutes for regular review, and supervision at home of glucose data by the patient and his/her family. It is important to teach children, adolescents, and their parents to use trends and patterns regardless of the clinical management tool they use.

## 6.2 | Glucose monitoring technologies

Increasingly, glucose monitoring device data can be downloaded onto the family's home computer or the manufacturer's website for family review and for transmission electronically to the diabetes care team when families require advice on management. This allows more frequent contact between the family and the diabetes care team for electronic or phone consultation. While this may lead to improved diabetes management, diabetes teams will need to determine whether adjustments in staffing requirements are needed to accommodate the additional time necessary to utilize this new technology, and some mechanism to reimburse for these services is essential. CGM and Flash glucose monitoring (FGM) devices (eg, Freestyle Libre) offer advantages including improved data collection and reporting.

CGM systems have three components. (1) A disposable glucose sensor with a cannula placed subcutaneously and changed every 6 to 14 days, (2) a wireless transmitter, connected to the sensor, and (3) a receiver to display the data which in some systems may be a smartphone. Data are provided every 5 to 15 minutes. The systems can provide auditory and vibratory warnings when BG levels exceed high or low preset thresholds. Setting of alerts should be discussed, as unnecessarily tight settings may lead to excessive alarms, leading to alarm fatigue and/or anxiety for children or their caregivers. FGM devices have two components. (1) Disposable glucose sensor inserted subcutaneously and worn for up to 14 days and (2) a wireless reader. Studies from the previous decade with earlier generation devices demonstrated that consistent use of CGM improves glycemic control in children. However, youth with T1DM also had less sustained use of CGM than adults. In young children aged 4 to 9 years CGM wear decreased significantly during a 26 weeks study and at the end of the study only 41% averaged >6 days/wk use of CGM. Similar trends are observed across childhood and adolescence, thus highlighting potential barriers to CGM use.<sup>46,47</sup> Factors impacting adherence may include technical difficulties, discomfort, frustration, and lack of perceived value for the technology. An adequate time investment in education and interpretation of data is necessary to assist patients in utilizing 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 BG testing (self-monitored blood glucose [SMBG]), particularly in the young, and better detection of nighttime hypoglycemia. These systems also provide alternatives for young persons involved in jobs/trades where SMBG is impractical. However, there is paucity of data on the usage of CGM in free-living conditions over longer periods in youth with diabetes. Limitations of

measurements in both hyper- and hypoglycemic extremes must be acknowledged with CGM and clinical context should always be considered; when in doubt, another glucose measurement technique should be used to confirm or refute the reported CGM glucose concentration.<sup>21</sup> Children and their caregivers should be taught the importance of using the glucose meter to check improvement during a hypoglycemic episode, because CGM cannot be relied upon as it reports data with a lag of up to 15 minutes or more.

CGM is also used in conjunction with pump therapy, as sensor-augmented pump (SAP) therapy, to deliver insulin or insulin and glucagon within "closed-loop systems" controlled by a computer-based algorithm, to create an "artificial beta cell." 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.

Mobile phone usage among adolescents is becoming nearly ubiquitous, and a high proportion of adolescents own smartphones (phones with a mobile computing platform). There has been a proliferation of applications (apps) for smartphones designed to enhance diabetes self-management.<sup>48,49</sup> These include apps for tracking data (eg, BG values, insulin doses, and carbohydrate counting), apps for teaching and training, food reference databases, and social blogs. Mobile health (mHealth) apps have the great potential to improve monitoring and decrease risk of hypoglycemia, particularly in the younger child. We are stepping onto the threshold of a new age in diabetes management, to improve chronic disease care beyond the traditional outpatient health care provider-patient encounter. However, currently there is lack of evidence regarding their clinical effectiveness. It should also be appreciated that there are challenges, such as lack of integration with the health care delivery system and potential threats to safety, privacy, and independence, especially for adolescents, with parents as constant followers of the child's glucose values. Care needs to be taken when using these data-capturing devices to empower patients and caregivers in the management of their diabetes, without promoting anxiety and obsession with glucose values. A mindful and careful approach to ensure respect and promote independence in children as they develop into young adolescents and adults is fundamental.

## 7 | NUTRITION

Nutrition is covered in ISPAD Clinical Practice Consensus Guidelines 2018: Nutritional management in children and adolescents with diabetes DOI: 10.1111/pedi.12738, but in general, the entire family should consume the same balanced diet recommended for the child with diabetes. Provided the family had a healthful diet before diagnosis, the child can continue to follow the family's dietary habits. The family should be taught how to handle food at festive occasions (small portion of calorie-dense foods, insulin dose changes, encourage activity) rather than avoid attending celebrations. In some cultures, periods of fasting may also be observed. Timely and sensitive discussions are needed regarding appropriateness and safety of fasting if it were to be practiced by the young person.

## 8 | EXERCISE

The child/adolescent should be encouraged to participate fully in physical activities, encouraged to have 60 minutes of physical activity daily, and taught when to consume an extra snack and/or adjust insulin dose with exercise (see ISPAD Clinical Practice Consensus Guidelines 2018: Exercise in children and adolescents with diabetes DOI: 10.1111/pedi.12755). The family and school staff should have access to glucagon and know how to use it in case of severe hypoglycemia. The diabetes team should be familiar with recent guidelines, and reinforce safe practices.<sup>50,51</sup> This is important to reinforce especially in families where girls are not allowed much physical activity, if diabetes is perceived as a disease (the “ill” child should not be “tired out”), or if school staff are fearful of assisting the child during exercise or activities outside the classroom. If hypoglycemia has occurred during activity, intensive education may be needed to overcome the fear of future hypoglycemia.<sup>52</sup>

## 9 | PSYCHOLOGICAL SUPPORT

The diagnosis of diabetes is often associated with a deep sense of loss and usually causes shock, despair, denial, fear, anger, and eventually coping, on part of the patient and each family member. This coping may be effective, or dysfunctional. The patient diagnosed in early childhood may go through this entire gamut of emotions during adolescence, as the reality of a chronic disorder sinks in. On an ongoing basis, diabetes care demands major lifestyle changes to be made by the entire family, and the stress of care can create or worsen psychological issues or conflicts in the family. Regular assessment of psychosocial needs of the family and provision of resources to address mental health needs may be as critical in achieving good control as insulin, monitoring, diet, and activity.<sup>53</sup>

## 10 | TRANSITION TO ADULT CARE

Diabetes is a common chronic condition diagnosed in childhood that will require lifelong medical care involving both pediatric and adult health care systems.<sup>54,55</sup> Emerging adulthood (late teens through mid-20s) is recognized as an interval marked by increasing independence and exploration of educational, vocational, social, and financial challenges and opportunities.<sup>56</sup> 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.<sup>57</sup> Therefore, even though transition is an expected process as adolescents’ age out of pediatric care, the challenge of integrating increased responsibility of diabetes management in the context of competing life priorities, may account for lapses in care and the deterioration of glycemic control often observed in this population.<sup>58–60</sup>

The age of transfer to an adult clinic varies by location and health care delivery system, and is influenced by local practices and

resources, patient and family preferences, and national policies.<sup>60–63</sup> However, regardless of exact timing, increasingly, clinical guidelines and literature recognize the significance of planned transition for emerging adults with diabetes to mitigate the risk of adverse outcomes.<sup>6,55,59,64–66</sup> Anticipatory guidance and identification of modifiable factors, such as self-management support, can promote higher levels of success as indicated by patient-reported satisfaction with care,<sup>59,67</sup> effective self-management posttransfer, and decreased gaps in care.<sup>68–73</sup> Discussion about transition to another care team or diabetes care provider at multiple visits before transfer occurs helps young people prepare for transition.<sup>73,74</sup> In addition, providing counseling on how care and practices may differ in adult clinics may be helpful to teens.<sup>57</sup> Peer mentoring can be effective to share experiences and strategize ways to overcome social barriers to diabetes care that may not be addressed in a medical context.<sup>75</sup> A 2011 Consensus Statement,<sup>76</sup> along with related resources from Got Transition/Center for Health Care Transition Improvement ([www.gottransition.org](http://www.gottransition.org)), set forth guidelines for health care delivery systems to plan for the transition from pediatric to adult care. In addition, a tool kit of resources specific to diabetes transition preparation and successful transfer of care is available online: (<http://www.endocrinetransitions.org/type-1-diabetes/>).

There are several reported models of support for transition between pediatric and adult care:

- 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 among young adults previously with history or risk for lapses in care.<sup>74,77,78</sup>
- Programs featuring transition coordinators or “patient navigators” decrease posttransition gaps, improve posttransition clinic attendance, and reduce DKA rates.<sup>79</sup> The role of navigator may be filled by 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.<sup>66,80,81</sup>
- Provider continuity between pediatric and adult health care systems can provide a level of familiarity to ease changes in health care settings.<sup>82,83</sup> 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.<sup>83,84</sup> 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.<sup>85,86</sup>
- Innovative uses of technology to support emerging adults in transition are promising. Shared medical appointments with telemedicine can simultaneously provide peer support and reduce barriers to in person visits.<sup>87</sup> Web-based and text messaging interventions have also been used to engage adolescents with chronic conditions between visits.<sup>88</sup>
- 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 are poised to facilitate ongoing education, clinical support, and promotion of self-management initiated in pediatric care.<sup>89–91</sup>

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 multifaceted with elements of longitudinal preparation in pediatric care, active engagement by patients and families in readiness assessments, peer support, health navigation guidance, and adult receivership clinics.

## 11 | BARRIERS TO CARE

There are many potential barriers to optimal diabetes care. These include financial burdens, psychosocial instability including broken homes, poor adjustment to the diagnosis, detrimental health beliefs, limited or inconsistent access to insulin, food, supplies, and care. In addition to personal challenges, great disparities exist in the level of pediatric diabetes care available to children, resulting from a wide range of factors across the world, from huge imbalances of geographic, economic, and scientific development to gender discrimination, and inappropriate or inadequate medical advice. Disparities are most apparent between well-educated majority populations and less-educated, poorer, racial-ethnic minority subgroups. Geography in and of itself does not limit optimal diabetes care.<sup>29</sup> However, sociodemographic factors such as race/ethnicity, socioeconomic status (SES), and parental marital status could influence youth with diabetes in terms of immediate and long-term management and care.<sup>92</sup> An additional contributing factor to optimal care in a clinic setting may be the time allocated to outpatient visits by the scheduling guidelines of an institution and the specific needs of any particular patient; this mismatch may be solved by more frequent visits, each planned to cover a specific item or topic.

Stigma is also a significant barrier to care for children with diabetes. Stigma has led to labeling of individuals with diabetes. Difficulties in admission to schools or universities have forced many children to hide their diabetes. Therefore, the diabetes care team and other health care providers can play an important role in advocating for equal opportunities and where needed, special facilities (eg, access to a safe, clean place to test glucose and administer insulin, in school or workplace) for children with diabetes.<sup>93,94</sup>

Routine vaccinations should be provided for children with diabetes according to age-related recommendations. While specific recommendations vary by region, annual vaccination against influenza is also generally recommended for all individuals with diabetes above 6 months of age,<sup>95</sup> and pneumococcal and meningococcal vaccines are also recommended. However, some children with diabetes still have difficulties in getting the standard pediatric vaccines because of the community physician's concerns.

## 12 | CARE FOR MINORITY CHILDREN AND CHILDREN OF RECENT IMMIGRANTS

Globalization and migration are great challenges to the health care systems of the developed as well as the developing countries. With

the urbanization movement in emerging countries, many children and their parents become dislocated as newcomers to cities, while leaving their home along with extended family members. Studies in different countries demonstrate that children with diabetes from new migrant families have poorer glycemic control, higher BMI, lower utilization of technologies and higher frequency of diabetes-related hospitalization than the general endemic population suggesting that specific psychosocial, cultural, and biological challenges have to be considered in the clinical care of these families.<sup>96,97</sup>

Barriers to treatment that negatively impact the care of minority children as well as children of recent immigrants may be unfamiliar to the diabetes team.<sup>98</sup> Recognition of these barriers is necessary to optimize care, and novel ways to overcome these unfamiliar cultural barriers requires cooperation, communication, and the establishment of trust among all team and family members.<sup>99</sup> Moreover, the perceived and, sometimes actual access to health care by immigrant and minority families may be different than that of the country's majority inhabitants. Awareness of these perceptions and differences requires cultural sensitivity, careful inquiry, and knowledge of the family's social circumstances. Proper care requires not only attention to usual medical needs but also attention to the varying and unique need for support required by minority and immigrant families to access and optimally utilize medical care.

- Licensed interpreters must be used when needed and may be of help to the diabetes team in understanding some of the cultural norms. Even an official interpreter might be known to the family, and this may influence communication between the family and the diabetes team. If a licensed interpreter is not available, a non-family member may serve as an interpreter. The child or other family member should only be used as an interpreter if no other option is available.
- Use of culturally sensitive tool boxes can aid in communication, counseling, diet advice, and encouraging empowerment and for altering preconceptions or negative and unhealthful beliefs about diabetes. An example of such materials is EthnoMed ([www.ethnomed.org](http://www.ethnomed.org)).
- Assistance in accessing care is an essential part of comprehensive diabetes care. Travel to clinics can be extremely challenging for children in rural communities, especially during emergencies. Parents can be encouraged to request their local health care providers to stay in touch with the diabetes care team, so that local care and emergencies can be handled better. It is very important to establish regional pediatric diabetes care centers to facilitate the implementation of standard diabetes care.
- Dietary patterns of migrant families may be very different, including religious taboos on certain foods, and must be understood for effective dietary advice to be given. South Asians have high carbohydrate diets, and many are vegetarians; conversely, communities originating in coastal areas may typically eat large amounts of sea food. Recent migrants may be forced to depend on food handouts, which may be different from local diet patterns and also from their native diet patterns.
- Migrant families or illegal immigrants may have difficulties in getting the health insurance which is available for local

residents. Reducing the financial burdens of diabetes care should also be one of the major concerns of the medical team for those patients.

- Knowledge of a family's cultural and religious beliefs can be critical to providing care. For example, fear of contagion, diminished job and marriage prospects and the stigma of a chronic disease may delay or prevent the family from providing urgent or necessary daily diabetes treatment.<sup>100</sup> Social stigmatization may result in the family keeping diabetes a secret, which may prevent the child with diabetes from eating and/or taking insulin at the appropriate times, or force him/her to eat inappropriately, leading to hypoglycemia or ketosis, or even death. Moreover, this can also prevent adequate care being provided by teachers, classmates, or peers in the event of emergencies such as hypoglycemia. Encouraging the family to inform at least a few critical persons such as the child's teacher or a close friend may be crucial for getting help in such circumstances. In addition, giving awareness talks in the schools attended by children with diabetes may considerably reduce stigmatization. In some regions, female patients might not receive appropriate diagnosis and treatment due to gender discrimination.
- Diabetes may be a deterrent to education and job prospects. In some countries, diabetes makes the person ineligible for several government jobs. Educational institutions, especially with residential requirements, have been known to refuse admission to applicants with diabetes. This may translate into even further, lifelong, dependence on family for covering health costs. It is particularly important for the family to be encouraged to educate the child and improve future earning capacity, to ensure continuing treatment is affordable during adulthood. The diabetes care team should also be alert to instances of such discrimination and may be able to prevent it. Getting societal and political support can be crucial to challenge instances of discrimination, whether by diabetes professionals, support groups, or both working together.

### 13 | ATTENTION TO LITERACY, NUMERACY (OF PARENTS AND CHILD)

Deficiencies in literacy and numeracy can make diabetes education and management very difficult. Even relatively simple tasks such as reading and recording values on a glucose meter and insulin doses may be difficult, especially for migrant workers' children who are left at home in remote areas, to be cared for by extended family members. 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: educational and instructional materials may not be available in the local language.

### 14 | QUALITY OF CARE, STRUCTURE OF CARE, PROCESSES OF CARE AND OUTCOMES

Diabetes care centers need methods to evaluate the quality of the diabetes services they provide and the outcomes of their management. Improvements in processes of care generally precede improvements in clinical outcomes. The impact of changes in the structure of care on clinical outcomes is less well studied in pediatric diabetes.

Ongoing evaluation of relevant outcomes is essential to the quality improvement process. These outcome measures will also guide the way for future research, innovation, and improvement in diabetes care. Benchmarking with gold standard practices promotes accountability and system wide improvements in diabetes care, as demonstrated by the 20 year experience from the German/Austrian Diabetes-Patienten-Verlaufsdokumentation (DPV)<sup>11</sup>. The establishment of a system for benchmarking of diabetes treatment in Norway resulted in significant improvements associated with changes in management and the quality of screening assessments. The Swedish National Pediatric Registry (SWEDIABKIDS) shows that the center differences have been significantly reduced during recent years. The mean HbA1c level for all children 0 to 18 years in 2016 was 56.9 mmol/mol (7.4%), compared with year 2010 when the corresponding value was 62.6 mmol/mol (7.9%). Quality improvement programs can result in improved adherence to recommended processes of care.<sup>101</sup> Key performance indicators including glycemic control, type of insulin therapy, and timely screening for early signs of complications are important benchmarking targets.

Adherence to recommended guidelines for albumin excretion screening leads to earlier detection of abnormal albumin excretion. In addition to intensifying treatment regimen to improve glycemic control, angiotensin converting enzyme (ACE) inhibitor or angiotensin receptor blocker (ARB) therapy has been shown to reverse this abnormality, with anticipated decrease in risk of nephropathy.<sup>35,36,102,103</sup> Likewise, recognition of early background retinopathy offers the opportunity to intensify and improve glycemic control, which would be expected to decrease the rate of progression to proliferative retinopathy.<sup>103</sup> Regular ophthalmological screening may also identify those requiring urgent ophthalmologic treatment to prevent vision loss. The impact of quality improvement programs on HbA1c levels is less clear. Open benchmark reporting of outcome data from all pediatric diabetes centers, as has been done in Sweden over the past 10 years, can identify best practices between centers and lead to improved glycemic control.<sup>104,105</sup>

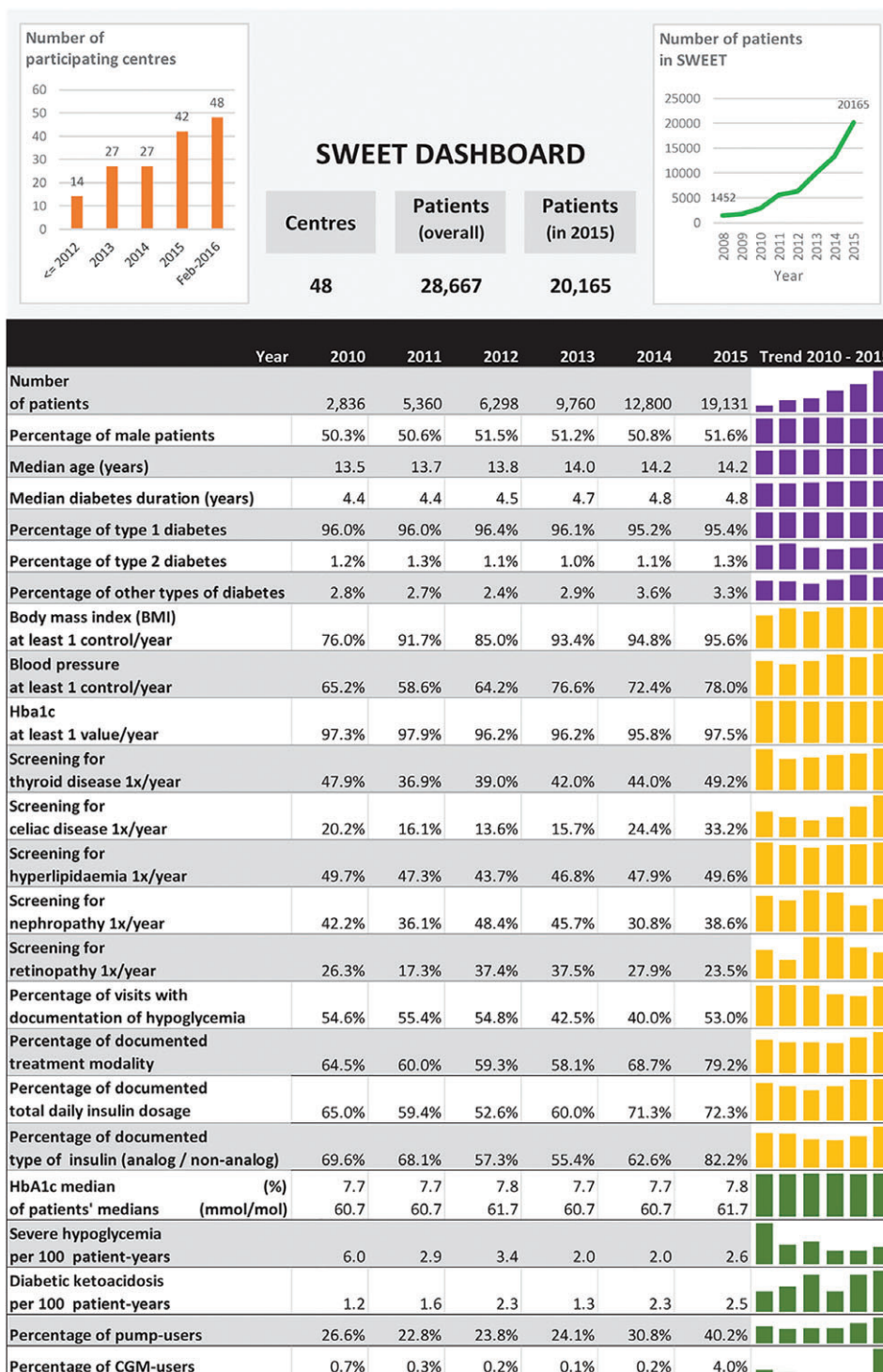
Although the level of glycemic control required to optimally decrease the risk of long-term complications was generally accepted to be an HbA1c of 7% to 8% (53-64 mmol/mol), after the SWEDIABKIDS data, the new target has been reduced in the British National Institute of Clinical Excellence (NICE) guidelines to 6.5% (48 mmol/mol).<sup>99</sup> Multicenter studies, including the Hvidore study, SEARCH for Diabetes in Youth, and the T1D Exchange Registry, have demonstrated that most sites are unable to achieve a mean HbA1c of  $\leq 7.5\%$  (58 mmol/mol) in the majority of children, especially in adolescents.<sup>106-108</sup> However, by using updated technology, for example, with alarms, a lower HbA1c level can be reached without a higher frequency of hypoglycemic



events. It must be emphasized that a lower HbA1c achieved by getting frequent hypoglycemic episodes is not desirable; thus, the HbA1c has to be seen in conjunction with the glucose monitoring results.

In situations where the HbA1c and glucose meter readings or glucose sensor reports are significantly mismatched, a hemoglobinopathy or other conditions affecting HbA1c should be suspected. HbA1c levels cannot be relied upon for glycemic control in persons with a hemoglobinopathy.<sup>109</sup>

Necessary quality “benchmark” information must be systematically collected or gathered from paper or computer records and analyzed at least as often as 12-month intervals, to determine improvement or deterioration over time. Standardized clinic data sheets, registries, and databases all facilitate these efforts. Adequate data management and statistical analysis capabilities are required to analyze outcome data for quality improvement assessment. Figure 2 represents the minimal dataset from the SWEET collaborative (Better



**FIGURE 2** Sample dataset from the SWEET collaborative (Better control in Pediatric and Adolescent diabetes: Working to create Centers of Reference), demonstrating measures collected annually and trends over time from participating centers



control in Pediatric and Adolescent diabetes: Working to create Centers of Reference), with indicators of both processes of care and clinical outcomes important to pediatric diabetes services.<sup>110</sup>

Markers of structure of care include the following:

- Composition of the diabetes care team.
- Facility available to the team and patients, including resources and space for patient care and education.
- Access to care (availability for phone consultation 24 hours/d, 7 days/wk)
- Performance and documentation of initial and ongoing diabetes education following current guidelines.

Comparisons of individual center results are an important part of quality improvement. Individual centers can compare their outcomes (eg, monthly or annual reports) to published guidelines or other pediatric diabetes centers. Consortia of diabetes centers or study groups that have agreed to collect and publish longitudinal data, such as the Hvidovre Study Group, the DPV, the SWEET study, the UK Clinical Registry, the US SEARCH for Diabetes in Youth study group, and the T1D Exchange, have provided helpful outcome data from multiple pediatric diabetes centers.<sup>9,11,106–108,110–116</sup>

Individual center results have also been published, but consistent longitudinal data from individual centers are less available than those of study groups. Multicenter studies have published analyses of some processes of care that may affect outcomes, but additional studies are needed to fully define best care practices. However, these datasets will allow pediatric diabetes care teams to identify processes of care that result in improvement in biological outcomes, improving quality of care for children throughout the world.

## 15 | CARE OF CHILDREN IN OTHER SETTINGS

Raising awareness of diabetes in the community is fundamental to promote optimal care and safety for children and adolescents in day-to-day living settings. A lack of familiarity and the associated fear of being responsible for diabetes tasks are significant barriers to adequate integration of children in their educational and social environments.

### 15.1 | Children with diabetes in the school setting

Normalization of day-to-day living and functioning in school settings for children should be a primary goal of diabetes care (see ISPAD Clinical Practice Consensus Guidelines 2018: Management and support of children and adolescents with type 1 diabetes in school DOI: 10.1111/pedi.12743). Children spend 40% to 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. Having received this information, schools should be able to make provisions for the child to keep/carry meter and insulin

and a place where testing and insulin administration can be done safely (eg, in the class room, 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 (eg, 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.

- Ideally, school personnel should be trained to provide or supervise care prescribed by the diabetes team. This includes access to food in case of potential hypoglycemia (eg, unusually vigorous play or physical activity), glucose testing, insulin dose verification and administration by injection or as a bolus with an insulin pump. The staff should be aware of factors that affect glucose levels, such as food intake and physical activity, and assist in insulin dose decisions or have a plan to communicate with parents as necessary. They must be provided contact numbers of parents and the health team for assistance in decision-making or emergencies.
- School personnel must be supportive of providing diabetes care and encouraging diabetes management during school hours.
- Testing BG in young children and older newly diagnosed children and adolescents until they are capable of performing the task independently. If CGM is used 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 BG measurement.
- Identification and treatment for all degrees of hypoglycemia. Although most teens are fairly independent with diabetes management at school, nonetheless, they may require assistance with management of moderate to severe hypoglycemia. In a recent communication by members of ISPAD, the majority felt it was appropriate for school staff to administer glucagon in the event of emergencies (personal communications). 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. A recent study showed that 75% of children in school experienced an episode of hypoglycemia requiring assistance from school personnel with a median number of five hypoglycemic episodes during one school year.<sup>42</sup> Newer, easier to use formulations of glucagon, such as intranasal glucagon and a stable glucagon analog, are in development and should facilitate glucagon administration at home or school. Parents should make sure glucagon is available at home and during travel for emergencies.<sup>117,118</sup>

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.<sup>119</sup> Provision of these materials should be encouraged. Such resources are available on websites, or as a DVD or in print, including the American Diabetes Association's Safe at School program, with educational slide presentations designed especially for school personnel ([www.diabetes.org/schooltraining](http://www.diabetes.org/schooltraining)), and the Australian Diabetes Council "Management of Diabetes in School" ([www.diabeteskidsandteens.com.au/teachers\\_and\\_schools](http://www.diabeteskidsandteens.com.au/teachers_and_schools)). 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.<sup>120-122</sup>

## 15.2 | Children with diabetes in organized camps

Many local and national diabetes organizations manage residential and day summer camps for children with diabetes. It is estimated that worldwide, 15 000 to 20 000 children annually attend diabetes camps.<sup>123</sup> Diabetes camps are usually staffed by professionals and volunteers trained in the management of children with diabetes. 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 children 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 or enjoy a safe camping experience with their family. 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.<sup>124</sup>

Camps specializing in children with diabetes should have:

- Adequate staff trained to manage children with diabetes
- Available insulin to meet the needs of the children
- Knowledge of insulin dose adjustments for the increased levels of activity that are usual at camps
- An understanding of how to adjust settings and maintain insulin pumps if they are used at the camp
- The ability to test glucose and ketones, and have adequate facilities to manage emergencies
- All staff trained to recognize and treat hypoglycemia
- Medical staff trained to identify and treat early ketosis and decide when referral to a medical facility should be initiated
- At least one staff member with knowledge of medical nutrition therapy, carbohydrate content of meals, and the principles of adjusting insulin doses for variable carbohydrate content of meals

- A plan to maintain a log of each camper's glucose levels and insulin doses. It is a usual practice to provide a parent or guardian with a copy of this log at the end of camp.

Most camps provide some education in 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 issues related to diabetes care and outcomes. Camp staff should understand, however, that the primary goal of camp is to provide an enjoyable recreational experience for each child and to interact with other children with diabetes in a safe environment.<sup>123,125</sup>

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

- Local (and national) support groups
- Advanced education sessions (eg, 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 | COST OF CARE AND COST BENEFIT ANALYSIS

In 2017, there were almost one-half billion people living with diabetes around the world, of whom ~37 to 38 million (~9%) had type 1 diabetes. The number of children (aged <20 years) was ~1 106 200 with 132 600 newly diagnosed cases every year and growing at a rate of ~3% per year. The total health care expenditure was estimated to be greater than USD\$ 775 billion dollars and equivalent to ~12% of all global health expenditure. These are, however, gross underestimates of true costs as they do not account for lost quality of life, lost opportunity and productivity as well as burden of care on the families. Diabetes imposes a large economic burden on the individual, their families, national health systems, and countries. Diabetes is a threat to sustainable global economic and social development.<sup>18,126</sup>

It is of great concern that ~80% of all expenditure is associated with treatment of complications from diabetes and only ~20% in primary care. In Australia and United Kingdom, similar trends were observed whereby the annual health costs per person with T1D diabetes increased by ~400% if a person developed micro-/macrovascular complications. This suggests that prevention of complications through improved early care of diabetes could significantly reduce health costs globally.<sup>127,128</sup>

There is vast disparity in health spending between regions and countries. In 2015, only 19% of global diabetes health expenditure was spent in low- and middle-income countries where 75.4% of people with diabetes live. For example, Switzerland spends approximately \$7244 (US dollars) per person with diabetes compared with Central African Republic, Myanmar, and Eritrea which spend \$70 per year per

person; thus, 100-fold less expenditure for the same condition with poorer health systems.<sup>42</sup>

Analysis of costs of care is important in helping to determine appropriate recommendations for care and in health policy decision-making.<sup>129</sup> It is clear that a disproportionate amount of resources are consumed by diabetes complications<sup>128,129</sup> which have modifiable risk factors early in life. Hence, an investment in gold standard care particularly during childhood and adolescence should be advocated for globally and is likely to be of significant economic benefit. Improved glycemic control through adequate education and regular glucose monitoring can decrease the risk of complications. Clear-cut data are limited, but it is obvious that regular home glucose monitoring is cost effective, decreasing costs of diabetes care by decreasing emergencies. Care in an emergency department or a short hospital admission for hypoglycemia or ketoacidosis exceeds the cost of several weeks of home glucose and ketone testing. Moreover, safe intensive diabetes management aimed at near-normal glycemia is impossible without frequent and consistent glucose monitoring. However, most studies are small and do not include long-term cost effectiveness, and few studies include pediatric diabetes.<sup>130</sup>

The cost of diabetes care has increased dramatically in the past 20 years with the introduction of insulin analogs, increased use of insulin delivery technologies (pumps), and glucose monitoring modalities. As continuous glucose sensor technology and closed loop system use increases, this will also add to the cost of care. 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. Regardless of the source of payment for care, information about cost-effectiveness is required to inform health care decisions.

Countries and health care systems are adapting differently to 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.

- Currently, analog insulins (both rapid- and long-acting) are 1.3 to 8 times as expensive as recombinant human regular and Neutral Protamine Hagedorn (NPH) insulin.<sup>37</sup> However, both rapid- and long-acting analogs have been shown to reduce the frequency of mild and moderate hypoglycemia. The short-term costs need to be assessed to determine if the long-term benefit results in lower lifetime costs, taking quality of life, long-term complications, and life expectancy into account. Given the reduced incidence of hypoglycemia, newer analogs may be even more cost-effective.<sup>131</sup>
- Limited available information does allow some assessment of the outcome of current insulin analog regimens using SMBG in an affluent society with calculation of a projected cost:benefit ratio over the lifetime of an adolescent
- Reports suggest that basal-bolus therapy and, more recently, insulin pump therapy produce better long-term outcomes with a beneficial overall lifetime cost (weighing lifetime injection therapy using a multiple daily injection [MDI] regimen with NPH as the basal insulin vs insulin pump therapy).<sup>132</sup>

- Glucose monitoring systems vary in cost and the type and mode of information imparted. FGM is low maintenance, less expensive than CGM and well-received by children and adolescents. iCGM does not need to be calibrated and can be used to make insulin dose decisions. However, it only provides glucose data when scanned. CGM provides data continuously, provides trends in glucose, and alarms if glucose is out of the predetermined range.
- SAPs and closed loop systems provide even greater advances, but at even greater initial cost. Data are emerging rapidly on the use of such early forms of closed loop systems as low glucose suspend in children and implementation of more fully closed loop systems.<sup>133-137</sup> (see ISPAD Clinical Practice Consensus Guidelines 2018: Diabetes technologies DOI: 10.1111/pedi.12731).<sup>138</sup> 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. Early cost-effectiveness estimates used data from randomized controlled trials, which were often of short duration; cost-effectiveness should be calculated not only for the immediate period but also projecting long-term effects on health and quality of life for throughout the lifespan for those with child-onset diabetes.<sup>138</sup> Advocacy for broad access and affordability of optimal therapies is needed, for most equitable delivery of care.<sup>56</sup>

## 17 | OVERALL ANALYSIS OF DIABETES HEALTH CARE COSTS AND UTILIZATION

It has been well documented that in adults, diabetes imposes a large economic burden<sup>139,140</sup>; however, there is very little information on the cost of diabetes in children and adolescents, especially for those with type 2 diabetes (see ISPAD Clinical Practice Consensus Guidelines 2018: Type 2 diabetes mellitus in youth DOI: 10.1111/pedi.12719). Yet such information is critical when assessing the economic burden of disease and evaluating the economic efficiency of diabetes prevention and control programs in this population. A population-based study conducted in Sweden reported that compared with the non-diabetic population, the direct medical cost for children with T1DM aged 0 to 14 years was 7.7 times higher. These costs included health care expenditure in primary health care, outpatient and inpatient care, and prescribed drugs. The additional cost per person with diabetes in children was 3930 Euros.<sup>141</sup> Additional data on cost of diabetes care in children with both T1DM and T2DM and cost-effective approaches to care are needed.<sup>138,142,143</sup> Data on the effect of different care models and practices on long-term outcomes are lacking and are essential to appropriate decisions in health care policy. Regarding new technologies, cost-effectiveness analyses are generally favorable. Recent studies in both Denmark and Sweden reported SAPs to be cost-effective in patients at increased risk of hypoglycemia or with uncontrolled diabetes; the cost-effectiveness increased with increase in HbA1c (with poorly controlled at baseline defined as HbA1c  $\geq 8.1\%$  (65 mmol/mol)).<sup>138,142</sup> In the Danish study, additional indirect costs that could be considered include loss of driving license for those with recurrent hypoglycemia.<sup>138</sup> Other studies have failed to demonstrate to show that these technologies are cost-

effective in adults, but may well be in children.<sup>138,142,143</sup> It is important to assess cost-effectiveness of new technologies in real-life settings, particularly for children, as those associated with high upfront cost brings risk of deeper disparities in diabetes care. In conclusion, current therapies hold greater promise to prevent acute and long-term complications, thus with potential to reduce future health care expenditures and improve well-being. Therefore, whenever possible, all children with diabetes should be offered the most effective care currently available.

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## APPENDIX A: LIMITED CARE

Whenever possible, follow the principles described in the main body of this chapter.

Great disparities exist in the level of pediatric diabetes care available to children, resulting from a wide range of factors across the world, from huge imbalances of geographic, economic, and scientific development to gender discrimination. Limited access to insulin, food and supplies, limited access to care, financial burdens, psychosocial instability, and detrimental health beliefs can all contribute to suboptimal care of children with diabetes across the world. For all children with diabetes, the importance of providing a good start with clear, positive messages, support, and advice cannot be overemphasized. In these settings it is imperative to establish, as early as possible, a systematic register of patients, demographics and treatment records. Such data is vital in defining the problem and needs of this population in order to effectively advocate for these patients and their families. Programs are underway for this very purpose through organizations such as the Life for a Child and the Changing Diabetes in Children programs (see links to these organizations on [www.ispad.org](http://www.ispad.org)). Champions in the health care arena need to be identified and supported in their advocacy roles.

Access to health care can be a large challenge for poor children, more so in developing countries. Shortages of providers with diabetes expertise are widespread. For example, in Ethiopia, which is densely populated, there is only one pediatric endocrinologist for more than 40 million children.<sup>144</sup> In China, there are only 57 pediatric diabetes specialists and 47 pediatricians for 100 000 children in urban and rural

areas, respectively. There are no data about the number of pediatric endocrinologists; multidisciplinary pediatric diabetes clinics are available only in China's leading children's hospitals. Sometimes lack of awareness means death before diagnosis, or soon after diagnosis.<sup>145-147</sup> Increasing awareness and education among health care personnel can help. Additionally, families can be put in touch with each other and can offer peer support and education. While there may not be in person access to the diabetes care team outlined in the core section, health care providers working with children with diabetes and their families need to provide self-management education and have regular follow up. Communication between visits may rely more heavily on telephone calls. Community health workers may serve as an extension of the specialized diabetes care team, meeting with families and identifying areas that require attention outside of in-person follow-up.

More than half the world's population is poor or extremely poor, and in large parts of the world, medical care is predominantly an out-of-pocket expense. Diabetes is an expensive condition to manage, and cost of diabetes care may be prohibitive without external support, for example, government support or health insurance. For example, in a study of factors associated with DKA in Ethiopia where the median monthly income was \$37, the cost of insulin (\$6/vial), BG testing (\$2/test), and HbA1c measurement (\$13) created great hardship.<sup>146</sup> The treatment prescribed from the onset should be appropriate for the family's economic and educational status. Where costs are borne by the family, options to reduce costs should be explored, for example, conventional rather than analog insulins; syringes rather than pen devices; careful reuse of syringes and lancets; meters with inexpensive strips; families forming groups to enable bulk purchase of diabetes care supplies, obtaining supplies from donor organizations, etc.

Availability of insulin and diabetes supplies, such as insulin syringes, glucose meters and glucose and ketone test strips, may be quite limited, particularly in remote areas. If the family does travel to urban centers for consultation, they can be encouraged to obtain sufficient quantities of insulin and supplies in the city. It is possible the individual family may take greater care with transporting and storing insulin at the correct temperatures than vendors for whom this is a niche product with very little profit.

It is also important to address practical issues around home diabetes management. Safe disposal of "sharps" (needles, syringes, lancets) must take into account local conditions. If nothing else is available, parents can be asked to collect all sharps in a thick-walled metal or plastic container (eg, shampoo bottle) and bring them on each visit to the clinic for safe disposal.<sup>3</sup> Insulin cannot be exposed to extreme temperatures, as described in the main chapter.

Food can be in scarce supply, and not all children have food on a daily basis. It is in such situations that multidose-modified basal bolus regimens are very useful. The child can take small doses of NPH insulin once or twice a day, and regular insulin only when food is eaten, the dose depending on the amount of food available. Diet in families with low SES may be high in fats, trans-fats, salt and processed (low fiber) carbohydrates. Parents are encouraged to use whole grains, for example, partly polished rather than white rice, home-baked bread rather than bread bought from the market, low fat milk and milk products (usually less expensive than full fat), salads instead of oily cooked vegetables, fresh fruit and roasted rather than deep-fried snacks; such

foods are often less attractive than heavily advertised sweetened (or diet) drinks and crisps. Intensive education and innovation may be necessary to address such situations.

International programs such as Life for a Child, Changing Diabetes in Children (CDiC) and Insulin for Life can alleviate resource shortages to a limited extent, and stability and consistency of providing these resources is essential. It may be more feasible and sustainable to motivate local governments and charitable organizations to help, with greater awareness of the problem. In Bangladesh, it has been shown that public health measures can make a big difference in diabetes care. Unfortunately, low costs options are often ignored by health care providers, corporations, and government.

Diabetes education typically uses written materials and numerical insulin dose calculations. When children and their caregiver(s) have limited literacy and numeracy, different approaches are needed. For example, the majority of Ethiopians have little or no education and females are less educated than males.<sup>148</sup> Females are usually the ones who are giving diabetes care, and because females are less educated this will have a negative impact on the care provided. Even relatively simple tasks such as reading and recording BG values and insulin doses may be difficult. Pictorial educational materials and simple instructions are essential for illiterate families. Innovative measures can be used, such as teaching the mother or child to draw the numbers because they cannot write them, providing premarked 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: educational and instructional materials may not be available in the local language. In these circumstances, self-help support groups can be of great value when available.

Poverty significantly increases vulnerability because it tends to be associated with illiteracy or poor education, social deprivation, little or no job security, and inadequate access to health care or institutional support. In many countries families must assume the cost of health care. The expenses incurred with a chronic disease can push a family further into poverty. Such families are then also at higher risk for discrimination. These children tend to have poor glycemic control, and therefore higher rates of acute and chronic complications and mortality. This worsens employability, income, cost of care, and quality of life. In extreme cases, insulin may be stopped due to financial stresses or gender discrimination. In such circumstances, support groups can play a significant role in improving care and even survival. Parents getting even minimal financial support and seeing older well-controlled patients who are successfully educated, working, married, etc. are motivated to look after their own child better.

On the positive side, many developing countries have robust family structures. Support may come from the extended family or community. Compliance may actually be better because of social conditioning to follow instructions, and provision of free or subsidized diabetes care supplies. Availability of "junk foods" may be limited and physical activity levels may be higher. Establishing a trusting relationship with good communication should allow for identification of the child's and family's resources and challenges, so that they can be successful in managing their diabetes.