



# From pediatric to adult care: a survey on the transition process in type 1 diabetes mellitus and the diabetes services in Italy

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## Abstract

**Aims** The present study assessed the transitioning process of young adults with type 1 diabetes mellitus (T1D) in Italy.

**Materials and methods** We asked Pediatric Diabetes Centers (PDC) and Adult Diabetes Centers (CAD) to fill in a web-based survey on the current state of services, the number of transitioning adolescents with T1D within the last year, observations on limitations, and future directions.

**Results** 93 centers (46 PDCs, 47 CADs) joined the study. The total number of subjects with T1D being followed by a PDC was 16,261 (13,779 minors and 2483 young adults), while CADs had 25,500 patients. The survey showed an uneven situation. Only some services had a dedicated diabetes team (78% of PDCs, 64% of CADs). 72% of PDCs and 58% of CADs reported a protocol dedicated to transition. The median age for transition was 19 (range 16–25 years); the time required for preparing transition, indicated by both PDCs and CADs, was 5.5 months. A high percentage of CADs (80%) confirmed receiving sufficient clinical information, mainly through paper or computerized reports. The transition process is hampered by a lack of resources, logistical facilities, and communication between services. While some services have a protocol, monitoring of results is only carried out in a few cases. Most specialists expressed the need to enhance integration and continuity of treatment.

**Conclusions** The current situation could be improved. Applying standard guidelines, taking into consideration both clinicians' and patients' necessities, would lead to a more successful transition process.

**Keywords** Type 1 diabetes · Transition · Survey · Health services

## Introduction

Type 1 diabetes mellitus (T1D) is one of the most prevalent chronic conditions during childhood. Its incidence and prevalence have steadily increased worldwide, posing a growing burden on public health [1].

During puberty, there is a gradual shift from parent-led diabetes management to self-management by adolescents [2,

3]. This increased responsibility can be perceived as burdensome by many young individuals with T1D [4].

The transfer from pediatric to adult care services can be associated with health deterioration in adolescents with chronic conditions, including T1D. This aggravation may manifest as poor glycemic control, increased hospitalization rates, and dissatisfaction with the transition experience [5–8]. Young adults who have had diabetes since childhood face greater challenges in transitioning successfully compared to those diagnosed as adolescents, as they have had more parental involvement in their diabetes management and less autonomy in diabetes-related tasks [5, 9].

The suboptimal coordination of the transition process from pediatric to adult care and reduced clinic attendance contribute to poor continuity of care and an increased risk of adverse outcomes [6, 10]. Distress, negative self-management, and psychosocial outcomes have been observed in a significant portion of subjects (more than 30%) after transfer [11].

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Previous trials to improve post-transfer follow-up rates yielded mixed results [12–15]. While some studies showed improvement in clinic attendance and metabolic control, the trend was not consistently maintained over time. Transition programs incorporating care coordination components showed promise in retaining participants [16, 17]. For instance, the Maestro Project used a patient navigator that provided education and support through various media [18]. The “Verona Diabetes Transition Project,” a structured transition program shared between pediatric and adult clinics, reduced the delay in establishing care with an adult provider [19].

Controlled studies in this area are limited, however. Many studies lack a comparison condition, making it challenging to determine the effectiveness of specific transition programs [20, 21]. The difficulty in measuring intervention effects, the inability to blind participants, and the lack of a standardized framework for evaluation and reporting outcomes hinder evidence generation [22]. Further research is necessary to establish best practices for facilitating the care of emerging adults with T1D, and randomized trials such as STEPSTONES-DIAB and GET-IT-T1D are currently underway [23, 24].

On a national level, no comprehensive assessment of the transition process for young adults with T1D has been conducted in Italy. In 2011, a joint effort of the leading national pediatric and adult study groups of diabetology (SIEDP, AMD, SID) [25] identified the critical issues in the transition process and suggested drafting a dedicated protocol. In 2019, a Diagnostic Therapeutic Assistance Path (DTAP) focusing on diabetes transition was proposed to the Italian Regional Healthcare Systems representatives. The aim was to share the decision-making processes and healthcare organization based on existing guidelines; each region was asked to implement DTAP through multi-professional working groups, and an efficacy evaluation was planned [26].

The newly published AMD/SID 2022 guidelines reiterate the desirability of a structured transition process, but also underline the poor evidence present in the literature on its favorable effects [27].

Our research, which is part of a national study supported by the Ministry of Health, aimed to evaluate the status of the T1D transition process from both the pediatric and adult perspectives, taking into consideration clinicians’ points of view. Clinicians’ insights in transition care can shed light on strengths, weaknesses, limitations, and potential interventions to improve the current situation.

## Materials and methods

The Transitioning in Diabetes, Epilepsy, and ADHD Patients’ Investigation, also known as the TransiDEA study, is an Italian initiative to evaluate the viability of programs designed for transitioning from adolescence to adulthood in three chronic conditions. The participation of patients, parents, and medical professionals in this study was voluntary.

The initial goal of the inquiry was to evaluate how the transition process was managed throughout adult and pediatric healthcare services to understand the current state of assistance. Two distinct surveys, one made specifically for Pediatric Diabetes Centers (PDC) and the other for Adult Diabetes Centers (CAD), were developed. The questionnaires’ contents differed depending on whether the relevant services were sending patients (pediatric) or receiving patients (adult).

The structure of the surveys included the following elements:

- An initial section covering screening questions concerning the characteristics of the centers, such as their geographic region, service type, number of patients with T1D, and presence of a dedicated team consisting of professional figures specialized in diabetology (physicians, nurses, nutritionists, and psychologists).
- Another section covering inquiries related to the transition process, including the number of individuals undergoing transition in the past year and, for centers with a formal preparation phase, the age at which preparation for transition started.

Specific queries designed for centers that actively refer young persons with T1D were classified as follows:

- a. For pediatric services referring to adult services: the effective transition age and the criteria employed for referral, general aspects such as age, clinical characteristics, and other relevant factors.
- b. For adult services: an assessment of whether they received sufficient and appropriate information from the pediatric service.
- c. The methods employed for referral or reception (e.g., letters, information sheets, phone calls, e-mails), whether interviews were arranged (including patient, family, or inter-service interviews), the involvement of other professional figures (such as psychiatrists, psychologists, nurses, administrative staff, therapists, social workers, and educators) and the required time for the whole process.
- d. Opinions regarding the participation of both services during the transition phase, the preferred duration of the

- transition period, the number of sessions deemed suitable, and the preferred location for the transition (e.g., PDCs, CADs, an alternative facility, remote options, or expressing no preference).
- e. Inquiries about the existence of transition protocols applied by the services.
  - f. Evaluation of whether the services implement a monitoring phase.
  - g. Aimed at determining whether the specialists wanted to report any limitations, unmet needs, or desired changes regarding the transition management. Those centers providing positive responses were allowed to explain their perceived limitations or propose potential future developments.

A letter outlining the study's goals was sent to the major pediatric and adult diabetes societies, SIEDP (Società Italiana di Diabetologia ed Endocrinologia Pediatrica) and AMD (Associazione Medici Diabetologi), along with an invitation to participate via a web-based questionnaire within a pre-determined timeframe (December 2021–May 2022). Clinicians from 61 pediatric and 150 adult centers were invited to complete the survey.

The number and percentage of respondents are included in the descriptive analysis offered in this report, and continuous variables are summarized using median values and interval ranges.

Involving patients and the general public in the planning, execution, reporting, or dissemination stages of our research was not practical during the earliest stages. We intend to actively involve them in the study's later phases, in particular in the third phase, when transition recommendations will be drawn up.

The study was notified to the IRCCS “Carlo Besta” Foundation Ethics Committee (8 September 2021, protocol n. 87).

## Results

### Adhesion and territorial distribution of participants

93 centers joined the study (46 PDCs and 47 CADs, respectively, 75% and 31% of those contacted initially). The total number of individuals with T1D in charge of PDCs was 16,261 (13,779 minors and 2483 adults), while CADs had 25,500 adults with T1D. 11 PDCs and 4 CADs had less than 100 patients, some of whom were very small (<50 patients); 22 PDCs and 35 CADs followed more than 200 subjects with T1D, with 13 very large centers (> 1000 patients).

At the time of the study survey, PDCs followed an average of 353 children and young adults, while CADs had an

average of 543 patients. 78% of PDCs and 64% of CADs had a dedicated team of professionals specialized in diabetology (physicians, nurses, nutritionists, and psychologists) (Table 1).

### The transition process

Almost all PDCs (93%) managed cases of transition in the previous year, for a total of 1193 subjects. 40 adult services (85%) experienced transitioning (528 young adults). CADs reported receiving patients mainly from PDCs ( $N=40$ ) and more rarely from other adult services ( $N=10$ ).

The declared age interval for transition was 16 to 25 years, but the median age was 19. The main criteria used for selection were age ( $N=35$ , 81%), level of development ( $N=21$ ), and clinical characteristics such as comorbidities or metabolic control ( $N=5$ ).

32 CADs (80% of services with patients in transition) answered that they received exhaustive clinical information, mainly through information sheets ( $N=22$ ). PDCs favor shared computerized medical records ( $N=23$ ). Other communication systems such as letters, phone calls, and e-mails, were used less. About 30% of both PDCs and CADs reported that an in-person or online meetings between services had taken place during the transition process.

### Services' role in the transition

The time required for preparing the transition, indicated by both PDCs and CADs, is 5.5 months, with a longer time frame for CADs (from 1 to 24 months, compared to 12 months for pediatric centers).

A substantial consensus about coordination between services emerged between PDCs and CADs. About 65% of adult and pediatric centers considered the simultaneous presence of both specialists' teams in caring for a patient during the transition phase to be good practice.

The ideal average duration of the transition process was reported to be 11–12 weeks; 2 meetings (range 1–4) were considered the best option for pediatricians and adult physicians.

76% of PDCs consider family involvement during the transition process to be helpful, compared to 55% of CADs. When asked about the meetings that should be held during the transition process, CADs gave priority to meetings with the patient alone (Fig. 1).

Most PDCs would prefer pediatric units as the location for the transition meetings; CADs indicated the adult service as their preference (Fig. 2).

**Table 1** Quantity and geographic distribution of the services that participated in the online survey

	PDCs	CADs
Number of services	46	47
Area		
North	21	28
Center	6	8
South and islands	19	11
Total number of patients with T1D	16,262	25,500
Minors (age < 18 years)	13,779 (85%)	
Young adults (age > 18 years)	2483 (15%)	
Patients/center	353 (min 20–max 1200)	543 (min 10–max 1700)
Services with a dedicated diabetes team	78% since 2003 (range 1970–2021)	64% since 2002 (range 1985–2021)

The table also shows how many services have a dedicated diabetic unit and how many subjects with T1D are cared for.

### Protocol and monitoring of outcomes

72% of PDCs and 58% of CADs that experienced transition during the last year reported having a transition process protocol. Only 39% of PDCs and 21% of CADs indicated that they have guidelines for monitoring the transition outcome, although the percentage is higher for centers with protocols (54 and 42%, respectively).

### Limitations, unmet needs, and desired changes in dealing with transitioning young adults with T1D

Over half of the pediatric and adult centers (64 and 51% of centers, respectively) underlined the presence of limits and obstacles in the transition, especially due to the lack of

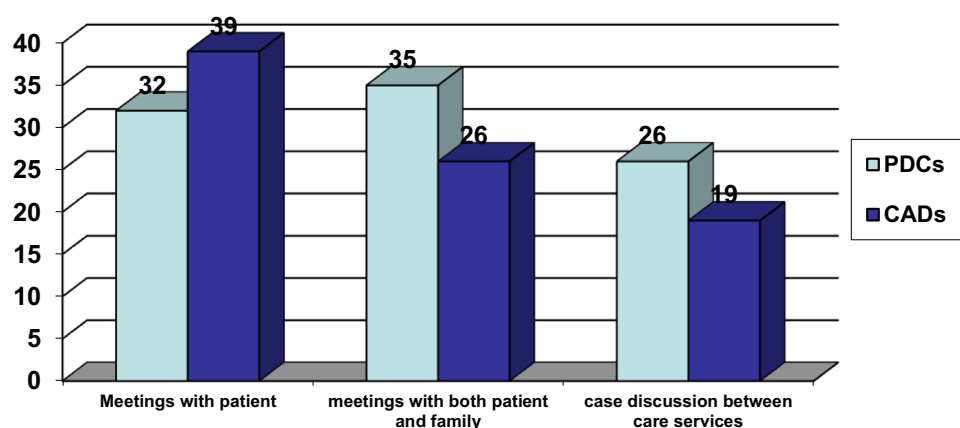
available resources and organizational problems (dedicated spaces, distance between centers, possibility of performing capillary glycosylate hemoglobin).

The lack of collaboration and integration between centers was also acknowledged. PDCs indicated the absence of a single reference physician in CADs and the excessive rigidity in the transition criteria (age) as limits. At the same time, CADs highlighted the lack of psychological support during the transition process as a limit.

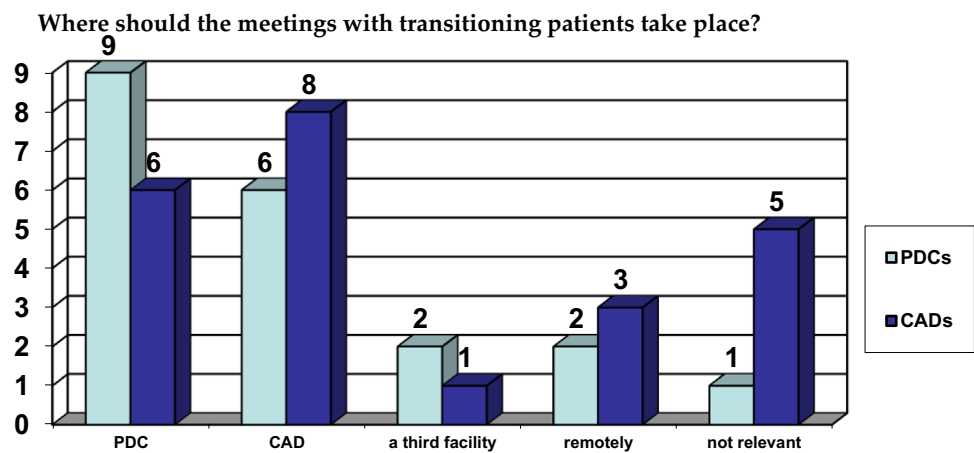
Over 70% of pediatric and adult centers expressed the need to implement changes that could improve and facilitate the transition process, particularly by identifying dedicated places, times, and personnel and sharing therapeutic/educational approaches and medical records among the centers.

**Fig. 1** PDCs and CADs responses about meetings that should be carried out during transitioning process (multiple choice possible, absolute number indicated)

**During the transition process, which of the following activities would you carry out?**



**Fig. 2** PDCs and CADs responses to where meetings regarding transitioning patients with T1D should be carried out (multiple choice possible, absolute number indicated)



Practical proposals were also presented, such as implementing out-of-hospital experiences with the participation of both teams (“transition camps”), drafting shared protocols, and evaluating satisfaction indicators.

## Discussion

The current study set out to depict the current state of Italy’s transition process. We asked the experts (PDC and CAD staff members) how they managed the assistance and what their perceptions were regarding problematic issues and areas for improvement.

With 93 respondents from 17 of the 20 Italian regions, 46 of whom worked in PDCs and 47 in CADs, we achieved good geographic coverage. Both very large (> 1000 patients) and very small (< 50 patients) centers joined the study, providing a fairly exhaustive collection of the different existing realities in the country.

The percentage of services that reported managing transition in the past year was similar for PDCs (93%) and CADs (85%), but the rate of young adults (> 18 years) who continue to be followed by PDCs is rather relevant (15% on the total number); young adults are distributed in 82% of PDCs. This result is consistent with the reported median age for actual transfer of 19 years and the broad age range for transitioning suggested by most clinicians, which was between 16 and 25 years.

The main reported criteria for starting the transition process were age (81% of centers). Still, other aspects, such as level of development and clinical characteristics, like comorbidities or metabolic control, were considered.

There is no recognized best practice concerning transition age in the literature. The right time to transition from pediatric or adolescent care to adult care depends on individual factors such as the patient’s maturity and healthcare functioning (i.e., hospital regulations and availability of appropriate youth care). Delaying the transfer depending on

individual developmental needs may be suitable [28] and can be linked to fewer first aid accesses and hospitalizations for diabetes complications [29].

Our survey revealed significant organizational problems impacting the transition process. First, only some services are structured with a dedicated diabetes team (78% of PDCs, 64% of CADs). The main critical issues that emerged from our survey, reported both in the pediatric and adult fields, are scarcity of space, dedicated time and resources, and difficulties in communication between services. Despite these issues, a high percentage of CADs (80%) confirmed receiving sufficient clinical information, mainly through paper or computerized reports.

Not all the services reported a protocol dedicated to transition (72% of PDCs and 58% of CADs that experienced transition cases during the previous year), and an even lower percentage had follow-up and outcome monitoring guidelines after the transition.

There is substantial agreement between PDCs and CADs on the timing of the transition (11–12 weeks) and the ideal number of meetings (2 meetings, range 1–4).

On the other hand, a lack of consensus emerged about the location of joint meetings between services (Fig. 2) and the degree of involvement of the family, with pediatricians being more oriented toward communication with caregivers (76% of PDCs vs 55% of CADs).

Garvey and colleagues [30] found that gaps in health-care continuity were predicted by several variables, including lack of an adult provider name or contact information; our study supports that this assertion as the absence of a specific reference at the adult center is reported by pediatricians as a critical issue.

Future studies should also investigate factors that may predict the transition from pediatric to adult care. Moreover, combining factors into a risk score to identify patients at the highest risk of loss may be clinically valuable to monitor them more closely [5, 31, 32].

In line with previous studies, it seems that physicians involved in the transition process, both from the pediatric and the adult sides, clearly perceive the limitations of the current situation and are inclined to implement improvement actions. For instance, Mc Dowell et al. [33] identified some barriers and facilitators adolescents face during their emerging adult years with T1D. The themes that arose from the analysis of transition experiences included the importance of support from key players, challenges navigating the health care system, mental health needs, managing day-to-day life with T1D, and early independence to ease the transition. In other studies, young adults report less support and guidance, lack of time to discuss T1D management, and accessibility issues in the adult care system [34–36]. A survey conducted by Goethals and colleagues [37] reported that diabetes care and education specialists needed a uniform approach in transition and additional mental health care resources. Some of these aspects, such as practical and organizational difficulties for the patients or insufficient availability of psychological support, also emerged from our interviews.

The next step of our project will be to investigate practical experiences in different diabetes centers across Italy, not only from the viewpoint of health professionals, but also from the perspective of young people with T1D and/or their caregivers. The final aim is to define standard guidelines to support a structured transition process involving all the stakeholders, including scientific societies and patient associations.

Our research provides, for the first time, a comprehensive picture of the transitioning process of adolescents with T1D in Italy.

A strength of the study was to induce all pediatric and adult T1D reference centers simultaneously, with the same tools and contents, to reflect on their transition practices.

The main limitation of the present study is a potential nonresponse bias, even if centers of different sizes and structures and from all Italian regions participated in the survey.

## Conclusions

Our survey offers a picture of the actual state of the transition process in Italy. The results confirm previous observations of challenges in the transition care of young adults with T1D. Some of the stated limits, especially those pertaining to coordination and communication within the health system, may be adjustable. Since diabetes outcomes in emerging adults may be related to the processes and timing of transition, future research should identify evidence-based interventions and support to reduce the risk

of long-term complications and address the psychosocial and healthcare needs of young adults with T1D.

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**Adult centers** (in alphabetical order by city): Alessandria (Gallo M), Bari (Modugno M), Bassano del Grappa (VI) (Beltramello G), Bologna (Pagotto U), Borgomanero-Arona (NO) (Ponziani MC), Brescia (Girelli A), Catania (Di Mauro M), Cava de' Tirreni (SA) (Fresa R), Carrara (Bacetti F), Chiavari (GE) (Ponzani P), Chivasso (TO) (Fornengo R), Cittadella (PD) (Simioni N), Como (Scinagulla L), Desio (MB) (Spreafico E), Ferrara (Monesi M), Firenze (Baggiore CM), Gaeta (LT) (Sepe M), Grosseto (Sambuco L), Iglesias – Carbonia (Guaita G), Livorno (Di Cianni G), Milano (Pintaudi B), Milano (Scavini M), Milano (Bertuzzi F), Modena (Piani D), Monfalcone (GO) (Assaloni R), Montecchio Emilia (RE) (Michellini M), Napoli (De Riu S), Padova (Avogaro A), Palermo (Ridola G), Parma (Buonadonna R), Pescara (Antonacci E), Piacenza (Bianco M), Pietra Ligure (SV) (Goretti R), Pordenone (Zanette G), Reggio Emilia (Manicardi E), Rimini (Babini A), Roma (Sabetta F), Salerno (Capuano G), Siena (Dotta F), Vercate (MB) (Mangone I), Vercate (MB) (Marelli G), Viterbo (Grande C).

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**Data availability** Data used to support the findings of this study are available upon request by contacting the authors directly (corresponding author: Vanna Graziani).

## Declarations

**Conflict of interest** The authors have no conflicts of interest relevant to this article to disclose. The authors have no relevant financial or non-financial interests to disclose. All authors certify that they have no affiliations with or involvement in any organization or entity with any financial interest or non-financial interest in the subject matter or materials discussed in this manuscript.

**Institutional review board statement** The study was notified to the IRCCS “Carlo Besta” Foundation Ethics Committee (8 September 2021, protocol n. 87). The study was performed following the ethical standards of the 1964 Declaration of Helsinki and its later amendments. We followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting guideline.

**Ethical standard** The study was notified to the IRCCS “Carlo Besta” Foundation Ethics Committee (8 September 2021, protocol n. 87). The study was performed following the ethical standards of the 1964 Declaration of Helsinki and its later amendments.

**Informed consent** Informed consent was not required for the research as no patient recruitment was carried out and no personal data was collected.

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