Appendix I – Supplementary Document S1

Title: Transition from paediatric to adult diabetes care in people with type 1 diabetes: an online survey from France

Short title: *T1D transition from paediatric to adult diabetes care*

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Questionnaire

Target	Young adult patients with type 1 diabetes who have experienced the transition.
Sample	• N = 100
Study objectives	• Evaluate the transition process of TDT1 from paediatrics to diabetology of adults from the patient's point of view: relationships with healthcare professionals, personal care and management of diabetes and treatment (schematic choice of basal insulins and rapid glycaemic targets, etc.), emotional and psychosocial concerns, role of support networks, etc. • Measure the satisfaction of patients with T1D with the transition process in terms of information, digital health solutions and other forms of support. • Generate information for Sanofi on living patients to support discussions with the committee of experts and communicate with the medical community. • Publish the results of the survey.
Structure	A- Profile B- Transition experience C- Patient satisfaction and needs
Number of questions	Total: 30 questions including 3 open questions

A. PROFILE

1.Your gender:
(*Single answer*)
□ Female
□ Male
□ Other [Please specify]
□ I prefer not to answer

2.You live:
(*Single answer*)
□ In France (overseas included)
□ Other [end of the investigation]

3. Your postal code:
[*Postal code of the field*]

4. Your year of birth:
(YYYY) [*Calendar*]

[if <18 years or if >30 years, end of the investigation]

5. What disease have you been diagnosed with?
(*Single answer*)
□ Type 1 diabetes
□ Type 2 diabetes [end of the investigation]
□ Another type of diabetes [end of the investigation]
□ None of these diseases [end of the investigation]

6. Have you been monitored in paediatrics for your diabetes?
□ Yes, and I am still being followed up in paediatrics for my diabetes [end of the investigation]
□ Yes, but now I am no longer being followed in paediatrics for my diabetes
□ No, I have never been followed up in paediatrics for my diabetes [end of the investigation]

6b. Since when have you not been followed in paediatrics for your diabetes?
□ For less than 6 months [end of the study]
□ For more than 6 months -> Since when, more exactly? (YYYY) [*Calendar*]

7. How old were you when your type 1 diabetes was diagnosed by a healthcare professional?
If in doubt, please give the best estimate.
[*Digital field*]
□ I don't remember

8. What is your level of education? If you are a student, please select the degree you are preparing.
(*Single answer*)
□ College or less
□ High school diploma (baccalaureate, BEP, etc.)
□ Bachelor or equivalent
□ Master
□ Doctorate
□ Other [*Please specify]*

9. What is your professional situation?
(*Single answer)*
□ I work full time
□ I work part-time for reasons independent of my diabetes
□ I do not work for reasons independent of my diabetes (student, unemployed, inactive, etc.)
□ I work part-time or do not work because of my diabetes

10. What was the pattern of your insulin treatment during these specific times of your care pathway?
(*Only one response per range*)

	Classic injector pens	Classic insulin pump	Latest-generation devices, for example, connected injector pens, firm loop and couple insulin pump has a continuous glucose measurement device	I don't know
In paediatrics, just before meeting the adult diabetologist for the first time	o	o	o	o
6 months after your final departure from paediatrics	o	o	o	o

11. How do you measure your blood glucose during these specific moments of your care journey?
(*At least one response per scope*)

	Classic blood glucose reader with strips (capillary test)	Continuous glucose measurement system (CGM or MCG)	Flash Blood Glucose Measurement System (FreeStyle)	I don't know
In paediatrics, just before meeting the adult diabetologist for the first time	o	o	o	o
6 months after your final departure from paediatrics	o	o	o	o

B. EXPERIENCE OF THE TRANSITION

12. In what type of setting were you followed by the paediatrician for your diabetes before switching to adult diabetes?
(*Single answer*)
□ A hospital site (CH, CHU, local hospital)
□ A private establishment, a clinic
□ A paediatrician in a city office
□ I was mainly monitored by my general practitioner
□ I don't know

13.About the first adult diabetology service that you attended after your departure from paediatrics.
(*Single answer*)
□ it was in the same establishment as my paediatric department
□ It was in a different hospital establishment or clinic different from the establishment of my paediatric department
□ It was a cabinet in town
□ I was not followed anywhere, just after my departure from paediatrics
□ I don’t remember

14. What was the main trigger for your transition from paediatrics to adult diabetes?
(*Single answer*)
□ A concerted decision following the opinion of the paediatrician
□ A decision of the paediatrician without consultation with me or my parents
□ The process naturally began at the age of 18
□ A wish from my parents/guardians
□ My own wish
□ My move (for example, from the start of higher studies or work)
□ The retirement or relocation of my paediatrician
□ Other [Please specify]
□ I don’t remember

15.How long has the preparation for your transition to the Adult Diabetology Department lasted (i.e., from your first contact with an adult diabetologist to your final departure from the paediatrics department)?
(*Single answer*)
□ Immediate transition (you left paediatrics when you first met your adult diabetologist) [*if the answer is "immediate" move to question 17*]
□ Less than 2 months
□ Between 2 months and 6 months
□ Between 6 months and 1 year
□ Between 1 year and 2 years
□ More than 2 years

Q16 will not be applied to those who responded to "immediate transition" to Q15.

16. What steps have prepared your transition from paediatrics to adult diabetology?
(*Multiple response*)
□ Paediatric consultation time in the absence of parents/legal responsible
□ One or more consultations with the paramedical team (specialized nurse, dietitian, psychologist, etc.)

□ One or more consultations with the adult diabetologist (while you are still being followed in paediatrics)
□ One or more consultations with the paediatrician and adult diabetologist together
□ More frequent consultations in early adult diabetology
□ None of these answers [exclusive]

17. Did you experience personal difficulties at the time you left paediatrics?
(*Multiple response*)
□ Fragilities of the family unit (conflict with parents, resignation of parents, etc.)
□ First departure from family home
□ Life test (mourning, serious illness of a loved one, etc.)
□ Denial of diabetes
□ Eating disorders
□ Psychological disorders
□ School or professional failure
□ Stress related to schooling (baccalaureate, etc.) or work (first job, etc.)
□ Other [Please specify]
□ None of these situations [exclusive]

18. Has your transition from paediatrics to adult diabetology delayed or disrupted a life project (studies, training, travel, travel, marriage, pregnancy, professional project, etc.
(Single answer)
□ Yes [*Which or which?]*
□ No

19. Which specialists have you consulted for the management of your diabetes (*at least one response per range*)

	When I was followed in paediatrics	Since I am no longer followed in paediatrics	Never [exclusive]	I don't remember [exclusive]
General practitioner	o	o	o	o
Pharmacist	o	o	o	o
Diabetologist or endocrinologist	o	o	o	o
Ophthalmologist	o	o	o	o
Specialized nurse	o	o	o	o
Paediatrician	o	o	o	o
Dietitian	o	o	o	o
Psychologist or Psychiatrist	o	o	o	o
Other **[Please specify]**	o	o	o	o

20. In the months following your final departure from paediatrics, did you encounter any difficulties in monitoring your diabetes in a new or unexpected way?
(*Multiple response*)

□ Yes, I had trouble following my diabetes (measurement of glycaemia, calculation of carbohydrates, administration of insulin, etc.)
□ Yes, I felt lonely facing my diabetes
□ Yes, I lost motivation
□ Yes, I had trouble getting prescriptions, certificates
□ No, not particularly [exclusive]
□ I don't remember [exclusive]

21. In the months following your final departure from paediatrics, did your diabetes unbalance unexpectedly?
(*Multiple response*)
□ Yes, I had unusual hypoglycaemia, and I was hospitalised because of this
□ Yes, I had unusual hypoglycaemia that did not enter hospitalisation
□ Yes, I had unusual hyperglycaemia, and I was hospitalised because of this
□ Yes, I had unusual hyperglycaemia that did not enter hospitalisation
□ No, not particularly [exclusive]
□ I don't remember [exclusive]

22. What subjects did you need information on during your transition from paediatrics to adult diabetes?

	I needed information and I got it from my medical team	**I needed information and I got it in another way than from my medical team (testimonials from patients, reading articles, etc.)**	**I needed information and didn't get it any [exclusive]**	**I didn't need information because I already know well the subject. [exclusive]**	**It is not an important subject for me [exclusive]**
What is T1D (its causes, complications etc.)	O	O	O	O	O
My general health status (evolution of my diabetes since childhood, family history, allergies, etc.)	O	O	O	O	O
My diabetes treatment (treatment regimen, insulin pens or insulin pump, blood glucose monitors, etc.)	O	O	O	O	O
Managing risks related to diabetes (what to do in case of hypo or hyperglycaemia, emergency numbers, etc.	O	O	O	O	O
Advice on managing diabetes at work or university/school	O	O	O	O	O
Management of diabetes-related insurance and administration	O	O	O	O	O
Advice on healthy living (alcohol, tobacco, exercise, sexual health, well-being, etc.)	O	O	O	O	O
Access to emotional and psychological	O	O	O	O	O

support (patient associations, etc.					

Question 23 Which of the following statements apply to your transition from adult diabetes? (*Only one response per row*)

	Strongly disagree	**Somewhat disagree**	**Somewhat agree**	**Strongly agree**
I feel I left paediatrics at the right time, neither too early nor too late.	O	O	O	O
Once in adult diabetology, I quickly became autonomous in the management of my diabetes.	O	O	O	O
My healthcare professionals were quick to give me confidence during my consultations in the absence of my parents.	O	O	O	O
My healthcare professionals have adapted the timing of this transition to my state of mind and the important events in my life.	O	O	O	O
My paediatric team explained to me early on that I was going to have to be managed in adult diabetes and why.	O	O	O	O
My paediatric team referred me to one or more adult diabetologists.	O	O	O	O
My paediatric team advised me to get in touch with a patient association	O	O	O	O
My paediatrician has given me or sent me my medical file (examination reports, prescriptions, etc.)	O	O	O	O

24. What aspects of the transition from paediatrics to adult diabetology do you most appreciate? *The first aspect that you select is the one that you apprehend the most, and so on. Don't select answers that you think aren't part of the aspects you're apprehending. If you want to change the order or delete a response from the ranking, you can deselect it by clicking on it again.*
1 = this aspect is the most important; 2 = this aspect is the 2nd most important; etc.

Randomised articles
□ The intervention of new healthcare professionals
□ The different organization of adult diabetology compared to paediatrics
□ Loss of contact with my paediatric medical team
□ The risk of decreased involvement of my parents in my medical follow-up
□ The risk of less involvement of the medical team for an adult than for a child
□ The impact of the change of service (or establishment) on my daily life
□ Meeting diabetic patients with serious complications
□ Meeting patients who manage their diabetes better

□ Self-management of medical appointments, prescriptions, and insurance
□ Other
□ I had no apprehension [exclusive]

The Q24b will be placed on those who checked "other" in Q24.

24b. What other aspect of the transition from paediatrics to adult diabetology do you understand? [*Free field*]

25. What benefits did you expect from your transition from paediatrics to adult diabetology? Did you get them?
Thank you for being as specific as possible.
[*Free field*]
□ None [exclusive]

26. Have you used the following services or tools to help you move from paediatrics to adult diabetology?
(*Several possible answers*)
□ Collective therapeutic education sessions (pedagogical support intended to help patients acquire the skills they need to best manage their disease)
□ Teleconsultation (remote medical consultation)
□ Digital health applications
□ Specialized website
□ Specialized paper diary
□ Brochure produced by a pharmaceutical company
□ Serious game (pedagogical game about diabetes)
□ Patient association
□ Patient community online
□ Other [Please specify]
□ I have not used any service or tool [exclusive]

C. PATIENT SATISFACTION AND NEEDS

27. Are you satisfied with how your transition from paediatrics to adult diabetology has been prepared?
(*Only one possible answer*)
□ Very satisfied
□ rather satisfied
□ Not very satisfied
□ Very dissatisfied

28. In hindsight, how could your transition from paediatrics to adult diabetology have gone better?
[*Free field*]
□ My transition from paediatrics to adult diabetology ideally strayed [exclusive]

29. What aspects do you think are important for the transition from paediatrics to adult diabetology to go as smoothly as possible?
The first aspect you select is the one that seems most important to you, and so on. Do not select answers that you think are not part of the aspects you consider important. If you want to change the order or delete a response from the ranking, you can deselect it by clicking on it again.
1 = this aspect is the most important; 2 = this aspect is the 2nd most important; etc.

Randomised articles
□ Have dedicated channels or spaces to avoid crossing diabetic patients with complications, upon arrival in diabetes in adults
□ Start this process by having your diabetes under control
□ Switch to a diabetes department at the same hospital centre as the paediatric department
□ Being able to choose the sex of your adult diabetologist
□ Receive support from parents/relatives throughout the process
□ Leave the patient as much as possible to choose the age at which he/she will start this process
□ Have the opportunity to consult a psychologist during this process
□ Meet, obtain information from patients who have already gone through this process
□ Meet the adult diabetes medical team some time before leaving paediatrics
□ Benefit from therapeutic education sessions
□ Other
□ None [exclusive]

The Q29b will be placed on those who checked "other" in Q29.

29b is What other aspect does it seem important to you for the transition from paediatrics to adult diabetology to go as smoothly as possible?
[*Free field*]

30. How do you assess the different aspects of your diabetes follow-up, in childhood and adulthood?

Please drag the cursor to the desired position left (0) for "very bad" - right (10) for "excellent".

- Child: support from relatives, including parents:
  0 (very bad) to 10 (excellent)
- Adult: support from relatives, including parents:
  0 (very bad) to 10 (excellent)
- Child: facilitates the use of monitoring devices (glycaemic reader, applications, etc.):
  0 (very bad) to 10 (excellent)
- Adults: easy to use monitoring devices (glycaemic reader, applications, etc.):
  0 (very bad) to 10 (excellent)
- Child: competence of the paediatric medical team:
  0 (very bad) to 10 (excellent)
- Adult: competence of the medical team of diabetology:
  0 (very bad) to 10 (excellent)
  □ I cannot answer, not being followed, or being too irregular [exclusive]
- Child: moral support from the paediatric medical team:
  0 (very bad) to 10 (excellent)
- Adult: moral support from the diabetes medical team:
  0 (very bad) to 10 (excellent)
  □ I cannot answer, having not followed, or having too irregularly [exclusive]
- Child: personal rigor in care:
  0 (very bad) to 10 (excellent)
- Adult: personal rigor in care:
  0 (very bad) to 10 (excellent)
- Child: food balance:
  0 (very bad) to 10 (excellent)
- Adults: food balance:
  0 (very bad) to 10 (excellent)