Patients' knowledge and barriers to ketone self-monitoring: Results from a prospective survey of T1DM patients from the French SFDT1 Cohort

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Disclosure

Pr. Jean-Pierre Riveline

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Context and objectives

SFDT1 = Suivi en **F**rance des personnes avec un **D**iabète de **T**ype **1.**

Why this matters: DKA remains life-threatening; guidelines recommend ketone checks during illness and severe hyperglycaemia.

Aims

1. Assess patients' knowledge of ketosis and DKA.
2. Evaluate ketone testing behaviours, perceived barriers, and associations with person characteristics (e.g., insulin modality, TIR, age, DKA history).
3. Exploratory multiple correspondence analysis to identify clusters.

Abbreviations: DKA = diabetic ketoacidosis; TIR = time in range

SFDT1 – prospective study design and patient count

Inclusion Criteria:

- T1DM Patients for >12 months at the time of survey
- Age ≥18 years
- Included in SFDT1 cohort
- SFDT1 data (Visit 1 or Visit 2) updated in the period of **01 Jan 2023 – 31 Dec. 2024**
- Not opposed to the use of their data as part of this specific research

Design: Cross-sectional online questionnaire (**April 2025**);

- 45 questions across five domains (management, DKA knowledge, ketone behaviours, barriers, attitudes to dual glucose–ketone sensor).

	N patients
Total potential survey population	3,045
Completed the survey	553
Informed consent for re-use of their data	551
With CGM data available	461
With glycemic data available 3 months prior to completion of questionnaire	362

Cohort profile

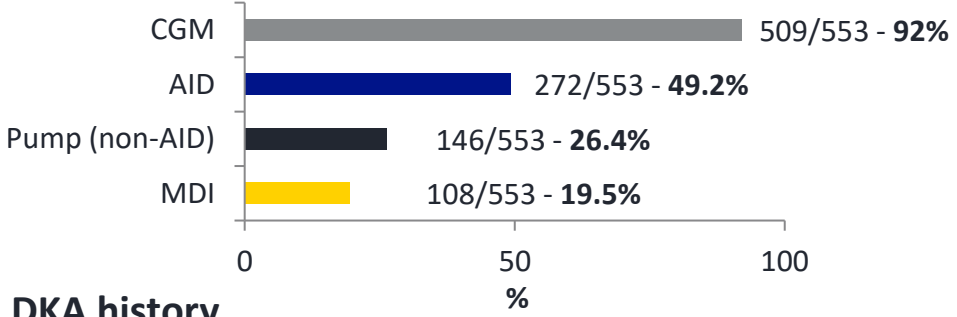
Demographics

- 45.8% male (n=253/553)
- mean age 46.2 years
- mean T1D duration 28.5 years.
- Mean age at diabetes diagnosis: 17.7 years

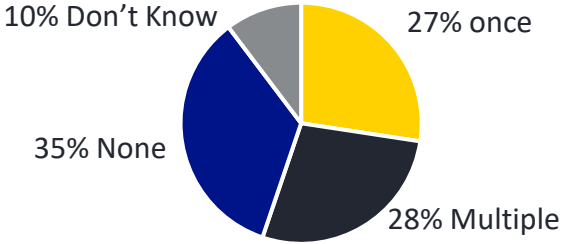
Glycaemia

- HbA1c (≤3 months) mean 7.1% (n = 362)
- TIR (last 14 days) mean 68.4% (n = 461)
- TBR <70 mg/dL: 5.5% (n = 461)
  - 4.0% at Level 1: 3.0-3.9 mmol/L
  - 1.5% at Level 2: <3.0 mmol/L
- 52.1% achieved TIR ≥ 70%
- Adverse events (previous 12 months)
  - Severe hypoglycaemia: 31 cases (8.8%)
  - DKA: 13 cases (3.7%)

Treatment technology



DKA history

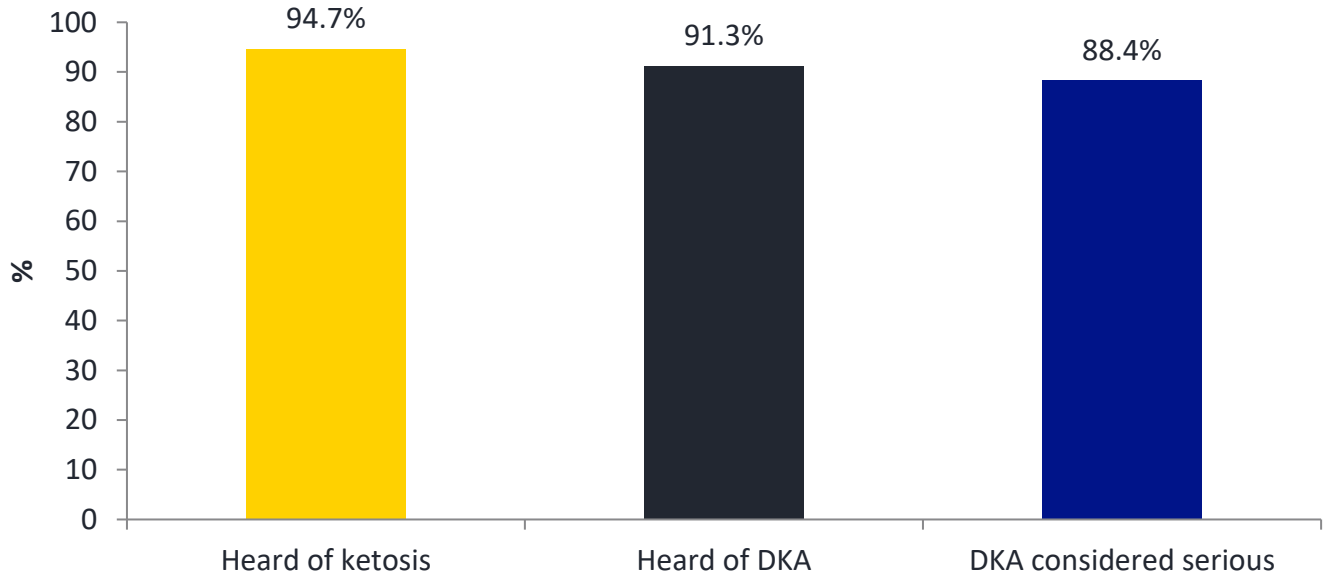


55.2% reported prior DKA

Well-controlled, highly tech-enabled and engaged cohort.

Abbreviations: HbA1c = glycated haemoglobin; TIR = time in range; CGM = continuous glucose monitoring; MDI = multiple daily injections; AID = automated insulin delivery

Awareness and prior DKA



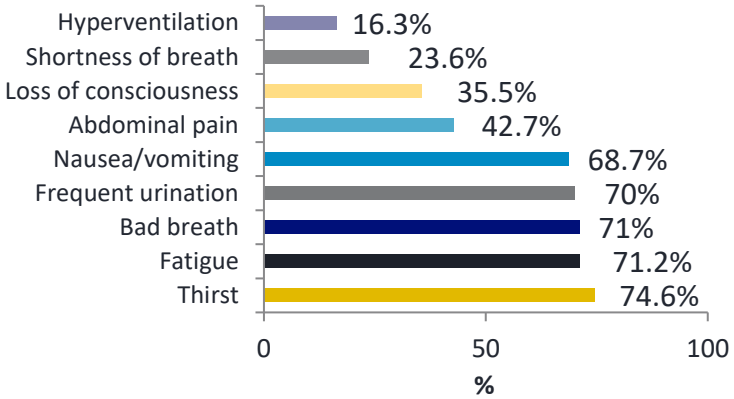
High awareness overall – 94.7% heard of ketosis

Perceived seriousness is lower in MDI vs pumps/AID (sig. across items); overall 88.4% consider DKA serious.

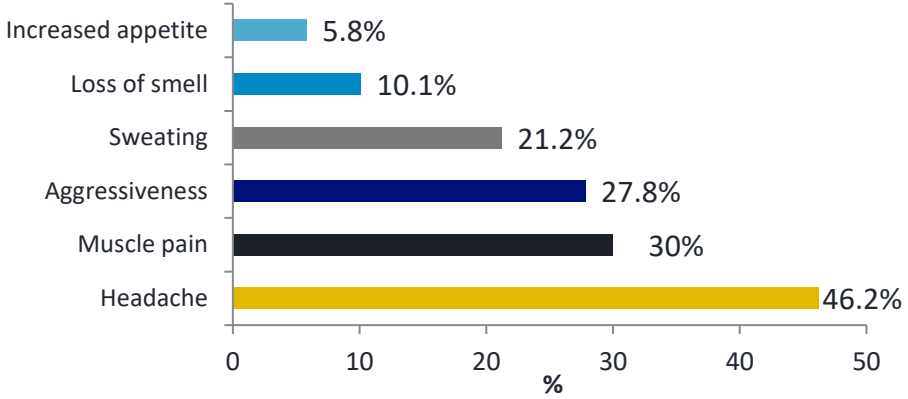
Abbreviations: DKA = diabetic ketoacidosis; MDI = multiple daily injections; AID = automated insulin delivery

Symptom recognition

True symptoms recognised:



Unrelated symptoms misattributed:



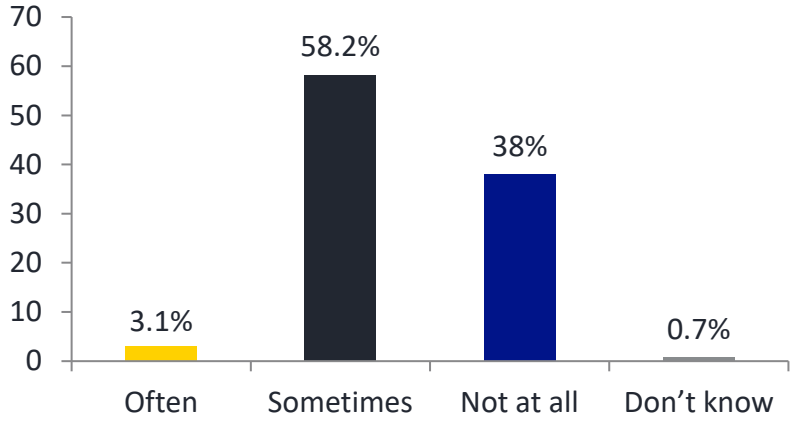
- Nearly one-third could not identify key symptoms such as nausea and vomiting
- Fewer than half recognised abdominal pain
- Critical respiratory signs rarely identified
- Many respondents misattributed unrelated symptoms
- Knowledge was higher among pumps/AID users, those aged <25 years or with prior DKA

Even in this well educated, well controlled population, there was low symptom awareness.

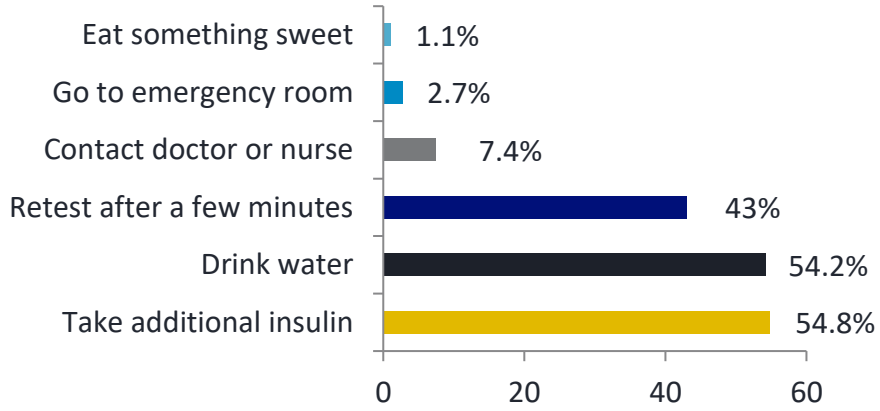
Abbreviations: AID = automated insulin delivery; DKA = diabetic ketoacidosis

Ketone testing: knowledge vs action

How often they test ketones:



Specific actions identified if ketones are high:

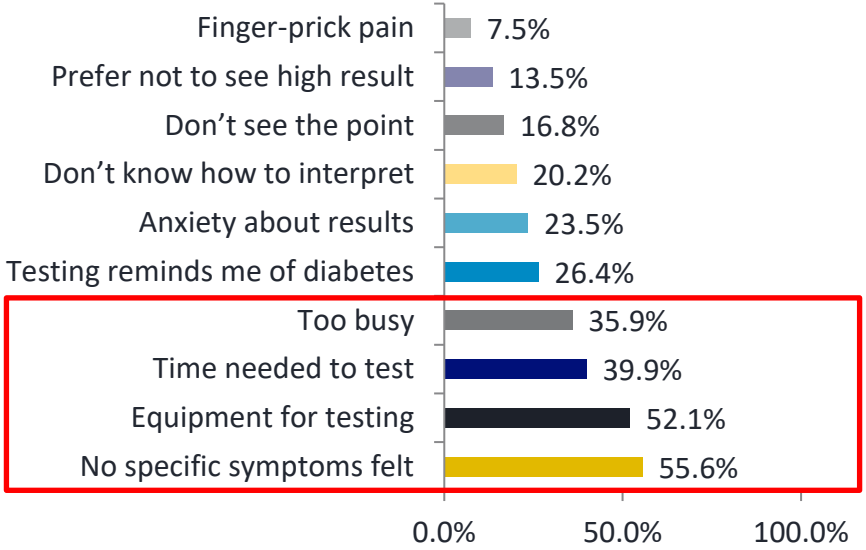


- Higher rates of testing in pumps/AID users and people with prior DKA
- Only around half identified specific actions that should be taken if ketones were high
- Few reported they would contact a healthcare professional (7.4%) or go to the emergency room (2.7%).

There is a clear gap between awareness and actions with 38% reporting that they never test ketones.

Abbreviations: AID = automated insulin delivery; DKA = diabetic ketoacidosis

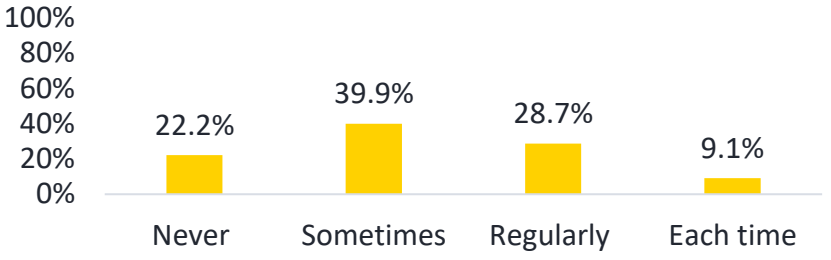
Barriers



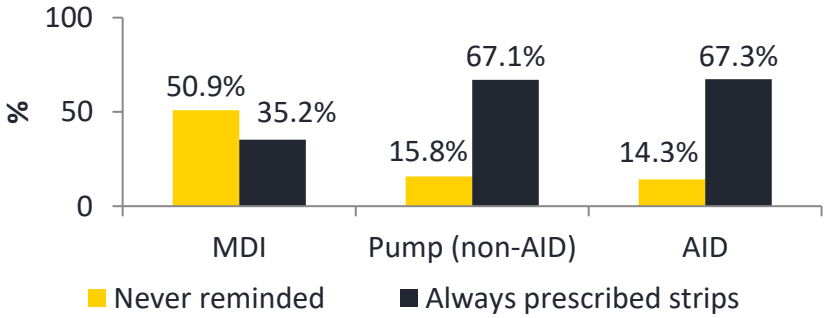
- Barriers to undertaking a ketone test were varied
- Most common: lack of symptoms, lack of equipment, time needed and being too busy

Abbreviations: AID = automated insulin delivery; MDI = multiple daily injection

Physician engagement



- Only 37.8% reported their physician regularly or always reminded them to test for ketones
- 22.2% said their doctor never reminded them

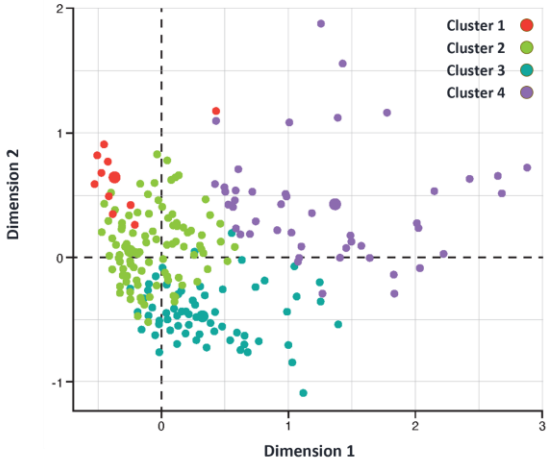


Behavioural phenotypes

Four clusters identified
(MCA on unconditioned items)

- **Cluster 1 (n = 17; 3.1%):** very good knowledge; test often; physician support; more female/younger; pump/AID; greater variability; prior DKA common.
- **Cluster 2 (n = 382; 69.1%):** very good knowledge; test sometimes; predominantly AID; good TIR; prior DKA present
- **Cluster 3 (n = 104; 18.8%):** good knowledge; unlikely to test; more male; 40% MDI; good glycaemic control; prior DKA present.
- **Cluster 4 (n = 50; 9.0%):** poor knowledge; never test; more male; MDI common; good control but hypoglycaemia episodes; few/no prior DKA.

Multiple correspondence analysis (MCA)



- Each point represents a respondent; coloured clusters group similar response patterns.
- Large centroids mark cluster centres.
- Right side = lower awareness of ketosis and DKA seriousness;
- Top left = frequent ketone testing and regular physician reminders.

Abbreviations: DKA = diabetic ketoacidosis; MCA = multiple correspondence analysis; TIR = time in range; MDI = multiple daily injections; AID = automated insulin delivery

Summary & Conclusions

In this well-controlled, highly engaged cohort (CGM 92%, mean HbA1c 7.1%, mean TIR 68.4%) with high DKA awareness; over half report a prior DKA, yet:

- **Gaps persist:** abdominal pain (42.7%) and respiratory signs (23.6% shortness of breath; 16.3% hyperventilation) are under-recognised; non-specific symptoms often misattributed.
  - Awareness and perceived seriousness higher in pump/AID vs MDI
- **Testing behaviour limited:** 38% never test. Very few contact an HCP (7.4%) or go to ER (2.7%) when ketones are high
- **Clinician engagement differs by modality:** MDI users are more often never reminded (50.9%) and less often always prescribed strips (35.2%) than pump/AID users (≥ 67%).
- **Barriers remain:** Poor symptom recognition, lack of equipment, time constraints
- **Technology appetite strong:** 82% expressed interest in dual glucose–ketone sensor

Conclusion:

- In a modern, well-controlled T1D cohort, awareness alone doesn't ensure timely ketone testing — closing the gap requires better symptom recognition, access to reliable and easy testing tools, time-saving workflows, and consistent clinician prompts, particularly for MDI users.

Abbreviations: AID = automated insulin delivery; MDI = multiple daily injection; DKA = diabetic ketoacidosis; HCP = healthcare practitioner; ER = emergency room