As practitioners, our perception and comprehension of type 1 diabetes (T1D) gets very precise with medical and fundamental research. However, it is still a challenge to take care of adolescents and young adults with such a chronic disease that upsets an already complicated transitional period.

Our objective in this study is to give voice to the adolescents and young adults by asking them open ended questions interrogating their knowledge about their disease.

Our aim is to understand more precisely what is well understood, what is not, and what are their topics of interest. This would allow us to adapt our therapeutic education programs to the specific needs of these newly autonomous patients.

We displayed a questionnaire made of 35 questions including 22 open-ended questions about T1D, insulin, glycemia, nutrition, sports, contraception and fertility. Between May and November 2017 in the University Hospital of Bicêtre, we asked patients between 11 and 25 years old, either hospitalized or consulting their diabetes referent, to fill the questionnaire. A control of their HbA1c was systematic the day of the consult or the first day of their hospital stay. Their free answers were then grouped into categories and enabled us to make a qualitative and quantitative analysis.

Cohort characteristics : 102 patients, mean age : 15.6 years, 60% of male and 40% of female. Their mean duration (± SD) of diabetes was 7.7 (± 4.1) years. 83.3% were autonomous on insulin injections/pump, 38.8% of the patients were on insulin pump. The mean HbA1c of the cohort was 8.7%.

### Results

#### What is well understood

For you, what are the possible complications of T1D (words in black) ?

Please circle the one(s) you fear the most (words in red).

#### What parameters cause glycaemia variation?

**Question 1: When should you control your glycaemia?**

Example of answer 1 : “When I wake up, when I change my pump, before a meal”

**Question 2: When do you really control your glycaemia?**

Example of answer 2 : “When I change my pump, when I feel weird, signs of hypoglycaemia”

% of concordance between answers : 33%

#### What could be imposed

- How does someone gets T1D?
- What is fasting glucose necessary for?
- What is the mecanism of action on insulin?
- How does alcohol act on glycaemia?

#### What they wonder about

- Do you fear to transmit T1D to your children?
- What topic would you like to know better about?