



# Involving YOUNG people with Type 1 Diabetes in reSearch and the development of healTh cARe activities

## A participatory research project involving adolescents with type 1 diabetes

### Background

Type 1 diabetes (T1D) is a complicated condition that requires constant monitoring and making many decisions. Living with T1D means to check blood sugar levels, inject oneself insulin, and be careful what you eat. In the life of a young adult there are a lot of things going on and youngsters don't want to control themselves all day and night. They want to rebel and feel free. A teenager living with T1D faces great challenges and is usually not asked to make suggestions on how to improve her or his situation. Being involved could help young adults to shape the diabetes care services that really support them.

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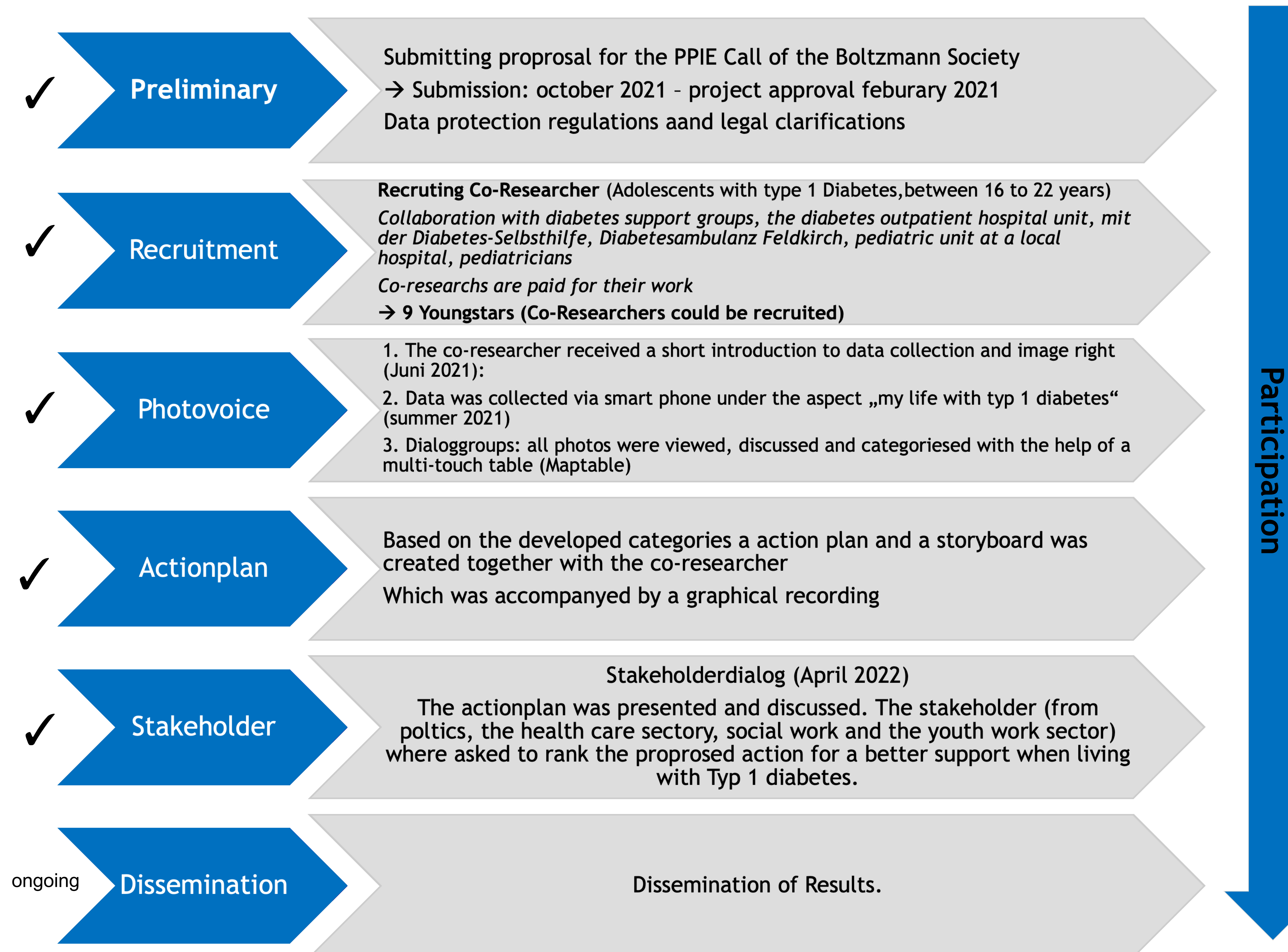
### Project Goals

- To systematically map the needs and resources of adolescents with T1D.
- To empower young adults living with T1D to communicate their needs towards decision-makers.
- To improve health care services, and develop strategies as well as supportive technologies - liberating the principle **"NO DECISION ABOUT ME - WITHOUT ME"**.

### Kooperationspartners

- Research Centre for User Centred Technologies at the Vorarlberg University for Applied Sciences
- aks Gesundheit GmbH
- Youth Work Vorarlberg
- Diabetes Support Groups
- Diabetes nurses in Vorarlberg
- Youngstars - Co-Researcher with Typ1 Diabetes
- Ludwig Boltzmann Gesellschaft GmbH

### Project Steps and Method



### Further Information:

project



projectvideo



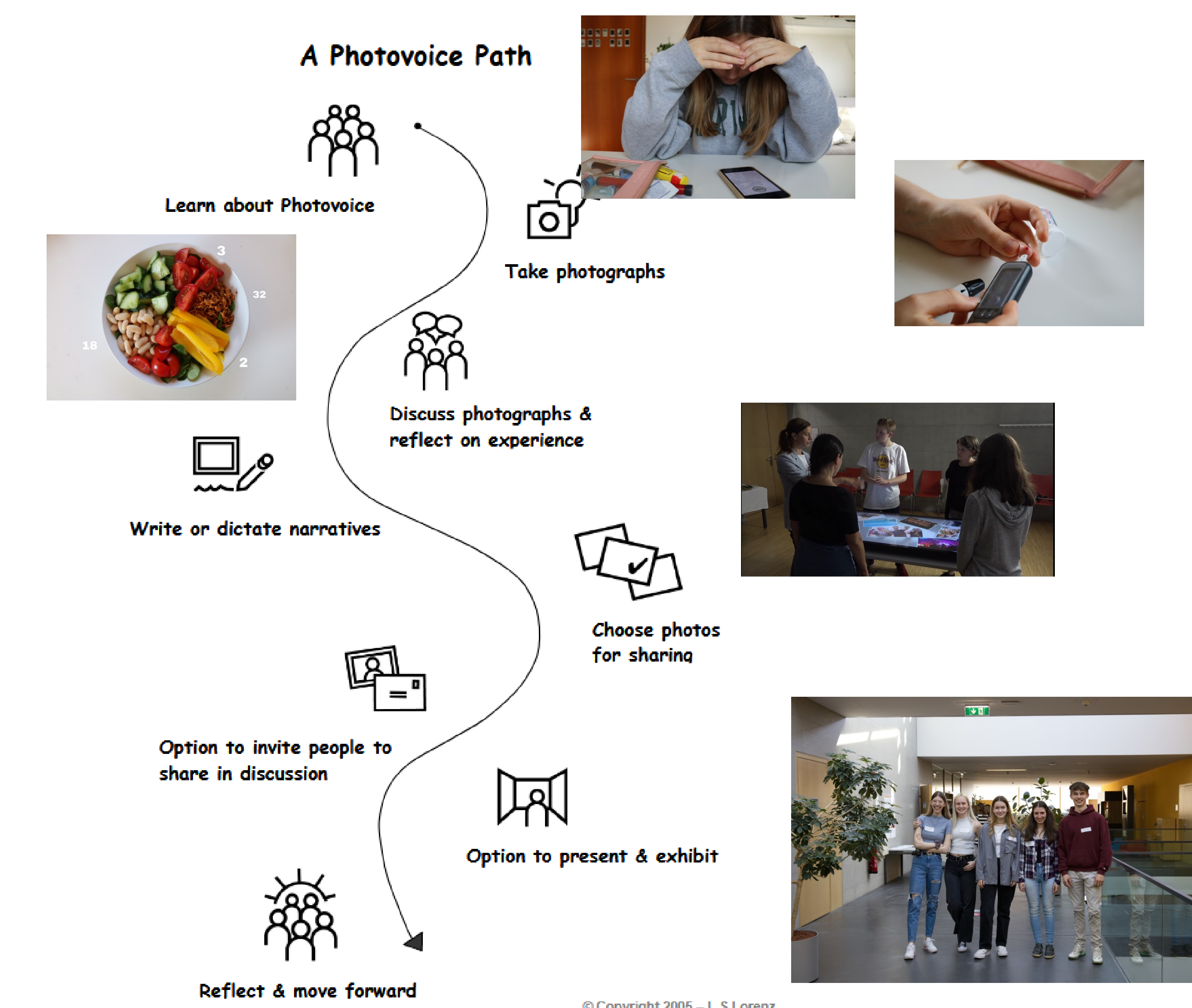
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### Conclusion

In course of this project participatory research methods (Photovoice) were used as a tool for empowerment. Involvement could help young adults to shape the diabetes care services that really support them.

### Methode - Photovoice



### Results - The Youngstars1 Action Plan

1. Improve transition from pediatric to adult unit
2. Provide medical support that is independent in terms of time and location (i.e. in case of relocation)
3. Ensure social support (especially when parents' can't offer support)
4. Provide easy explanations to describe T1D to the people around you
5. Further develop technical support (i.e. sensors, insulin-pump)
6. Improve health literacy across the life-course
7. Individualize nutritional recommendations
8. Raise more T1D awareness in society
9. Prevent bullying and identify it at an early stage