

## Retention to birth cohort studies is challenging.

We sought the experiences of primary caregivers and their participating children aged  $\geq 3$  years.



### Caregivers

1090 caregiver surveys sent  
550 completed & returned



### Children

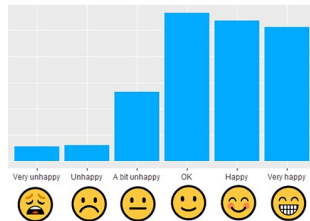


847 child surveys sent



324 completed & returned

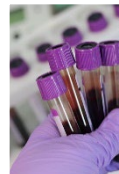
Caregivers rated higher satisfaction than children



## What motivates caregivers to enrol and stay engaged?



a positive research experience due to trusted relationships with staff



contributing to research



monitoring their child for type 1 diabetes (T1D)

## What motivates young children?

+ virtual reality headsets, toys and helping.



## What makes caregivers think about leaving longitudinal research?



Blood tests were the most common reason for wanting to leave and the least liked part of the study for children.



Time / work / family commitments



Surveys and paperwork

**Self collection:** participation during COVID and in regional and remote areas was acceptable to families



**Conclusion:** frontline staff retention is key to cohort retention plus flexibility, appreciation & feedback of study results