

NPDA – patient/carer perspective

SDM

05 08 21

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PPI lead



Background and context

- **Contacts**
 - Families with Diabetes Network
 - Digibete
 - Juvenile Diabetes Research Foundation
- **Previous surveys**
 - Psychology – 2015 (855 responses)
 - Outcomes – check year (613 responses)
 - CGM – 2016 (593 responses)
- **Organisational responses**
 - + 10 families

What we asked about

- Main areas of concern
- Greatest benefits
- Areas for improvement
- Transitioning
- Outputs

Main areas of concern

- Access and funding for technology
- Psychological and emotional support
- National variation in care especially related to ethnicity and deprivation
- Unequal access to technology
- Out of hours support
- Ward safety
- Continuity of care
- Covid impact

Greatest benefit

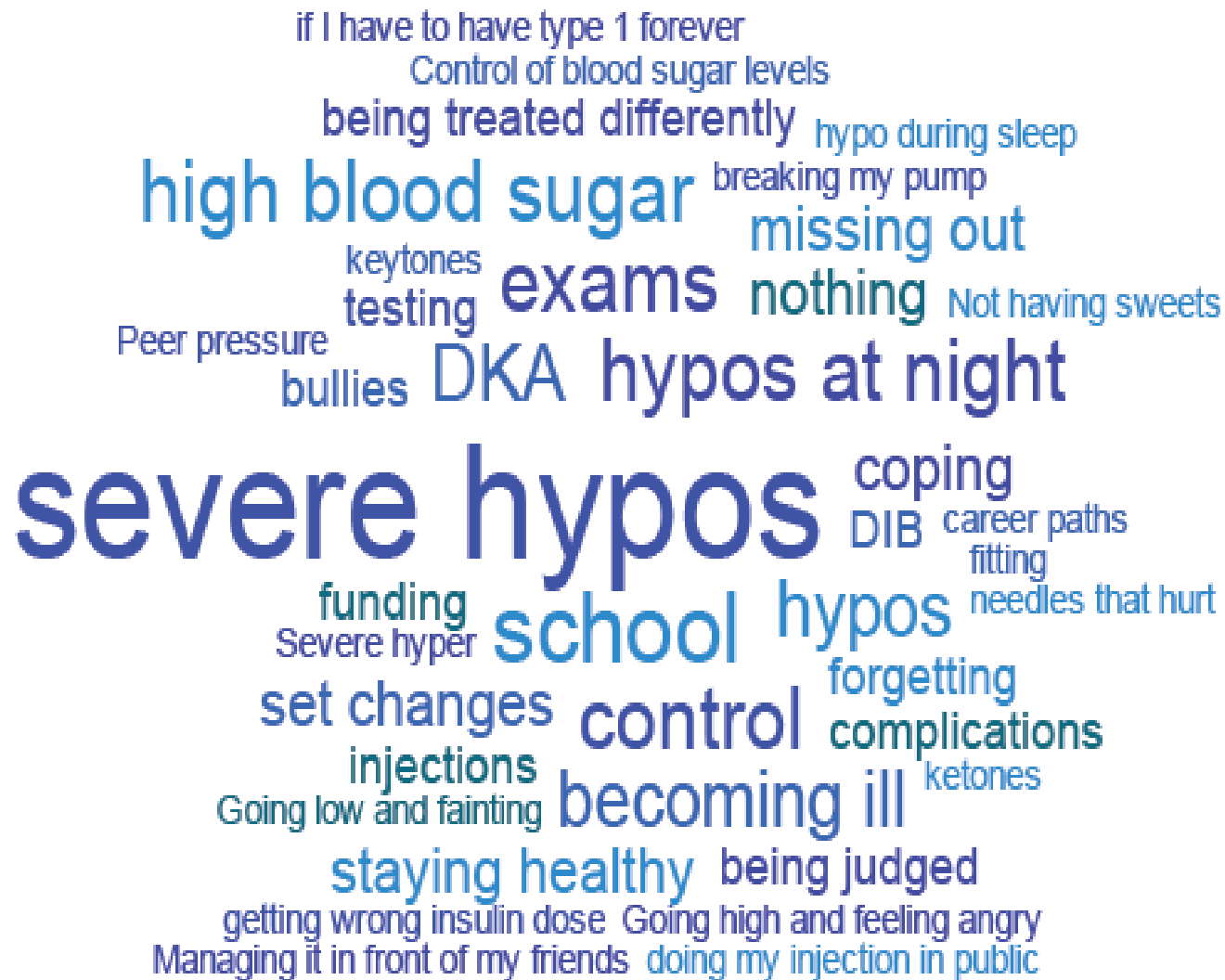
- Relationship with the teams
- Technology – specifically CGM
- Psychological support
- Peer to peer support
- Structured education

Areas for improvement

- Availability of embedded psychological support
- More funding for national peer support
- Access to technology
- Equality of access to all the above to all communities
- Out of hours care
- Ward knowledge and safety
- Consistency in teams
- GP awareness

- Variable experiences
- Under resourced adult teams
- Tech-related funding issues
- Losing family support and parents not allowed into appointments
- Fear the lack of personal relationships in adult services

Children and YP – short term



C & YP - long term

transition to adult care will my kids have diabetes

being lonely my future health coma

having to do it myself its for life and every day

hypos in sleep my children getting diabetes

severe hypo work dying amputation

not being able to have children

illness travel

alcohol

eyesight

complications

being a burden

feet nothing

brain damage university not getting a career

driving forgetting stuff leaving home

losing limbs not losing weight not being able to have kids

doing cannulas by myself organ failure brain-damage

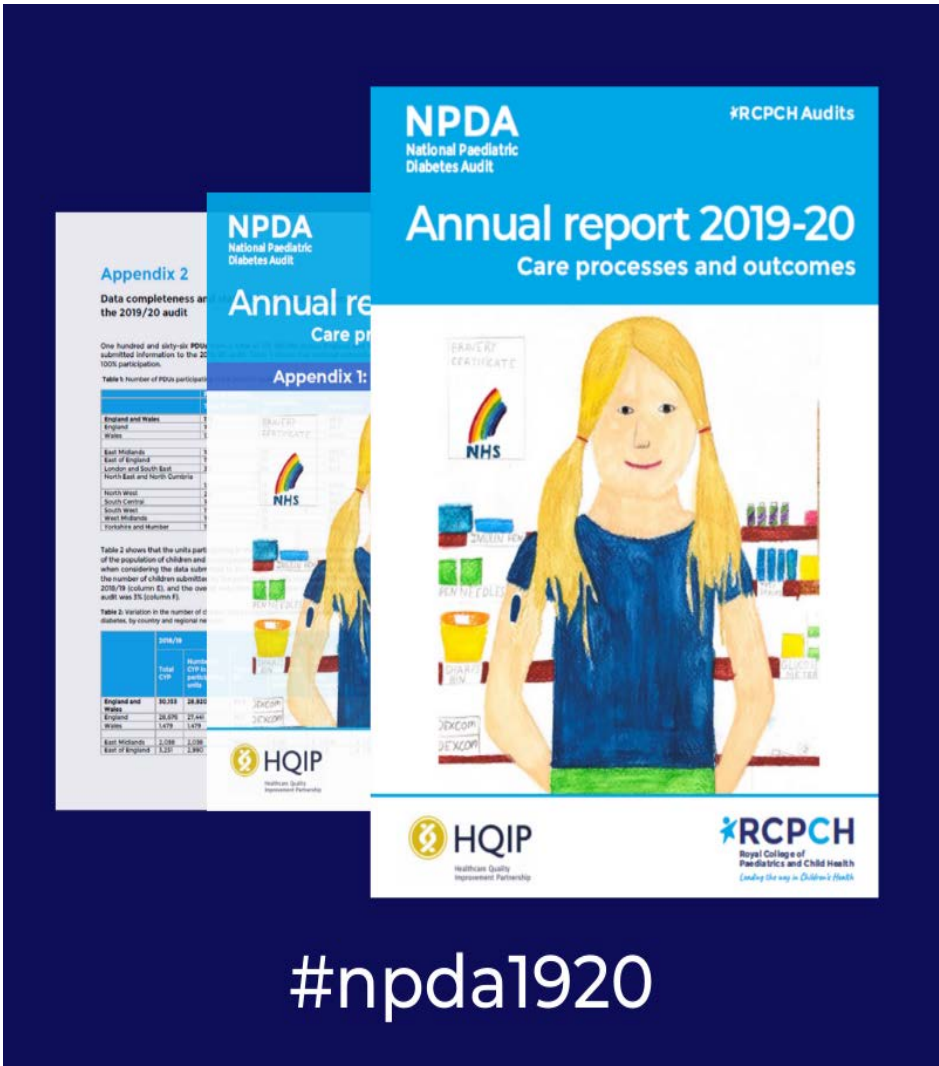


HQIP

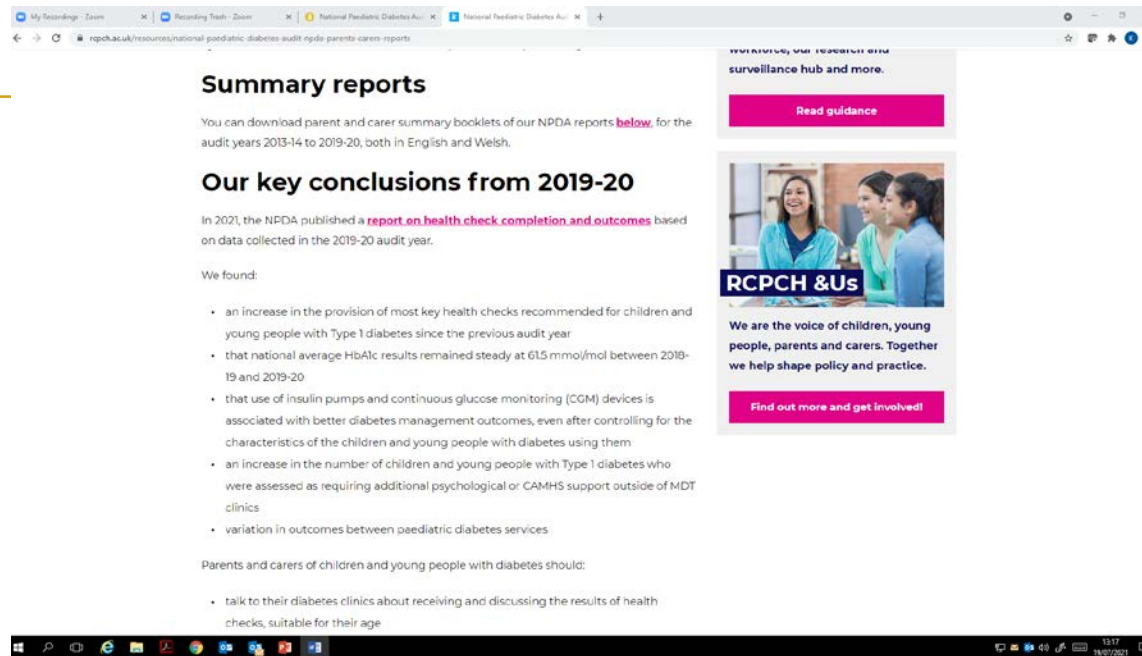
Healthcare Quality
Improvement Partnership

Outputs

- Visually appealing, well presented
- Easy to read and follow
- Helpful and reassuring
- Useful guide to understand the importance of checks and assessments
- Highlights the needs of children
- Makes me realise that we're not alone



#npda1920



- Lack of awareness
- Diabetes teams' role in signposting
- More comparison data available to families
- Foot checks data
- Admissions data
- More information on;
 - Psychology screening
 - CGM funding
 - Technology comparisons
 - Inequalities

Conclusions

- Relationships
- Technology
- Psychology
- Raising awareness
- Dissemination of outputs for information