

Developing an acceptable and feasible blood glucose management intervention for children, young people, and families living with

TYPE 1 Diabetes

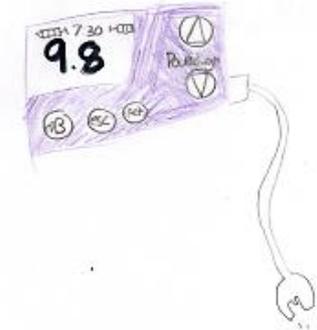
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Introduction

- **Less than 1 in 5** children & adolescents living with T1D achieve an HbA1c < 7.5%.
- **Fear of hypoglycaemia (FoH)**
 - Physically aversive
 - Present in 60% of families
 - Reduce QoL
 - Hypoglycaemia avoidance behaviours
- **Structured educational programmes**
 - CASCADE (Christie et al., 2009)
 - DEPICTED (Gregory et al., 2011)
- What about addressing child's & parent's **FoH & behaviour change?**



(LO)
Diabetes
I feel shaky
A hairnet helps
Blood is thin
Eat glucos
Test in 15 min
Exercise can
make you low
Shakiness ~~is a~~
hands

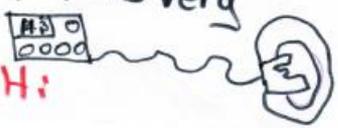
Aim

- **Design an intervention to:**
 - Address fear of hypoglycaemia
 - Improve overall metabolic control
 - Reduce the daily burden of living with Type 1 diabetes
- **Pilot the intervention**
 - Acceptability
 - Feasibility

I WANT....

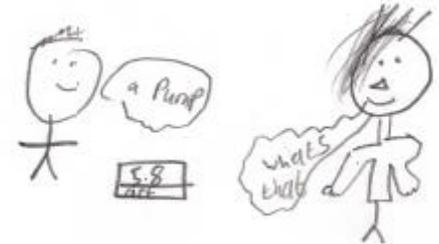
- NO SYMPATHY FOR DIABETES!
- TO BE TRUSTED
- DO THINGS FOR MY-SELF
- I AM NORMAL
- TO EAT WHEN I WANT

my pump is very nice it says Hi!



Phase I: Developing Intervention

- Interviews with research & medical teams
- Interviews with young people (median age = 10 years, range 9-16 years) & parents
 - Separate YP and parents session
 - Clinical psychologists & diabetes clinical nurse specialist
 - Single group over 1 day with easy to understand content vs. 4 sessions
 - General problems with diabetes vs. focusing on hypoglycaemia



The Intervention

- What affects blood glucose level
- Potential impact of long term high HbA1c
- Effects of hypo- & hyper-glycaemia on daily living
- Self-management techniques
- Talking to people about diabetes with confidence



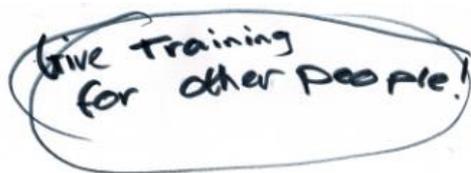
I AM NORMAL

Know
MYSELF

LISTEN
TO
ME

Refinement & Evaluation

- **Phase 2: Refining intervention**
 - 3 focus groups with different ages (8-10, 10-11, 14-16 years old)
 - Amendments made from feedback of audio recordings
- **Phase 3: Pilot study**
 - Families with YP 8-16 years old with T1DM
 - Mixed models approach to assess:
 - Feasibility
 - acceptability
 - effectiveness



Diabetes is not able to be caught!



Phase 3: Feasibility

- **Recruitment rate:**
 - 34 out of 89 families approached consented (33%)
- **Final attendance & drop out:**
 - 1 family withdrew & 11 cancelled within a week of the group
 - Final 22 families participated in 7 groups (2-4 families per group)
 - 1 group cancelled due to insufficient participants
- **Barriers to participation**
 - Unwilling to miss school: N = 38
 - Other commitments: N = 17
 - General disinterest: N = 7
 - Transportation issues: N = 4

Phase 3: Acceptability

	Child Mean (Range)	Parent Mean (Range)
Recommendation	9.0 (6.5 – 10)	9.6 (7.5 – 10)
Recommendation at follow up	9.1 (8 – 10)	9.4 (5 – 10)
Usefulness of the day	8.6 (5 – 10)	8.9 (7 – 10)
Enjoyment of the day	8.9 (3 – 10)	9.1 (5 – 10)
Comfort speaking about diabetes before	6.0 (1 – 10)	8.5 (1 – 10)
Comfort speaking about diabetes after	7.4 (3 – 10)	8.8 (1 – 10)

General enjoyment of the day...

“I enjoyed the day because we got to explain how we feel and share what we’re going through” – Girl, 9

“I did not expect to be blown away by the amazing experience that I had with the group and in the parent only session. The day was engaging, funny, and relaxed. Every aspect of it worked. Genius.” – Parent

“The day has boosted my child’s confidence. She was very apprehensive about attending but was made to feel relaxed and valued during the day.” – Parent

Parents enjoyed listening to their children...

“It was good to see that she can manage it, and understands what affects her blood sugar and see her confidence grow from sharing her knowledge with others.”

“It was nice that he realized he is very knowledgeable. It also made me see how wonderful and amazing he is.”

Both parents & YP liked sharing ideas...

“It’s good to know that others are going through the same situation, it makes you feel connected. Otherwise you think you’re the only one. You don’t get many opportunities like this.” – Parent

“It was interesting to see how other people are affected differently by low or high blood sugar.” – Boy, 13

“It was amazing to realize that others felt the way I did.” – Girl, 11

Leaflet designed by YP

What you can do to help:

- * Be positive
- * Spread awareness of type 1 diabetes
- * Know my hypo and hyper symptoms
- * Know how to treat a hypo
- * Check that I've taken insulin

Please remember to:

- * Not treat me differently
- * Give me space
- * View me as a person, not as a diabetic
- * Trust me
- * Not underestimate what I know

TYPE 1 Diabetes

I WANT...
 @INDSYMPATHY FOR DIABETES!
 @TO BE TRUSTED
 @DO THINGS FOR MY-SELF
 @I AM NORMAL
 @TO EAT WHEN I WANT

LISTEN TO ME

Give training for other people!

We would like to thank everyone who attended the groups for their thoughtful contributions and for giving us their permission to share their ideas with others

University College London Hospitals **NHS**
NHS Foundation Trust

What young people would like everyone to know about Type 1 Diabetes

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IT'S most likely that...
 • I will not die!
 • I will eat in class!
 • I am "normal"!
 • You could offend me!

Know MYSELF

What you need to know:

I don't eat sweets in school for fun - I need it for my diabetes

Diabetes is not from eating too many sweets

I can eat as many treats as people without diabetes

It's not the same as allergies

There is not 1 type of diabetes

Diabetes cannot be caught like Ebola or flu

I miss the start of PE when my blood sugar is low

My pancreas stopped producing insulin

How much insulin you need depends on blood glucose levels

When this happens you get ketones.

Things I have when I'm low

I AM NORMAL

I HAVE A DUND

I HAVE INSPECTORS

RIGHT NOW NETWORKING WHAT SHOULD BE NETWORKING

YOU are about fizzy drinks

Jelly babies, Hot dog, Pizza, Juice, Insulin, apple juice, Diet

5.2

Annoying things people do:

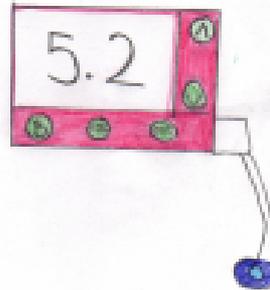
- * Not letting me eat what everyone else are eating
- * Asking too many questions
- * Being overprotective
- * Mistaking pump for a phone
- * Excluding me from activities
- * Think that type 1 and type 2 diabetes are the same

Qualitative outcome measures

- Recognition of personal strengths
- Learning about diabetes
- Improving self-management

“I know more about diabetes than I think and know how to look after myself.” – Boy, 13

“I will be more aware of what happens when I’m high or low, and pay more attention to what my body is telling me.” – Boy, 13



“I’ve learned more about diabetes today than I did in three years!” – Parent

Quantitative outcome measures

- Range of questionnaires on management, QoL, & FoH
 - Underpowered
 - Trend of increase in avoidance of hypoglycaemic risk

Child baseline Mean (SD)	Child follow-up Mean (SD)	Parent baseline Mean (SD)	Parent follow-up Mean (SD)
53.2 (23.5)	59.2 (12.8)	67.0 (18.3)	79.5 (16.6)

- Reduction in hypoglycaemic episodes (median = 9 vs 4 times)
- With No increase in HbA1c

Summary

- Developed an **acceptable** programme for YP & families with TID
- Need to review **feasibility**
 - Not easily generalizable to clinic environment
 - Holiday vs weekends
 - Run as part of clinical service targeting younger patients
- Inform design of **future RCT**
 - Median contacts for follow-up data = 5.5 (range 1-20)
 - Clinics, phone, & email/post
 - 4 lost to follow-up



Best initiative for children,
young people and emerging
adults

SANOFI DIABETES 

THANK YOU!

Patients & Families

- Lucy Casdagli
- Madeline Harris
- Emily Storr
- Hannah Duncan
- Louise Potts
- Laura Rose

