



Paediatric Diabetes: Positive Eating, Activity & Self (PDPEAS)

Subgroup of the NW CYP Diabetes Network

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September 2021

Listening to the experiences of CYP & their families living with type one diabetes:

'I wish I could just eat what I want to'

'It's great, I don't have to eat massive meals any more (just started on pump)'

'They'll think I'm fat and greedy if I put in boluses for all my snacks'

'My body feels odd' (15% weight loss/gain around diagnosis)

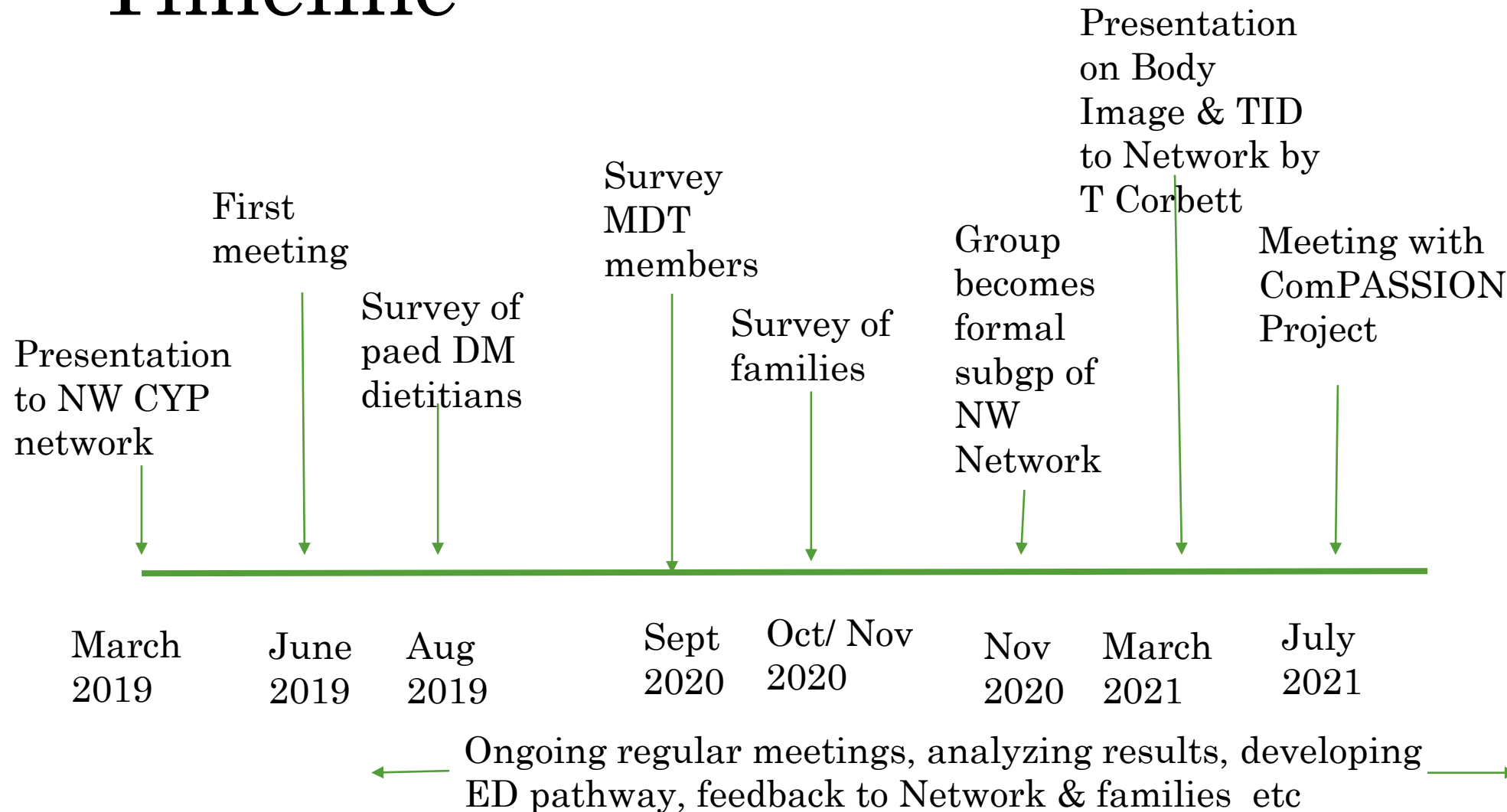
'She's obsessed with chocolate, it's all she talks about'

'He's hungry all the time, he's wolfed it before I've even sat down' (parents hadn't increased carbs in past year)

'It's sometimes easier to give something I know isn't ideal, I just want her to eat something.'

(T1D + Coeliac)
'There's nothing I can eat'

Timeline



PDPEAS Terms of reference

- Initiated by a group of dietitians, psychologists and a parent, to further develop CYP's diabetes care.
- Aiming to foster a healthy and enjoyable relationship with food, activity and body image in CYP living with diabetes.
- Developed in response to comments from CYP and their families, surveys of dietitians and families, and continuing evidence of disordered eating and eating disorders in CYP living with Diabetes.
- Multidisciplinary working and consistency are key. All professional groups within the MDT represented, along with interested stakeholders, to offer an holistic approach.

Survey of paediatric diabetes dietitians August 2019

- Online survey (surveymonkey) used to review what dietitians discuss with CYP and families in the first 4 weeks following diagnosis, and also the importance of different topics.
- 20/20 Dietitians from the North West region responded
- 13 questions asking what topics discussed in practice and how important it is to discuss these topics + 2 free-text questions.

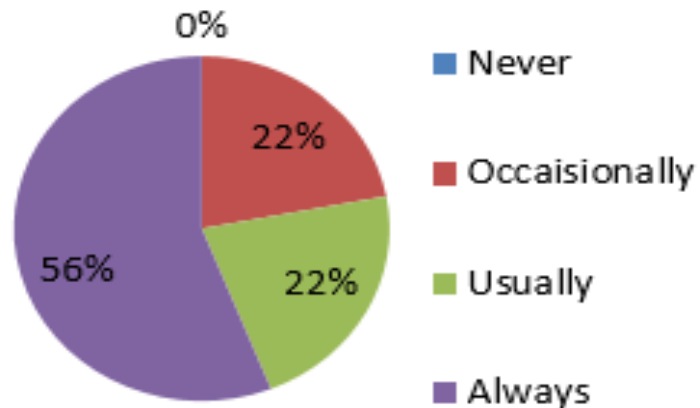
Results

- Little variation in dietitians' discussion and value of nutrition topics: healthy eating, including fruit and vegetables/dairy/pulses, using glycaemic index, having a meal routine, carbohydrate counting and encouraging activity
- The following show topics with most varied responses + reflections from dietitians' group when results presented in September 2019

Limiting Snacking

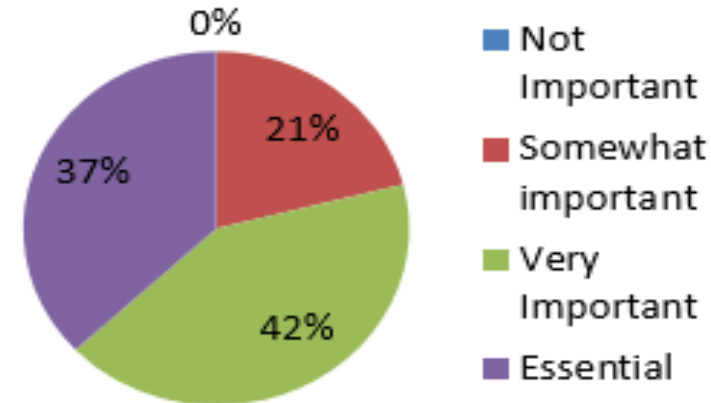
As part of newly diagnosed education (within 4 weeks of diagnosis) which topics do you discuss

In Practice



As part of newly diagnosed education (within 4 weeks of diagnosis) Which topics do you feel are important to discuss

Importance

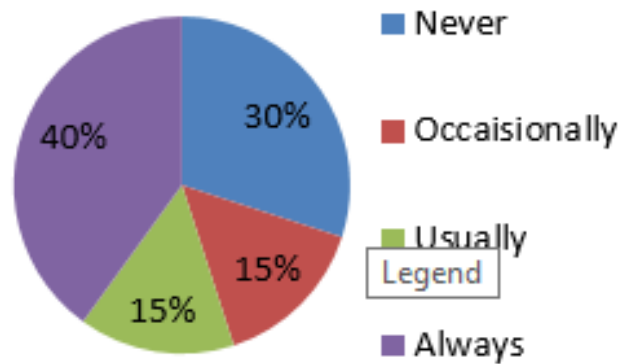


Some teams currently advise against snacking altogether, reflecting a more restrictive approach prioritising good glycaemic management; others feel that restricting snacks is not helpful, does not support a healthy relationship with food (HRF), and can lead to young people hiding the fact that they snack.

Appetite regulation, hunger and fullness

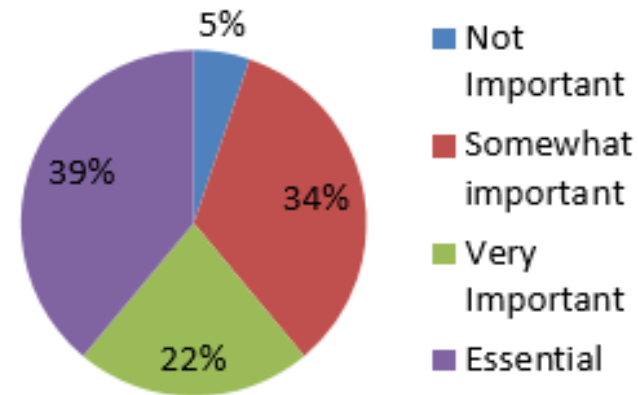
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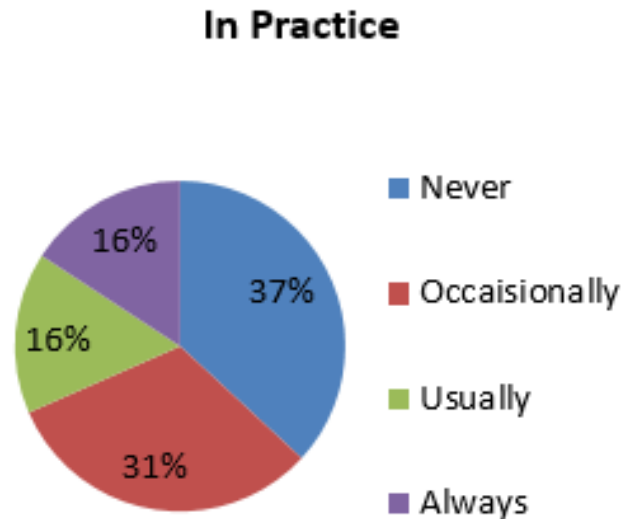
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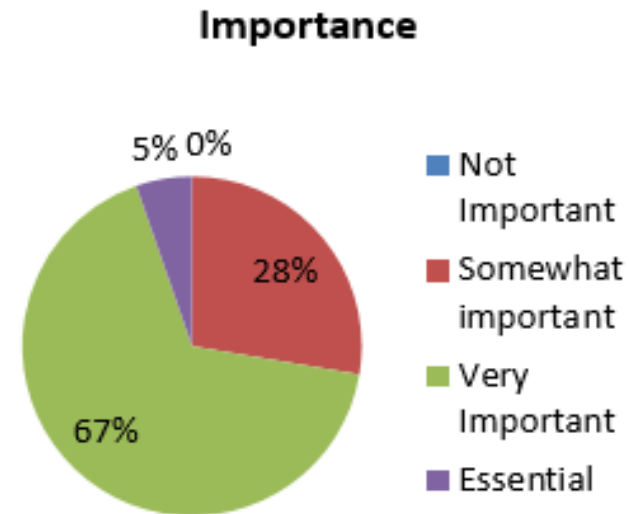


How relationship with food may change

As part of newly diagnosed education (within 4 weeks of diagnosis) which topics do you discuss

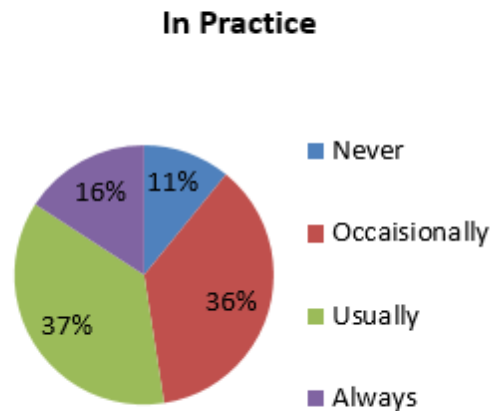


As part of newly diagnosed education (within 4 weeks of diagnosis) Which topics do you feel are important to discuss

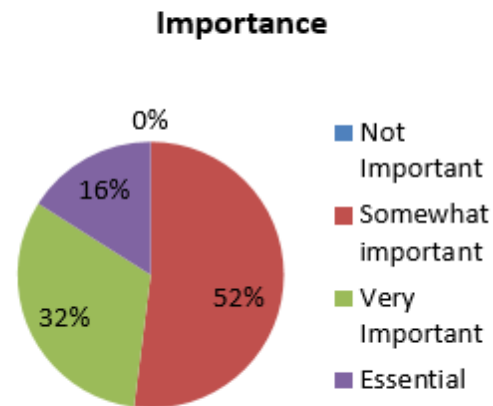


Weight fluctuations

As part of newly diagnosed education (within 4 weeks of diagnosis) which topics do you discuss



As part of newly diagnosed education (within 4 weeks of diagnosis) Which topics do you feel are important to discuss



Much discussion in relation to weight. CYP are weighed and measured at MDT clinics without necessarily understanding why. Inappropriate comments regarding weight sometimes overheard.

The attitude and language used within the clinic setting towards a young person above a healthy weight range generated concern, as did the lack of dietitians' confidence in discussing body image and body respect.

Summary of dietitians' reflections

- A more person-centred approach is necessary
- Need to include topics such as changing relationships with food, appetite regulation, weight fluctuation, and reasons for growth monitoring
- Training need identified for teams around attitude and language towards CYP above a healthy weight range, and re body image.
- Interest in developing practice to foster a healthy relationship with food
- Lack of resources.
- It appears that a holistic approach can be lost, due to an increased focus on numerical values of food/blood glucose levels and insulin dose.

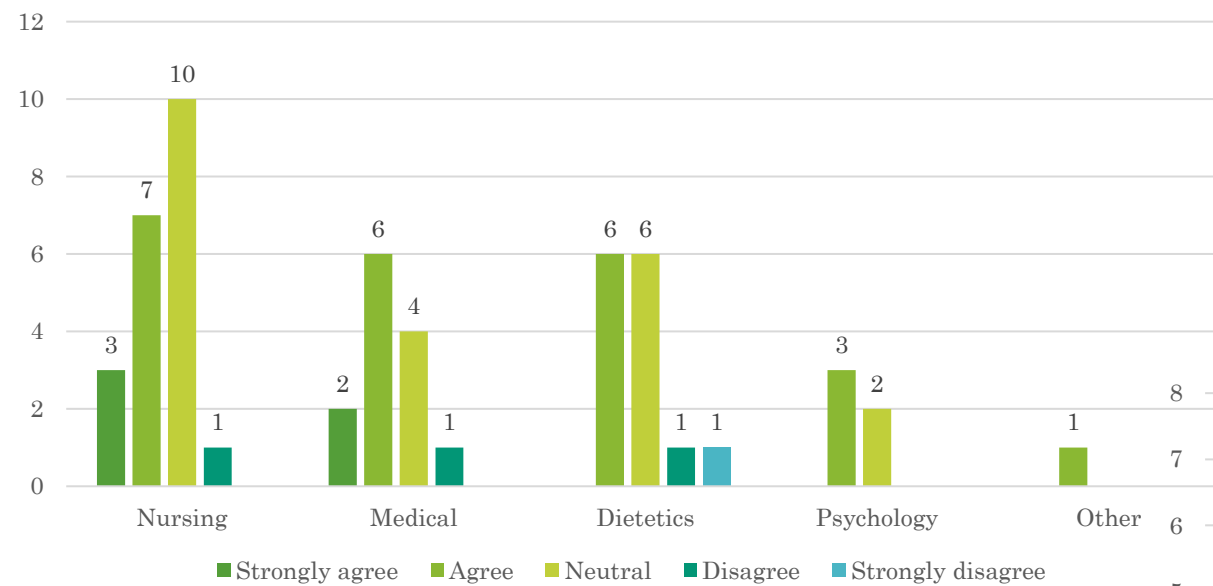
Survey of MDT professionals

September 2020

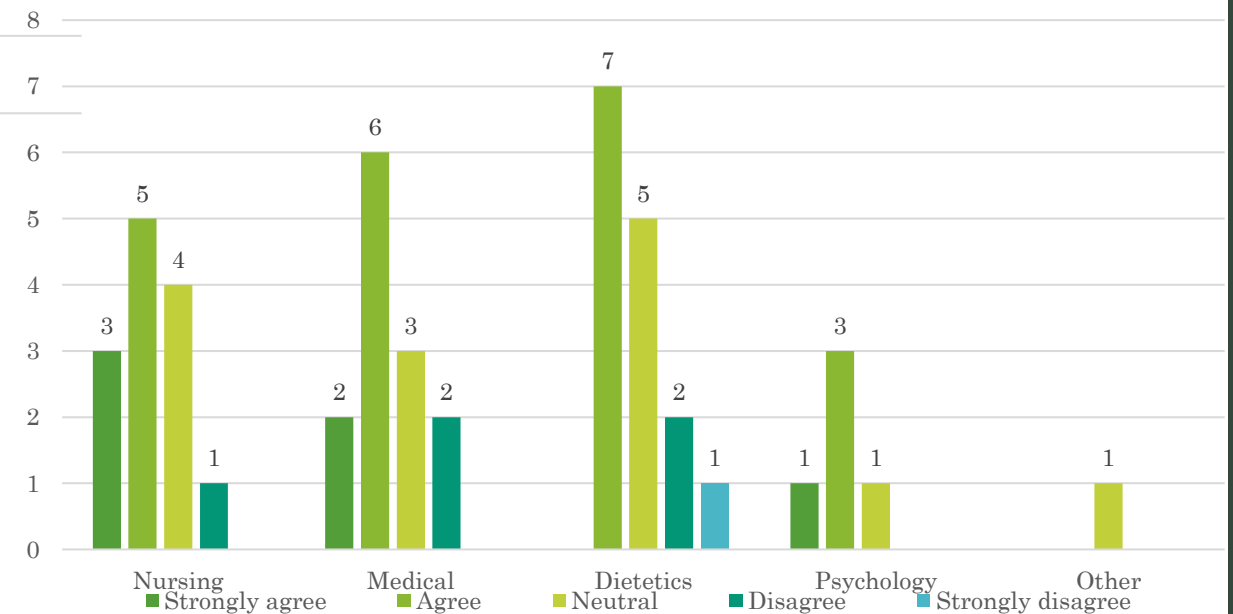
- 54 MDT members at Network meeting questioned using Slido Live Survey tool
- Reported confidence in understanding and discussing relationship with food, awareness of how living with T1DM can impact on relationship with food, alert to missing insulin to control weight, relevant to role to encourage enjoyable activity.
- Confirmed need for resources to discuss healthy relationship with food
- A minority expect perfect BG management

Weight and shape

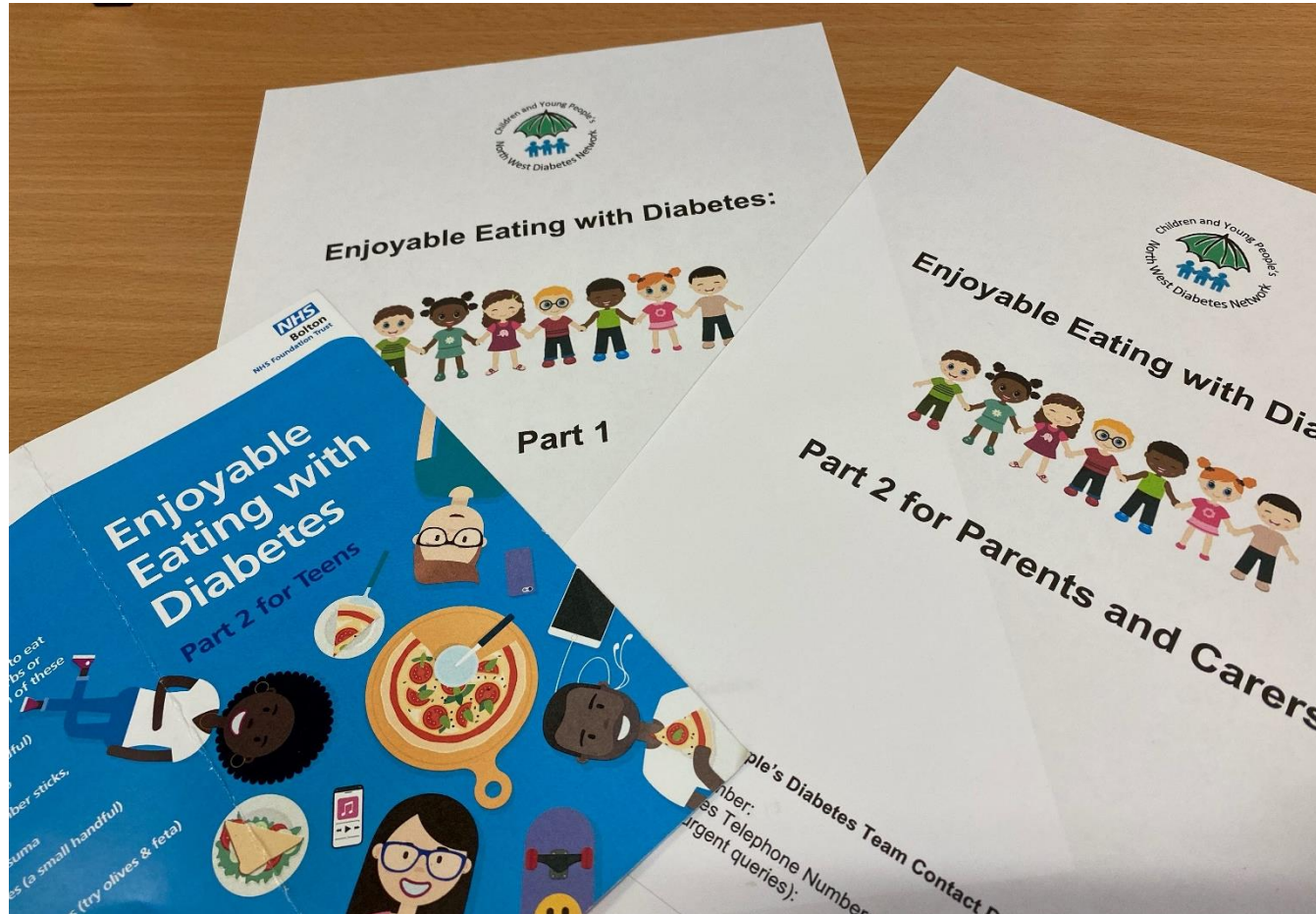
Q8. I feel comfortable in having conversations around weight and body shape



Q9. I feel confident in using language relating to weight and body shape that is not stigmatising/judgemental



Resource development



Parents' survey November 2020

- A survey monkey was sent to parents nationally (through MDTs and Digibete) asking about the CYP and family's experiences around food and eating since T1D diagnosis.
- 386 parents responded, providing a wealth of information.
- 4 Key themes from quantitative data (46 questions, responses ranging from strongly agree - - -> strongly disagree)

Impact on parents/carers

‘Because my child/young person has diabetes, I give more attention to meal content and timings than if my child/young person did not have diabetes’ 78% agree

‘I feel guilty when my child/young person has sweet foods/drinks’
60% disagree
22% agree

‘I think about how many carbohydrates my child is eating more than his/her appetite’

38% agree

Impact on the whole family

‘Mealtimes
are
stressful
due to
diabetes
factors’
44% agree

‘As a family we
find
carbohydrate
counting easy’
68% agree

‘There is conflict
in the home
because siblings
can eat differently’
15% agree
67% disagree

Impact on CYP's relationship with food and their body

Since diagnosis,
it is more
difficult for my
child/young
person to eat
spontaneously
63% agree
25% disagree

My child/young
person eats to keep
their blood sugar
levels up, even
when they are not
hungry
42% agree
35% disagree

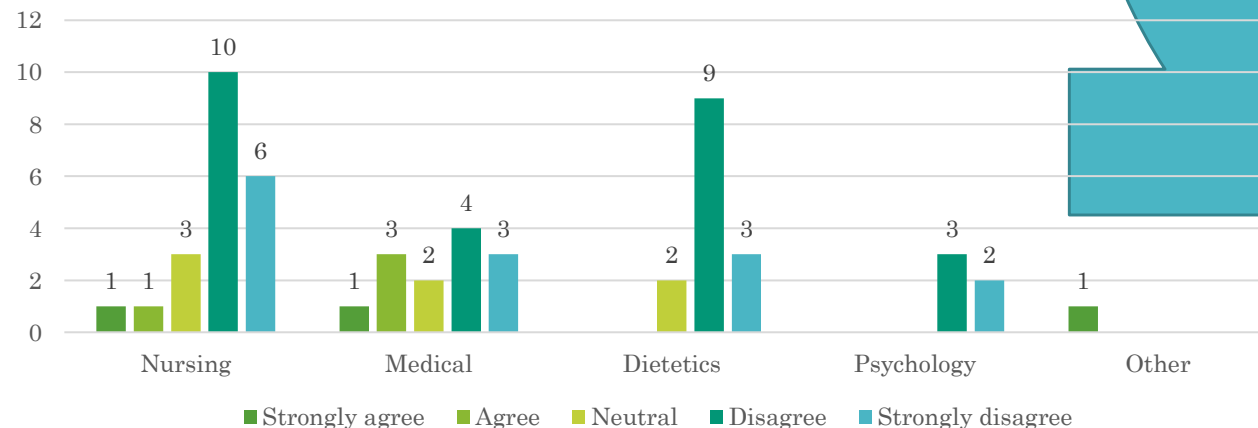
My child is concerned
about their weight/body
shape.
32% agree
50% disagree

Feedback on how the diabetes is managed

'I feel able to ask the Diabetes Team for support around what my child/young person eats'
86% agree

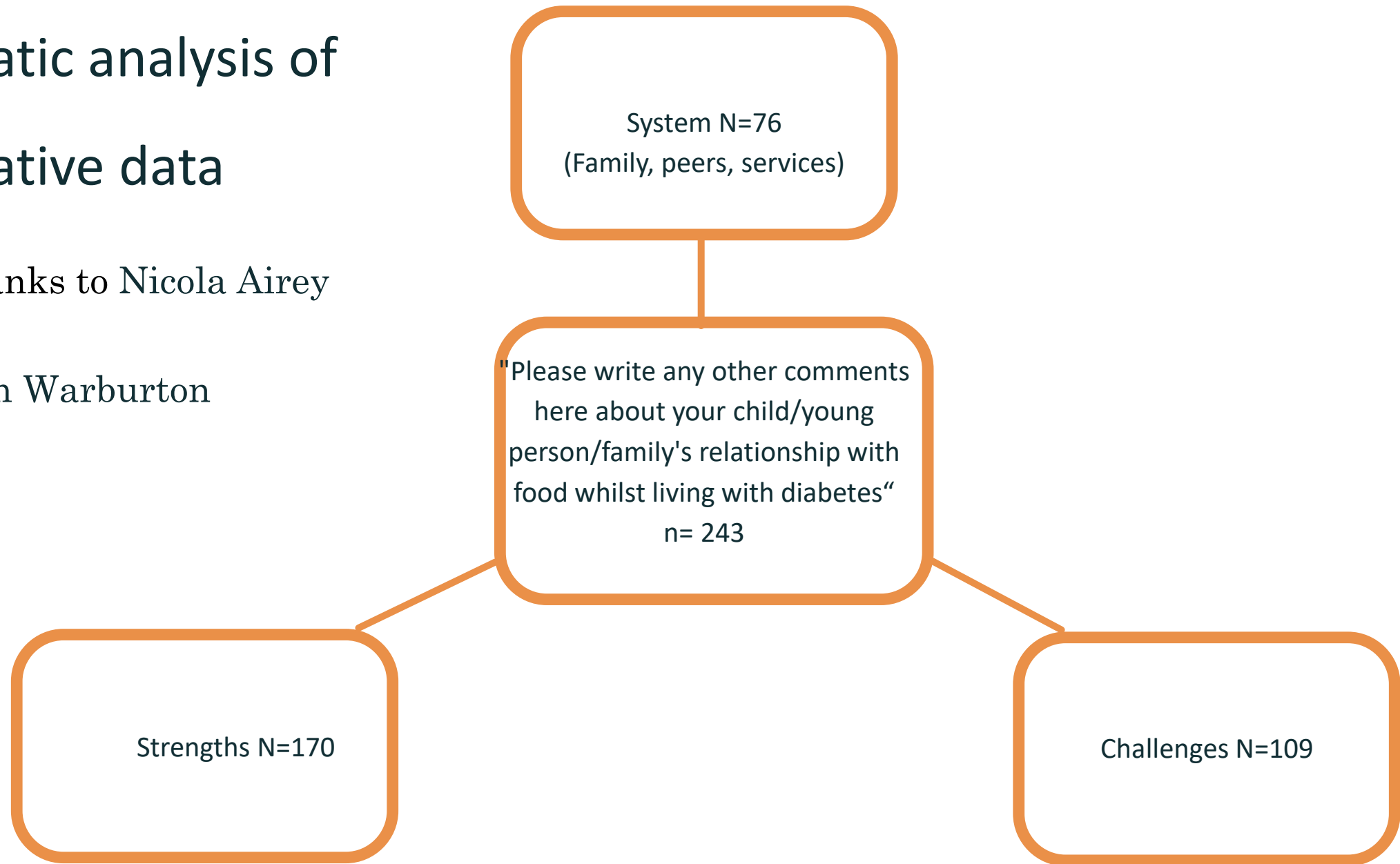
'The Diabetes Team expects perfect blood sugar management'
16% agree
22% neutral
62% disagree

Q6. I expect perfect blood sugar management by CYP and their families



Thematic analysis of qualitative data

With thanks to Nicola Airey
and Ruth Warburton



“the clinic has been very supportive about food over the many years we’ve been attending even with a very fussy eater”

System - Services

“*I do so wish that the hospital dieticians and paediatrics would advocate a low-carb, healthy diet and not deem the opposite as acceptable*”

“the clinic are worried that we parents will restrict their diets and cause mental problems/eating disorders. So they go over the top about what you eat.”

System continued:

“ massive challenge for us all, a real balancing act ”

“ *he finds it so hard when friends/family eat stuff he's not allowed around him
leaving him feeling deprived* ”

“ I am more reluctant for him to go to a friend's house or stay away
from home as I feel others won't know how to manage it ”

“ *we as a family eat the same way so she doesn't feel any different* ”

Challenges

“ *he would rather go without now sometimes so no insulin is required* ”

“ we always talk about carb counting, always having to talk about diabetes, exhausting ”

“ *I feel guilty for eating without needing an injection (parent)* ”

“ my daughter recently started restricting her carbs as is worried about weight gain ”

“ we try our best to do everything the right way ”

Strengths

“We eat more home cooked food but don't fuss over getting take- aways or if my son wants to eat lots of snacks because of a party. Everything in moderation”

“ Having a pump makes near-normality far more achievable & we feel fortunate in that

“ We try to make better food choices as a family and have a greater understanding of GI and a balanced approach ”

“ My son is very independent for a 12 yr old boy, he always works his carb count out (with me double checking) he will use scales to weigh out food and over all has a good relationship with food ”

Including Connected Eating Principles

Diabetes Dietetic Education (NICE, 2015; Smart et al., 2018)	Connected Eating (Aphramor, 2015) **	Suggested additions to current practice in diabetes education from diagnosis
Eat a healthy balanced diet; the Eatwell Guide	Understand that food is relational; let food serve a range of roles and meet a range of needs (social, cultural, pleasure etc)	Appreciate the wider context of food and eating, enjoyment of food and the role it plays in our lives; acknowledge changing relationships with food; offer support to include /manage favourite foods and those causing blood glucose spikes

** Aphramor, L (2015) Mindfulness in healthy weight and diabetes
Journal of Diabetes Nursing, 19, 401-7

Identify carbohydrates within meal/snack; Carbohydrate counting; weigh/quantify portion and calculate insulin dose based on insulin to carb ratio; nutrients; glycaemic index	Legitimise foods by using descriptive words (such as cold, crunchy, sweet, spicy) instead of value-laden words (good/bad, healthy/unhealthy, positive/negative, 'treats')	Use descriptive, legitimising words and encourage families to discuss foods in this way; avoid associating any type of carbohydrates with negative language
Regular meal routine with limited snacking and grazing	Provide developmentally appropriate structure to meals/snacks (time, place) as circumstances permit	Discuss developmentally appropriate meals and meal times; focus on inclusion rather than limitations where possible; acknowledge some loss of spontaneity in eating and that there may need to be changes to amounts/timings of some foods/drinks to support overall health

Carbohydrate counting; insulin timing; treatment for hypoglycaemia; adjust food for activity	Use different ways of knowing including awareness of body signals – hunger, fullness, emotions, energy levels; support children to eat to appetite, selecting from a variety of foods (provided by adult with taste/nutrients/likes etc. in mind)	Encourage tuning into body cues; expect variations in appetite and include CYP in decisions around meal size; enable CYP to understand how their body responds to different foods; encourage flexibility in insulin regiment; recognise that managing blood glucose levels is challenging and that while food may be used to avoid hypoglycaemia, regardless of hunger, to minimise this where possible; encourage appropriate treatment of hypoglycaemia;
BMI; healthy weight; energy balance; regular activity for health and to manage weight if appropriate	Health gain; body respect; body diversity; focusing on self-care, self-worth and enjoyable activity	Acknowledge that there can be significant fluctuations in weight around diagnosis, weight gain associated with intensive insulin therapy, and the impact of these; monitor height and weight sensitively; use body respectful, non-stigmatising language and value the person's qualities; encourage activity for enjoyment and self-care rather than for weight or blood glucose management

Eating and Diabetes: These are issues that some families find challenging. Are any of these challenging for you?

- Mealtimes being stressful due to diabetes factors
- Completely avoiding certain foods/drinks (because advised to avoid, or due to blood glucose spikes).
- Thinking about how many carbs are being eaten more than appetite
- Not being able to eat as spontaneously (what you like, when you like) or feeling restricted
- Eating to keep blood glucose levels up/making sure all meal is eaten, even when not hungry, to avoid hypos
- Using convenience foods rather than home-made foods, or packed lunch rather than school dinners, just to make carb counting easier
- Taking food without parent knowing/avoiding eating /avoiding carbs
- Child avoids taking insulin (or avoiding insulin for any other reason)
- Not trying new foods incase they are not liked and impact on blood glucose levels
- Conflict at home because siblings eat differently
- Feeling guilty about having sweet foods/drinks
- Worries about weight/body shape

Other work

- Exploring body image for CYP living with T1D including impact of wearing technology : literature review, considering patient stories
- Alder Hey and Manchester teams developing an Eating Disorder pathway with local ED teams, to range from early difficulties in relationship with food/body to full ED. Aiming to produce a document that can be ratified by the NW network
- Connecting with others eg ComPASSION project (Dorset), Surrey University team (looking to develop / assess a parenting intervention to prevent disordered eating in CYP with T1D). Please let us know of anything relevant that you are involved with!
- Regular feedback / training for NW Network
- Producing summary of results from parents' survey for parents, with feedback on how these are informing service development (to go out through Digibete)

Reflections & Learning points

- Intra and interdisciplinary working + parent input have been invaluable
- Proud of what we have achieved so far
- Benefits of formalizing the group as a Network subgroup and contributing to the National Network's Five Year Service Delivery Plan – hope will embed this approach into structured education and diabetes care nationally
- We designed our surveys with enthusiasm to understand more as clinicians. These have given us a wealth of data but we had not sufficiently considered how we would analyse this data at the start.
- In future more advice needs to be sought whilst designing survey re data analysis.
- Significant challenges in getting papers published
- Would like to draw on experiences of those in academia and now exploring this more

Thank you

- Any comments or questions welcome!