



Beyond NPDA:

Making Annual Screening Actionable

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Acknowledgements & Thank you...

Lauren Murphy, Assistant Psychologist, for scoring & analysing a huge amount of data!

DCH Children's Diabetes Team for their openness to my inclusive screening process & embracing my many recommendations!

All of you – who already do a lot of work on psychological screening



Plan for the next 20min

- *National picture on annual psychological screening*
- *What are we trying to achieve?*
- *DCH Annual Psychology Screening Results 23/24*
- *Psychology Actions & Reflections*



Standards for Psychological Care for Children and Families with Diabetes

Produced by the South West Diabetes Network
June 2023

NHS

4.1 Annual Psychological Screening by MDT

Annual psychological screening for diabetes related emotional distress should be undertaken during routine reviews by members of the diabetes MDT. Such assessment can be undertaken by any member of the MDT using standardised or individualised methods under the guidance of diabetes integrated psychology services

Classification: Official
Publication reference: PRN00153



2023/25 NHS Payment Scheme Annex C: Guidance on best practice tariffs

30 March 2023

- | | |
|----|--|
| I. | Discussion of the mental health and wellbeing of a patient should be an integral part of a patient's review with their MDT. Each patient must be assessed at least annually by their MDT as to whether additional psychological support is needed. The provider of formal psychological support for diabetes-related problems must be an integral part of the MDT. |
|----|--|

ISPAD GUIDELINES



ISPAD Clinical Practice Consensus Guidelines 2022: Psychological care of children, adolescents and young adults with diabetes

Maartje de Wit¹ | Katarzyna A. Gajewska^{2,3} | Eveline R. Goethals⁴ | Vincent McDarby⁵ | Xiaolei Zhao⁶ | Given Hapunda⁷ | Alan M. Delamater⁸ | Linda A. DiMeglio^{8,9}

Screening for symptoms of depression, diabetes distress and disordered eating in children aged 12 and above using validated tools should be done at the initial visit, at periodic intervals and when there is a change in disease, treatment, or life circumstance. **B**

NICE National Institute for Health and Care Excellence



Diabetes (type 1 and type 2) in children and young people: diagnosis and management

NICE guideline
Published: 1 August 2015
Last updated: 11 May 2023

www.nice.org.uk/guidance/ng18

- | | |
|---------|---|
| 1.2.109 | Diabetes teams should have access to mental health professionals to support them in psychological assessment and providing psychosocial support. [2004] |
| 1.2.113 | Offer screening for anxiety and depression to children and young people with type 1 diabetes who have persistent difficulty with blood glucose management. [2004] |



National Variation in Screening

- *WHO FOR*: Screening varies based on the age of the child and parents not always screened
- *WHO BY*: Mostly, MDTs are completing screening rather than Clinical Psychologists directly
- *WHAT*: No consensus on what to screen
- *WHICH*: Mix of validated questionnaires and/or unvalidated briefer screening
- *WHY*: Length and purpose varies



INTEGRITY | RESPECT | TEAMWORK | EXCELLENCE



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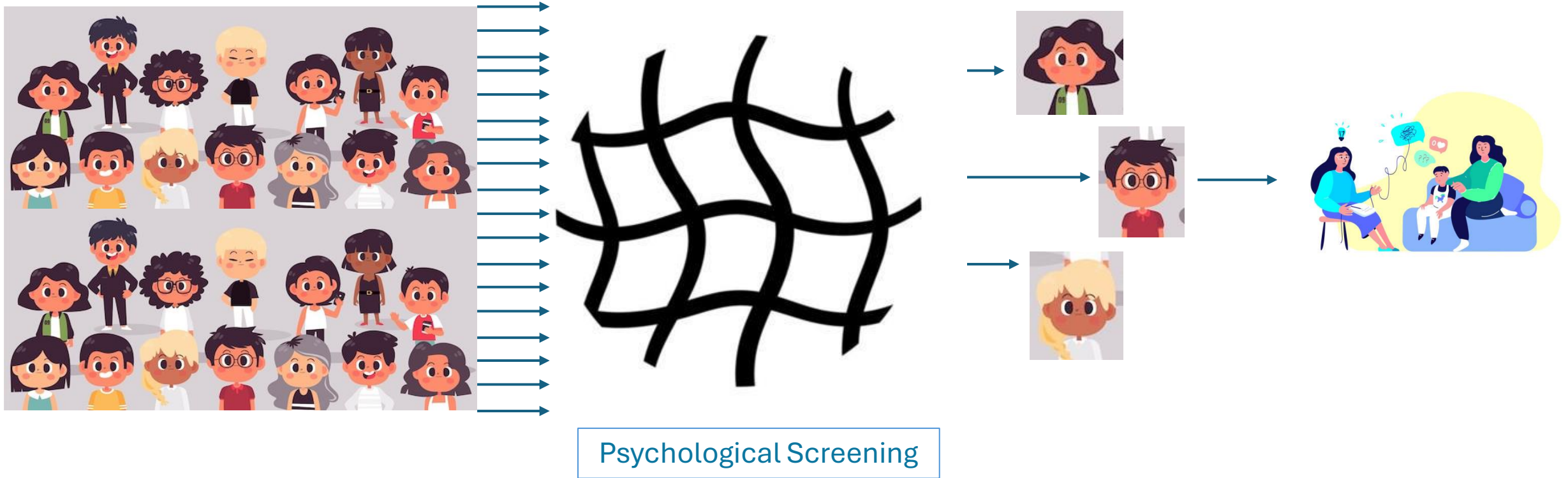
Assistant
Psychologist

Outstanding care for people in ways which matter to them



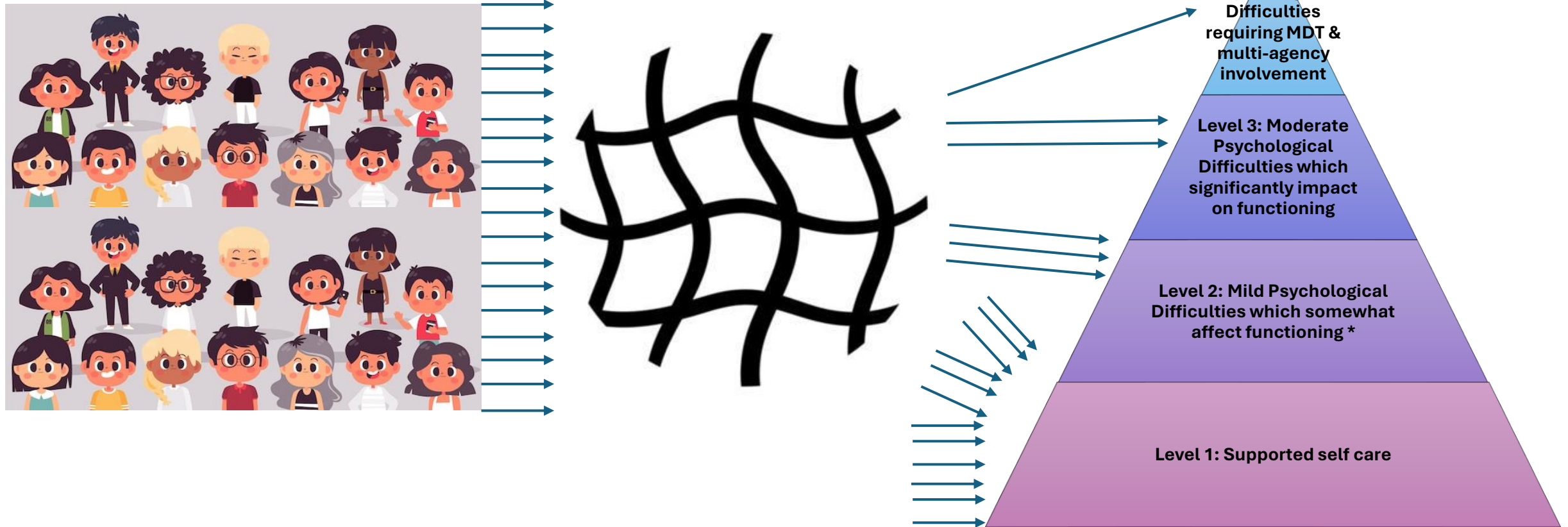
Why screen?

“Identifying psychological difficulties which may require further support...”





Individual Level Data

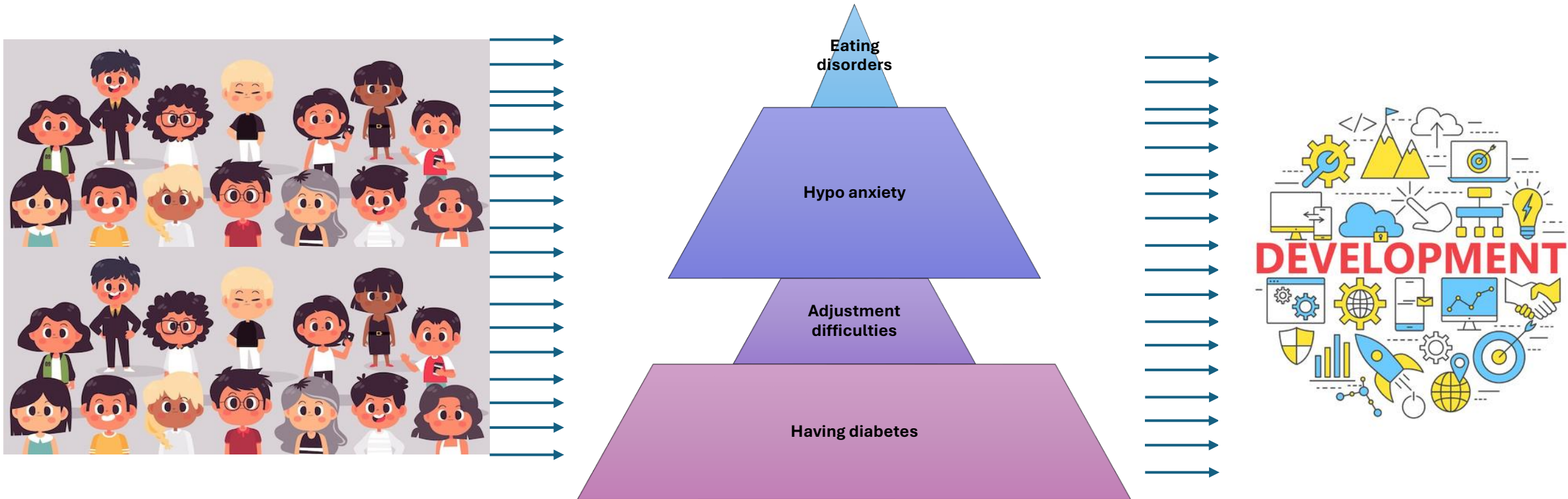


Shifting the aim of screening: actionable advice for **all** regardless of level of need

Gaining good quality information about psychosocial circumstances around diabetes, which any member of the MDT can support with i.e. Individual Level Data



Caseload Level Data



Understanding psychological needs across the caseload is a service user-led way to develop the service
Provides an opportunity to consider how to use psychology time **efficiently** and shift focus to **preventative or proactive work**



Our Tool

Holistic – diabetes, school, mental health, eating disorders, relationships, coping skills, conflicts, social circumstances, food security, quality of life, self-efficacy, burnout,

Whole Family Approach – for child and parent to complete and including wider systemic questions around family life

Detailed enough – to provide *actionable advice* for the team, rather than dichotomous decision making on psychological need (which NDPA requires!)





Children's Diabetes Team
Wellbeing Questionnaires for Children & Young People aged
12 – 18 years



As well as looking after your diabetes, we want to make sure that all areas of your life are as brilliant as they can be!

This booklet will ask you some questions about diabetes, friendships, school and how you feel. Your parent(s)/carer(s) have a booklet to fill in too. This asks them about family life and looking after diabetes.

We will give you a booklet like this once a year to fill out.
This is to make sure we are doing the best job we can at helping you and your diabetes.

Please answer every question and try to be honest!

When you have finished, the clinical psychologist in the diabetes team will look at your answers. They will tell the diabetes team about any difficulties you might have so we can help.

If everything is ok, you won't hear from the psychologist. If the psychologist needs to talk to you or your parent(s) or carer(s) a bit more about your answers, they will phone you.

If you have any questions about this booklet, please ask your diabetes nurse.

Name: _____

Age: _____

Today's Date: _____

Please circle the face which best fits with how you feel about....

| | | | | | |
|---|--|--|--|--|--|
| Eating and drinking things I enjoy | | | | | |
| Having diabetes | | | | | |
| My learning at school/college OR Work | | | | | |
| Getting along with the people I live with | | | | | |
| Doing <u>things</u> I enjoy & having fun | | | | | |
| Coming to the diabetes clinic | | | | | |
| Coping with my feelings | | | | | |
| Friendships/Relationships | | | | | |
| My weight and shape | | | | | |

If any of these things are not going well can you tell us a bit more about it?

Is there anything you would like the diabetes team to know about your life at the moment?
This could be things you are proud of, new hobbies you've started, things you are finding hard or any changes happening (e.g. house moves, sibling difficulties, losses).

Quality of Life Question: Taking into account your health and wellbeing, where you live, what you do and your relationships, how would you rate your quality of life? (please circle)

| | | | | |
|-----------|------|-----------------------------|------|-----------|
| 1 | 2 | 3 | 4 | 5 |
| Very Poor | Poor | Neither Poor <u>or</u> Good | Good | Very Good |

The next two questionnaires will ask you about your mood in recent weeks.

Mood Questionnaire - Over the last 2 weeks, how often have you been bothered by any of the following problems?

| To answer, please circle the appropriate number | Not at all | Several days | More than half the days | Nearly every day |
|--|------------|--------------|-------------------------|------------------|
| Little interest or pleasure in doing things | 0 | 1 | 2 | 3 |
| Feeling down, depressed, or hopeless | 0 | 1 | 2 | 3 |
| Trouble falling or staying asleep, or sleeping too much | 0 | 1 | 2 | 3 |
| Feeling tired or having little energy | 0 | 1 | 2 | 3 |
| Poor appetite or overeating | 0 | 1 | 2 | 3 |
| Feeling bad about yourself — or that you are a failure or have let yourself or your family down | 0 | 1 | 2 | 3 |
| Trouble concentrating on things, such as reading the newspaper or watching television | 0 | 1 | 2 | 3 |
| Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual | 0 | 1 | 2 | 3 |
| Thoughts that you would be better off dead or of hurting yourself in some way | 0 | 1 | 2 | 3 |

Worry Questionnaire - Over the last 2 weeks, how often have you been bothered by any of the following problems?

| | Not at all | Several days | More than half the days | Nearly every day |
|--|------------|--------------|-------------------------|------------------|
| Feeling nervous, anxious or on edge | 0 | 1 | 2 | 3 |
| Not being able to stop or control worrying | 0 | 1 | 2 | 3 |

How often do you worry about having hypos? (please circle)

| | | | | |
|-------|--------------------------------|-----------------------------------|-------------------|-------------------|
| Never | Rarely (Once every few months) | Sometimes (Several times a month) | Often (Most Days) | Always (Everyday) |
|-------|--------------------------------|-----------------------------------|-------------------|-------------------|

How do you manage these fears about hypoglycaemia?

- ☐ Take less insulin than I need
- ☐ Don't implement changes from clinic
- ☐ Snack frequently
- ☐ None of these – although I worry it doesn't affect my diabetes management
- ☐ Avoiding exercise or social activities
- ☐ Other: _____
- ☐ Avoid being alone
- ☐ Check blood glucose frequently

Diabetes Questions

Please tick the extent to which you agree with each of these statements:

| | Strongly disagree | Disagree | Neutral | Agree | Strongly agree |
|---|-------------------|----------|---------|-------|----------------|
| I feel confident in my knowledge about diabetes | | | | | |
| I am able to do the things which will improve my diabetes control | | | | | |
| In most situations I know what to do to manage my diabetes | | | | | |
| We are organised and have routines around diabetes | | | | | |
| There are a lot of arguments at home about diabetes | | | | | |
| Our family communicate well about diabetes | | | | | |
| I feel overwhelmed or burnt out by my diabetes | | | | | |
| I feel sad, <u>frustrated</u> or discouraged by out of target results | | | | | |
| I feel I must be perfect with <u>diabetes</u> | | | | | |
| I find it hard to be honest with people about my diabetes | | | | | |
| I struggle to control my eating (e.g. eating too much or restricting food) | | | | | |
| I am happy with the diabetes technology I have and feel confident using it | | | | | |
| I lack motivation to look after my diabetes | | | | | |
| There are things happening in my life which really affect my ability to look after diabetes | | | | | |
| Losing weight is important to <u>me</u> | | | | | |
| I feel comfortable managing my diabetes at school/college/work | | | | | |

Do you worry so much about needles, injections and blood tests that it gets in the way of your wellbeing and diabetes care?
YES NO

Is there anything else you would like to say about your diabetes?

Thank you!

3 Versions:

- 7 – 11 year olds
- 12 – 18 year olds
- Parents



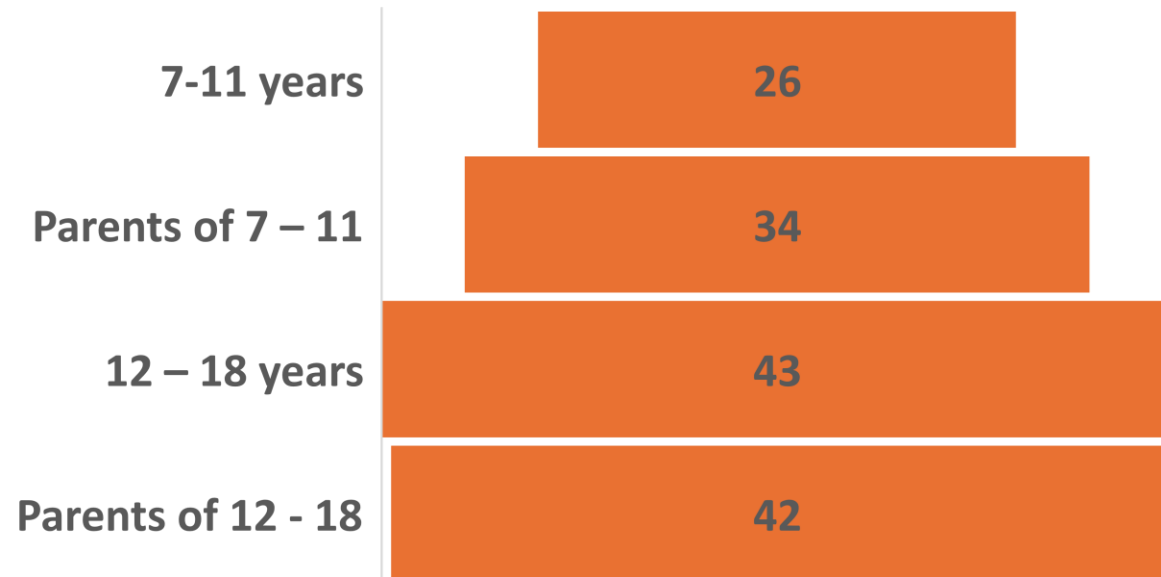
DCH Psychology Screening Results 23/24

Active caseload of 87 patients

80% completed screening

Remaining 20% - clinical discussion (DNA) or newly diagnosed or under 7

145 questionnaires collected!





Individual level data

Process:

- Questionnaires completed during annual screening appointment with nursing
- Scored by psychology
- Traffic light system to help team understand strengths & struggles

ANNUAL REVIEW OF PSYCHOLOGICAL WELLBEING (12-18 years)

Child's Name: [REDACTED]
Parent/Carer name: [REDACTED]
Date: 07/08/23

Child's age: 10
Additional Needs: ASD
Services involved: None

| | Child View | Parent View | Comments |
|---|------------|-------------|--|
| Eating and drinking things I enjoy | 4 | | |
| Having diabetes | 3 | | |
| Coming to the diabetes clinic | 2 | 4 | |
| My weight and shape | 3 | | |
| Self-efficacy in relation to diabetes** | 7 | | |
| Family organisation/routines with diabetes | 3 | 4 | Not confident in her knowledge about diabetes or knowing what to do to manage her diabetes in most situations |
| Arguments at home about Diabetes | 2 | 3 | |
| Family communication around diabetes | 3 | 3 | |
| Burnout/Motivation*** | 2 | | |
| Feeling sad, discouraged, frustrated by out of target results | 2 | | |
| Feel I must be perfect with diabetes | 4 | | |
| Honestly with diabetes | 2 | | |
| Technology & confidence using it | 3 | | |
| Things are happening in my life which affect diabetes | 2 | | |
| Confidence managing diabetes at school/college/work | 4 | | |
| Fear of hypoglycaemia | 1 | | Take less insulin than I need, snack frequently, check BG frequently, don't implement changes from clinic (CHLD) |
| Medical anxiety - Needles, injections, blood tests | No | Yes | |
| Food security | 4 | 4 | |
| My learning at school/college or experience at work | 4 | 4 | |
| Getting along with the people I live with | 4 | | |
| Doing things I enjoy & having fun | 5 | | |
| Coping with my feelings | 4 | 4 | |
| Child/YP Friendships/Relationships | 4 | 4 | |
| My child's wellbeing | | 2 | |
| My ability to manage my child's behaviour | | 4 | |
| Good relationship with my child | | 4 | |
| Concerns about child's development | | 3 | |

KEY:

- Diabetes Related Questions
- No concerns/going well
- Neutral/Neither good nor bad
- Concerns/Not going well
- Not applicable

| Child/YP Wellbeing | Score | Comments |
|---------------------------------------|-------|--|
| Depression Screen | 9 | |
| Anxiety Screen | 2 | |
| Eating Disorder Screen* | 8 | Struggling to control her eating, neutral feelings about weight, shape & losing weight |
| Quality of Life Score (5 = excellent) | 4 | |

| Parental Wellbeing | Score | Comments |
|---------------------------------------|-------|---|
| Depression Screen | 0 | |
| Anxiety Screen | 0 | |
| Perceived Diabetes Distress | 14 | Sometimes upset by child's diabetes or felt unable to manage/cope |
| Quality of Life Score (5 = excellent) | 4 | |

| | |
|--|---|
| Things the family want the team to know: | Dad: Teenage years and pressures for [REDACTED] mean short term impact on diabetes control |
|--|---|

Summary/Suggestions for team:
Discuss with [REDACTED] how clinic experience can be improved
Assess fear of hypos and impact on her - may need some supervised work to address her fear or referral to psychology.
Come back to psychology to discuss
Burnout and motivation need open discussion - MI approach may help
Struggling to control eating - is this related to her fear of hypos? Explore with her

| Action for Psychology | Team to bring back to psychology if needed |
|-----------------------|--|
| Call notes: | |
| Outcome of call | N/A |

KEY

- Low Risk/Low stress
- At Risk/Medium stress
- High Risk/High stress

Outcomes:

- Feedback emailed to named nurses including:
 - ✓ personalised recommendations based on scores for low level difficulties
 - ✓ areas for team to monitor or follow up on
 - ✓ recommendations for clinic
- Individuals with higher needs had psychology triage calls and/or offered psychology assessment
- Summaries attached to clinic handovers so results informed future routine clinic appointments
- Summaries used in high HbA1c meetings & Psychology Consultation to inform formulations & team thinking



Caseload level data

All data entered into Excel and analysed

Areas going well.....

74%
(12-
18)



100%
(7-11)

82 –
100%



82 –
85%



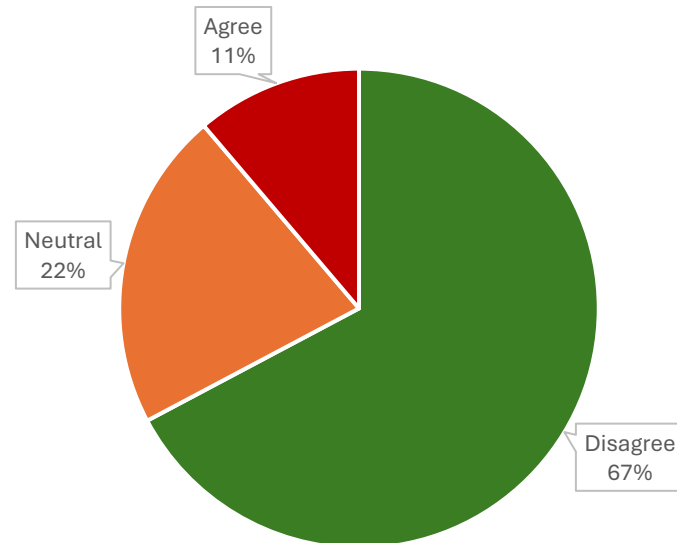


Areas Going Well (cont.)



Diabetes Conflict – only 11%

There are a lot of arguments at home about diabetes

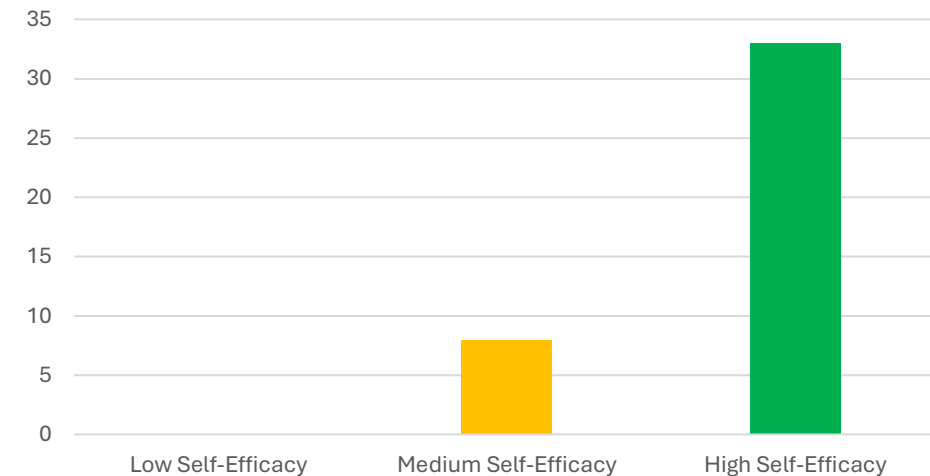


I feel confident in my knowledge about diabetes

I am able to do the things which will improve my diabetes control

In most situations I know what to do to manage my diabetes

Self-Efficacy of 12 - 18 year olds





Key Struggles for Our Families at DCH

1. Having Diabetes
2. Other factors in life affecting diabetes
3. Burnout
4. Body Image & weight
5. Fear of hypoglycaemia
6. Coping with emotions



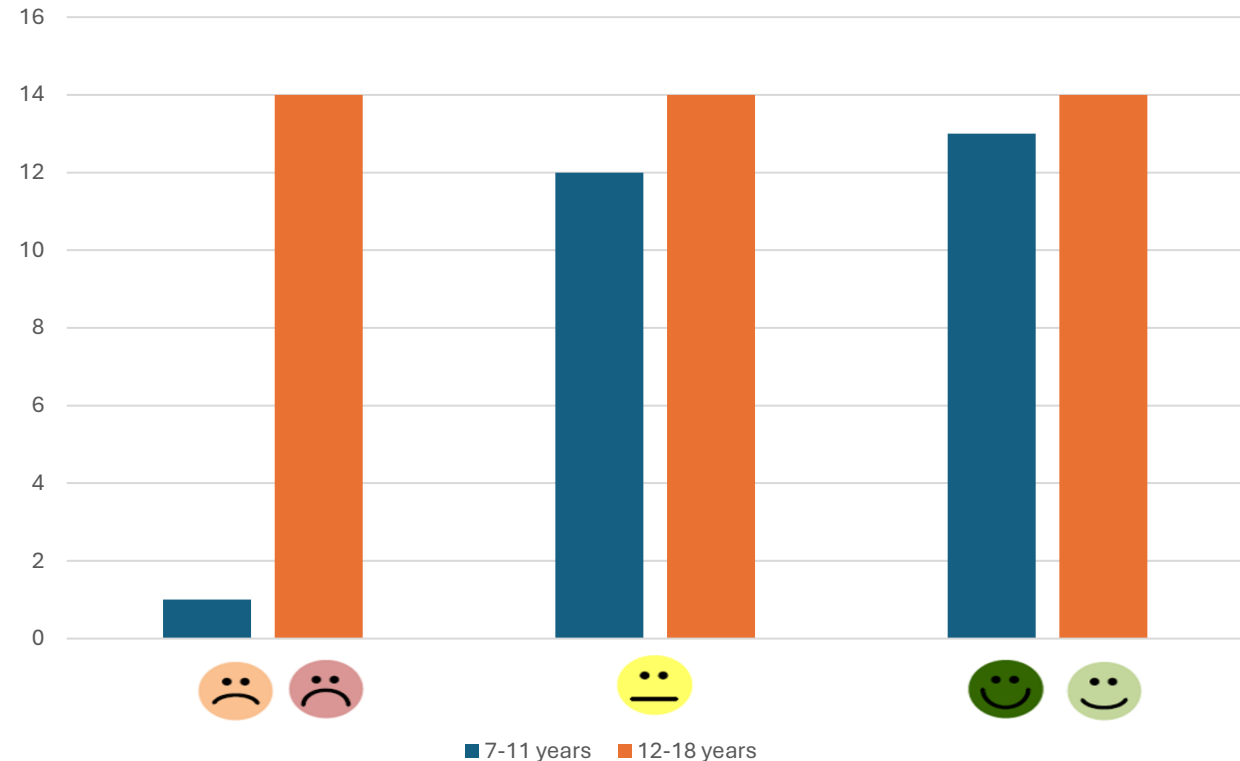


1. Having Diabetes

Psychology Action Point

Team Reflection & MDT Training on:

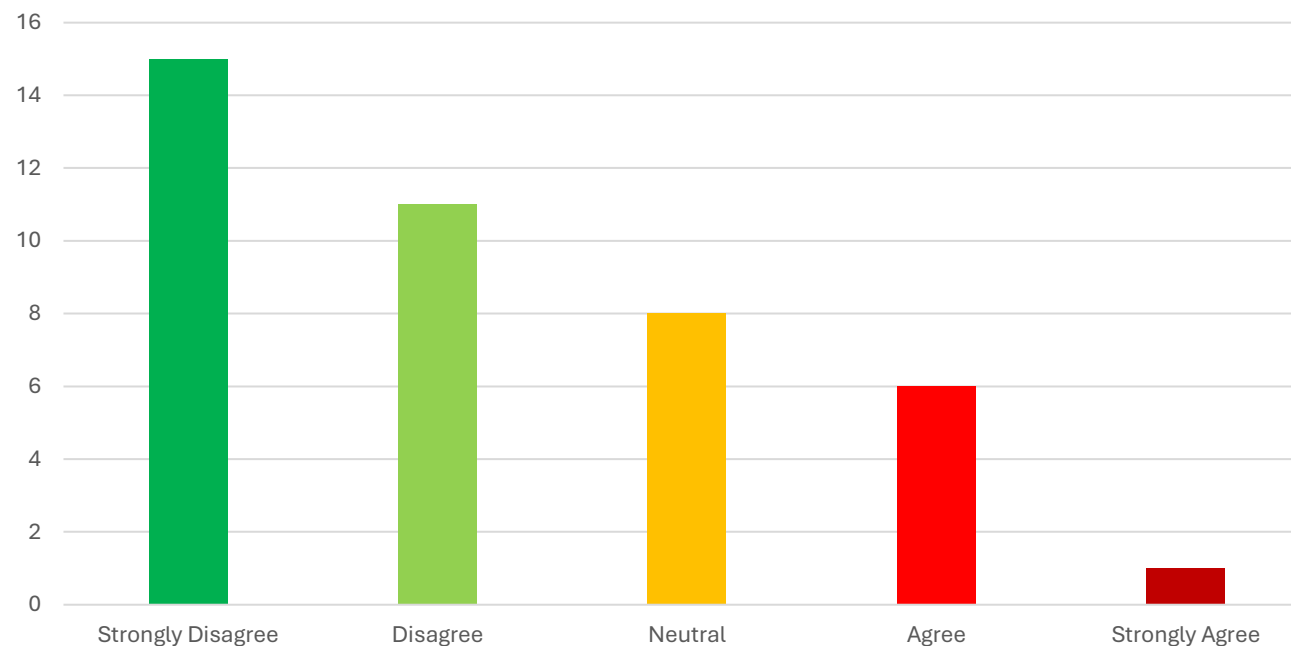
- How to spot and name emotions in clinic
- How to validate emotions
- How to normalise
- Importance of compassion
- Neurodevelopment and why teens might be more upset about diabetes





2. External Factors

There are things happening in my life which really affect my ability to look after diabetes (12-18)



Whilst two thirds of young people feel external factors are not impacting their diabetes, a third aren't sure or feel they are!

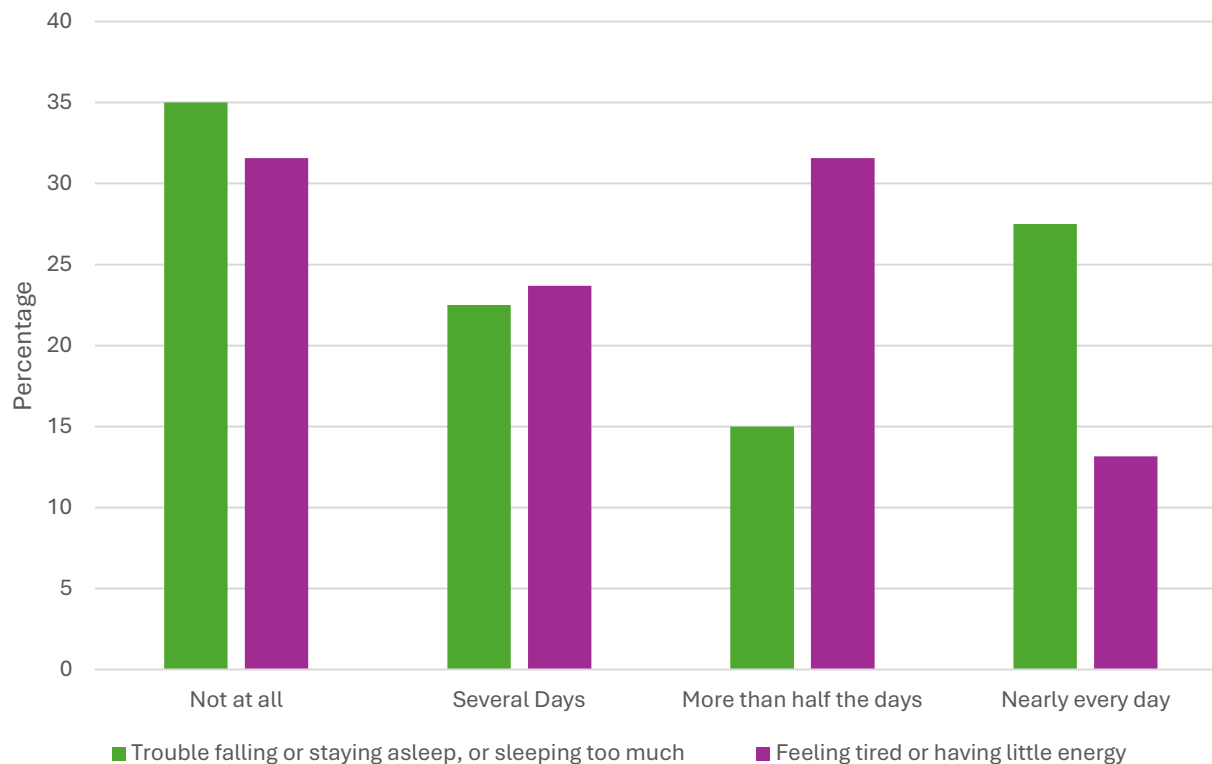
Psychology Action Point

Team reflection on the importance of asking about this routinely in clinic



2. External Factors - Sleep

Sleep & Energy in 12 - 18 year olds



42.5% have difficulties sleeping more than half the days (compared with 20-30% in general population)

45% feel tired or have little energy more than half of days

Psychology Action Point

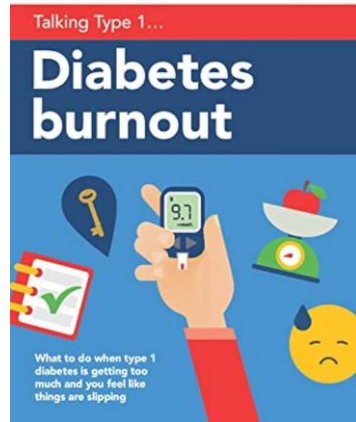
Reflection with the team

How much does diabetes account for sleep difficulties (e.g. alarms, sensor position) & lack of energy (e.g. high BG)?

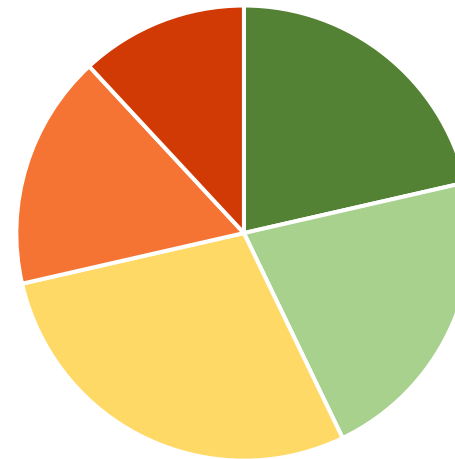
How much does poor sleep & a lack of energy impact on a young person's ability to self-care?
Are we routinely asking about sleep quality and giving advice?



3. Burnout



I feel sad, frustrated or discouraged by out of target results



Strongly Disagree Disagree
Neutral Agree
Strongly Agree

Psychology Action Points

Review resources we're using for burnout & develop further as needed

Consider running group or workshop on burnout

Team training given on validating and normalising emotions

% Agree of Strongly Agree (n = 42)

I feel overwhelmed or burnt out by my diabetes 40%

I lack motivation to look after my diabetes 17%



4. Body Image

**1 in 4 young people are unhappy with their weight and shape
(26%)**

**Over a third of young people feel that they struggle to control their
eating (36%)**

**Over a third of young people agree that losing weight is important
to them (37%)**



Whilst this is largely comparable with YP without diabetes, we know our group are more at risk.

Psychology Action Points

Adding more formal ED screen to next year's screening (mSCOFF)

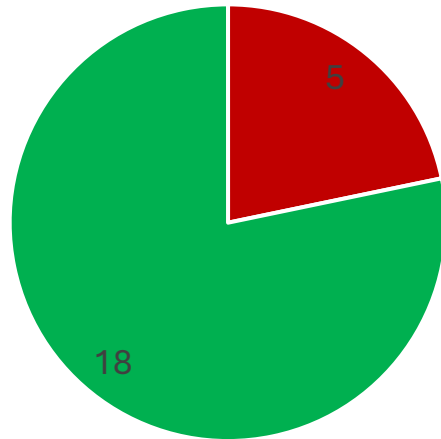
Team reflection on language, weighing and how we discuss weight with young people. Building confidence in curious, compassionate conversations around body image and impact on diabetes

Developed handout around body image including signposting



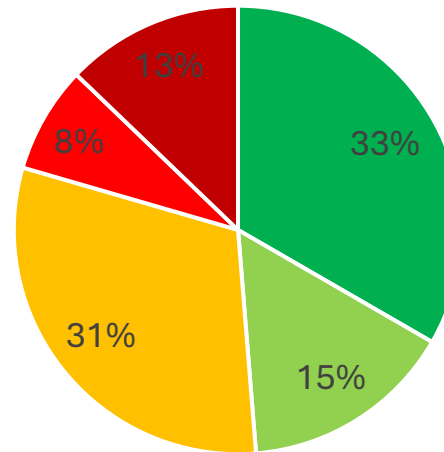
5. Fear of Hypoglycaemia

FoH in 7 - 11 year olds



■ Yes ■ No

FoH in 12 - 18 year olds



■ Never ■ Rarely ■ Sometimes ■ Often ■ Always

Psychology Action Points

Initial conversations with the team on digging deeper into FoH including asking about impact on functioning

Psychology reflection on what psychoeducational resources can be developed for MDT to use with YP

Planned training session on anxiety management for MDT

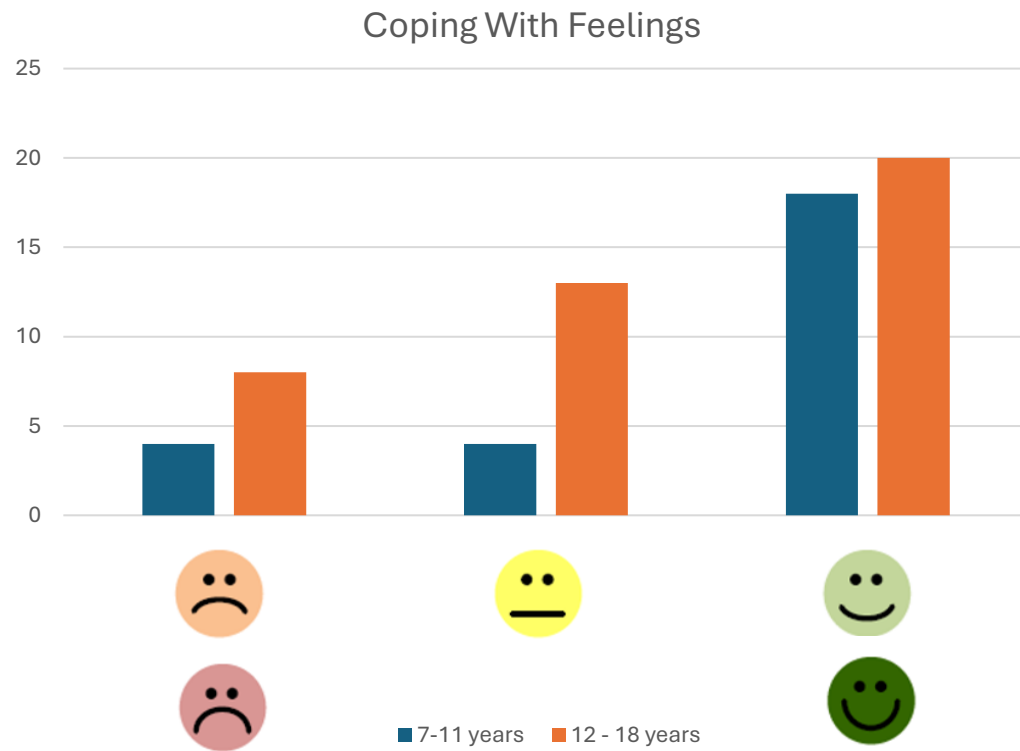
20% of CYP asked stated they were worried about hypoglycaemia most days or everyday (n=13)

21% of parents of 7-11 year olds & 16% of parents of 12-18 year olds worry about hypos (n = 13)

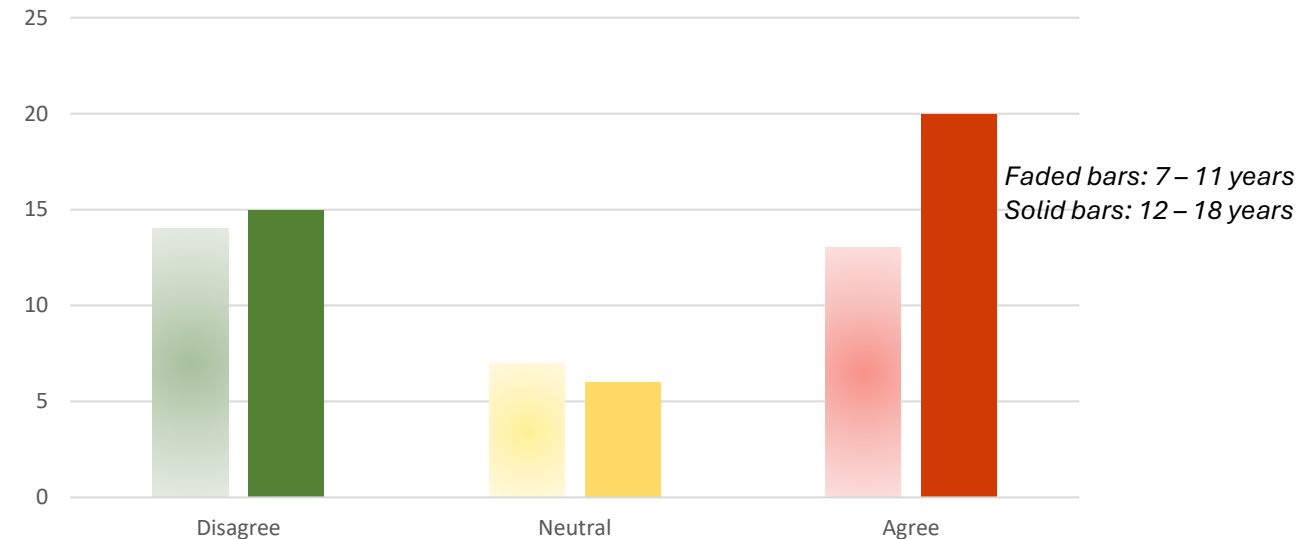


6. Coping with Feelings

20% teenagers don't feel they cope with emotions,
with a further 30% feeling 'ok' about their coping



"I am worried about my child's wellbeing"



Struggles are not unnoticed! 44% of parents worry about
their children's wellbeing

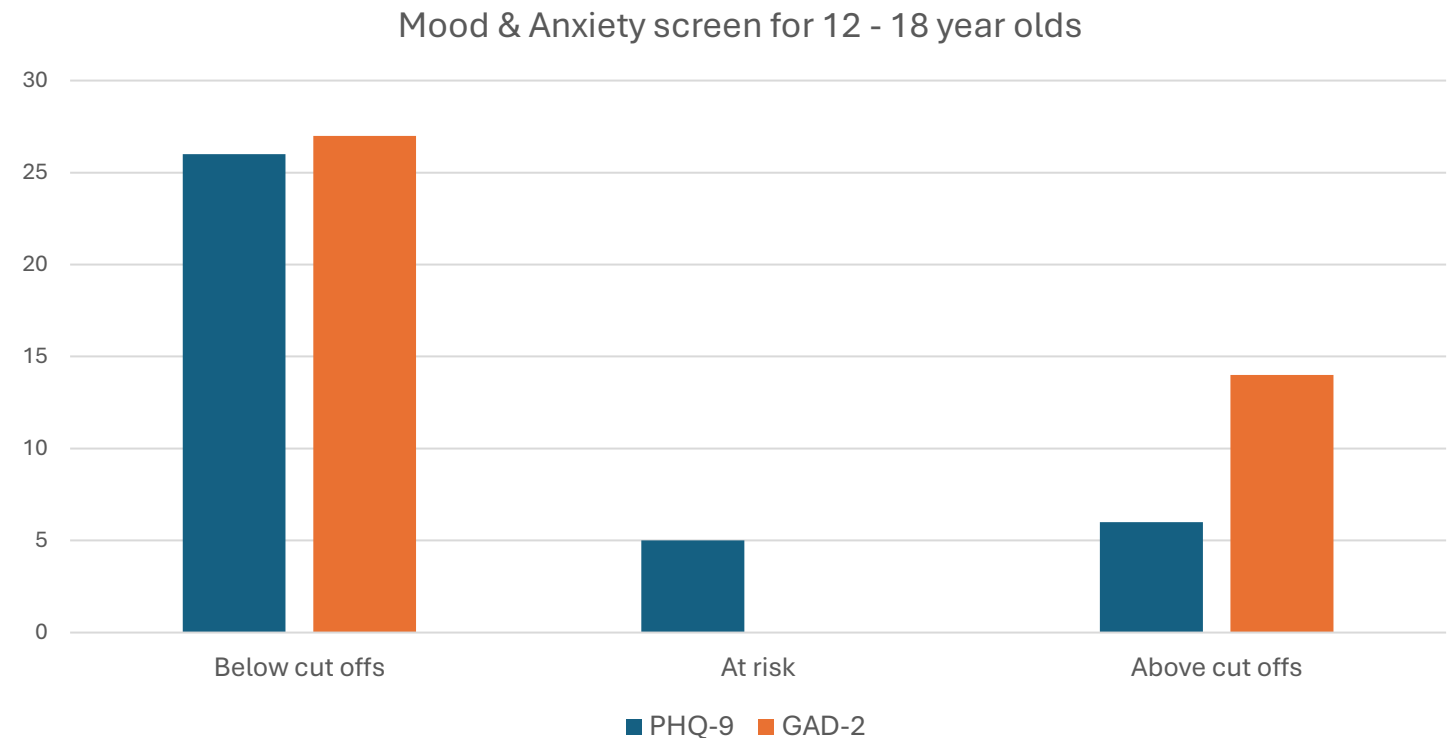


6. Coping with Feelings

However, self-reported emotional struggles tend to be sub-clinical

Just 15% of young children and 16% of teenagers scored above cut offs for depression

Possible anxiety disorders were slightly higher, at 19% in young children & 34% in teens





6. Coping with Feelings

Whilst significant mood and anxiety disorders are relatively low...

Coping with feelings is an area of difficulty and...

A lot of parents are worried about their child's wellbeing



Psychology Action Points

Further reinforces the idea that everyone has a role to play in supporting emotional health

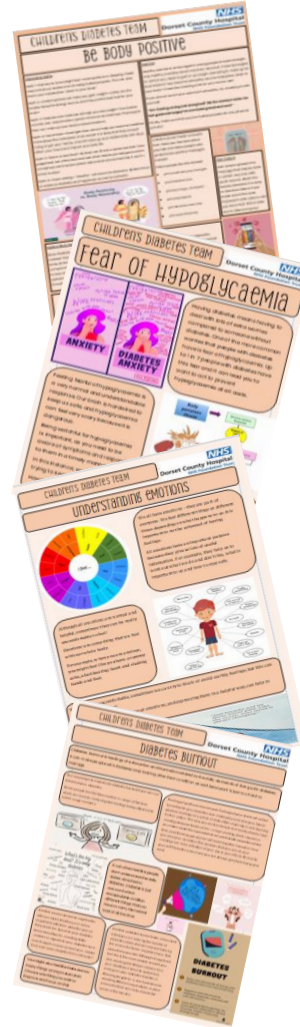
Raises the question: How can psychology support teams to have curious, compassionate conversations about feelings in clinic?

Psychology to consider workshop for parents on supporting teens with emotional wellbeing



Plans for 2024/2025...

- Further analysis of 23/24 data –relationship between psychological outcomes, hbA1c, technology use & deprivation quintiles
- Working through psychology actions:
 - Training for the MDT
 - Improve resources & signposting
 - Develop workshops (trainee task!)
- QI project for annual screening – trialling joint psychology & nursing review
- Modified questions, reduced length, shared feedback to families and the team (strengths, struggles, plan)





Reflections & Summary

- This isn't the 'only' or 'right' way to do screening
- All teams are different + psychology resource and capacity varies significantly
- Developing our process has been time-intensive but data rich
- Fine balance between using 'too much' psychology resource on screening or 'not enough'
- Benefits to making screening 'detailed enough' to make conversations more meaningful. If screening is too 'light' things get missed and it's harder to identify lower level needs





Reflections & Summary

- Value in analysing data at a caseload level:
 - What data are you sitting on?
 - Who can help you analyse it?
 - How can you use this?
- Results here are specific to our caseload & may not represent your local population's needs
- Consider with your teams how your current screening in serving you and your families
- Is there scope to make screening more actionable in terms of supporting patients as well as how we develop services?





INTEGRITY | RESPECT | TEAMWORK | EXCELLENCE



Dorset County Hospital
NHS Foundation Trust

thank
you

Any Questions?

Outstanding care for people in ways which matter to them