

## Parliamentary Inquiry into Diabetes – September 2023

### *Requested Information regarding the Young Adult Diabetes Services (YADS) at Liverpool Hospital*

#### BACKGROUND

The Liverpool Hospital Young Adult Diabetes Service (YADS) was established in November 2020. This clinic was established as part of the South-West Sydney Diabetes strategic framework. The YADS clinic provides clinical services to transition patients aged 15-20 years old living with diabetes (type 1, type 2 or MODY) from the paediatric services to adult services. The transition clinic provides a bridge for adolescents to take upon more autonomy and responsibility in managing their chronic condition.

The YADS clinic provides clinical services to patients living in the Liverpool and Fairfield local government areas (LGAs). Most diabetes transition clinics, captures patients in the age group from 16-25 years old. However, the YADS clinic restricts the age group to 15-20 years old due ***challenges in meeting patient demands with the clinical resources available***. The YADS clinic currently has 72 active patients and referrals are accepted from Westmead Children's Hospital, Randwick Children's Hospital, Campbelltown paediatric diabetes clinic, new patients diagnosed through the emergency department and general practitioners in primary care.

The Liverpool Hospital YADS service has current funding for a clinic once a week (Thursday):

- 0.2FTE staff specialist endocrinologist
- 0.3FTE diabetes clinical nurse specialist
- 0.2FTE dietician
- 0.2FTE social worker (our current social worker role is current unfilled at the time of writing)

There is no permanent administrative officer funding for the YADS clinic.

In comparison to another transition clinic in a Western Sydney hospital, which was established in 2001. They provide care for 300 diabetes transition patients and 100 cystic fibrosis patients. They cater for patients aged 15-25 years old with type 1 and type 2 diabetes mellitus. They run two clinics a week and have funding for:

- 0.2FTE staff specialist endocrinologist and 0.2 FTE visiting medical practitioner
- 3 endocrinology advanced trainees for one of the clinics
- 0.8FTE diabetes clinical nurse consultant
- 0.6FTE diabetes clinical nurse specialist
- 0.1FTE dietician

Ideally, the YADS clinic at Liverpool should be accepting patients aged 15-25 years old (rather than 15-20 years old), before moving to the adult type 1 diabetes clinic, as the majority of adolescents benefit from the extra support that the transition clinic can offer them. More resources for the YADS clinic, will also hopefully reduce the risk of patients being lost to follow up during a critical stage of maturation and life development. Engaging more patients with long term management of their diabetes mellitus, will hopefully reduce complication risk and hence, disease burden later in life.

## CLINIC IMPACTS AND OUTCOMES

In addition to running outpatient clinics, the YADS clinic also provides proactive support and education to patients. The clinic has managed four patients with mild diabetic ketoacidosis as outpatients, preventing the need for an emergency department presentation or inpatient admission between October 2022 to May 2023.

The establishment of the YADS clinic has particularly helped manage the patient load at Westmead Kid's Hospital and the Campbelltown adolescent/transition diabetes clinic. It has also reduced travelling times for families from the Liverpool and Fairfield LGA as clinics are made more readily available to them closer to home.

Since 20<sup>th</sup> April 2023, YADS has commenced asking patients to complete the Diabetes Distress Screening Scale (DDSS) survey as part of the screening tool to assess mental health status. The DDSS is a 17-question patient self-assessment of their perception of their diabetes, based on four domains during the past month:

- 1) Emotional burden
- 2) Physician-related distress
- 3) Regimen-related distress
- 4) Interpersonal distress

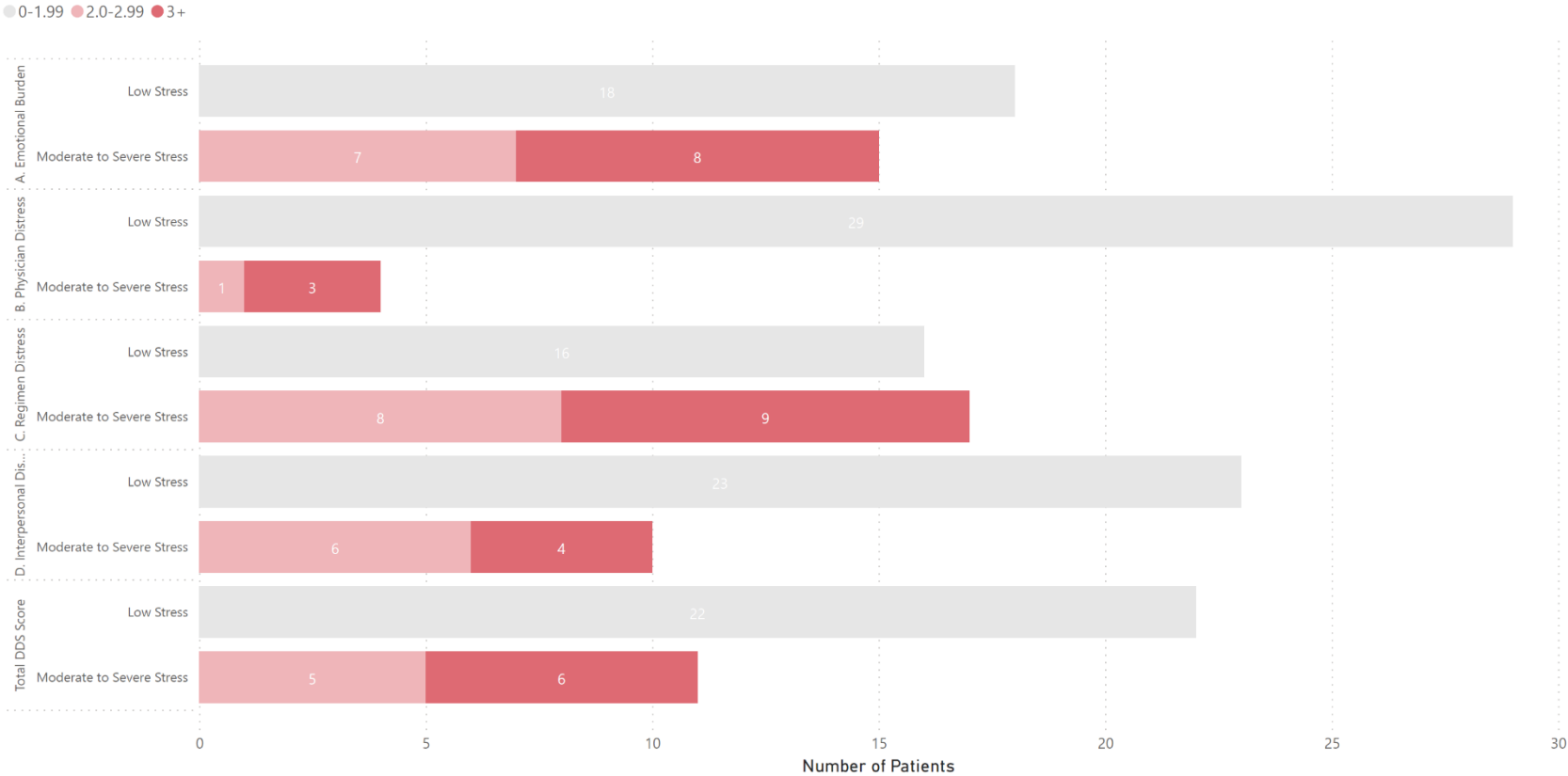
For each question, patients are asked to rate themselves from 1 to 6 – where 1 indicates “not a problem” to 6 which indicates “a very serious problem” (*please see Appendix 1*). Current research suggests that a mean item score 2.0-2.9 should be considered “moderate distress” and a mean item score  $\geq 3.0$  should be considered “high distress”. Current research also indicates that associations between DDS scores and behavioural management and biological variables (e.g. HbA1c) occur with DDS scores of  $\geq 2.0$

During the implementation of the DDSS in the YADS clinic, there was interruptions to the staffing, which meant that there is incomplete data collection during the three active months. A total of 33 data collections was gathering during this period, with data still being actively collated. The available data till September 2023 demonstrates a high level of moderate to severe distress in the clinic in the “emotional burden” and “regimen distress” domains in screened YADS population (*please see Figure 1*). Ongoing data collection may indicate the need for clinical psychology services within the YADS clinic to help young adults manage the psychological challenges of living with a chronic condition.

Figure 1: YADS Clinic Data for Diabetes Distress Screening Scale (April – Sept 2023)

Domain	Count of Value	Sum of Value	Min of Value	Max of Value	Average of Value	Median of Value
A. Emotional Burden	33	72.20	1.00	5.00	2.19	1.80
B. Physician Distress	33	46.25	1.00	5.25	1.40	1.00
C. Regimen Distress	33	72.60	1.00	4.40	2.20	2.00
D. Interpersonal Distress	33	55.31	1.00	5.00	1.68	1.33
Total DDS Score	33	63.22	1.06	3.71	1.92	1.53
<b>Total</b>	<b>165</b>	<b>309.58</b>	<b>1.00</b>	<b>5.25</b>	<b>1.88</b>	<b>1.40</b>

Diabetes Distress Screening Scale



## THE DIABETES DISTRESS SCREENING SCALE

**DIRECTIONS:** Living with diabetes can sometimes be tough. There may be many problems and hassles concerning diabetes and they can vary greatly in severity. Problems may range from minor hassles to major life difficulties. Listed below are 2 potential problem areas that people with diabetes may experience. Consider the degree to which each of the 2 items may have distressed or bothered you DURING THE PAST MONTH and circle the appropriate number.

Please note that we are asking you to indicate the degree to which each item may be bothering you in your life, NOT whether the item is merely true for you. If you feel that a particular item is not a bother or a problem for you, you would circle "1". If it is very bothersome to you, you might circle "6".

	Not a Problem	A Slight Problem	A Moderate Problem	Somewhat Serious Problem	A Serious Problem	A Very Serious Problem
1. Feeling overwhelmed by the demands of living with diabetes.	1	2	3	4	5	6
2. Feeling that I am often failing with my diabetes routine.	1	2	3	4	5	6

## DDS

**DIRECTIONS:** Living with diabetes can sometimes be tough. There may be many problems and hassles concerning diabetes and they can vary greatly in severity. Problems may range from minor hassles to major life difficulties. Listed below are 17 potential problem areas that people with diabetes may experience. Consider the degree to which each of the 17 items may have distressed or bothered you DURING THE PAST MONTH and circle the appropriate number.

Please note that we are asking you to indicate the degree to which each item may be bothering you in your life, NOT whether the item is merely true for you. If you feel that a particular item is not a bother or a problem for you, you would circle "1". If it is very bothersome to you, you might circle "6".

	Not a Problem	A Slight Problem	A Moderate Problem	Somewhat Serious Problem	A Serious Problem	A Very Serious Problem
1. Feeling that diabetes is taking up too much of my mental and physical energy every day.	1	2	3	4	5	6
2. Feeling that my doctor doesn't know enough about diabetes and diabetes care.	1	2	3	4	5	6
3. Feeling angry, scared, and/or depressed when I think about living with diabetes.	1	2	3	4	5	6
4. Feeling that my doctor doesn't give me clear enough directions on how to manage my diabetes.	1	2	3	4	5	6
5. Feeling that I am not testing my blood sugars frequently enough.	1	2	3	4	5	6
6. Feeling that I am often failing with my diabetes routine.	1	2	3	4	5	6
7. Feeling that friends or family are not supportive enough of self-care efforts (e.g. planning activities that conflict with my schedule, encouraging me to eat the "wrong" foods).	1	2	3	4	5	6
8. Feeling that diabetes controls my life.	1	2	3	4	5	6

	<b>Not a Problem</b>	<b>A Slight Problem</b>	<b>A Moderate Problem</b>	<b>Somewhat Serious Problem</b>	<b>A Serious Problem</b>	<b>A Very Serious Problem</b>
9. Feeling that my doctor doesn't take my concerns seriously enough.	1	2	3	4	5	6
10. Not feeling confident in my day-to-day ability to manage diabetes.	1	2	3	4	5	6
11. Feeling that I will end up with serious long-term complications, no matter what I do.	1	2	3	4	5	6
12. Feeling that I am not sticking closely enough to a good meal plan.	1	2	3	4	5	6
13. Feeling that friends or family don't appreciate how difficult living with diabetes can be.	1	2	3	4	5	6
14. Feeling overwhelmed by the demands of living with diabetes.	1	2	3	4	5	6
15. Feeling that I don't have a doctor who I can see regularly enough about my diabetes.	1	2	3	4	5	6
16. Not feeling motivated to keep up my diabetes self management.	1	2	3	4	5	6
17. Feeling that friends or family don't give me the emotional support that I would like.	1	2	3	4	5	6



## DDS17 SCORING SHEET

### INSTRUCTIONS FOR SCORING:

The DDS17 yields a total diabetes distress scale score plus 4 sub scale scores, each addressing a different kind of distress. To score, simply sum the patient's responses to the appropriate items and divide by the number of items in that scale. The letter in the far right margin corresponds to that item's subscale as listed below. **We consider a mean item score of 3 or higher (moderate distress) as a level of distress worthy of clinical attention.** Place a check on the line to the far right if the mean item score is  $\geq 3$  to highlight an above-range value.

We also suggest reviewing the patient's responses across all items, regardless of mean item scores. It may be helpful to inquire further or to begin a conversation about any single item scored 3 or higher.

#### Total DDS Score:

- |                           |              |                |
|---------------------------|--------------|----------------|
| a. Sum of 17 item scores. | _____        |                |
| b. Divide by:             | _____17_____ |                |
| c. Mean item score:       | _____        | $\geq 3$ _____ |

#### A. Emotional Burden:

- |                                     |             |                |
|-------------------------------------|-------------|----------------|
| a. Sum of 5 items (1, 3, 8, 11, 14) | _____       |                |
| b. Divide by:                       | _____5_____ |                |
| c. Mean item score:                 | _____       | $\geq 3$ _____ |

#### B. Physician-related Distress:

- |                                 |             |                |
|---------------------------------|-------------|----------------|
| a. Sum of 4 items (2, 4, 9, 15) | _____       |                |
| b. Divide by:                   | _____4_____ |                |
| c. Mean item score:             | _____       | $\geq 3$ _____ |

#### C. Regimen-related Distress:

- |                                      |             |                |
|--------------------------------------|-------------|----------------|
| a. Sum of 5 items (5, 6, 10, 12, 16) | _____       |                |
| b. Divide by:                        | _____5_____ |                |
| c. Mean item score:                  | _____       | $\geq 3$ _____ |

#### D. Interpersonal Distress:

- |                               |             |                |
|-------------------------------|-------------|----------------|
| a. Sum of 3 items (7, 13, 17) | _____       |                |
| b. Divide by:                 | _____3_____ |                |
| c. Mean item score:           | _____       | $\geq 3$ _____ |