Supplementary Material

Preferences of parents for mental health services to suit children with chronic medical conditions

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Appendix A.

Survey text:

Introduction

Thank you for agreeing to take part in this survey.

You are free to withdraw at any time until you submit the survey at the end. We do not collect information that identifies you, so once you submit the survey we cannot withdraw your information.

First, we will give you some background information to help you complete the survey. After that you will be asked to make a series of choices between services. Then we will ask some questions about you and your child to help us understand your choices.

Background information

Children's emotions and behaviour

All children have times when they feel and act upset, sad, worried, or angry. However, sometimes they could do with some extra help with how they are feeling, thinking, or behaving. Signs that they may need extra support include:

- The worry, anger or sadness go on for more than 3 weeks
- It stops them doing things they usually enjoy, such as sport, being with friends, singing, gaming etc.
- Having more difficulties than other children of a similar age
- Less interest in school or social activities
- Worries or fears out of proportion to what is going on in their lives
- Sadness or feelings of hopelessness that don't go away
- Difficulty with paying attention or organising themselves e.g. to get homework done on time
- Avoiding others and wanting to be alone most of the time
- Aggressive, angry, or impulsive behaviour
- Persistent troubles with sleep

These sorts of difficulties can be more common in children who have long-term physical health problems. Dealing with the challenges of physical health problems can be stressful for children and their families. It can have an impact on many aspects of daily life. Difficulties with emotions and behaviour can also make it more difficult to manage the child's physical health.

There are many people who can help a child including parents, friends and health professionals. This type of care can include talk therapy, psychology, or counselling. It will usually involve weekly or fortnightly visits. Families will often be referred to a mental health service by their GP. Some services are subsidised by Medicare, the NDIS, or private health insurance.

Getting help if you are concerned about your child

If you are concerned about your child's emotions or behaviour, please seek help. Your child's GP is often a good place to start. You may also wish to discuss these issues with your child's paediatrician or other staff who look after your child at The (ANONYMISED HOSPITAL). The following may also provide useful information or suggest ways to get help:

- Parentline <u>https://parentline.com.au/</u> or phone 1300 30 1300
- Raising Children Network <u>https://raisingchildren.net.au/</u>
- Maternal and child health line phone 13 22 29 or http://www.education.vic.gov.au/childhood/parents/support/Pages/mchline.aspx
- Beyondblue Healthy Families <u>https://healthyfamilies.beyondblue.org.au/</u>
- Headspace <u>https://headspace.org.au/friends-and-family/mental-health/</u>
- Kids helpline <u>https://kidshelpline.com.au/parents/issues/helping-kids-identify-and-express-feelings</u>

In a crisis:

- Emergency services phone 000
- CAMHS (Child and Adolescent Mental Health Services) <u>https://www2.health.vic.gov.au/mental-health/mental-health-services/area-based-services/services-for-children-and-adolescents</u>
- Lifeline phone 13 11 14 or <u>https://www.lifeline.org.au/</u>
- Kids helpline phone 1800 55 1800 or https://kidshelpline.com.au/

About this survey

For this next section of the survey, please imagine that you want help for your child about their emotions or behaviour. You can imagine that he or she has some issues with emotions or behaviour as outlined above. Please imagine that you are at an outpatients clinic visit at the hospital. You have asked about where you could get help.

We will ask you to think about a number of scenarios such as the one below – each will describe two different mental health services that you might be offered.

| | Mental health service A | Mental health service B | No mental health service |
|----------------------|----------------------------|----------------------------|-----------------------------|
| Recommended by | No specific | By your child's GP | |
| someone you know | recommendation | | |
| Approximate travel | 10 minutes | 90 minutes | |
| time from your | | | |
| home | | | |
| Available hours | Business hours plus | Business hours | |
| | evenings and | | |
| | weekends | | |
| Cost to you out of | \$200 | No cost | |
| pocket per visit | | | |
| Knowledge about | Knows about impact | No specific | |
| impact of chronic | | knowledge | |
| health problems on | | | |
| children | | | |
| First available | 6 months | Within one week | |
| appointment | | | |
| Which of these three | Mental health service | Mental health service | No mental health |
| would you choose? | А | В | service |
| | | | |
| | | | |

Each scenario offers you three options. The first two options will describe mental health services for your child. The third option will be not to see any service regarding your concerns.

Each service will involve seeing someone with expertise in children's mental health and behaviour. You would see the same person at each visit.

The options will be described by six factors about the person or service your child would see. The factors are described below. You will be able to refer back to this list when completing the questions to remind yourself of what each factor means. To see the list, click on the links provided in the upcoming scenarios. The services will always be described by these six factors but they will differ from one scenario to the next.

Recommended by someone you know

This means whether the service was recommended for your child by someone you know. This will be described as

- Recommended by another parent whose child has a chronic health problem
- Recommended by your child's GP
- Recommended by the (ANONYMISED HOSPITAL) clinic
- No specific recommendation

First available appointment

How long it would be until an appointment at the service is available for your child.

- Within a week
- 1 month
- 3 months
- 6 months

Knowledge about impact of chronic health problems on children

Whether the person at the mental health service knows about the impact of chronic physical health problems in children. This could come from experience and/or training. This would mean knowing about the impact on children's daily life, school, mental health, and social activities, and experiences such as going to hospital. This will be described as:

- Knows about impact
- No specific knowledge

Travel time from your home

This means how long it takes on average to travel from your home to the service, by your usual means of transport. This will be described as:

- 10 minutes
- 30 minutes
- 60 minutes
- 90 minutes

Cost to you out of pocket per visit

How much you will pay for each visit after Medicare rebates, private health insurance, or NDIS coverage. It will be described as:

- No cost
- \$15

- \$85
- \$200

Available hours

This means whether the service is open only during business hours or also open on evenings and weekends. Business hours means 8.30am-5.30pm on Mondays to Fridays. It will be described as:

- Business hours
- Business hours plus evenings and weekends

Please compare the options in each scenario. Then choose the option you most prefer from the three on offer and tick the box for that option. Then of the remaining two options, choose the service you most prefer and tick the box for that option.

There are no right or wrong answers; we are interested in your views.

Please assume that all other aspects of the services are the same across all scenarios.

The next page provides a practice question to help you get used to the process.

Practice scenario

Imagine that you are concerned about your child's mental health or behaviour. Imagine that they were showing some of the signs of mental health issues that were described to you earlier. Please imagine that you decided to seek help for this. You asked your GP or the hospital clinic for advice on who could help. In both services the person would be an expert in children's mental health and behaviour. You would see the same person at each visit. Please assume that any factors not described below are the same across each service. Choose the option you would choose if offered these in real life.

| | Mental health service A | Mental health service B | No mental health service |
|------------------|----------------------------|----------------------------|-----------------------------|
| Recommended by | No specific | By your child's GP | |
| someone you know | recommendation | | |

| Approximate travel time from your home | 10 minutes | 90 minutes | |
|--|---|----------------------------|--------------------------|
| Available hours | Business hours plus evenings and weekends | Business hours | |
| Cost to you out of pocket per visit | \$200 | No cost | |
| Knowledge about impact of chronic health problems on children | Knows about impact | No specific knowledge | |
| First available appointment | 6 months | Within one week | |
| Which of these three would you choose? | Mental health service A | Mental health service B | No mental health service |
| | | | |

You will now be asked to consider twelve scenarios. The description of each factor is available by clicking the text if you wish to refer to it.

Choice scenarios

You will now be asked to consider twelve scenarios. The description of each factor is available by clicking the text the text if you wish to refer to it.

In each scenario, imagine that you are concerned about your child's mental health or behaviour. Imagine that they were showing some of the signs of mental health issues that were described to you earlier. Please imagine that you decided to seek help for this. You asked your GP or the hospital clinic for advice on who could help. In both services the person would be an expert in children's mental health and behaviour. You would see the same person at each visit. Please assume that any factors not described below are the same across each service.

[Series of 12 choice sets as outlined in separate document]

[After 6 choice sets display message:]

Half way there! Just six more scenarios to go.

Post DCE questions

Now some questions about you and your child to help us understand the choices you just made

- 1. When you were choosing between services, which was the most important factor to you? (*Pick ONE*)
 - Travel time from your home
 - Knowledge about the impact of chronic health problems on children
- Available hours
- Recommended by someone you know
- Cost to you out of pocket per visit
- First available appointment
- 2. Did you ignore any of the factors describing the services? (Tick all that apply)
- Travel time from your home
- Knowledge about the impact of chronic health problems on children
- Available hours
- Recommended by someone you know
- Cost to you out of pocket per visit
- First available appointment
- 3. What is your postcode?
- 4. How old is your child?
- 5. Which outpatients clinic does your child attend at the (anonymised) Hospital?
- Diabetes
- Epilepsy
 - Epidermolysis bullosa
- Non-CF bronchiectasis
 - Other (please specify)_
- 6. How old was your child when they first developed the physical health condition for which they are treated at the (anonymised) Hospital?
- 7. How often does your child attend healthcare appointments? (Pick ONE)
 - Weekly or more
 - Monthly
 - Every 3-6 months
 - Once a year or less
- 8. What is the highest level of education you have completed? (*Pick ONE*)
 - Primary school (did not attend high school)
- High school year 11 or below
- Completed high school (year 12, form 6, HSC)

| TAFE or Trade Certificat | te or Diploma |
|--------------------------|---------------|
|--------------------------|---------------|

Undergraduate university degree (i.e., bachelor, diploma)

Postgraduate university degree (i.e. postgraduate diploma, masters, PhD)

9. Which of these best describes your current employment status? (Pick ONE)

Employed full-time - please write your main occupation

Employed part-time - please write your main occupation

Not employed in paid work (unemployed, retired, student, home duties, unable to work)

Other (please specify)

10. How many children under 18 live in your household?

- 11. How many adults live in your household?
- 12. Before tax is taken out, which of the following ranges best describes your HOUSEHOLD'S income over the last 12 months? Please include income from all sources, including wages, investments and government pensions and benefits.

\$20,001 to \$40,000
\$40,001 to \$60,000
\$60,001 to \$80,000
\$80,001 to \$125,000
\$125,001 to \$150,000
\$150,001 to \$200,000
\$200,000 and more
Prefer not to say

13.

A) Has your child ever seen any services for emotional or behavioural problems? This includes services received at school, in a community clinic, from a doctor or in a hospital.

[If yes to A):]

Yes No

B) What type of service did they see? (Tick all that apply)

GP
Paediatrician
Psychologist
Headspace
Child and Adolescent Mental Health Service (CAMHS)
Psychiatrist
School counsellor

| Counsellor or family therapist |
|--------------------------------------|
| Social worker |
| Nurse |
| Occupational therapist |
| Phone helpline such as Kids Helpline |
| Other (please specify) |
| |

[Also if yes to A):]

C) Do you think your child got as much help from that service as needed for their emotional or behavioural problems?

| No, they needed a little more help |
|------------------------------------|
| No, they needed a lot more help |

Yes

[If no to A):]

D) Do you think your child has needed help for emotional or behavioural problems?

Yes, they needed a little help

Yes, they needed a lot of help

[If C) or D) indicate more help needed]

Which of the following reasons kept you from seeking or receiving help with your child's emotions or behaviour? (Tick all that apply)

- I preferred to handle my child's problems on my own, or with help from family or friends
- I wasn't sure if my child needed help

I wasn't sure where to get help

I thought that the problem would get better by itself

- There was a problem getting to a service that could help us
- We couldn't afford it
 - I couldn't get an appointment for my child when it was needed
 - I was concerned about what other people might think

My child refused help, didn't turn up for an appointment, or didn't think they had a problem

Thank you very much for taking part in this survey.

Do you know other parents whose children attend clinics at the (anonymised) Hospital? If so, we would be grateful if you could forward this link to them so that they could complete the survey as well.

[Add shareable link]

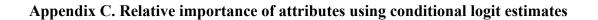
If you would like to know about the findings when they are available, please email this request to <u>xxxxxxxxxx</u>

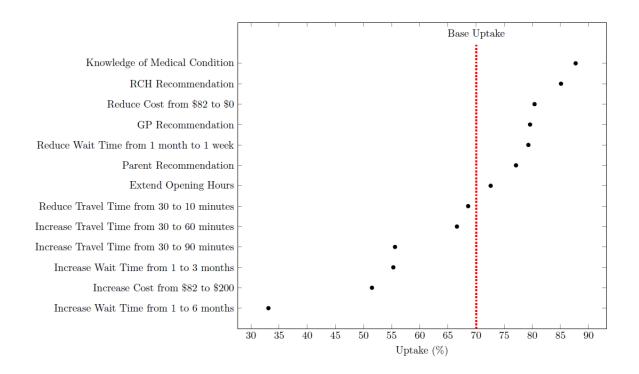
Space is provided here for any feedback or comments you would like to provide:

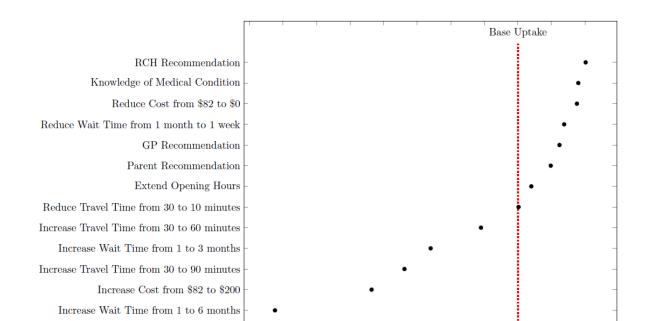
| Attribute | Level | β | s.e |
|-------------------------------------|---|---------|-------|
| Alternative-specific constant (ASC) | Either service (vs. none) | 4.20** | 0.70 |
| Cost | (continuous) | -0.01** | 0.002 |
| Travel time | (continuous) | 0.01 | 0.01 |
| Travel time ² | (continuous) | -0.00** | 0.00 |
| Knowledge of medical condition | No knowledge (base) | | |
| | Has knowledge | 1.15** | 0.11 |
| Opening hours | Standard opening hours (base) | | |
| | Extended opening hours | 0.09 | 0.08 |
| Recommendation | No recommendation (base) | | |
| | Recommended by parent | -0.24 | 0.28 |
| | Recommended by GP | -0.06 | 0.36 |
| | Recommended by (ANONYMISED HOSPITAL) | 0.83** | 0.31 |
| Wait time | 1 week (base) | | |
| v ar mie | 1 month | -0.51** | 0.13 |
| | 3 months | -1.17** | 0.15 |
| | 6 months | -2.13** | 0.19 |
| Sociodemographic variables | Interacted with attribute variable | 2.20 | 0.15 |
| Age | ASC | -0.03 | 0.05 |
| More than high school education | Recommended by parent | 0.52 | 0.28 |
| 6 | Recommended by GP | 0.50 | 0.36 |
| | Recommended by (ANONYMISED HOSPITAL) | -0.11 | 0.32 |
| Single parent | Extended opening hours | 0.28* | 0.14 |
| Income | Cost | 0.00** | 0.00 |
| Unmet mental health care needs | Recommended by parent | 0.57* | 0.26 |
| | Recommended by GP | 0.53 | 0.32 |
| | Recommended by (ANONYMISED HOSPITAL) | 0.34 | 0.32 |
| | | BIC 1 | 710 |

Appendix B. Conditional logit model coefficients

*p<0.05, **p<0.01







Uptake (%)

Appendix D. Relative importance of attributes with calibration to 85% uptake in base case

Appendix E. Relative importance of attributes using paediatrician visit as base case

