MONASH University
Medicine, Nursing and Health Sciences

INTRO/CONSENT

Project title: Understanding parent agreement with basic data collected during treatment of toe walking
Project ID: 30310

Research team:
A/Prof Cylie Williams: cylie.williams@monash.edu
Antoni Caserta: antoni.caserta@monashhealth.org
Desiree Polt: Parent
A/Prof Verity Pacey: verity.pacey@mq.edu.au
Dr Kelly Gray: kelly.gray@mq.edu.au

Why are we doing this research?

- To understand what outcome measurements matter to parents who have children undergoing treatment for toe walking.
- To develop a set of core outcome measures that both clinicians and parents of children with toe walking agree with.

Who can participate?

You can participate if you are:

- a parent of a child who currently toe walks.
- your child has been assess by a health professional for toe walking treatment outcomes within the past 6 months.

This research is unfunded.

What do I have to do?

If you would like to participate:
- We will ask you for consent to participate through checking a box below that you have read this information
- Complete a survey that may take up to 20 minutes.
- You have the option to leave your email if you want a summary of the results or be contacted about the next stage of this research. The next stage will be developing an assessment rated by parents.

What happens if I don't want to finish the survey?

If you wish to stop the survey:
- You can close the browser window at any time.
- Any data that you have provided will be included in the research.

What will happen to my answers?

- Your answers will be stored in line with Australian Privacy Regulations.
- After the survey closes, we will write a report that will be published. Your answers in this report will stay private.

Risks and Benefits to participation

- We anticipate the only risk is that of inconvenience due to time. We hope the findings will assist aligning outcomes with things that matter more to parents in the future.

Should you have any concerns or complaints about the conduct of the project, you are welcome to contact the Principal Investigators or the Executive Officer, Monash University Human Research Ethics Committee (MUHREC), depending on your concern:

Questions
Principal Investigators:
A/Prof Cylie Williams
School of Primary and Allied Health Care, Monash University
email: cylie.williams@monash.edu Ph: 03 9904 4344

Complaints:
Executive Officer
Monash University Human Research Ethics Committee (MUHREC)
Room 111, Chancellery Building E,
24 Sports Walk, Clayton Campus
Research Office
Monash University VIC 3800

Tel: +61 3 9905 2052
Email: muhrec@monash.edu
Fax: +61 3 9905 3831

This research has been approved by the Monash University Human Research Ethics Committee.

For more detailed information about this research please click on the below link.
Long explanatory statement

To consent, and participate in this research, please check the box below
By checking, you are confirming you are the parent of a child who toe walks, you meet the inclusion criteria and you have read the above information about the study.

- ○ I have read the above information and consent
- ○ I do not consent

ABOUT YOU

Please scroll and click on the country you currently reside:

What is your relationship to the child or children who toe walk?

- ○ Mother
- ○ Father
- ○ Legal guardian
- ○ [ ] Other (please describe)

How many children do you have under the age of 18?

- ○ 1

- 2
- 3
- 4 or more

How many of your children currently toe walk?

- 1
- 2
- 3 or more

What is the age group for your youngest child who is currently being treated for toe walking?

- Under 3 years
- 3-5 years
- 6-10 years
- >10 years

What diagnosis or reason for your youngest child's toe walking?

- Idiopathic toe walking
- Cerebral palsy
- Autism spectrum disorder
- Tethered Cord
- Charcot Marie Tooth
- Unknown
- [ ] Other (Please specify)

Thinking about your 2nd child who currently toe walks, what is their age group?

- ○ Under 3 years
- ○ 3-5 years
- ○ 6-10 years
- ○ >10 years

What diagnosis or reason for your 2nd child's toe walking,

- ○ Idiopathic toe walking
- ○ Cerebral palsy
- ○ Autism spectrum disorder
- ○ Tethered Cord
- ○ Charcot Marie Tooth
- ○ Unknown
- ○ [ ] Other (Please specify)

Thinking about your 3rd child who currently toe walks, what is their age group?
(We are only asking for up to 3 children who currently toe walk)

- ○ Under 3 years
- ○ 3-5 years
- ○ 6-10 years
- ○ >10 years

What diagnosis or reason for your 3rd child's toe walking,

- ○ Idiopathic toe walking
- ○ Cerebral palsy
- ○ Autism spectrum disorder

- ○ Tethered Cord
- ○ Charcot Marie Tooth
- ○ Unknown
- ○ _____ Other (Please specify)

Which health professional/s have you seen in the past 6 months for your child or children's toe walking (check all that apply)

- ☐ Paediatrician
- ☐ Neurologist
- ☐ Orthopaedic surgeon
- ☐ Rehabilitation specialist/Physiatrist
- ☐ Physiotherapist/Physical Therapist
- ☐ Podiatrist
- ☐ Occupational Therapist
- ☐ Orthotist
- ☐ _____ Other (please specify)

Please indication your level of satisfaction with the following statements.

When responding, please think about the questions and assessments your child's health professional asks or does.

	Extremely dissatisfied	Somewhat dissatisfied	Neither satisfied nor dissatisfied	Somewhat satisfied	Extremely satisfied

I am satisfied with the questions my health professional asks during to understand how treatment is progressing	○	○	○	○	○
I am satisfied with the assessments my health professional does during treatment to understand how treatment is progressing	○	○	○	○	○

Please check any treatment recommended for your child (or children) in the past 6 months? (Please check all that apply)

	Recommended and you said no to this treatment	Recommended and you're waiting to start this treatment	Currently having this treatment (or had in the past month)	Has not recomme
Surgery for the calf, ankle or foot (Please provide more details if required)	☐	☐	☐	☐
Botox	☐	☐	☐	☐
Serial casting	☐	☐	☐	☐
Ankle foot orthoses (AFOs)	☐	☐	☐	☐
Supramalleoli orthoses (SMOs)	☐	☐	☐	☐

Foot orthoses (FOs)	☐	☐	☐	☐
Exercises to strengthen muscles	☐	☐	☐	☐
Stretches	☐	☐	☐	☐
No treatment or watching and waiting	☐	☐	☐	☐
Night splints	☐	☐	☐	☐
Other (please specify)	☐	☐	☐	☐

We surveyed health professionals about base data or outcome measures they think are important to collect during treatment of idiopathic toe walking, **not the tests they used to help make a diagnosis.** We also interviewed parents about what treatments or treatment success looks like while undergoing toe walking treatment.

These outcome measures may be important to any child who is toe walking, not just those with idiopathic toe walking.

These are type of questions and measures health professionals told us were important to themto understand how treatment is progressing.

Please check how important these measures are to you in relation to your child's toe walking treatment outcome or progress?

	Not at all important	Slightly important	Moderately important	Very important
How often your child toe walked in the last week	○	○	○	○

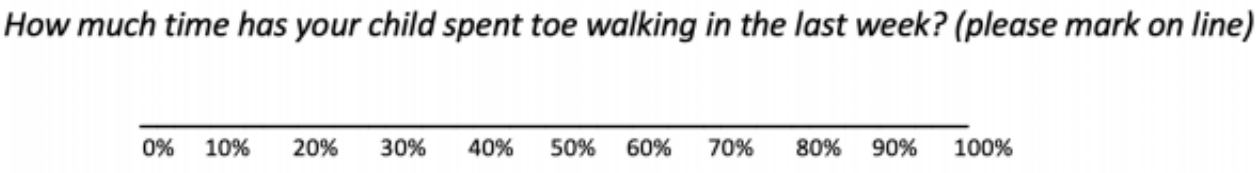
How satisfied you are with the amount of toe walking your child is currently doing	○	○	○	○
How well you have been able to follow or do any of the treatment prescribed	○	○	○	○
Worst pain felt in legs today	○	○	○	○
Worst pain felt in legs while being active	○	○	○	○
Measurement of ankle range of movement	○	○	○	○
Strength of the muscles at the front of the leg	○	○	○	○
Distance of walking (or walking speed)	○	○	○	○

Please list any other questions or assessments of toe walking treatment that are important to you or your child that aren't listed above?

(In answering, some people find it easier to think about some of the questions or measures that your health professional asks or assessments performed that really matter to you or your child.)

You responded that asking how often your child toe walks is not important, or only slightly important to you.
Can you provide more detail on why you answered this way?

Health professionals proposed a question about time spent toe walking could be collected on a scale like this:

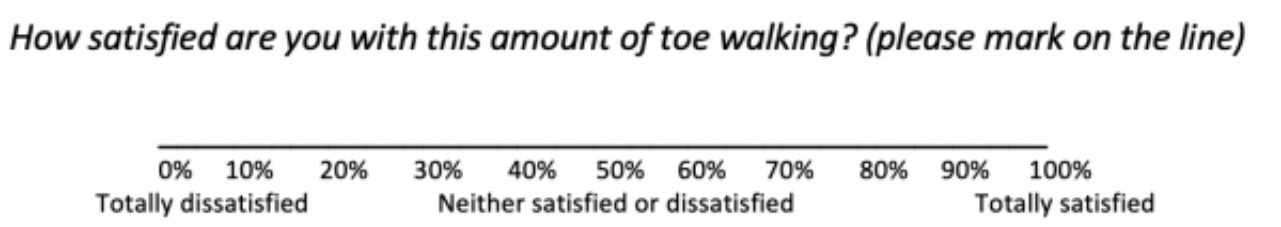


Now you have seen this, please rate your agreement if this scale could be used during treatment.

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
About of time spent toe walking scale	○	○	○	○	○

You responded that asking how satisfied you are with the amount your child toe walks not important, or only slightly important to you.
Can you provide more detail on why you answered this way?

Health professionals proposed asking about satisfaction with toe walking amount and it be collected on a scale like:

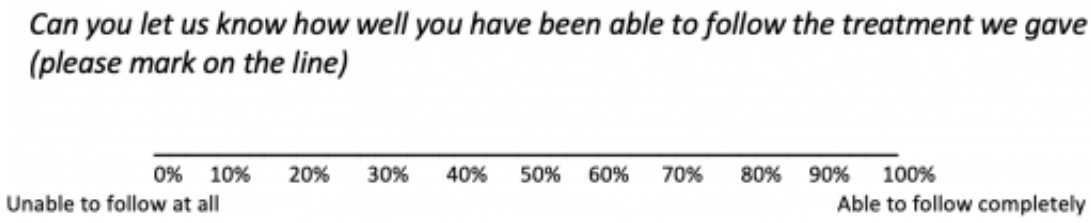


Now you have seen this, please rate your agreement if this scale could be used during treatment.

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
Satisfaction with amount of treatment	○	○	○	○	○

You responded that asking about how well you have been following or doing any of the treatments is not important or slightly important to you.
Can you provide more detail on why you answered this way?

Health professionals proposed a question about how you could follow the toe walking treatment could be collected on a scale like:



Now you have seen this, please rate your agreement if this scale could be used during treatment.

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
How well you have been able to follow or do any of the treatment prescribed	○	○	○	○	○

You responded that being asked about today's pain is not important, or only slightly important to you.
Can you provide more detail on why you answered this way?

Health professionals proposed a question asking your child to rate their worst pain today on a scale appropriate for their age.

*Pain today (Mark a **T** on appropriate scale): Child response*
Ask the child 'What is the worst pain you get in your legs today?'

*Pain on activity (Mark an **A** on appropriate scale): Child response*
Ask the child 'What is the worst pain you get when moving about?'

Clinician note:
Pick either Face or VAS depending on child's age / ability.

Now you have seen this, please rate your agreement if this scale could be used during treatment.

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
What is the worst pain today	○	○	○	○	○

You responded that being asked about worst pain while being active is not important, or only slightly important to you.
Can you provide more detail on why you answered this way?

Health professionals proposed a question asking your child to rate their worst pain on activity on a scale appropriate for their age.

*Pain today (Mark a **T** on appropriate scale): Child response*
Ask the child 'What is the worst pain you get in your legs today?'

*Pain on activity (Mark an **A** on appropriate scale): Child response*
Ask the child 'What is the worst pain you get when moving about?'

Clinician note:
Pick either Face or VAS depending on child's age / ability.

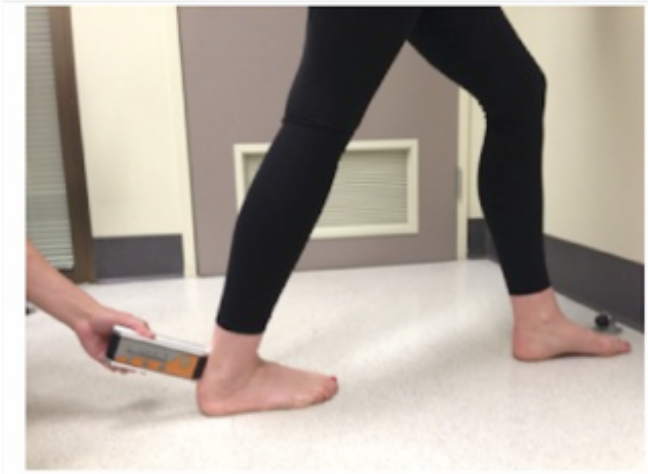
Now you have seen this, please rate your agreement if this scale could be used during treatment.

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
What is the worst pain while being active	○	○	○	○	○

You responded that taking a measurement of ankle range of motion is not or only slightly important to you.
Can you provide more detail on why you answered this way?

Health professionals proposed this measure be collected through either a method called the weight bearing lunge (in the picture and collected with a smart phone or other measurement tool), **OR** a method with your child laying on their tummy with leg straight or knee bent.

Ankle range of motion (weight bearing lunge preferred):



	Left	Right		Left	Right
With knee straight Non weight-bearing			With knee bent Non weight-bearing		

Now you have seen this, please rate your agreement if this assessment could be used during treatment.

Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

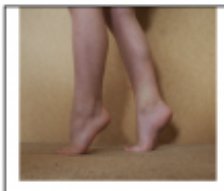
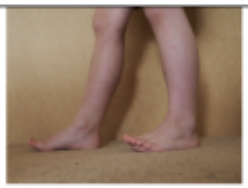
Measurement of ankle range of movement through either measure	○	○	○	○	○

You responded that measuring the strength of muscles at the front of legs is not or only slightly important to you.
Can you provide more detail on why you answered this way?

Health professionals proposed a strength assessment could be collected with a walking scale measurement

Gait scale

Ask the child 'Can you try to walk on your heels?'
You may wish to demonstrate as well.
Observe child walking for 10 steps.

				
0 – Unable to get heels or midfoot to the ground	1 - Unable to get heels to ground. Midfoot strike present.	2. Able to get heels to ground. Unable to walk 10 steps with great toe dorsiflexed	3. Able to get heels to ground and walk 10 steps with great toe dorsiflexed. However, plantar surface of forefoot remains on ground.	4. Able to get heels to ground and walk 10 steps with the plantar surface of the forefoot off the ground.

Now you have seen this, please rate your agreement if this scale could be used during treatment.

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

A strength measure with a walking scale	○	○	○	○	○

You responded that measuring the distance (or speed) your child is able to walk is not or only slightly important to you.
Can you provide more detail on why you answered this way?

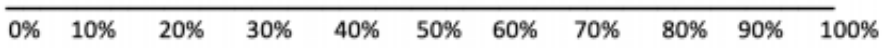
Health professionals proposed walking distance (or speed) could be collected with a walking test call the **6 minute walk test (6MWT)**. This involves your child walking for 6 minutes between two spots, to see how far your child can walk in 6 minutes.

Now you have seen this, please rate your agreement if this scale could be used during treatment.

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
Measurement of distance (or speed)	○	○	○	○	○

You responded that being asked how often your child walks on their toes is important to you.
Health professionals proposed this question could be collected on a scale like this:

How much time has your child spent toe walking in the last week? (please mark on line)



Looking at the above scale, please rate:

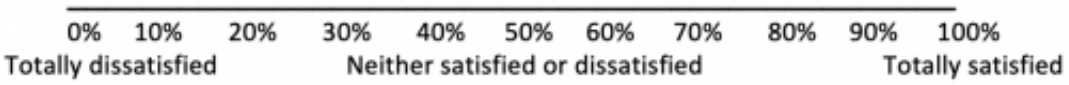
	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
The scale seems fitting	○	○	○	○	○
The scale seems suitable	○	○	○	○	○
The scale seems applicable	○	○	○	○	○
The scale seems like a good match for the question	○	○	○	○	○
I could complete this question about my child and their toe walking **without** my health professional	○	○	○	○	○

If you disagreed with any of the statements, please describe why?

You indicated that how being ask how satisfied you are with treatment is important to you.

Health professionals proposed this question be collected on a scale like this:

How satisfied are you with this amount of toe walking? (please mark on the line)



Looking at the above scale, please rate:

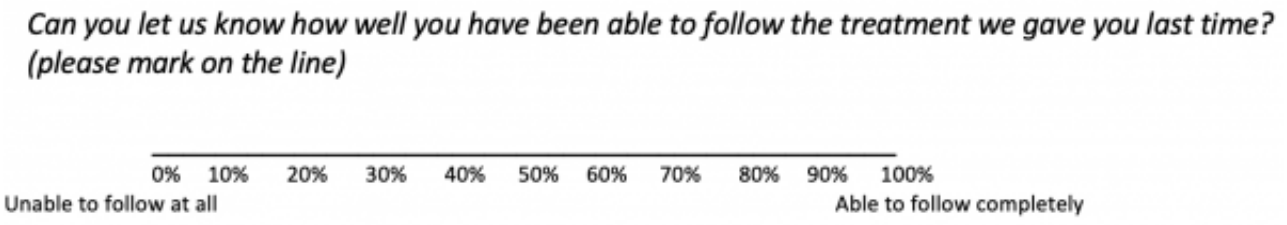
	Completely disagree	Disagree	Neither agree nor disagree	Agree	Completely agree
The scale seems fitting	○	○	○	○	○
The scale seems suitable	○	○	○	○	○
The scale seems applicable	○	○	○	○	○
The scale seems like a good match	○	○	○	○	○
I could complete this question about my child and their toe walking **without** my health professional	○	○	○	○	○

If you disagreed with any of the statements, please describe why?

You indicated that how being asked how well you have been able to follow treatment is

important to you.

Health professionals proposed this question be collected on a scale like this:



Looking at the above scale, please rate:

	Completely disagree	Disagree	Neither agree nor disagree	Agree	Completely agree
The scale seems fitting	○	○	○	○	○
The scale seems suitable	○	○	○	○	○
The scale seems applicable	○	○	○	○	○
The scale seems like a good match	○	○	○	○	○
I could complete this question about my child and their toe walking **without** my health professional	○	○	○	○	○

If you disagreed with any of the statements, please describe why?

You indicated that how being asked about pain is important to you.

Clinicians proposed this question be collected on a scale like this. They proposed they ask your child and depending on their age, they record the question using a pain scale commonly used for children of different ages.

*Pain today (Mark a **T** on appropriate scale): Child response*
Ask the child 'What is the worst pain you get in your legs today?'

*Pain on activity (Mark an **A** on appropriate scale): Child response*
Ask the child 'What is the worst pain you get when moving about?'

Clinician note:
Pick either Face or VAS depending on child's age / ability.

Looking at the above scale, please rate:

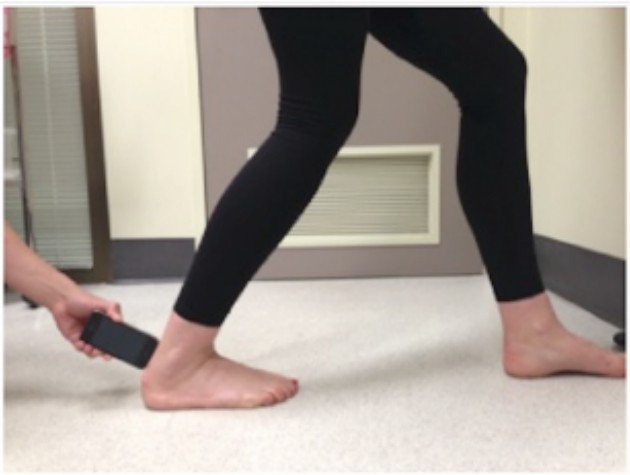
	Completely disagree	Disagree	Neither agree nor disagree	Agree	Completely agree
The scale seems fitting	○	○	○	○	○
The scale seems suitable	○	○	○	○	○
The scale seems applicable	○	○	○	○	○
The scale seems like a good match	○	○	○	○	○

My child or I could complete this question about any pain relating to my child's toe walking **without** my health professional	○	○	○	○	○

If you disagreed with either of the statements, please describe why?

You indicated that having ankle range measured is important to you.
Clinicians proposed this measure be collected through either a method called the weight bearing lunge (in the picture and collected with a smart phone or other measurement tool), or with your child laying on their tummy with leg straight or knee bent.

Ankle range of motion (weight bearing lunge preferred):



	Left	Right		Left	Right
With knee straight Non weight-bearing			With knee bent Non weight-bearing		

Looking at the above measure/s, please rate:

	Completely disagree	Disagree	Neither agree nor disagree	Agree	Completely agree
Using the two types of ankle range measures options seem fitting	○	○	○	○	○
Using the two types of ankle range measures seems suitable	○	○	○	○	○
Using the two types of ankle range measures seems applicable	○	○	○	○	○
Using the two types of ankle range measures seems like a good match	○	○	○	○	○
I could be taught to do the measurement in the picture at home to monitor my child between appointments	○	○	○	○	○

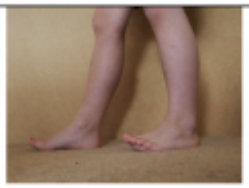
If you disagreed with any of the statements, please describe why?

You indicated that strength assessment is important to you.

Clinicians proposed this could be collected with a walking scale measurement.

Gait scale

Ask the child 'Can you try to walk on your heels?'
You may wish to demonstrate as well.
Observe child walking for 10 steps.

				
0 – Unable to get heels or midfoot to the ground	1 - Unable to get heels to ground. Midfoot strike present.	2. Able to get heels to ground. Unable to walk 10 steps with great toe dorsiflexed	3. Able to get heels to ground and walk 10 steps with great toe dorsiflexed. However, plantar surface of forefoot remains on ground.	4. Able to get heels to ground and walk 10 steps with the plantar surface of the forefoot off the ground.

Looking at the above assessment, please rate:

	Completely disagree	Disagree	Neither agree nor disagree	Agree	Completely agree
The scale seems fitting	○	○	○	○	○
The scales seems suitable	○	○	○	○	○
The scale seems applicable	○	○	○	○	○
The scale seems like it a good match	○	○	○	○	○

I could be taught to rate the scale in the picture at home to monitor my child between appointments	○	○	○	○	○

If you disagreed with any of the statements, please describe why?

You indicated that walking distance (or speed) is important to you.
Clinicians proposed this could be collected with a walking test call the **6 minute walk test (6MWT)**. This involves your child walking for 6 minutes between two spots, to see how far your child can walk in 6 minutes.

Looking at the above assessment, please rate:

	Completely disagree	Disagree	Neither agree nor disagree	Agree	Completely agree
The assessment seems fitting	○	○	○	○	○
The assessment seems suitable	○	○	○	○	○
The assessment seems applicable	○	○	○	○	○
The assessment seems like a good match	○	○	○	○	○

I could be taught to do this assessment at home to monitor my child between appointments	○	○	○	○	○

If you disagreed with any of the statements, please describe why?

End

Thank you for your views. Please click next to submit your responses.

If you would like to provide your email to receive a summary of the results or be contacted about further research on validating any parent measures that arise from this research, please provide your email below.

- ☐ No further contact
- ☐ I would like to receive a summary of the results. My email is:
- ☐ I would like to hear more about the development of a parent assessed outcome measure. My email is:

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