

Outcomes from a Paediatric Complex Concussion Service

What are the outcomes & service delivery requirements for children and teens in a Complex Concussion Service?

A Model of Care Review

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Queensland
Government

Background: Concussion in Children & Adolescents

Children are more likely to get a concussion than adults

- As many as 20% of children sustain concussion before the age of 16yrs
 - Falls & sports most common cause
 - Impacts greater in kids
 - brain injury occurs during period of rapid development & psychosocial change
- **Approx 2500 children in QCH per year**
- **Of those up to 30% have persisting symptoms >1mth**

• Symptoms include:

- Headaches,
- Difficulty concentrating & paying attention
- Memory issues
- Balance problems, dizziness, visual disturbance
- Sleep problems
- Mood disturbances



Managing Persisting Post Concussion Symptoms (PPCS) in Children

What's the Evidence?

PPCS can lead to life altering changes in:

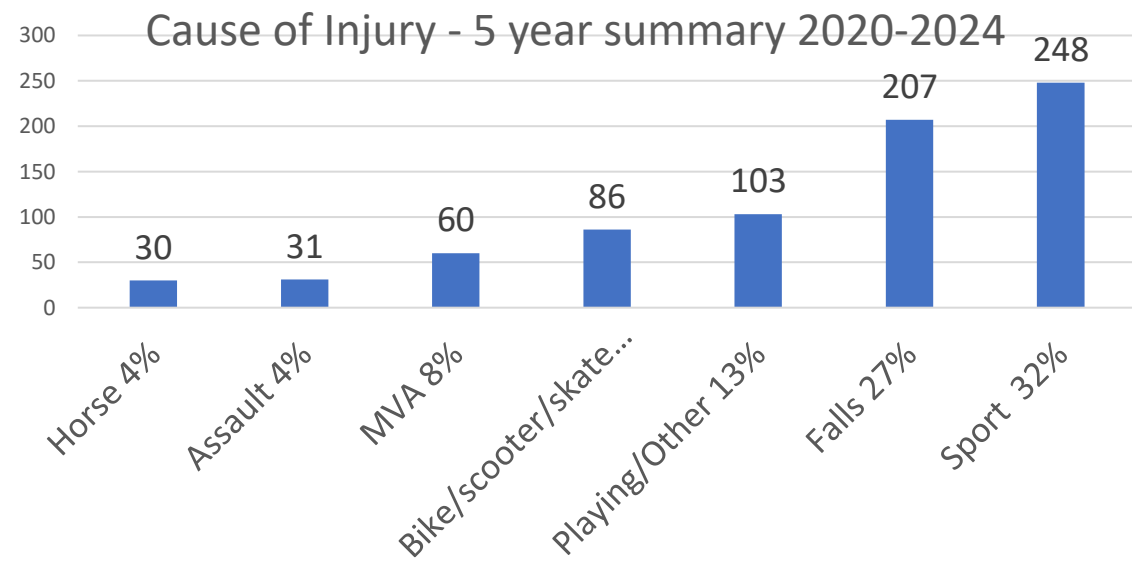
- Physical
- Cognitive
- Psychological health

Impacting

- School participation
- Community participation
- Quality of Life of patients & their families

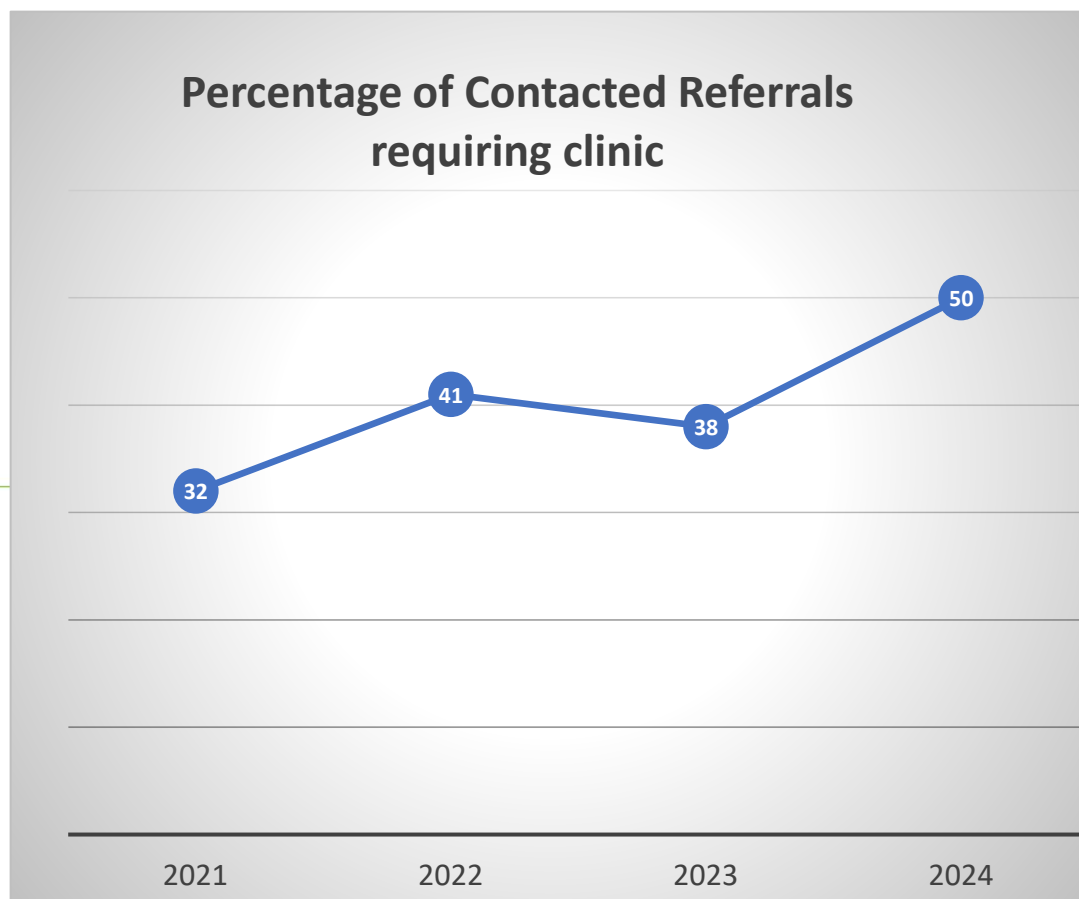


- What we know:
 - If symptoms for > 4 weeks: MDT concussion team is best practice
- There is very little literature on the outcomes of patients referred to Paediatric Complex Concussion services
 - Most outcomes are reported after concussion in sport
 - **Only about 1/3 of our pts have sports related concussions**



Qld Paediatric Rehab Service -Complex Concussion Clinic Model

- Up to 200 referrals per yr (sport-related 32%)
- Increasing complexity over time



Referral criteria for the Complex Concussion Clinic

The Complex Concussion Clinic accepts patients who have:

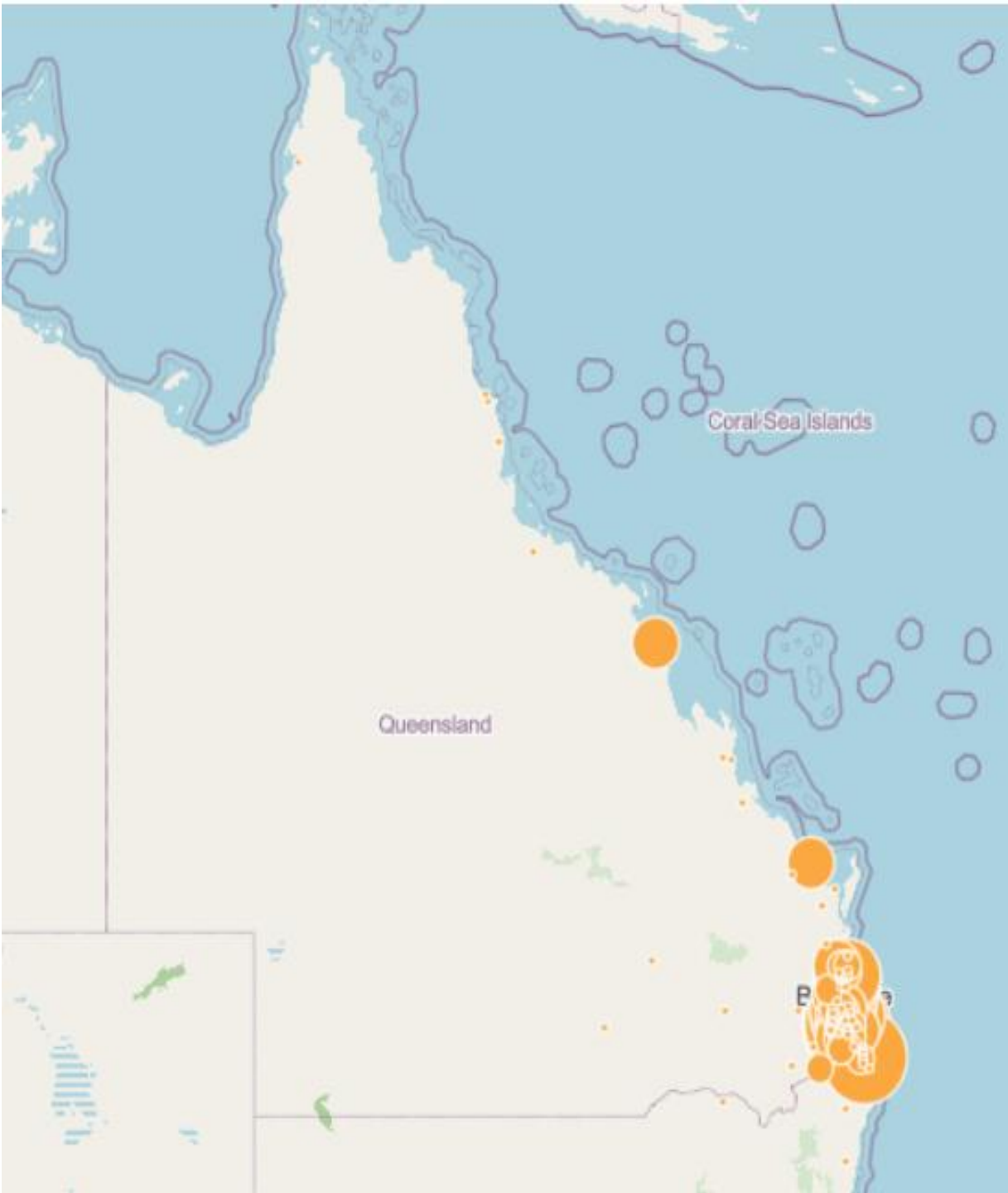
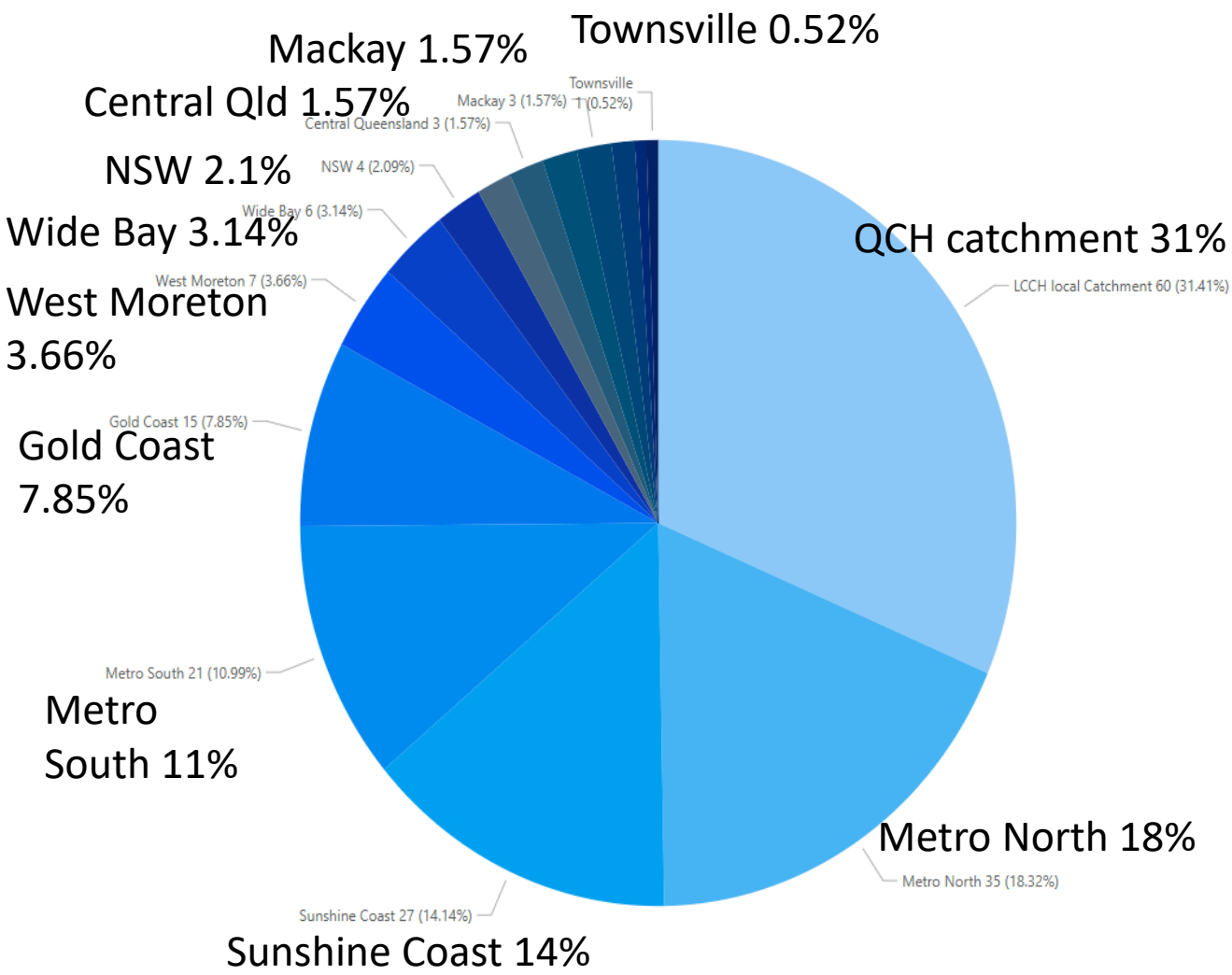
- persistent post concussive symptoms beyond 4 weeks **OR**
- are high risk of persistent symptoms (.eg. more than 3 concussions or previous concussions where symptoms lasted longer than 7 days) **OR**
- multiple repeat presentations to the emergency department

Exclusion Criteria: Time since injury must not exceed 12 months unless discussed with the Complex Concussion Clinic Paediatrician.

QPRS Complex Concussion Clinic Model

- Initial nurse-led standardised assessment, education, triage and management
- Clinic: MD, nursing, physiotherapy, neuropsychology (OT and SW as needed)
 - Exercise tolerance, vestibular function, physiology, neurological examination, neuropsychological assessment and brief intervention
- Interventions tailored to clinical phenotype
- Most ongoing allied health therapies take place in community
- New intensive day treatment program for last year

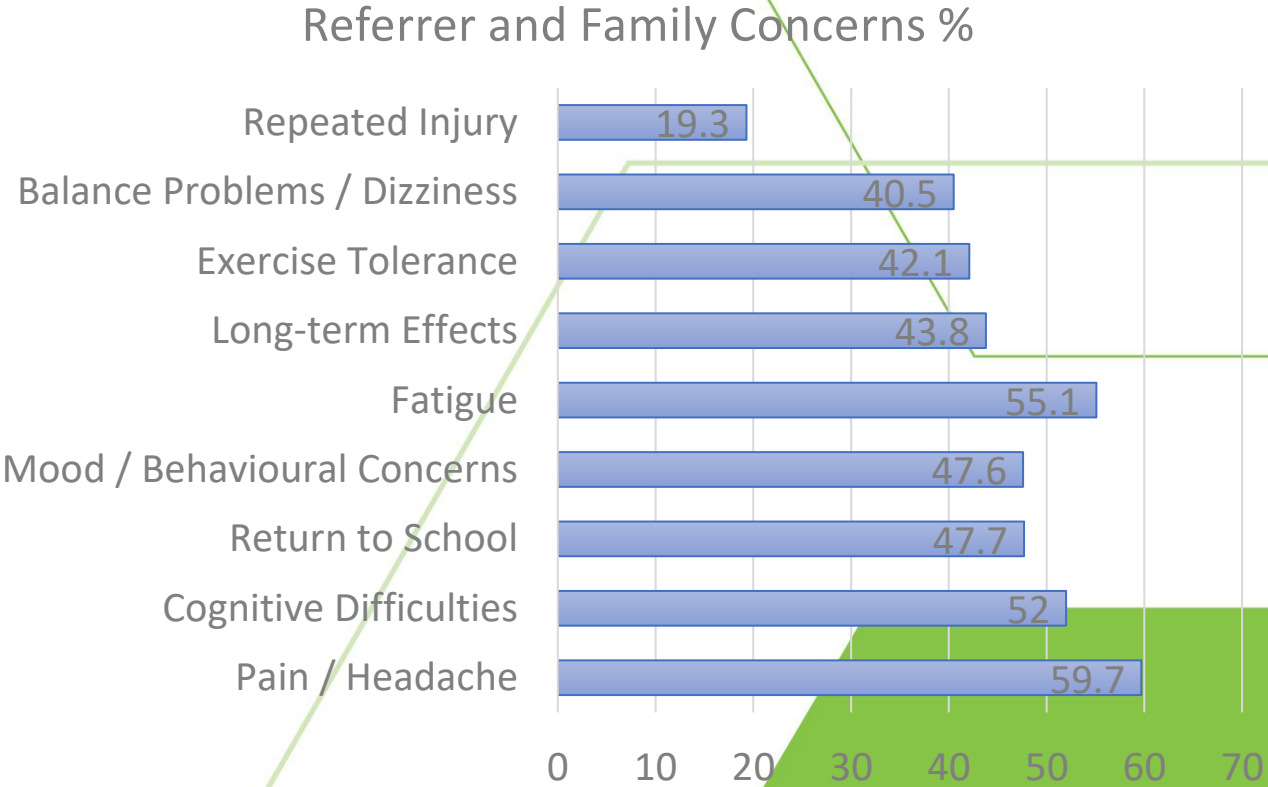
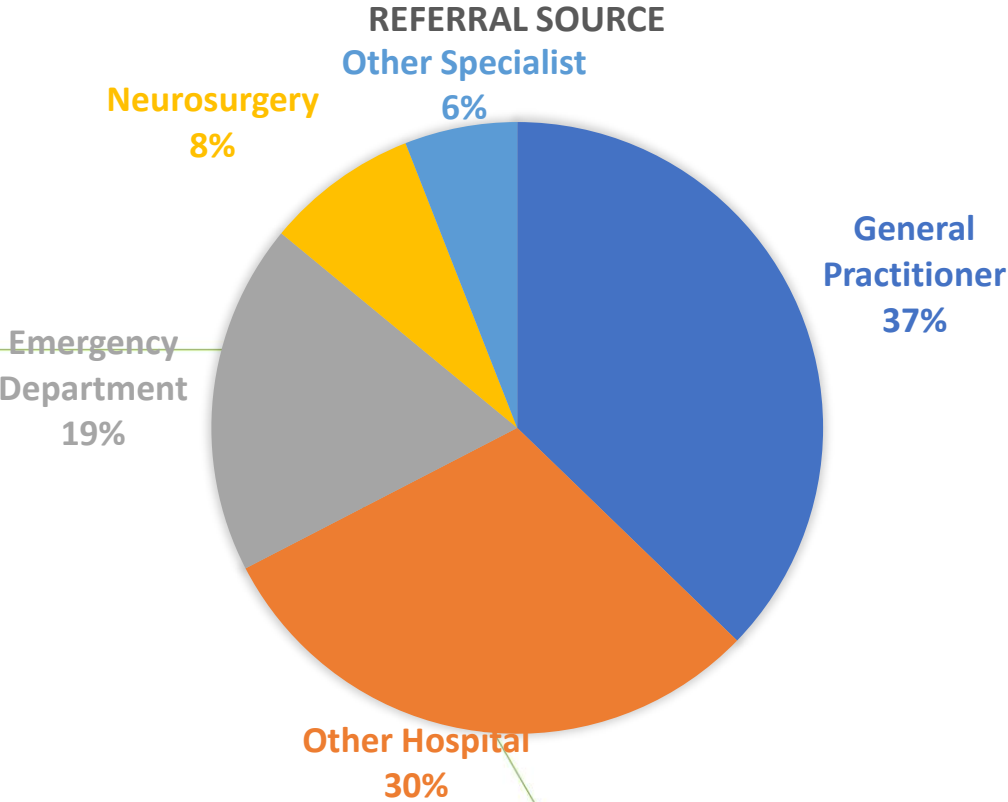
Complex Concussion Clinic: Percentage of Patients by Postcode



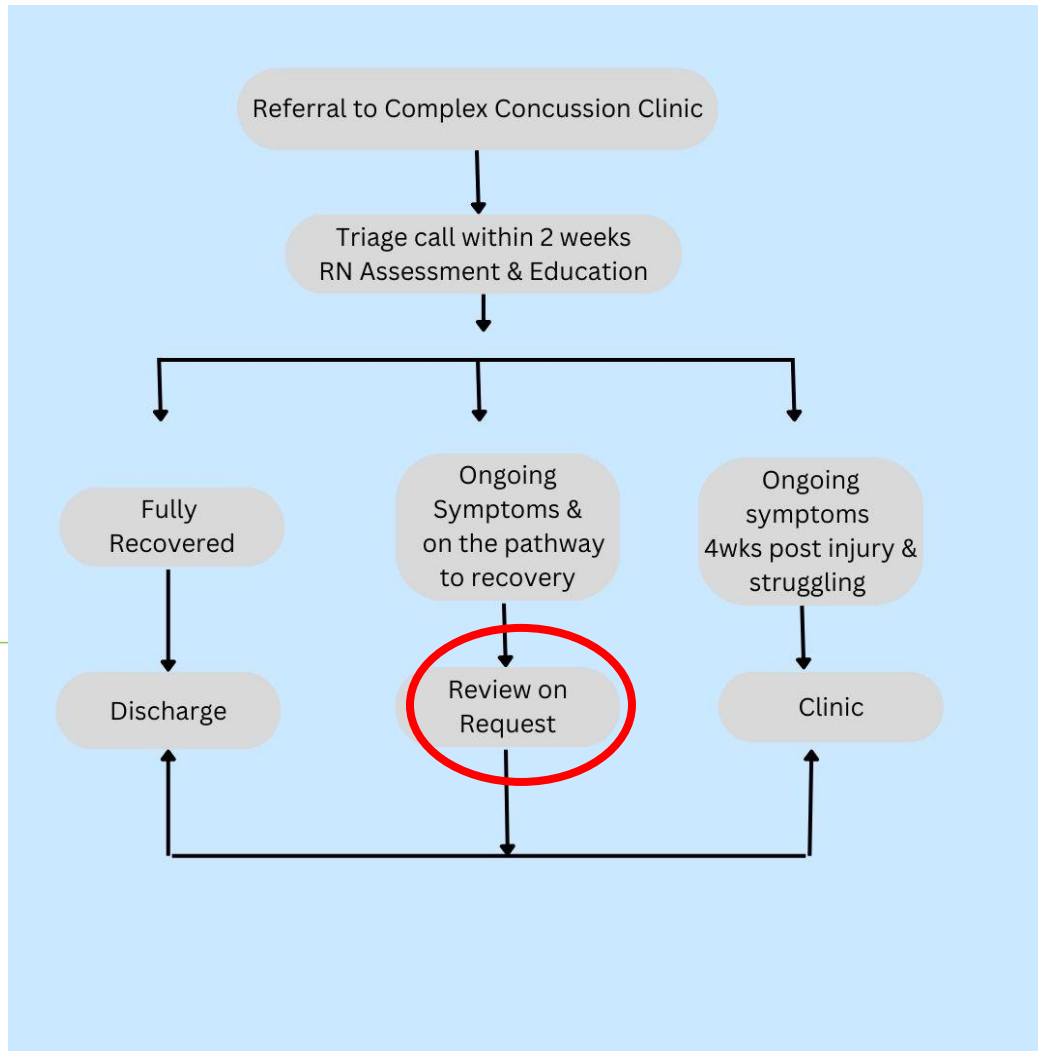
Complex Concussion Clinic Patients

	Age At Referral (Years)
Mean	11.8
Median	12.7
Mode	15.3
Youngest	2.4
Oldest	18

	Duration Post-Injury (Days)
Mean	59.8
Median	34
Mode	21



Qld Paediatric Rehab Service- Complex Concussion Clinic Review



Book to Clinic:

- Persisting heavy symptom load or
- Have not returned to school at 4 wks post injury or
- Clinicians or parents are worried

Patient-initiated follow-up:

We assume if we don't hear from our "Review on Request" group of patients = they have recovered.

But have they?



Project- Outcomes from Paediatric Complex Concussion Clinic

- Aim:
 - To understand the recovery and function of patients 1-2 years post initial engagement with our Complex Concussion service
 - To understand the long-term impact of the injury and recovery on the patient and family
 - To investigate family satisfaction with the care they received from our complex concussion service and what are the gaps in our care and service



Project Design: Quality Improvement Project

- Type: Mixed method cross sectional study design
 - Quantitative and qualitative
 - Location: Single centre project
 - Population:
 - Children and adolescents who have sustained a concussion or mild traumatic brain injury
 - And were referred to the QPRS Complex Concussion Clinic
 - Who were referred between Jan 2021-Jan 2023
 - Consent to study
- Protocol :
 - Recruitment of pts, data collection & chart review between April 2023
 - PREM & PROMS Phone call follow up late 2023

Project: Outcome Measures

- Patient Reported Outcome Measure (PROM) Questionnaires
 - Post concussion symptom inventory (PCSI)
 - Paediatric quality of life questionnaire (PQoL)
 - Family burden II questionnaire (FB)
- Compared Initial PCSI on initial Post Acute Concussion Evaluation form
- Patient Reported Experience Measure (informal PREM)
 - Feedback on
 - their child's recovery,
 - experience of our service &
 - what were other health services they sought

Post-Concussion Symptom Inventory Ages 13-18 (PCSI-SR13) Pre/Post Version

Patient Name: _____ Today's date: _____
 Birthdate: _____ Age: _____

Instructions: We would like to know if you had any of these symptoms before your injury. Next, we would like to know if these symptoms have changed after your injury. Please rate the symptom at two points in time- Before the Injury/Pre-Injury and Current Symptoms/ Yesterday and Today.

Please answer all the items the best that you can. Do not skip any items. Circle the number to tell us how much of a problem this symptom has been for you.

0 = Not a problem 3 = Moderate problem 6 = Severe problem

		Before the Injury/ Pre-Injury						Current Symptoms/ Yesterday and Today							
1	Headache	0	1	2	3	4	5	6	0	1	2	3	4	5	6
2	Nausea	0	1	2	3	4	5	6	0	1	2	3	4	5	6
3	Balance problems	0	1	2	3	4	5	6	0	1	2	3	4	5	6
4	Dizziness	0	1	2	3	4	5	6	0	1	2	3	4	5	6
5	Visual problems (double vision, blurring)	0	1	2	3	4	5	6	0	1	2	3	4	5	6
6	Move in a clumsy manner	0	1	2	3	4	5	6	0	1	2	3	4	5	6
7	Sensitivity to light	0	1	2	3	4	5	6	0	1	2	3	4	5	6
8	Sensitivity to noise	0	1	2	3	4	5	6	0	1	2	3	4	5	6
	[Office Use Only] Physical	Total Pre=						Total Post=							
9	Irritability	0	1	2	3	4	5	6	0	1	2	3	4	5	6
10	Sadness	0	1	2	3	4	5	6	0	1	2	3	4	5	6
11	Nervousness	0	1	2	3	4	5	6	0	1	2	3	4	5	6
12	Feeling more emotional	0	1	2	3	4	5	6	0	1	2	3	4	5	6
	[Office Use Only] Emotional	Total Pre=						Total Post=							
13	Feeling mentally "foggy"	0	1	2	3	4	5	6	0	1	2	3	4	5	6
14	Difficulty concentrating	0	1	2	3	4	5	6	0	1	2	3	4	5	6
15	Difficulty remembering	0	1	2	3	4	5	6	0	1	2	3	4	5	6
16	Get confused with directions or tasks	0	1	2	3	4	5	6	0	1	2	3	4	5	6
17	Answer questions more slowly than usual	0	1	2	3	4	5	6	0	1	2	3	4	5	6
18	Feeling slowed down	0	1	2	3	4	5	6	0	1	2	3	4	5	6
	[Office Use Only] Cognitive	Total Pre=						Total Post=							
19	Fatigue	0	1	2	3	4	5	6	0	1	2	3	4	5	6
20	Drowsiness	0	1	2	3	4	5	6	0	1	2	3	4	5	6
21	Sleep more than usual	0	1	2	3	4	5	6	0	1	2	3	4	5	6
	[Office Use Only] Sleep/ Fatigue	Total Pre=						Total Post=							
22	In general, to what degree do you feel "differently" than before the injury (not feeling like yourself)?	No Difference 0 1 2 3 4 Major Difference Circle your rating with "0" indicating "Normal" (No Difference) and "4" indicating "Very Different" (Major Difference)													
PCSI Total Symptom Score		Pre (sum 4 domains) =						Post (sum 4 domains) =							
[Office Use Only]		PCSI Total Adjusted Symptom Score (Post-Pre) =													

Project: Participants

N=284 eligible btw Jan 2021-2023

127 met inclusion criteria

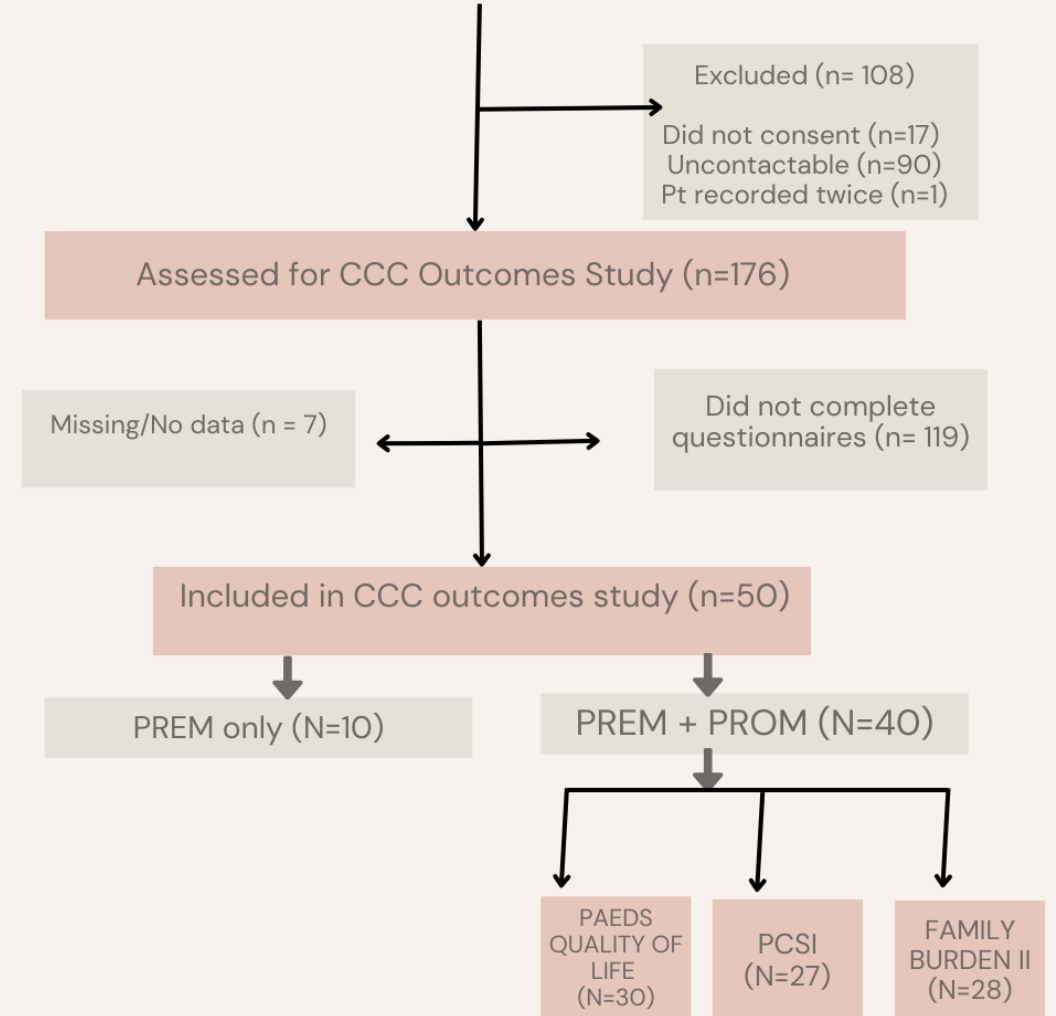
- 50 patients answered surveys

- **All keen to discuss their experience** (N=50)
- Quantitative outcome measures (PROM) (N=30)

Age: 14.3 SD 3.5 years; 61% male

- 8% under 10 year olds (n=4)
- 20% 10-12 year olds (n=10)
- 72% **13-18 year olds (n=36)**
- 31 phone call; 19 seen in clinic
- Post Concussion Symptom Inventory (PCSI) total score higher in clinic pts
 - $F(1,49)=109.7$; $p<0.001$

Total patient referrals to QPRS Complex Concussion Service
Jan 2021-2023 (n= 284)



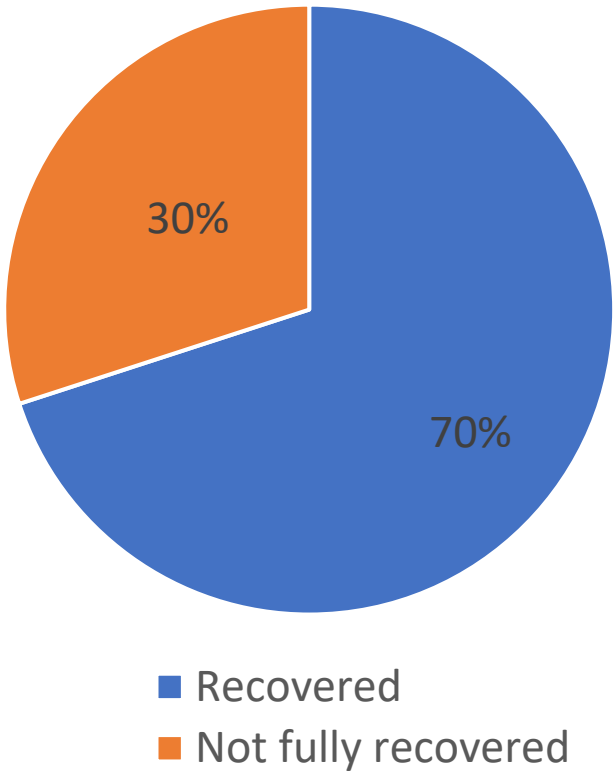
Results: Recovery & Satisfaction

78% reported ongoing symptoms

Most Common Persisting Symptoms:
Headaches,
Sleeping more,
Fatigue,
Sad,
Emotional

What's a typical Australian adolescent PCSI baseline?

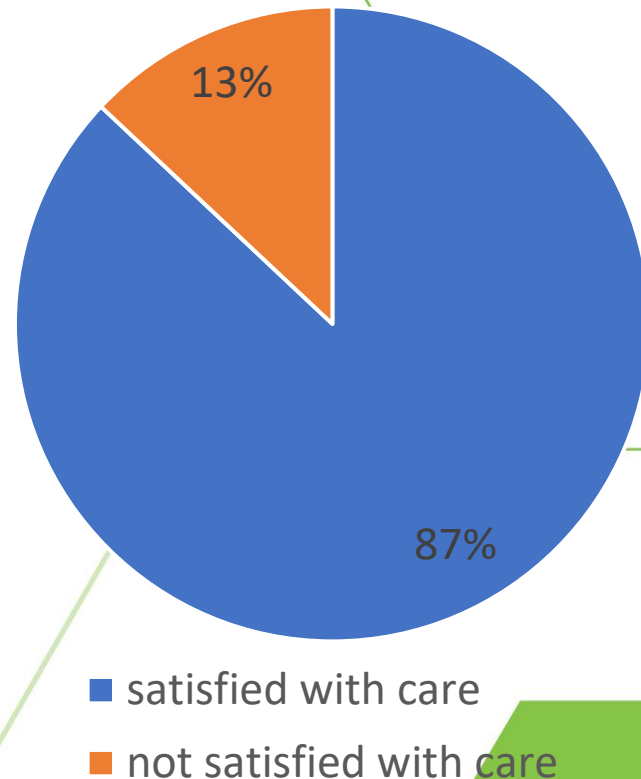
Recovery 1-2 years post injury



*10% had not returned to fulltime school

*20% had not returned to sports

Satisfaction with Care



* 16% had not returned to usual activities

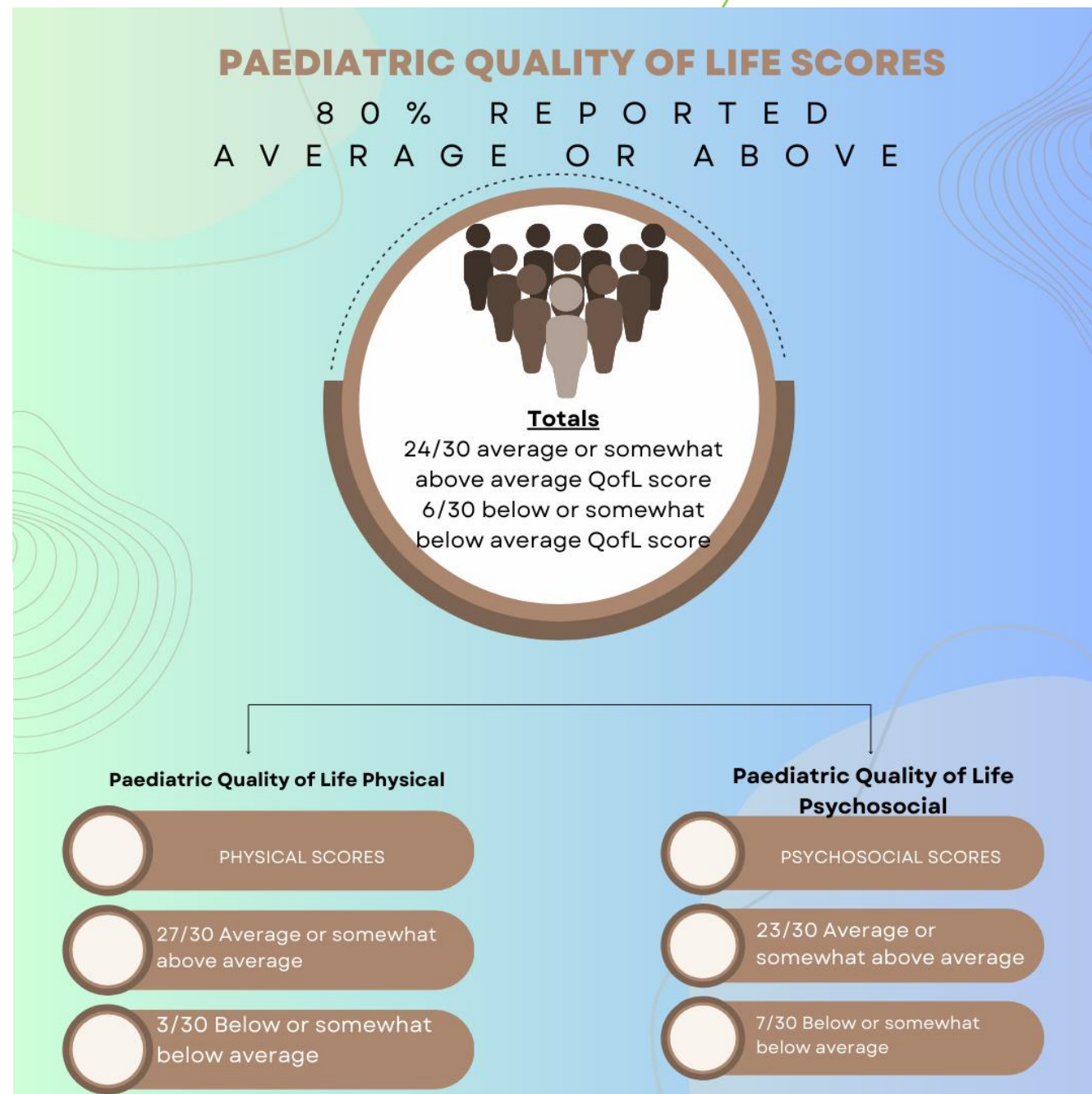
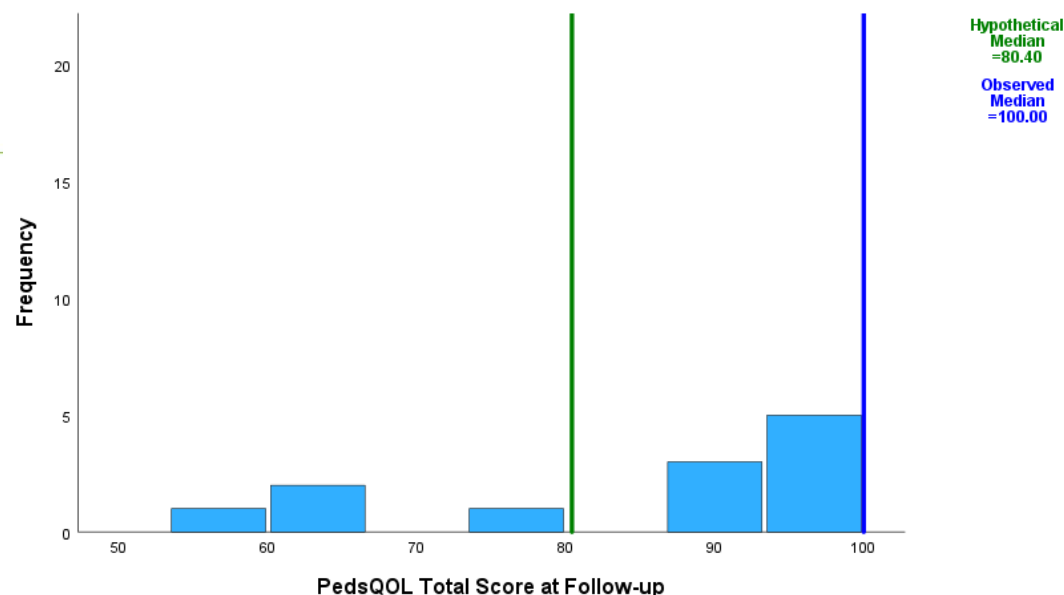
Results - Quality of Life Scores

80% reported average or above average quality of life
(Total PedQL mean

- Physical (mean 93, median 100) >
- Psychosocial (mean 82, median 92))
- $Z=3.7$ $p<0.001$

NB: 77% (23/30) also had premorbid dx or previous concussions

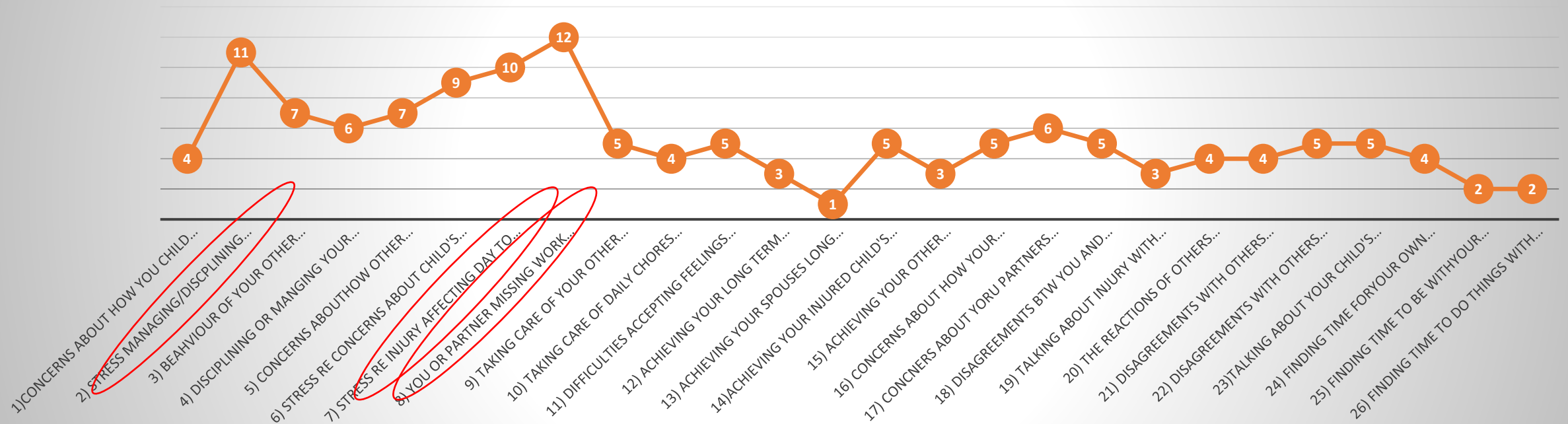
- ADHD, ASD, Anxiety, developmental dx, ABI



Results -Family Burden II Questionnaire

- **68% of families reported the injury causing stress to the family (19/28 pts)**
- **39% of families reporting extreme stress**
- **Overall mean FBII= 0.49 (SD 0.38)**
- Some families reporting up to 11 areas of extreme family stress as a result of the injury

Number of families reporting stress post their child's concussion



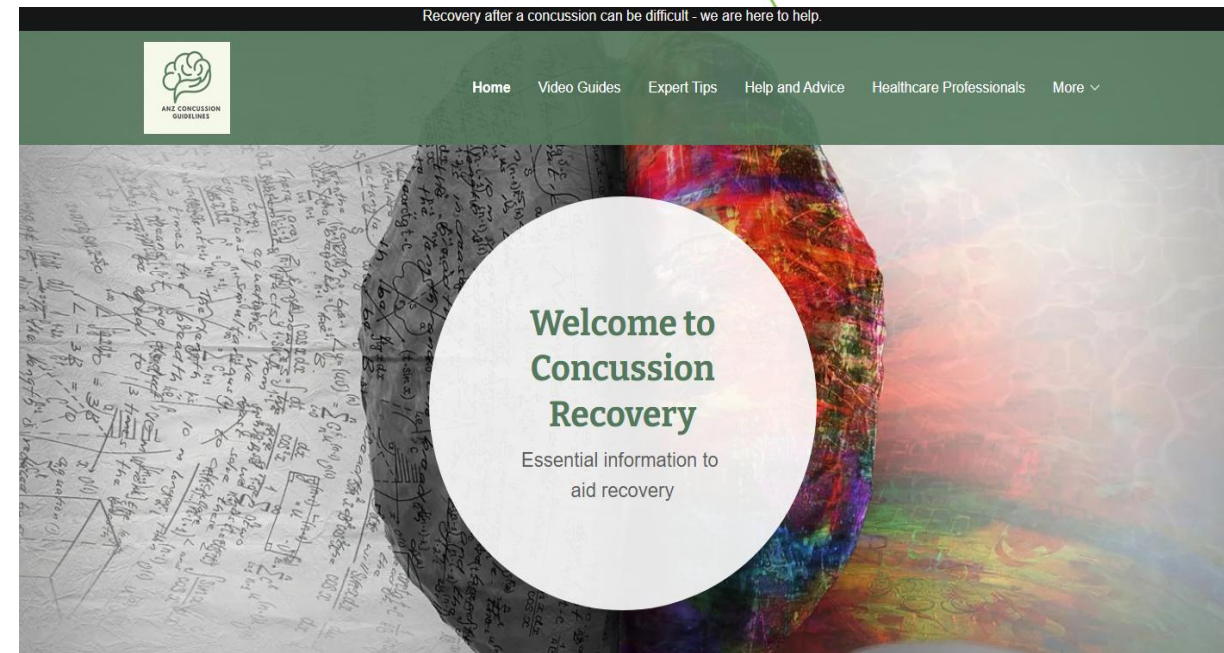
More Qualitative Results: Satisfaction

50 participants

- Most families found our Complex Concussion Clinic helpful
- 68% (34 pts) engaged with community resources
 - Mostly GP, counselling/psychology and physio
 - - in keeping with our model of care
- Most common Feedback from Families was:
 - Request for Faster access to support
 - Request for more support and education (beyond our routine care)
 - More acknowledgement of the stress on the family
 - More ONGOING support
 - More support with return to school
- 68% (34/50pts) of these patients were “Review on Request” but most did not reach out for further review

Routine CCC care:

- QCH Concussion Fact Sheets- symptoms, school & sports
- www.kidsconcussion.com.au
- Certificate for school
- Education, contact details & encouragement to call anytime



Project Summary

- Many patients were still not fully recovered 1-2 years post injury,
- Many were seeking/needing help outside our clinic,
- Families were stressed and asking for more support,
- Most families did not re-engage with us for more help

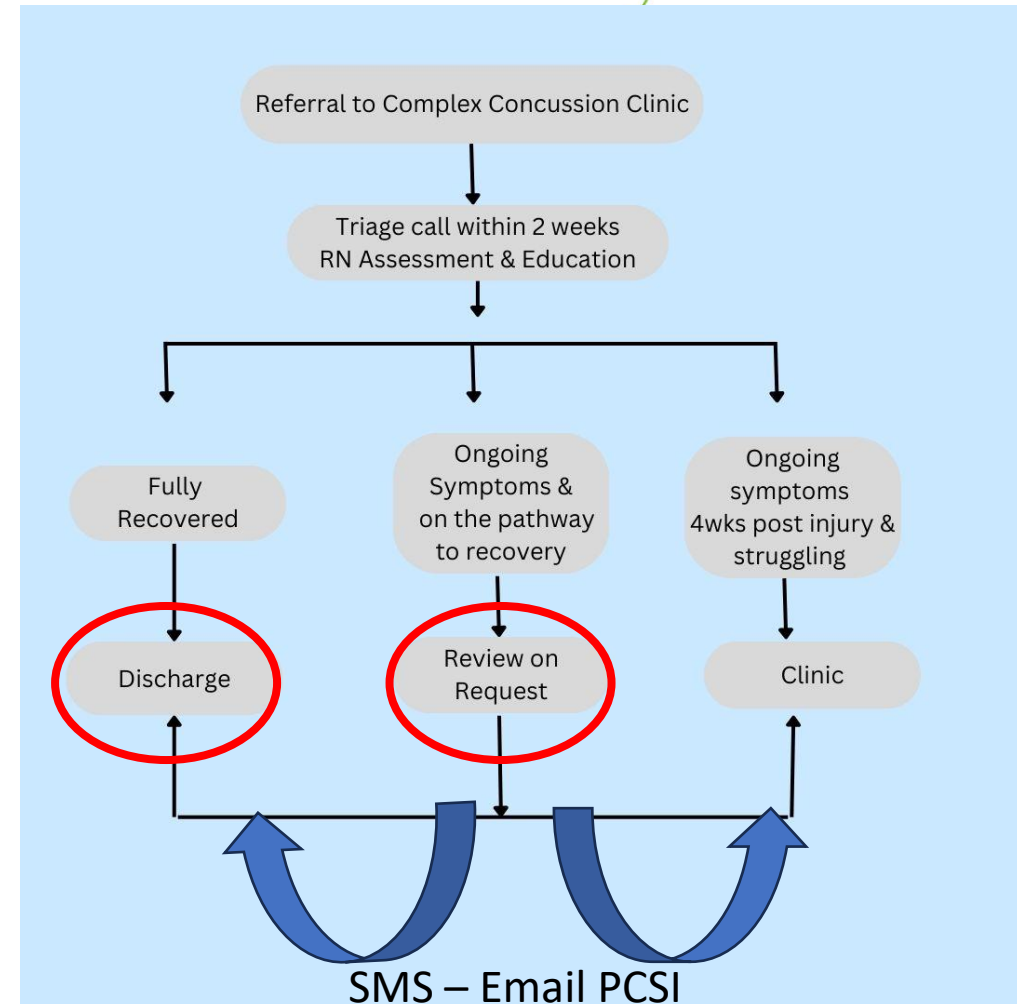


What Next? Model of Care Review

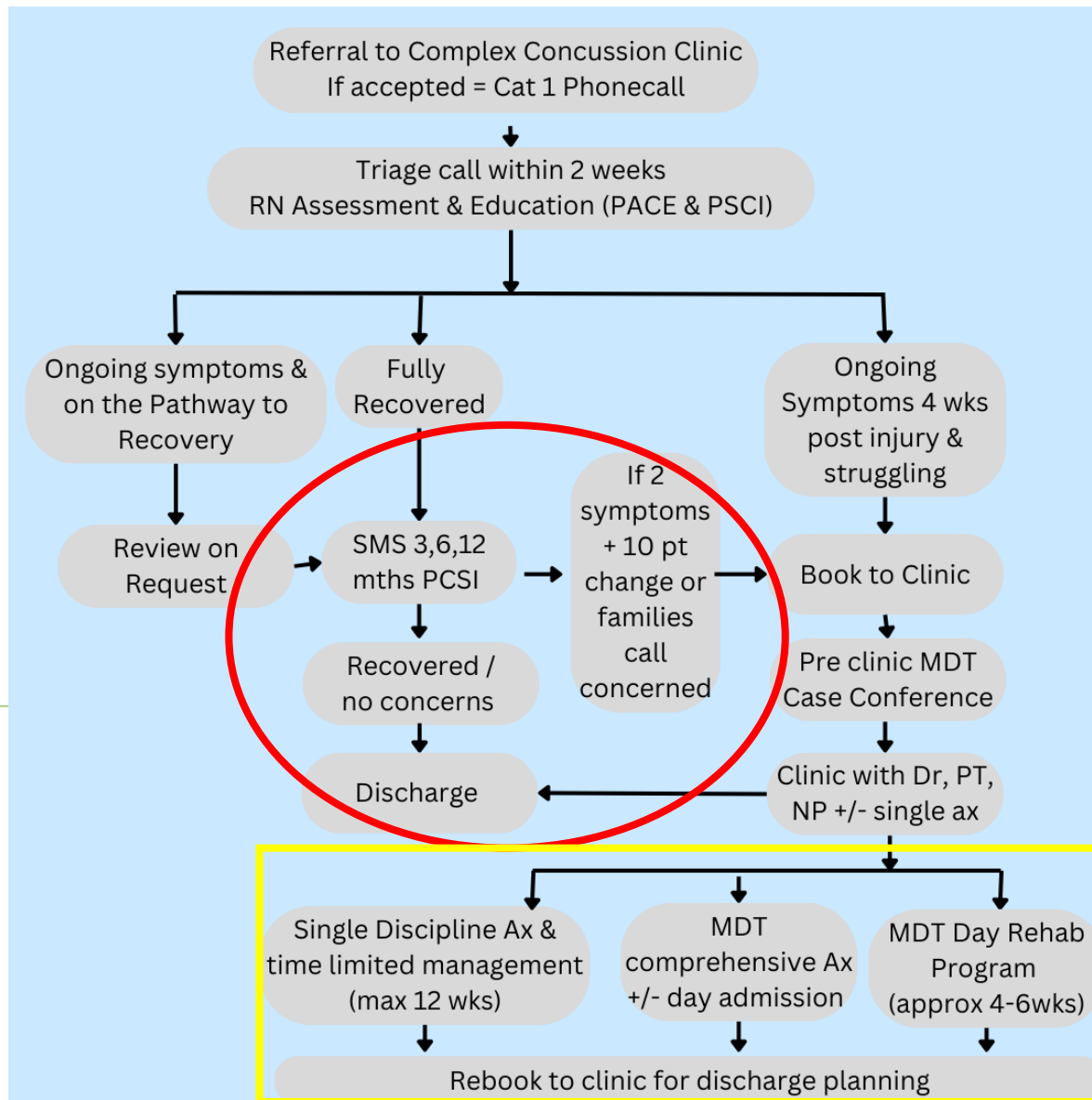
- Feedback has been useful to guide service changes which includes:
 - **Rehab Approach:** Increase Validation, Empathy & Trauma informed care
 - **Support:** Increase follow up supports/services
 - **New pathway of Care for patients with various levels of Clinical Intervention**
 - Single assessment in clinic
 - Single discipline assessment and therapy program (time limited max 12wks)
 - MD Ax +/- Day Rehab Program (6 weeks max) including telehealth options
 - **Closed Loop Telemonitoring Concussion Care Project**

Model of Care Changes: More Support Closed Loop Telemonitoring Concussion Care Project

- Created Automated SMS followup to all families
 - At 3, 6, 12mths post initial contact to review recovery progress
 - Questionnaire automated using REDCAP, Digital Information and Integration of systems.
 - From here we can re-engage or discharge patients
 - $2 < \text{symptoms}$ or $10 \text{ pt change on PCSI} = \text{r/v in clinic}$ otherwise at end of 12mths = discharge
- To close the loop in the care for these patients



Complex Concussion Clinic: MOC Changes for 2025

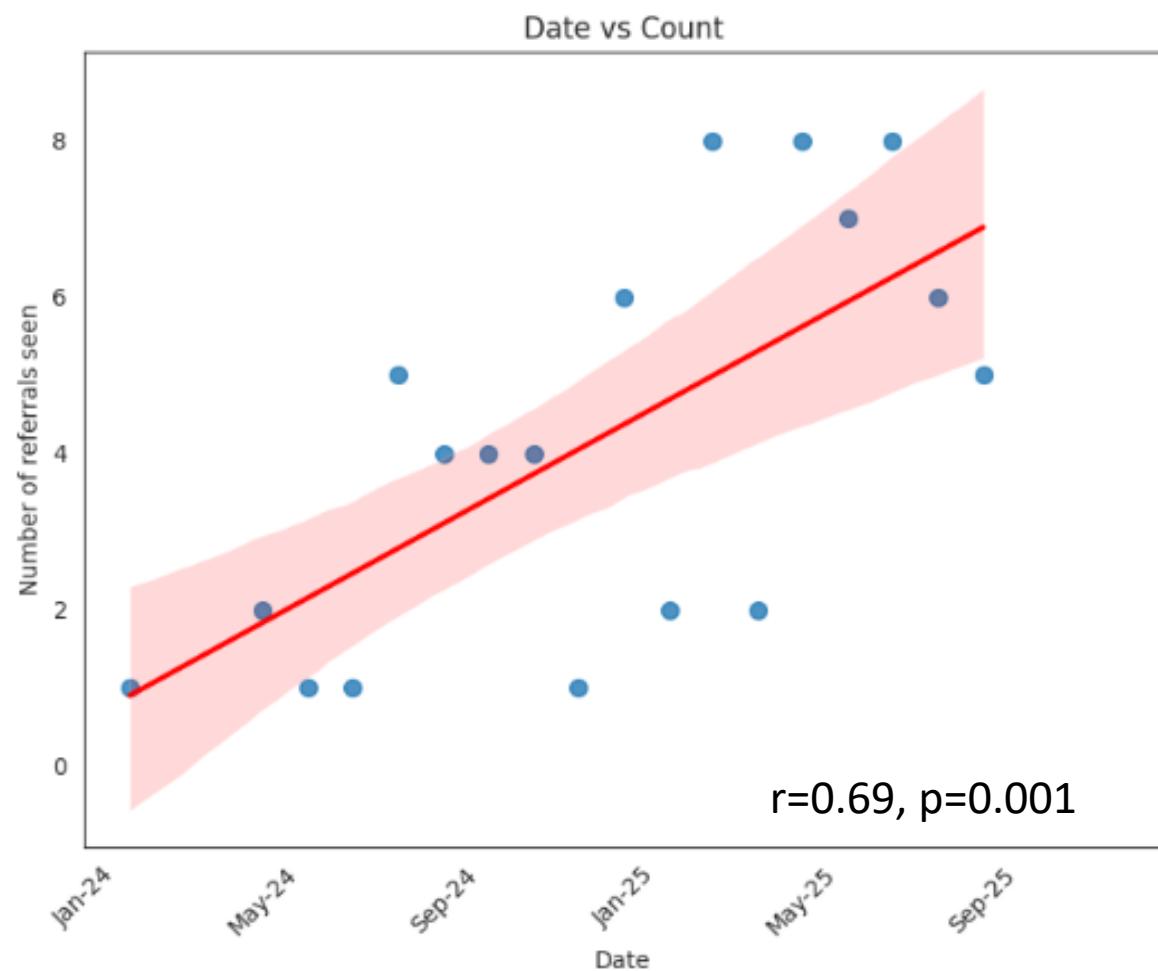
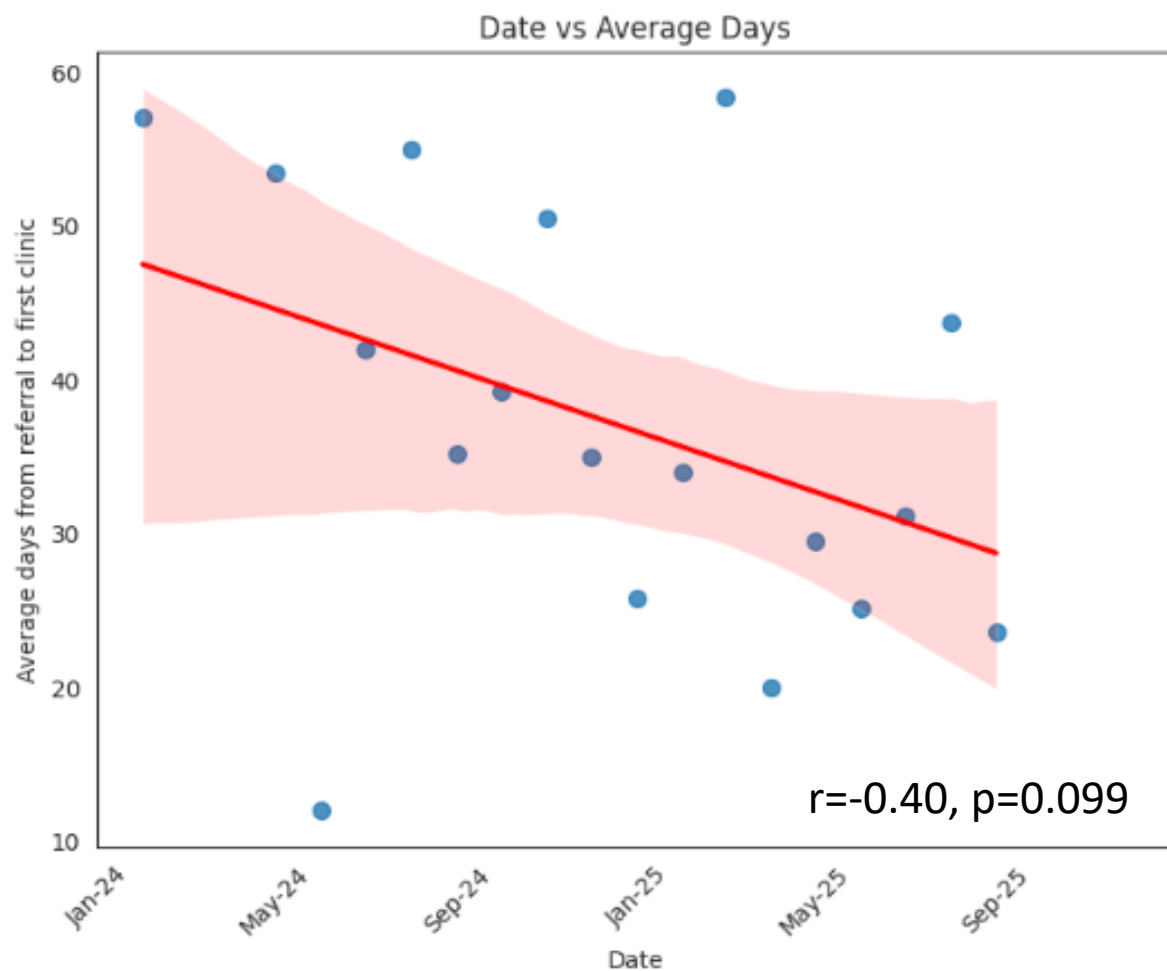


- More follow up support & completion of care
 - Developed a closed-loop telemonitoring system with support of a SERT grant
- Pilot new model of care
 - Various intensive therapy options including telehealth

*NB: all patients accepted currently receiving the follow up SMS 3,6 & 12mths

Complex Concussion Clinic: New MOC Outcomes

Whilst patient numbers increasing, wait time from referral to 1st clinic is decreasing



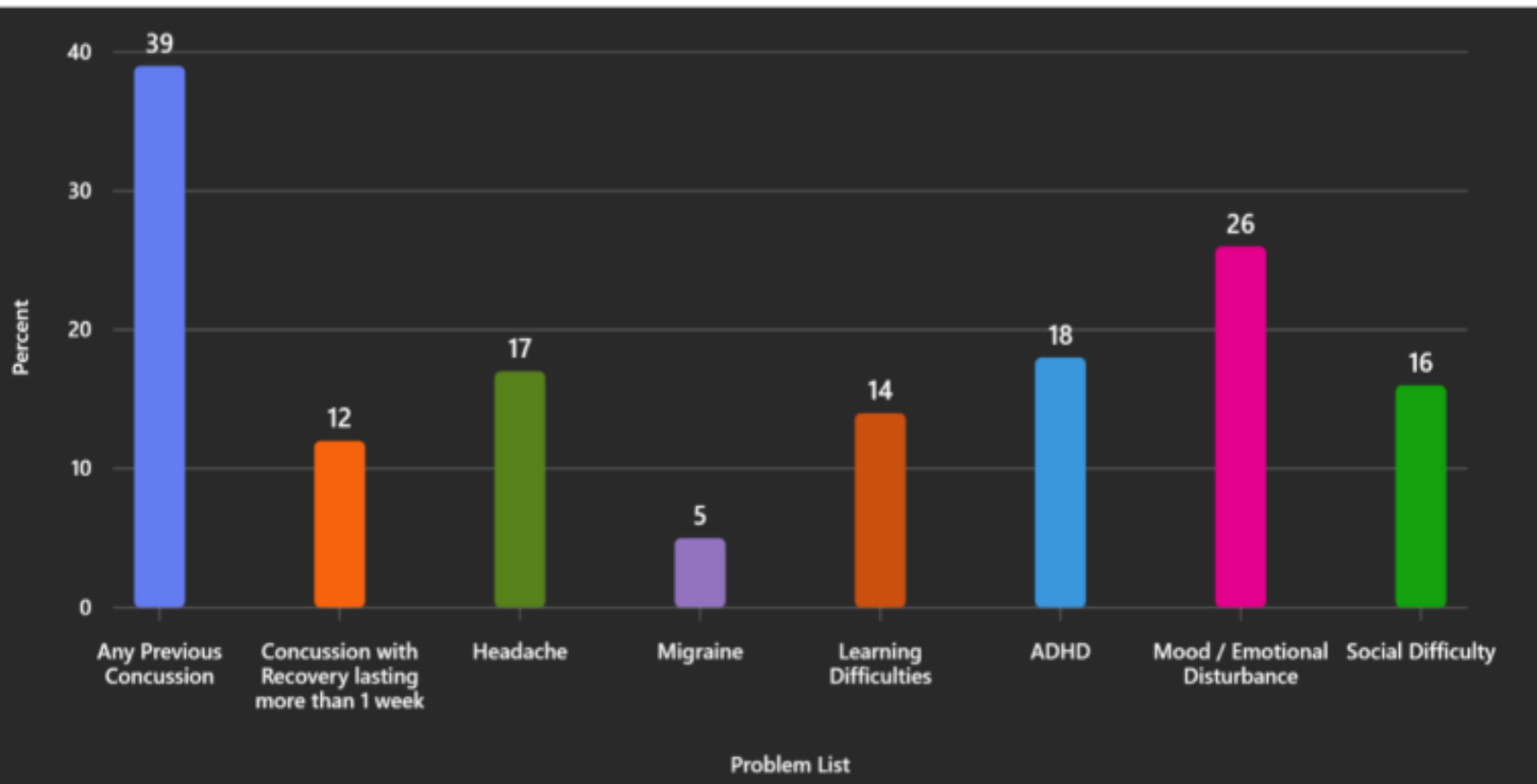
Complicating Premorbid Factors

These factors are associated in literature with persisting symptoms however they were not factors that brought the patients into clinic. Nor were pre-injury symptoms.

Severity of symptoms (PCSI) was determining factor for clinic review.

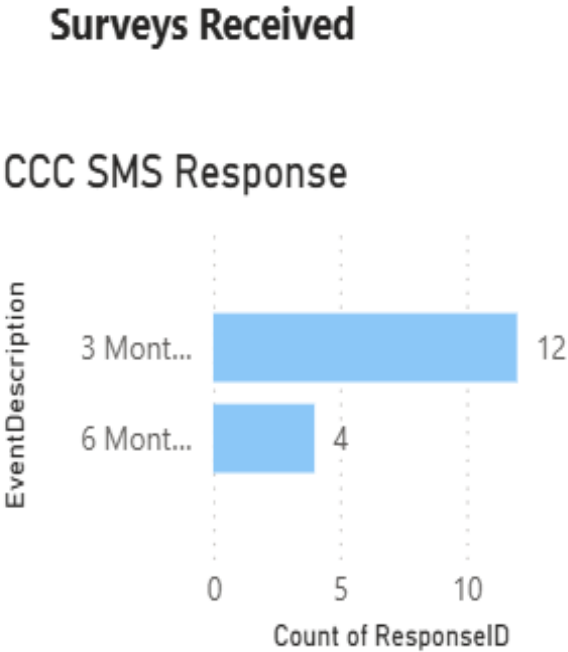
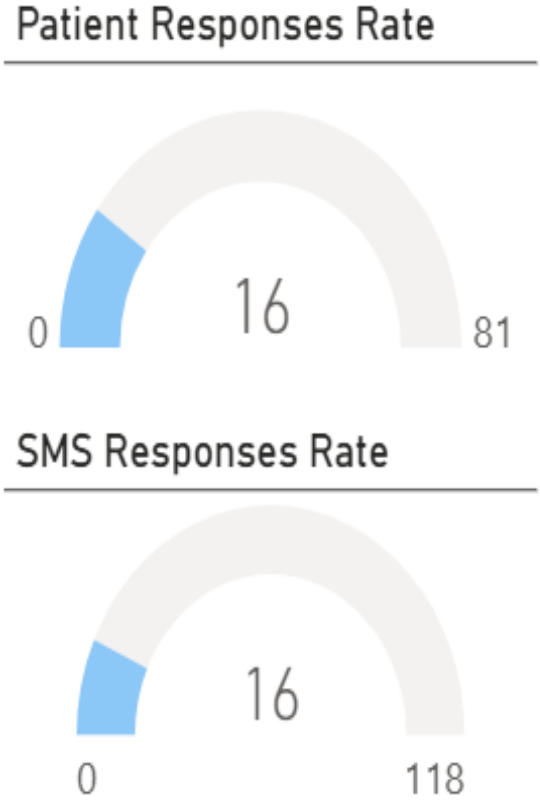
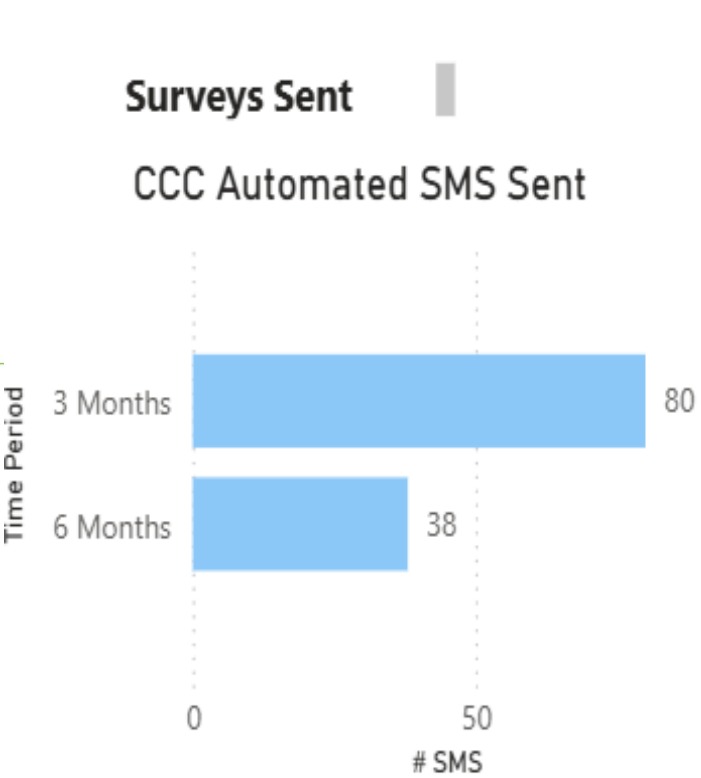
Who needed to come to clinic?

- **Pre injury PCSI:** No difference between *clinic vs phone call only* groups
- **Post injury PCSI:** statistically different between the *clinic vs phone call only* groups
- **Mechanism of Injury :** No differences across groups



Complex Concussion Clinic: Closed Loop Telemonitoring Outcomes to date

- 3mth text
 - 12/80 pts replied (15% response rate)
- 6mth text
 - 4/38 pts replied (10% response rate)



Complex Concussion Clinic: Closed Loop Telemonitoring Outcomes to date

PCSI Mean Scores

	Pre-Injury	SD	Post-Injury	SD	Difference	SD
Physical	1.9	3.7	10.8	10.4	9.1	9.5
Emotional	1.6	3.2	6.8	7.1	5.2	6.4
Cognitive	1.7	3.3	8.6	8.6	6.9	7.7
Sleep	0.4	1.3	4.9	4.9	4.5	5.0
Total	5.5	9.4	30.8	26.5	25.6	24.4

PCSI Scores of those who have replied to the 3 and 6 months SMS

		Physical	Emotional	Cognitive	Sleep	Total
3 Months	Mean	8.8	5.8	5.3	4.7	24.5
	Median	5	4	1	2	16.5
	SD	9.5	6.5	7.7	6.3	23.9
	Lowest	0	0	0	0	0
	Highest	34	22	22	18	81
	N	12	12	12	12	12
6 Months	Mean	10.8	7	6.3	2	26
	Median	5.5	6.5	3.5	2	17.5
	SD	14.7	7.2	8.3	2.3	31.5
	Lowest	0	0	0	0	0
	Highest	32	15	18	4	69
	N	4	4	4	4	4

Follow up Summary

3-Month Text Response

- 10/12 patients report ongoing symptoms
- Average PCSI: improved from 30 → 24

6-Month Text Response

- 2/4 patients had ongoing symptoms

Support Requests

- 5/16 patients requested follow up call
- No patients required clinic appointments
- Care provided via telehealth or existing clinic bookings

Symptom Detail (3-6 months post initial call)

- 12/16 pts reported ongoing symptoms
 - 5 new diagnoses: Autism, FND (x2) , Eating disorder, new concussions
 - 2 patients: felt back to normal despite symptoms
 - 1 patient: mild symptoms, no further support needed

Complex Concussion Clinic Goals & Next Steps

Goal of the New Model of Care

- Provide better statewide Paediatric Complex Concussion Care
 - Provide care earlier and more options for intervention
 - Support to reduce the symptom load & get back to usual activities ASAP
 - Reduce patient and family stress
 - Reduce families needing to search for more help
 - Close the concussion care loop

Next Steps

- Review of New Model
 - Collect and respond to our SMS responses
 - Provide day rehab treatment programs and collect outcomes
 - Survey the families for their feedback
 - Is anyone is still seeking help outside our clinic?
 - Are patients back to school and their usual activities?
 - Is this new model improving family stress levels?

Acknowledgements

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