NSW Paediatric Rehabilitation Services

Goal directed medication prescribing in paediatric cerebral palsy: A shared approach across the NSW PRS Network

HNEkidsRehab - Alysha Gill (Occupational Therapist), Dr Saranya Subbaraman (Registrar), Dr Heather Burnett (Staff Specialist)

Rehab2Kids - Johnny Leung (Physiotherapist), Penelope Ingle (CNC), Dr Anna Ward (Staff Specialist), Susanna Jetson (Occupational Therapist), Rebecca O'Donnell (AHA)

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Background

Prescribing oral medications for tone management in cerebral palsy (CP) has historically lacked consistency

Challenges

- Difficulty assessing the functional impact of tone medications

Current Issues

- Family persistence with ineffective medications
- Lack of measurable standardized outcomes for functional performance and family/child satisfaction
- Reduced clarity for families/patients about expected medication outcomes and clinician uncertainty about how to manage medications

(Mink, 2013; Rice et al., 2013)

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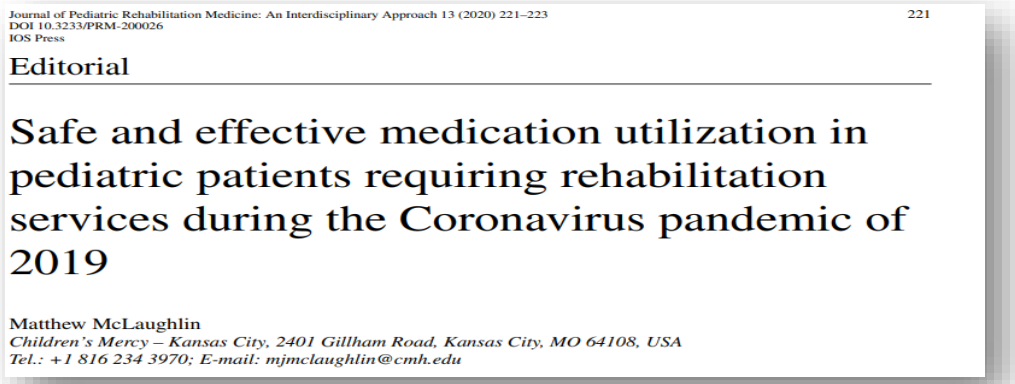
Literature



Journal of Pediatric Rehabilitation Medicine: An Interdisciplinary Approach 13 (2020) 221–223 221
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Editorial

Safe and effective medication utilization in pediatric patients requiring rehabilitation services during the Coronavirus pandemic of 2019

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Journal of Paediatrics and Child Health
RACP Specialists. Together

Original Article

National surveillance of oral medication prescription for children with dystonic cerebral palsy

Adrienne Harvey, Natasha Bear, James Rice, Giuliana Antolovich, Mary-Clare Waugh

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SYDNEY CHILDREN'S HOSPITAL RANDWICK

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"I wasn't sure whether to start or not"

The journey towards consistent management of hypertonicity

Susanna Cahill (OT), Johnny Leung (PT), Pene Ingle (CNC)
With Dr Anna Ward and Rebecca O'Donnell (AHA)

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(Cahill et al., 2023; Harvey et al., 2021; McLaughlin, 2020)

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Aim

Primary Objectives

- Develop a structured, goal-directed approach to medication prescribing in paediatric cerebral palsy using the Canadian Occupational Performance Measure (COPM) (Law et.al., 1990)
- Align medications with individualized functional goals for children and families

Secondary Objectives

- Assess utility of the COPM for medication prescribing
- Evaluate effectiveness of this approach
- Structured framework for side effect monitoring

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Timeline

Jan 2024

- **Commenced project**
- Project aim
- Inclusion/exclusion criteria
- Chose standardised outcome measure
- Determine project design, local resourcing and documentation

Feb 2024

- Commenced **recruitment and implemented** new local/rural process
- **Collaborated** with Rehab2Kids
- Adapted **medication proformas** to local HNE processes

Aug 2024

- Formalised and **consolidated process**
- Continued **recruitment**

Oct 2024

- **Formalised processes and roles** within the team
- Streamlined data collection

Feb -Sep 2025

- **Analyse data** collected over the last 18 months
- **Liaise** with Rehab2Kids on our progress

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Design

- 44 participants
- John Hunter Hospital Research Governance and Ethics

***Inclusion*:**

- Children aged 0-18 years seen in Cerebral Palsy and Movement Disorder clinics
- Commencing new medications or significant dose changes
- Patient/family willing to participate in setting and evaluating goals via telehealth

***Exclusion*:**

- Medication prescribed for sialorrhea
- Botulinum toxin treatment

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Current Method

Former Method

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HNEkidsRehab
621 Hunter Street
NEWCASTLE NSW 2300
Telephone: (02) 49257 868
Facsimile: (02) 49257 909

Community Health Services
CHILDREN, YOUNG PEOPLE AND FAMILIES

Date:

Re:
DOB:
MRN:

Oral Baclofen for Spasticity Management-(60mg/day dosing Regime)

This letter is to inform you that the above child is trialling a medication for the management of spasticity. This medication is to help reduce the spasticity of the muscles.

It is important that the dose of the medication is gradually increased. Usual dose is 30mg per day for those <20kg or 60mg per day for those >20 kg. Dose maximum 2 mg/kg/day (to maximum of 80 mg per day for adult size child)

We recommend the following regimen with Baclofen 10 mg tablets (60mg/day dosing regime)

Week	Breakfast	Lunch	Dinner
1	-	-	1 tablet
2	1 tablet	-	1 tablet
3	1 tablet	1 tablet	1 tablet
4	1 tablet	1 tablet	2 tablets
5	2 tablets	1 tablet	2 tablets
6	2 tablets	2 tablets	2 tablets

Important:

- If your child has a good effect before they reach the maximum dose, stay on that dose. You do not need to increase it any further.
- **Do not stop** the Baclofen without consultation with the HNEkidsRehab team. It must be **slowly weaned.** If your child has been on the maximum dose of baclofen for one month without a good effect, contact the HNEkidsRehab team to discuss next steps.
- Baclofen can be safely taken with most other medications, including gabapentin, paracetamol and Ibuprofen.
- Common side effects include drowsiness, floppiness of the muscles and worsened constipation. Some children with epilepsy will experience more seizures when taking baclofen.

Contact HNEkidsRehab on 4925 7868 or hnelhd-hnekidsrehab@health.nsw.gov.au with any concerns about this medication.

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Hunter New England Local Health Network

HNEkidsRehab
621 Hunter Street
NEWCASTLE NSW 2300
Telephone: (02) 49257 868
Facsimile: (02) 49257 909

Community Health Services
CHILDREN, YOUNG PEOPLE AND FAMILIES

GOALS

The goals identified for this medication trial are listed below. This will be reviewed in a follow-up Telephone/Teams call at **Week 12.**

	Goals
1	
2.	
3.	
4.	
5.	

SIDE EFFECTS:

Like all medications there could be side effects. None of these are common. These may include:

- Excessive drowsiness,
- Excessive floppiness of the muscles,
- Constipation
- Possible increased tendency to develop a fit. (Fits are not an absolute contraindication to use Baclofen)

If you are concerned about any side effects, please contact your local GP or the HNEKids Rehab team as soon as possible.

Contact for HNEKidsRehab - HNELHD-HNEKidsRehab@health.nsw.gov.au
Drs Heather Burnett or Helen Wilson/CNC Sharon Fenwick Ph. 02 49257 868

Dr Heather Burnett
Rehabilitation Staff Specialist
HNELHD-HNEKidsRehab@health.nsw.gov.au

Cc:Local GP +/- Paediatrician via Family

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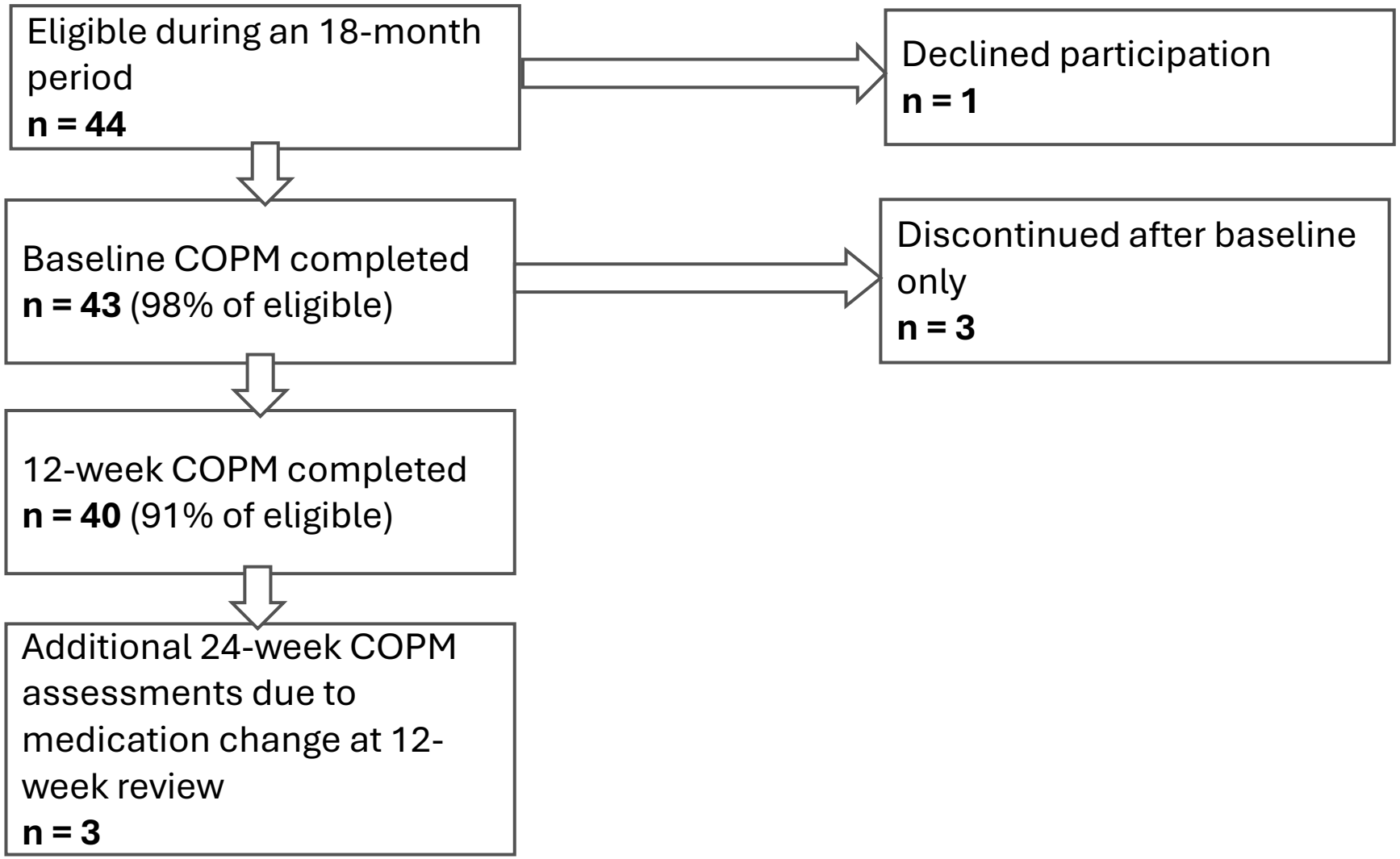
Participants Overview



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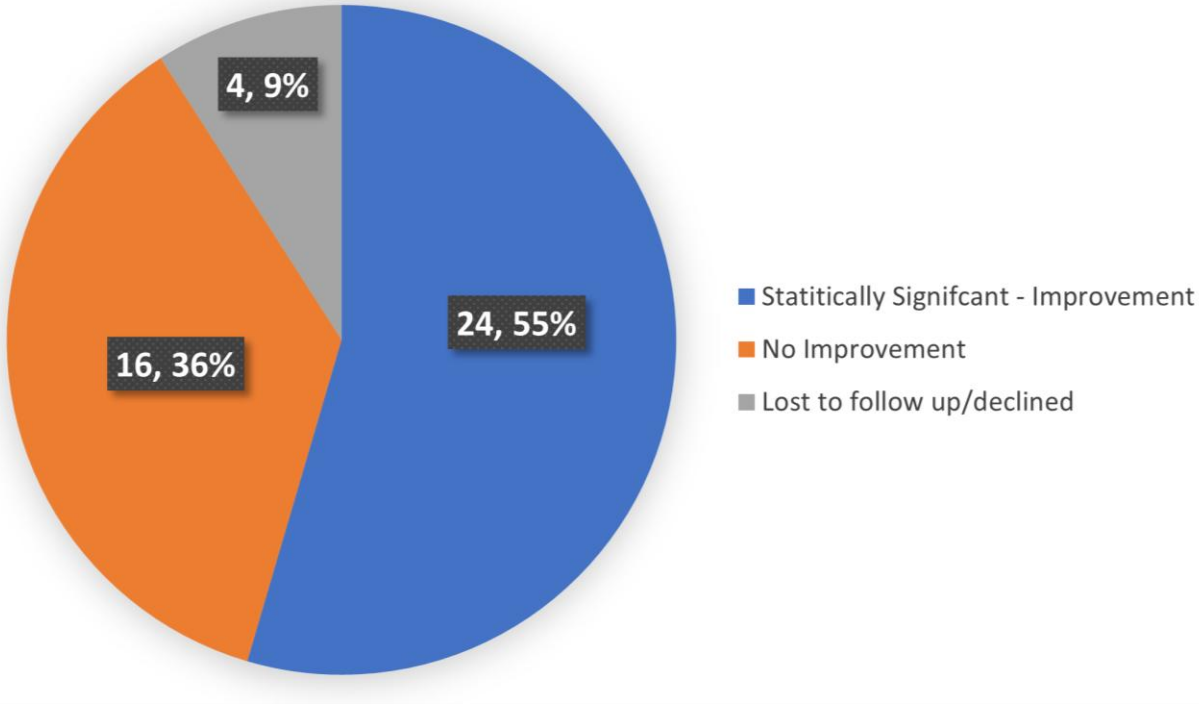
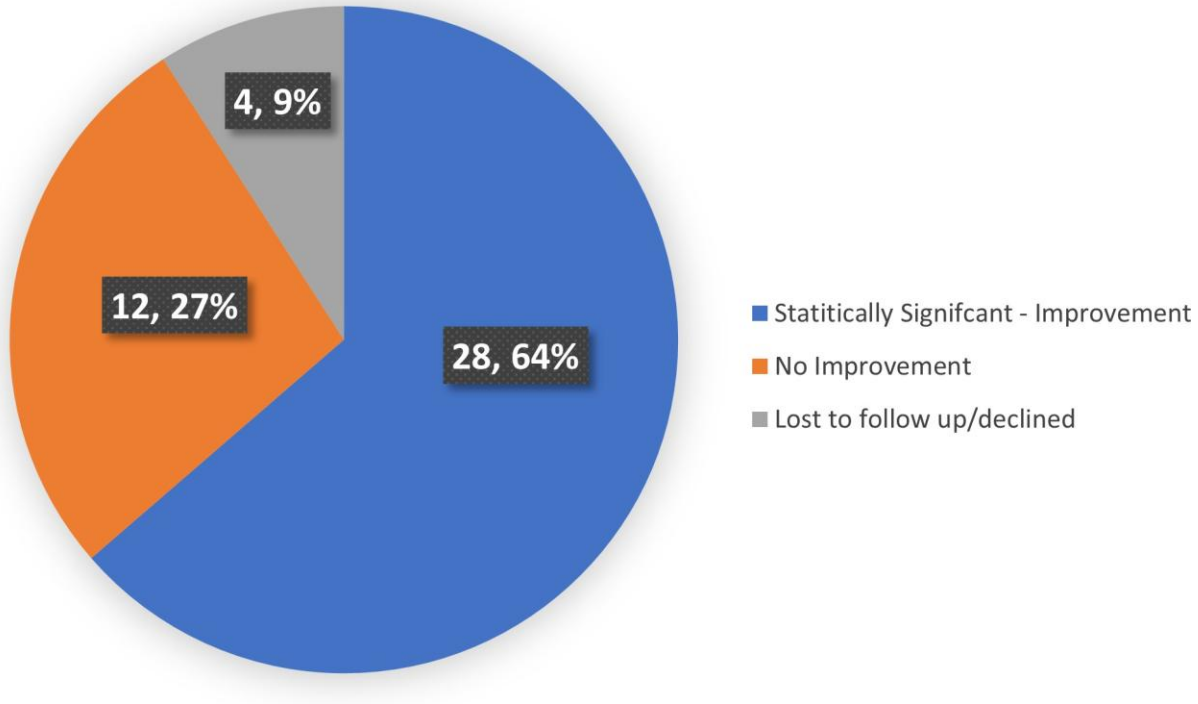
Results - Patient Level



Changes in Performance



Changes in Satisfaction

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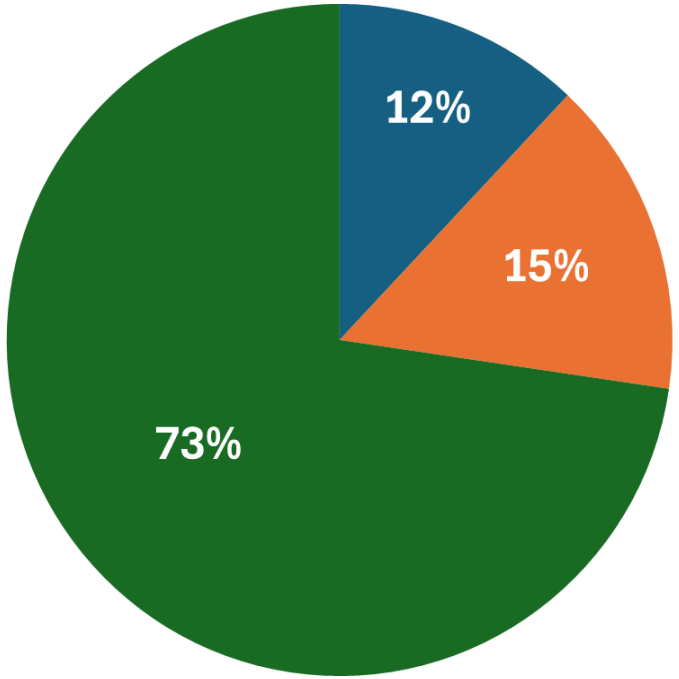
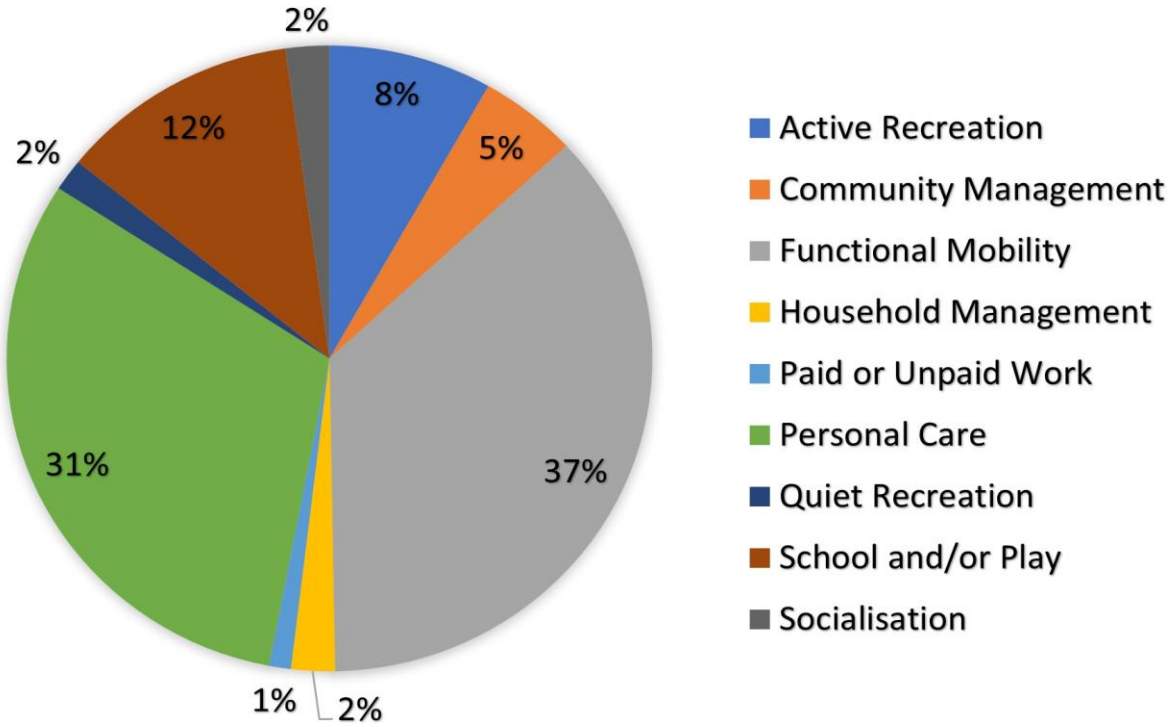
Results - Themes and Subthemes



Theme Split for Goals



Sub Theme Split for Goals

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Sub Themes

Table 2: Goal Outcomes by Subtheme (Performance and Satisfaction; clinically significant defined as ≥ 2 points)

Subtheme	Goals (n)	Perf ≥ 2 (n)	Sat ≥ 2 (n)	% Perf Sig	% Sat Sig
Functional Mobility	67	30	36	44.8%	53.7%
Personal Care	57	32	38	56.1%	66.7%
School and/or play	22	14	10	63.6%	45.5%
Active Recreation	15	10	8	66.7%	53.3%
Community Management	9	7	6	77.8%	66.7%
Socialisation	4	4	4	100.0%	100.0%
Household Management	4	3	3	75.0%	75.0%
Quiet Recreation	3	2	2	66.7%	66.7%
Paid or Unpaid Work	2	1	1	50.0%	50.0%

- Most frequent: Functional Mobility (67 goals)
- Strongest proportional gains: School/Play and Active Recreation
- Smaller sub-themes like Socialisation also showed strong responses

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Result - Medication Level

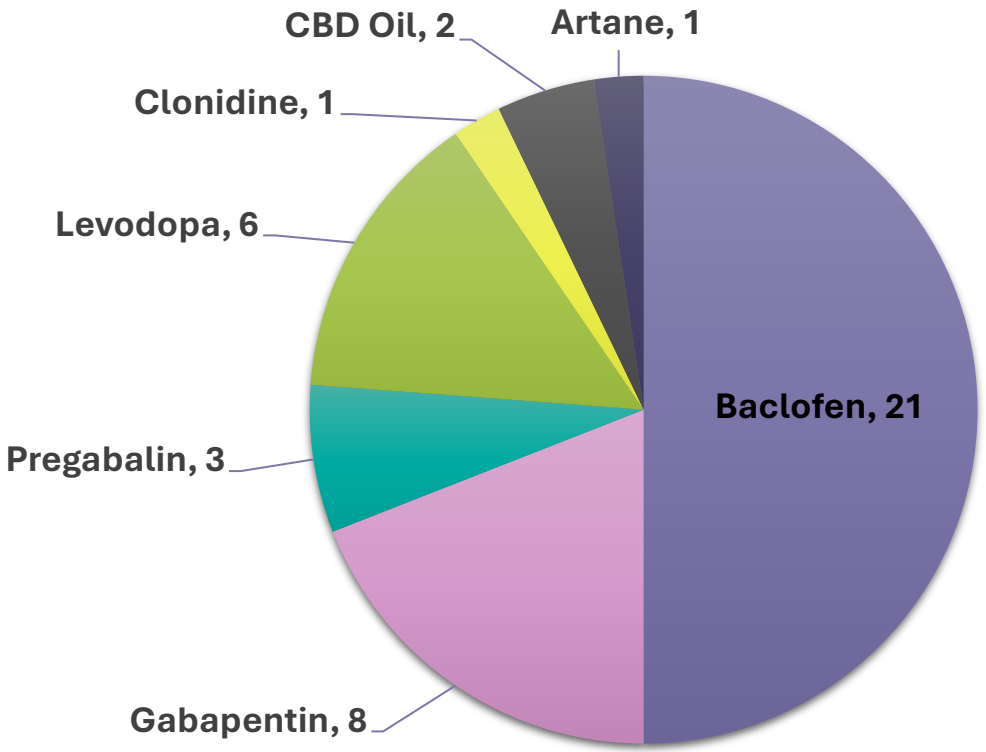

Table 3: Medication and Clinically Significant COPM Changes (≥ 2 points)

Medication	Patients	Perf. Sig.	Perf. Sig. %	Sat. Sig.	Sat. Sig. %
Baclofen	21	10	47.6	12	57.1
Gabapentin	8	5	62.5	5	62.5
Pregabalin	3	2	66.7	3	100.0
Levodopa	6	5	83.0	4	67.0
Clonidine	1	0	0.0	1	100.0
CBD Oil	2	2	100.0	2	100.0
Artane	1	0	0.0	1	100.0

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Medication Specific

What It Means

- Family response varied by **goal type** (not uniform across meds).
- COPM enabled prescribing to be shaped by **family-identified goals**, not just tone change.
- Current audit sample too small → **no firm medication–goal correlations yet**.
- Future prospective studies with larger samples needed.

Table 4: Medication–Subtheme outcomes (counts): clinically significant COPM change defined as ≥2 points

Medication	Subtheme	Goals (n)	Perf ≥2 (n)	Sat ≥2 (n)
Artane	Functional Mobility	2	0	2
	Personal Care	3	2	3
Baclofen	Functional Mobility	41	17	16
	Personal Care	28	14	16
	School and/or Play	15	9	8
	Active Recreation	8	4	4
	Community Management	5	5	5
	Socialisation	3	3	3
	Household Management	1	1	1
	Quiet Recreation	1	1	1
CBD Oil	Functional Mobility	3	1	2
	Personal Care	5	4	4
	Active Recreation	1	1	1
Clonidine	Functional Mobility	2	0	2
Gabapentin	Functional Mobility	14	8	8
	Personal Care	12	6	7
	Community Management	2	2	2
	Active Recreation	2	2	2
	School and/or Play	2	0	2
	Paid or Unpaid Work	1	0	1
Levodopa	Functional Mobility	3	2	2
	Personal Care	6	5	5
	School and/or Play	1	1	1
Pregabalin	Functional Mobility	2	2	2

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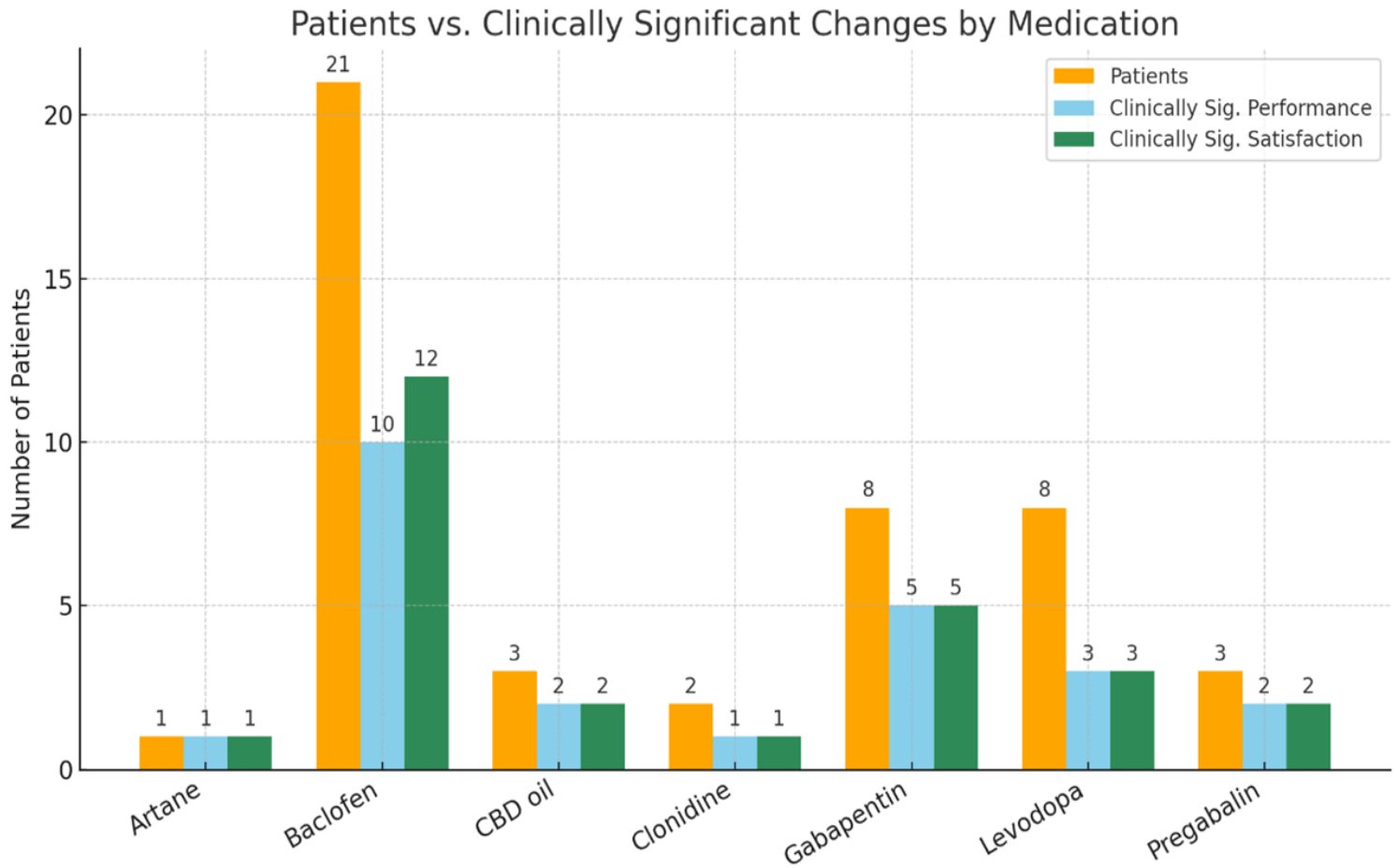
Results - Patient Level



Side Effects

1 patient improved in both domains but required an additional medication to manage adverse effects.

Interventions for Non-Responders

- 6 continued same medication
- 2 reverted to previous dosage
- 6 ceased medication
- 2 had adjustments

(dose change or new agent added)

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In Summary

- 91% participation rate among eligible patients
- COPM enabled prescribing to be linked directly to **family-identified goals**, improving clarity and shared decision-making.
- Families valued **specific goal improvements** and **medication tolerability** even when overall COPM scores were not significant.
- Sub-theme patterns (Self-care, Functional Mobility) dominated, but smaller areas (Socialisation, Community Management) also showed gains.

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Clinical Reflections

Positives

- Families value quantifiable goals to track progress
- Extra family support from clinicians
- Real-world outpatient data, high participation
- Families feel empowered and involved
- Fewer phone calls to nursing staff about medication queries
- Early management of side effects
- Telehealth adequate modality
- COPM is an effective outcome measure

Limitations

- COPM does not account for external factors impacting goals
- Small sample sizes for medications
- Assessor variability
- Inconsistent reporting when different parents complete pre/post-intervention COPM
- Increased workload for registrars, allied health and admin staff with no additional staffing

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Conclusion

Where to next…

- Prospective multicentre study with longitudinal follow up data
- Qualitative data evaluation
- Digital/AI solutions (apps) could streamline goal capture and analysis, reducing labour burden
- Potential to tailor prescribing medication to functional goals that matter most to families
- Collaboration with Rehab2Kids for literature publication

Sustainability

- JMO orientation / handover
- Business case opportunities
- Expansion across HNEkidsRehab services e.g. Brain Injury Service, General Rehab, Spinal
- Continued collaboration across NSW PRS

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