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Using Consumer Surveys to Impact the Scope of Clinical Practice Guidelines

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Background: The Unknown

2006: American Physical Therapy Association (APTA) Orthopedic Section began CPG development

2009: APTA Pediatric Section began CPG development

2011 Institute of Medicine: Clinical Practice Guidelines We Can Trust

3.2 Patient and public involvement should be facilitated by including (at least at the time of clinical question formulation and draft CPG review) a current or former patient, and a patient advocate or patient/consumer organization representative in the GDG.

2012: APTA initiates CPG training for authors: Addresses need for consumer representation beyond an advisory panel

Currently 32 published guidelines from 8 specialty academies.

Consumer involvement rates had not been reviewed.



Background: Survey Benefits

- **Increased relevance to consumers** (Kottner,2019; Haesler, 2022; Khodyakov, 2019; Proctor, 2020; Cronin, 2018; Coenen, 2020)
- **Identifies differences in consumer and developer priorities** (MacLellan, 2021;Tong 2016; Proctor, 2020; Zanker, 2022; Coenen, 2020)
- **Expands guideline compliance among clinicians** (Kottner, 2019; Yawn, 2012; Cluzeau, 2012; Kelson, 2012; Petrovic, 2020; Marcelo, 2023)
- **Improves quality of care** (Proctor, 2020; Cronin, 2018; Blackwood, 2020; Tong, 2016; Miller, 2017; Barkocy, 2021)
- **Reduces variability in care** (Barkocy, 2021)
- **Provides insight about the strength of recommendations** (Haesler, 2022)
- **Offers consumer education** (Cronin, 2018)
- **Boosts consumer representation** (Khodyakov, 2019)



Aims and Methods

Aim: To explore the frequency and impact of surveys to increase consumer representation in APTA sponsored clinical practice guidelines.

Methods: Review of all published

- APTA Academy sponsored CPGs
- Physical Therapy Journal CPG publications by other entities
- Literature review of published survey results used to inform APTA or PTJ CPGs



Results: The Numbers

32 APTA Academy sponsored +15 PTJ Non-APTA = 47 CPGs published from 2004 - 2023

	APTA Supported CPGs n=32			Physical Therapy Journal CPGS n=15		
	No Survey	CPG Survey	Cited Survey	No Survey	CPG Survey	Cited Survey
No reported consumer involvement			1	1		
1-2 consumers involved	1	1			1	
3 or more consumers involved	2		8	7	5	1
Consumer surveys of clinicians	16	6	6			
Consumer surveys of people/families with the condition		5	2			



Results: Impact

- **Congenital Muscular Torticollis (2013)**
 - Validated the need and priorities for content. 85% of topics were addressed in original 2013 CPG
- **Chronic Neurological Condition Core measures (2018)**
 - Surveys of MDs, PTs and patients with spinal cord injury, Parkinson's Disease and Strokes agreed on the same 3 outcomes as the most critical to measure
- **Ankle Foot Orthoses (2021)**
 - Clinicians focused on the examination; consumers wanted more education about selection, use and costs. Both wanted info on effectiveness and long term impact.
- **Down Syndrome (In progress)**
 - Parents/caregivers surveyed and young adults with Down Syndrome participated in focus groups
 - Validated the critical issues to address
- **CP Mobility (In progress)**
 - Validated interventions that both consumers and clinicians agreed were priorities
- **Developmental Coordination Disorder (2020)**
 - Priorities identified as needs for DCD definition, differential diagnostics and quick reference guide.



Limitations

- APTA CPGs are produced through volunteer efforts
 - No singular methodological process so variations exist.
 - Conducting a survey + systematic review requires more time and support
- Updated CPGs may not reflect the use of consumer surveys if professional adoption has been strong.
- Recruiting adequate numbers of consumers is difficult.



Conclusions

- Consumer surveys in APTA CPGs
 - Increased representation
 - Validated the need for selected CPGs
 - Impacted the scope, content and language in CPGs
 - Increased the publication yield for guideline author groups
 - May delay CPG progress if author group has limited time
- Need to find more opportunities to
 - Train author groups to include surveys
 - Consider standardizing consumer surveys to inform CPG scope/content



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