Using Consumer Surveys to Impact the Scope of Clinical Practice Guidelines

Sandra L Kaplan PT, DPT, PhD, FAPTA
kaplansa@shp.Rutgers.edu
Rutgers University, Newark, NJ, USA

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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

<table>
<thead>
<tr>
<th></th>
<th>APTA Supported CPGs n=32</th>
<th>Physical Therapy Journal CPGS n=15</th>
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<tbody>
<tr>
<td>No reported consumer involvement</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>1-2 consumers involved</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>3 or more consumers involved</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>Consumer surveys of clinicians</td>
<td>16</td>
<td>6</td>
</tr>
<tr>
<td>Consumer surveys of people/families with the condition</td>
<td>5</td>
<td>2</td>
</tr>
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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