

‘A Healthy Life for a Child with Medical Complexity’: 10 Domains for Conceptualizing Health¹

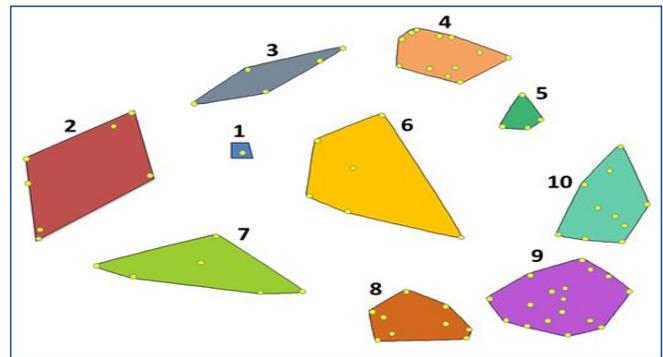
INTRODUCTION: Children with medical complexity² (CMC) have serious and complex chronic illnesses that result in very different health trajectories than other children. It is unclear how well traditional pediatric health outcome measures apply to CMC. We sought to identify potential measures that align with a broad view of health for CMC – one that might also help redefine health for all children. Research was conducted at UCLA and University of Wisconsin-Madison by Elizabeth Barnert, Ryan Collier, and colleagues.

METHODS: We recruited a national sample of 125 CMC experts for group concept mapping (GCM). Respondents first completed internet-based idea generation by providing unlimited short responses to the focus prompt, “A healthy life for a child or youth with medical complexity includes: _____”. The resulting 707 statements were consolidated into 77 unique ideas. Participants then sorted the ideas into groups based on similarity and rated items on importance and measurement feasibility. Using GCM software, we analyzed responses and developed cluster maps (based on idea similarity) and “go-zone” maps (based on importance and measurability).

SUMMARY OF FINDINGS: Experts identified 10 key health outcome domains that are important for all health systems to achieve for their CMC patients.

1. basic needs
2. inclusive education and services
3. child social integration
4. current child health-related quality of life
5. long-term child and family self-sufficiency
6. family social integration
7. community system supports
8. health care system supports
9. high-quality patient-centered medical home
10. family-centered care

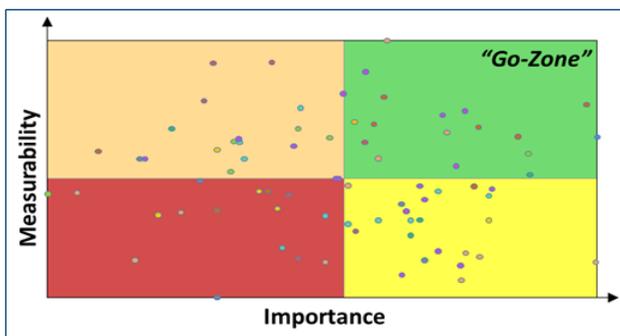
Cluster Map of Health Outcome Domains



TOP 5 “GO-ZONE” OUTCOMES: IMPORTANT AND FEASIBLE TO MEASURE

1. having basic needs met, such as housing, food, clothing, and safety (Domain 1)
2. comprehensive and uninterrupted health insurance that covers all equipment, service, or care needs (Domain 8)
3. parents/caregivers who understand and have the skills to manage the child's health at home (Domain 4)
4. services and supports they need to remain in the community (Domain 2)
5. access to necessary and high-quality specialty medical care (Domain 8)

Health Outcome “Go-Zone” Map



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1 Barnert et al., Experts’ A Healthy Life for a Child with Medical Complexity: 10 Domains for Conceptualizing Health, Pediatrics. 2018 Aug;127
2 CMC are most commonly conceptualized as having a combination of significant family-identified service needs; chronic, severe conditions; functional limitations; and high healthcare use (Cohen et. al, 2011).