

Supplemental Information

DOMAIN DESCRIPTIONS AND STATEMENTS LISTED IN ORDER OF IMPORTANCE AS IDENTIFIED BY PARTICIPANTS

Domain 1: Basic Needs

CMC having their basic needs met

76: having basic needs met, such as housing, food, clothing, and safety

Domain 2: Inclusive Education

Access to an education system that fully supports CMC and allows the opportunity for maximal participation in school

1: minimal absences from school because of outpatient and inpatient health services

6: living in a community that works to accommodate their needs

10: school and/or district liaisons for parents who have CMC

20: an individualized education plan that is used to optimize learning and development

58: minimal absences from school because of the child's health

64: education for the school on how to care for the children

65: maximal access to learning and educational and/or social participation in school

Domain 3: Child Social Integration

The opportunity for full social immersion and acceptance by a community that empowers CMC

15: freedom from bullying, discrimination, abuse, or neglect because of their disability

60: participating in school, family, and other social or recreational activities that bring pleasure or enrichment

16: being part of a community of shared values and beliefs

68: access to role models who have thrived with similar conditions

55: time outdoors

Domain 4: Current Child Health-Related Quality of Life

Physical, emotional, and social aspects related to the health and developmental status of CMC

2: feeling loved and valued

28: hope

3: frequent positive emotions and infrequent stress or emotional distress

72: having a resilient, well-functioning family

26: absence of pain

30: living in a home with a family

57: goals for his or her future

19: consistently high-quality and restful sleep

37: self-confidence

17: celebrating milestones

74: self-identification as just a "normal" kid or family

32: a home that looks and feels like a home, not being overwhelmed by medical equipment

Domain 5: Long-term Child and Family Self-Sufficiency

The presence of confident and self-reliant management of care for CMC

29: parents and/or caregivers who understand the condition well and have the skills to manage the child's health

38: living in a family that understands how to access services for the child

27: successful transition to maximum levels of physical, social, and work independence

18: large spans of time without, or "vacations" from, medical appointments or procedures

Domain 6: Family Social Integration

Access to family social supports that allow the family to fully participate in the child's life and remain active in the community that they live in

66: parents who are able to fully participate in their children's care without fear of losing their jobs or income

46: respite care

75: nutrition that is both culturally and medically appropriate

73: supporting siblings through programs such as sibling support groups, actively participating in social and/or recreational activities, and 1-on-1 time with parents

39: having venues for the child and family to have their voices heard, such as through family and/or youth advisory councils

59: the family not being limited to where they can live geographically because services are only available in certain cities or regions

Domain 7: Community System Supports

Access to social and physical supports that allow CMC to navigate their homes and communities

- 23: adequate benefits that cover the children's needs and provide them the services and supports they need to remain in the community
- 5: access to technology that is used to optimize functional status
- 14: freedom from transportation barriers to care
- 52: funding to help families find accessible housing and transportation (Americans with Disabilities Act of 1990)
- 44: easy and timely access to legal help as needed
- 63: support from foundations and organizations

Domain 8: Health Care System Supports

Access to supports that allow CMC to obtain all needed health care services

- 40: comprehensive and uninterrupted health insurance that covers all equipment, service, or care needs
- 69: access to necessary and high-quality specialty medical care
- 36: timely access to medical equipment and supplies
- 35: adequately trained home health providers that can meet complex medical needs
- 42: easy, immediate access to language interpretation, including sign language
- 71: consistent access to physical, occupational, and speech therapy needed to support functioning
- 54: technology that efficiently enhances access to health care providers, services, and data exchange

33: counseling and other support for health care and educational professionals to prevent burnout so that they can better provide care

47: access to data about center-specific quality and outcomes compared with other centers

Domain 9: High-Quality Patient-Centered Medical Home

Access to and use of high-quality comprehensive and specialty health care

- 11: comprehensive care that includes case management, an education system, medical providers, and the child and family
- 7: minimizing medical errors
- 4: a system that is able to be rapidly flexible to meet the needs of the children, whose needs can change quickly
- 45: timely access to comprehensive coordinated health care, including subspecialty, behavioral and/or mental, dental, rehabilitative, and home services
- 51: access to behavioral and/or mental health professionals who are trained to provide care to these children and families
- 77: having providers who act respectfully toward all types of families (eg, lesbian, gay, bisexual, and transgender families; grandparents as primary caregivers; and adoptive and/or foster care families)
- 12: smooth transitions between primary care, urgent and emergency department care, hospitalizations, and home
- 43: a medical home that is family centered, continuous, comprehensive, coordinated, compassionate, and culturally competent
- 41: culturally and linguistically competent care

50: care that can adapt quickly to the changing needs of the family, in periods of stability, rapid decline, or the end of life

8: a single, immediately accessible point of contact for care coordination

34: an accessible, shared plan of care that members of the care team, family, and others can access and update regularly

31: a system that includes continual home care and follow-up through periods of exacerbation but also during the periods of stability

25: a planned and coordinated transition to appropriate care services in adulthood

49: screening and identification of conditions that benefit from early intervention

62: comprehensive and up-to-date documentation of baseline status

53: access to reproductive and/or sexual health care and developmentally appropriate sex education

Domain 10: Family-Centered Care

The presence of a beneficial partnership between providers, patients, and families that places families at the center of planning and decision-making related to the child or youth's health

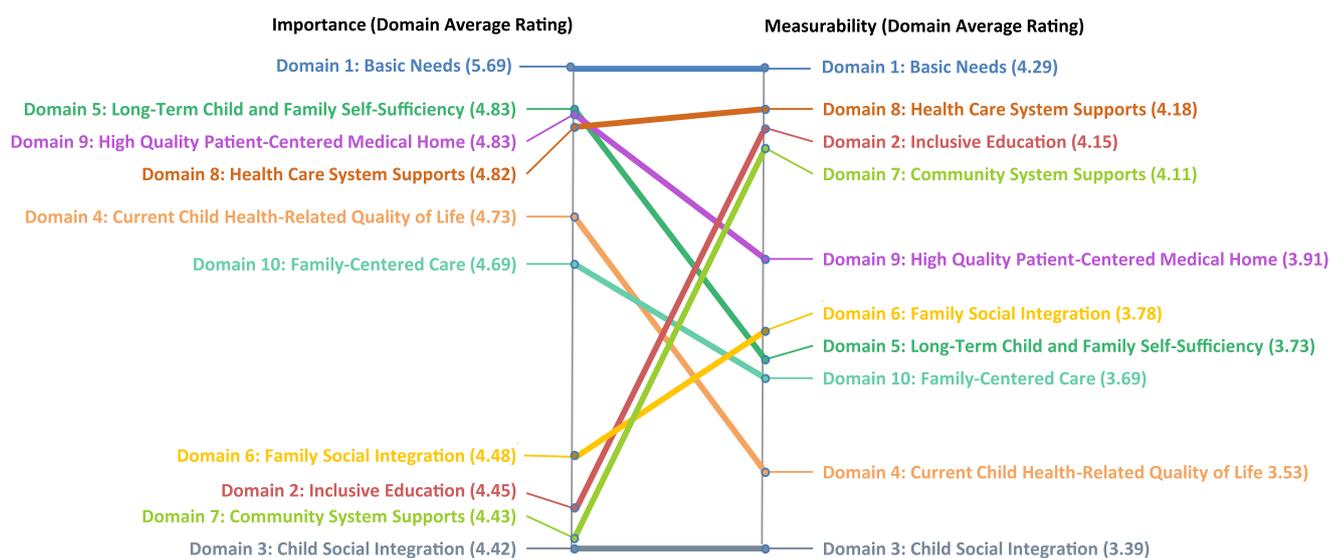
70: the child or youth being included in decision-making regarding his or her medical care whenever appropriate and possible

67: shared patient-centered goal-setting with care teams that know the child's and family's needs

61: prioritizing services based on youth and family goals

22: being able to articulate family needs and being

comfortable talking to medical providers	24: consideration of family health literacy	13: minimizing time in health care settings as much as possible
21: focusing on wellness and/or prevention rather than just the condition	56: advance planning for end-of-life care	48: minimizing caregiver burden by scheduling medical visits together or on evenings and weekends
	9: a strength-based approach to care	



SUPPLEMENTAL FIGURE 4

Pattern match importance and feasibility of each domain.