



Research paper

Collaborative design of a health care experience survey for persons with disability



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ABSTRACT

Background: When assessing results of health care delivery system reforms targeting persons with disability, quality metrics must reflect the experiences and perspectives of this population.

Objective: For persons with disability and researchers to develop collaboratively a survey that addresses critical quality questions about a new Massachusetts health care program for persons with disability dually-eligible for Medicare and Medicaid.

Methods: Persons with significant physical disability or serious mental health diagnoses participated fully in all research activities, including co-directing the study, co-moderating focus groups, performing qualitative analyses, specifying survey topics, cognitive interviewing, and refining survey language. Several sources informed survey development, including key informant interviews, focus groups, and cognitive testing.

Results: We interviewed 18 key informants from key stakeholder groups, including disability advocates, health care providers, and governmental agencies. We conducted 12 total English- and Spanish-language focus groups involving 87 participants (38 with physical disability, 49 with mental health diagnoses). Although some details differed, focus group findings were similar across the two disability groups. Analyses by collaborators with disability identified 29 questions for persons with physical disability and 38 for persons with mental health diagnoses. After cognitive testing, the final survey includes questions on topics ranging from independent living principles to health care delivery system concerns.

Conclusions: The Persons with Disabilities Quality Survey (PDQ-S) captures specific quality concerns of Massachusetts residents with physical or mental health disability about an integrated health plan. PDQ-S requires further testing elsewhere to determine its value for quality assessment more generally and to other populations with disability.

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Many federal and state health care reform efforts aim to control costs while maintaining care quality for high-cost populations, such as persons with disability. Under the 2010 Patient Protection and Affordable Care Act, the new Center for Medicare and Medicaid Innovation (CMMI) within the Center for Medicare & Medicaid

Services (CMS) launched a demonstration program targeting individuals dually eligible for Medicare and Medicaid, a costly population with high disability rates and substantial health and supportive care needs.^{1,2} In particular, CMMI sought demonstrations that integrate long-term services and supports (LTSS) with other health care services, including behavioral health. CMMI aimed for demonstrations to achieve “better health, better health care, and lower per capita costs.”³

In this context, quantifying “better health care” raises special considerations, especially whether quality measures reflect the

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values and experiences of demonstration participants with disability. Although researchers have been developing quality measures for decades, feedback from targeted populations is often gathered in the final stages of the design process. Developers of national quality metrics have aimed to create better measures of care concerns for persons with disability, including LTSS and integrated care.^{4,5} Nevertheless, individuals with disability still question whether CMS's standard quality metrics adequately capture how health services affect well-being and quality of life from their perspectives.^{5–9} For example, we analyzed the 12 quality metrics employed to assess One Care, CMMI's demonstration program in Massachusetts.^{10–21} Although the measures assessed many topics that concern persons with disability, important gaps remain.²²

This paper describes our collaborative process for developing the Persons with Disability Quality Survey (PDQ-S), which aims to assess quality of care explicitly from the viewpoints of individuals with disability enrolled in One Care. Massachusetts disability rights advocates and researchers designed PDQ-S together as part of a project funded by the Patient-Centered Outcomes Research Institute (PCORI) that aimed for consumers to participate actively in One Care quality assessment. We sought to model true inclusivity in survey design – moving beyond token feedback after topics were determined, items drafted, and the questionnaire designed to demonstrate the impact and benefits of full integration of persons with disability at all stages of the design process. Below, we briefly review One Care and then review our collaborative activities across four phases of PDQ-S development. Although PDQ-S has some specific One Care components, we aspired for the survey to capture quality concerns of persons with disability within integrated health care systems more broadly, making it applicable – perhaps with minor modifications – elsewhere.

Health care delivery system and policy context

In August 2012, Massachusetts was the first state selected by CMMI's Financial Alignment demonstration's Massachusetts One Care is unique among CMMI's demonstrations in targeting fully dually eligible beneficiaries ages 21 through 64 (i.e., all persons have Medicare because of disability, and they all receive the full range of Medicaid benefits).²³ For its fully-integrated care model, One Care chose dually capitated payment in which both Medicare and MassHealth (Massachusetts Medicaid) capitated reimbursements to participating One Care plans. Another unique feature requires community-based LTSS coordinators to function independently from One Care plans. By emphasizing care coordination, including LTSS, One Care aims to support members “to live healthier, stay more active, and be more independent.”²⁴

Massachusetts disability rights advocates worked extensively with governmental officials to design One Care. To support these activities, several disability rights organizations created Disability Health Alliance (DHA), which in January 2013 published a Mission Statement articulating their goals for One Care. DHA acknowledged potential benefits of care integration but cautioned that capitated reimbursement generates incentives to provide less care. Furthermore, DHA questioned whether standard health plan quality metrics would adequately capture disability advocates' concerns about One Care quality, especially relating to LTSS and effects on enrollees' quality of life.²⁵

Overview of research

To address these concerns, DHA leaders joined local researchers in seeking PCORI support to develop disability-centric quality measurement and monitoring approaches for One Care. PCORI-funded projects aim to “incorporate patients ... throughout the

[research] process ... consistently and intensively.”²⁶ Given available resources and the heterogeneity of disabling conditions, we focused on the two highest-cost subgroups of One Care members: persons with serious mental illness (SMI), with or without coexisting substance use; and individuals with significant physical disability (SPD) needing assistance with daily living activities.

The project was co-led by a researcher with physical disability and two community based advocates representing persons with SMI and SPD. Following rigorous survey design principles, two survey scientists guided PDQ-S development. However, persons with the lived experience of SMI or SPD co-led all development efforts and made final decisions on survey content. The project team solicited input at twice-yearly meetings (and as required between meetings) from a Research Oversight Committee (ROC), which included local researchers expert in LTSS and clinical care for persons with disabilities and representatives from SMI and SPD advocacy organizations. To obtain additional advice, we empanelled a six-person Consumer Analysis Team (CAT), including three members with SMI and three with SPD who worked with advocacy groups. All collaborators on this study received either salary support or consultation payments for their contributions.

We started by systematically compiling and analyzing the content of One Care quality metrics used by CMS and MassHealth.²² This comprehensive analysis identified gaps in the quality measures from the perspective of persons with disability. This review also identified concrete examples of how existing surveys approach certain concepts, problematic phrasing of questions, and other insights into designing surveys for this population. We then developed PDQ-S in four phases, described below. The Massachusetts General Hospital (MGH)/Partners HealthCare Institutional Review Board (IRB) approved all aspects of this study.

Phase 1: key informant interviews

Phase 1 methods

Phase 1 involved 30-min telephone or in-person key informant interviews²⁷ with persons representing major One Care stakeholders. These interviews aimed to obtain participants' views about critical quality considerations confronting One Care, particularly for enrollees with SMI or SPD and relating to LTSS. To guide these interviews, we developed an 8-item, semi-structured, open-ended interview protocol (available upon request) based primarily upon DHA mission statement observations about measuring quality in fully-integrated service delivery programs for persons with disability. ROC members reviewed the draft interview protocol.

Selection of key informants was critical to gathering insights that would best inform PDQ-S development. We aimed to interview 10–15 individuals representing persons with SMI or SPD as well as other One Care stakeholders, including health care and LTSS professionals, health plan leaders, and state and federal government officials. Project co-directors with SMI and SPD developed initial lists of potential key informants, along with recommendations from ROC members. Our final key informant list aimed to maximize diversity of stakeholder perspectives within our target sample size.

After administering verbal informed consent, one researcher conducted the interview, while a research assistant took detailed notes. Using conventional content analysis to identify key themes,^{28,29} we reviewed these notes sequentially as we conducted interviews.

Phase 1 results

We conducted 14 key informant interviews, 3 involving more

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