PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE
FINAL RESEARCH REPORT

Reporting Care Experiences of People with Significant Physical Disability or Serious Mental Illness to Primary Care Clinics

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ABSTRACT

Background: Persons who are dually eligible for Medicare and Medicaid generate disproportionately high costs. Individuals younger than 65 years of age who qualify for Medicare because of disability are especially costly, as they require expensive long-term services and supports (LTSS) needs. To explore efficient health care delivery models for these beneficiaries, the Centers for Medicare & Medicaid Services (CMS) initiated demonstration programs for dually eligible individuals. The Massachusetts One Care program is CMS's only demonstration program nationwide that targets younger beneficiaries: individuals aged 21 to 64 years. As CMS and Massachusetts Medicaid designed One Care, which involves dually capitated payments to plans and covers all services including LTSS, local disability advocates voiced concerns about threats to care quality. They argued that persons with disability should be the ones leading efforts to assess One Care quality, highlighting fears related to independent living in communities.

Objectives: This study aimed to test the comparative effectiveness for improving patient-reported health care experiences of 2 informational interventions in a 12-month period: (1) the "**YES Health**: **Y**our **E**xperience, **S**peak up for better health care" initiative, in which disability advocates developed brief topical surveys and gathered information from One Care enrollees with significant physical disability or serious mental illness; and (2) the Persons With Disability Quality Survey (PDQ-S), developed collaboratively with persons with disability.

Methods: We focused on English- and Spanish-speaking One Care members with either serious mental illness or significant physical disability. This cluster randomized controlled trial randomly assigned 27 primary care practices with ≥50 One Care members meeting these specifications to 3 study arms differing by information provided to practice directors and primary care providers (PCPs): (1) quarterly YES Health reports plus results from baseline administration of PDQ-S to 720 enrollees before YES Health implementation; (2) PDQ-S results only; and (3) no study information. We administered PDQ-S again 1 year later and used difference-in-differences analyses of results across the 2 years to assess intervention outcomes. After YES Health concluded, we surveyed the 221 PCPs listed as serving sample members at the 27 practices.

Results: Led by individuals with significant physical disability or serious mental illness, YES Health engaged 45 persons—with disabilities from the 9 randomly assigned practices—in surveys evaluating their One Care quality. Topics selected for the quarterly YES Health quality surveys were One Care plans and care teams, communication with clinicians, LTSS, and transportation. However, PCPs at the 9 study arm 1 practices did not engage with the disability advocates, despite repeated outreach. With minimal exceptions, we found no differences across the 3 study arms in PDQ-S member-reported outcomes. Of the 110 eligible PCPs who responded to the survey (54.4%), few reported knowing about YES Health or baseline PDQ-S results.

Conclusions: Individuals with disability successfully designed and implemented YES Health. Nonetheless, the inability to engage PCPs in collaborative interactions likely contributed to YES

Health having no effect. Future research should consider approaches toward developing effective patient-physician partnerships to improve care.

Limitations and Subpopulation Considerations: This study may have limited generalizability beyond the context of dually eligible individuals aged <65 years in integrated care delivery systems with dually capitated reimbursement.

BACKGROUND

Policy Context

Persons who are dually eligible for Medicare and Medicaid compose 16% of Medicare beneficiaries and 15% of Medicaid recipients; however, this population generates 27% of Medicare spending and 39% of Medicaid expenditures.[1] All dually eligible persons must meet Medicaid low-income requirements. Nearly two-thirds of dually eligible individuals are aged 65 or older, receiving Medicare through "old age" provisions. The other third generally qualifies for Medicare through entitlement for Social Security Disability Insurance (eg, disabled former workers).[1] This younger population is particularly costly, with substantial needs for both medical care and long-term services and supports (LTSS) to facilitate independent living in the community and participation in daily life activities.

To control costs while maintaining care quality for dually eligible and other resource-intensive populations, the 2010 Patient Protection and Affordable Care Act (ACA) mandated experiments with innovative health care delivery models. To initiate and oversee these experiments, the ACA created the Center for Medicare and Medicaid Innovation (CMMI). In July 2011, in collaboration with another newly mandated office—the Medicare-Medicaid Coordination Office (MMCO)—CMMI announced its financial alignment demonstration for dually eligible beneficiaries.[2-6] CMMI expressed special interest in demonstrations that integrate LTSS with other health care services, including behavioral health.

Massachusetts officials welcomed this opportunity. According to a 2011 report, of the roughly 105 000 dually eligible Massachusetts residents aged 21 to 64 years in fee-for-service Medicaid (MassHealth) plans, 79% had physical, 65% had behavioral, and 14% had developmental diagnoses or disability, and 60% had more than 1 of these conditions.[7] Although only 3% of the population lived in institutions, dually eligible individuals generated $1.3 billion in MassHealth and $1.2 billion in Medicare costs. The higher MassHealth expenses reflected substantial LTSS needs, which are covered by Medicaid but not Medicare: 35% of total spending went to LTSS compared with only 22% for inpatient services.[7]

In August 2012, Massachusetts was the first state to receive a memorandum of understanding under CMMI's financial alignment initiative, and state officials started designing One Care. This program is unique among CMMI's demonstrations in targeting fully dual eligible beneficiaries aged 21-64 (ie, all persons qualify for Medicare because of disability).[4,8] One Care opted for dually capitated payment in which both Medicare and MassHealth capitate reimbursements to participating One Care plans. In this fully integrated care model, a unique feature involves requiring community-based LTSS coordinators to function independently from One Care plans.[6,8]

Perspectives of Massachusetts Disability Rights Advocates

As reported elsewhere, the Massachusetts disability rights advocacy community participated actively with MassHealth officials in designing One Care:

> *Beneficiary engagement in the design and implementation of One Care has been a hallmark of the demonstration and has occurred at numerous levels. The state has well- developed disability and behavioral health consumer advocacy communities, and state leaders were open to actively engaging in discussions and some decision-making with these community-based consumer advocacy partners.*[6]

To support their One Care advocacy, several disability rights organizations created the Disability Health Alliance (DHA), which in January 2013 published a mission statement articulating its goals for One Care. While recognizing potential benefits from One Care, DHA urged caution:

> *The Demonstration seeks to integrate our health and support services and their funding into a single system that will better meet our needs. Integration has the potential to improve our access to medical care and to long term services and supports while preventing unnecessary complications of disability and chronic illness. Integration also brings a serious risk that our needs will not be better met. If too much of the combined money is spent on medical services and too little on support services, then our*

> *health and independence will suffer. Capitated financing inevitably creates incentives to provide less care, which puts some of the state's most vulnerable individuals at risk of dangerous underservice.*

DHA questioned whether standard quality metrics used to measure health plan performance would adequately capture disability advocates' concerns about One Care quality, especially relating to LTSS and implications for enrollees' quality of life. DHA argued that individuals with disability should assume leading roles in defining and measuring care quality, reflecting priorities relating to community-based living and LTSS.

Having persons with disability lead, design, and perform assessments to improve their own care could yield especially compelling benefits. Individuals with disability often require wide-ranging services across the full continuum of care, from complex tertiary care to LTSS. Persons with the lived experience of disability are best positioned to judge whether these diverse services are well integrated and meet their multidimensional needs, not only supporting independent community-based living but also maximizing health, wellness, and quality of life. Furthermore, despite efforts to improve measures of integrated care and LTSS quality,[9,10] others—beyond DHA—also question whether common quality metrics adequately capture how health services affect well-being and quality of life for persons with disability.[10-13]

Given these considerations, DHA disability advocates sought funding from governmental and private sources to support the advocates conducting independent monitoring of care quality after One Care's October 1, 2013, start. However, those resources never materialized.

This PCORI project aimed to pursue DHA's goals of consumers leading evaluations of One Care.

Project Overview

Guided by the DHA mission statement, we aimed to test the effectiveness of consumer-driven quality information in improving the One Care experiences of English- and Spanish-speaking enrollees with serious mental illness or significant physical disability. Here, we report the results of a cluster randomized controlled trial (see the “Study Design” section) to compare the effectiveness of 2 informational interventions in a 12-month period:

- The “**YES Health**: **Y**our **E**xperience, **S**peak up for better health care” initiative, in which disability advocates designed tools and gathered information from One Care enrollees with serious mental illness or significant physical disability about their care experiences and reported results quarterly to primary care providers (PCPs) and practice managers
- Baseline information from the Persons With Disability Quality Survey (PDQ-S), developed collaboratively with persons with serious mental illness or significant physical disability, administered to One Care members before the start of YES Health and mailed to PCPs and practice managers

We administered PDQ-S a second time, after the 12-month YES Health initiative concluded, and used difference-in-differences methods comparing the baseline and subsequent PDQ-S results as our outcome measure. Our major research question was the following: Compared with baseline PDQ-S results, does providing information defined and generated by consumers about care quality to PCPs and primary care practice managers improve enrollees’ subsequent perceptions of their quality of care? We hypothesized that PCPs would use consumers’ views to shape their quality improvement activities, thus producing changes important to and detectable by One Care enrollees.

Role of Persons With Disability in the Design and Conduct of This Study

As noted above, the DHA mission statement motivated and drove this project’s goals and activities. Based on their active participation in One Care design,[6] the disability rights advocates felt empowered to take charge of their own quality oversight and to interact with health care providers about improving their care. Over the course of this study, the interdisciplinary study team repeatedly returned to this mission statement for guiding principles when making critical decisions. The project’s principal investigator has a significant physical disability; she co-led the study with 2 disability rights advocates, 1 with significant physical disability and the other in recovery from a psychiatric diagnosis (both were salaried staff of the study). In addition, the project team solicited input at twice-yearly meetings (and as required between meetings) from a research oversight committee (ROC), which included local researchers with expertise in LTSS and clinical care for persons with disabilities, as well as representatives from physical disability and serious mental illness advocacy organizations. To obtain additional advice, we empaneled a 6-person Consumer Analysis Team (CAT), including 3 members with physical disability and 3 with serious mental illness. All collaborators received either salary support or consultation payments for their contributions. Persons with disability are coauthors of papers from this project and have participated in other dissemination efforts.

Our review of the literature failed to find any other completely consumer-led quality measurement initiative like YES Health. Therefore, we view YES Health as an innovative effort in which consumers themselves identified the quality concerns; collected and analyzed data about care quality; and gave this information to primary care practices and PCPs. Another important and singular feature of YES Health was the self-identification of the consumers leading this effort as individuals with significant physical disability or in recovery from serious mental illness.

DESCRIPTION OF INTERVENTIONS EVALUATED IN THIS STUDY

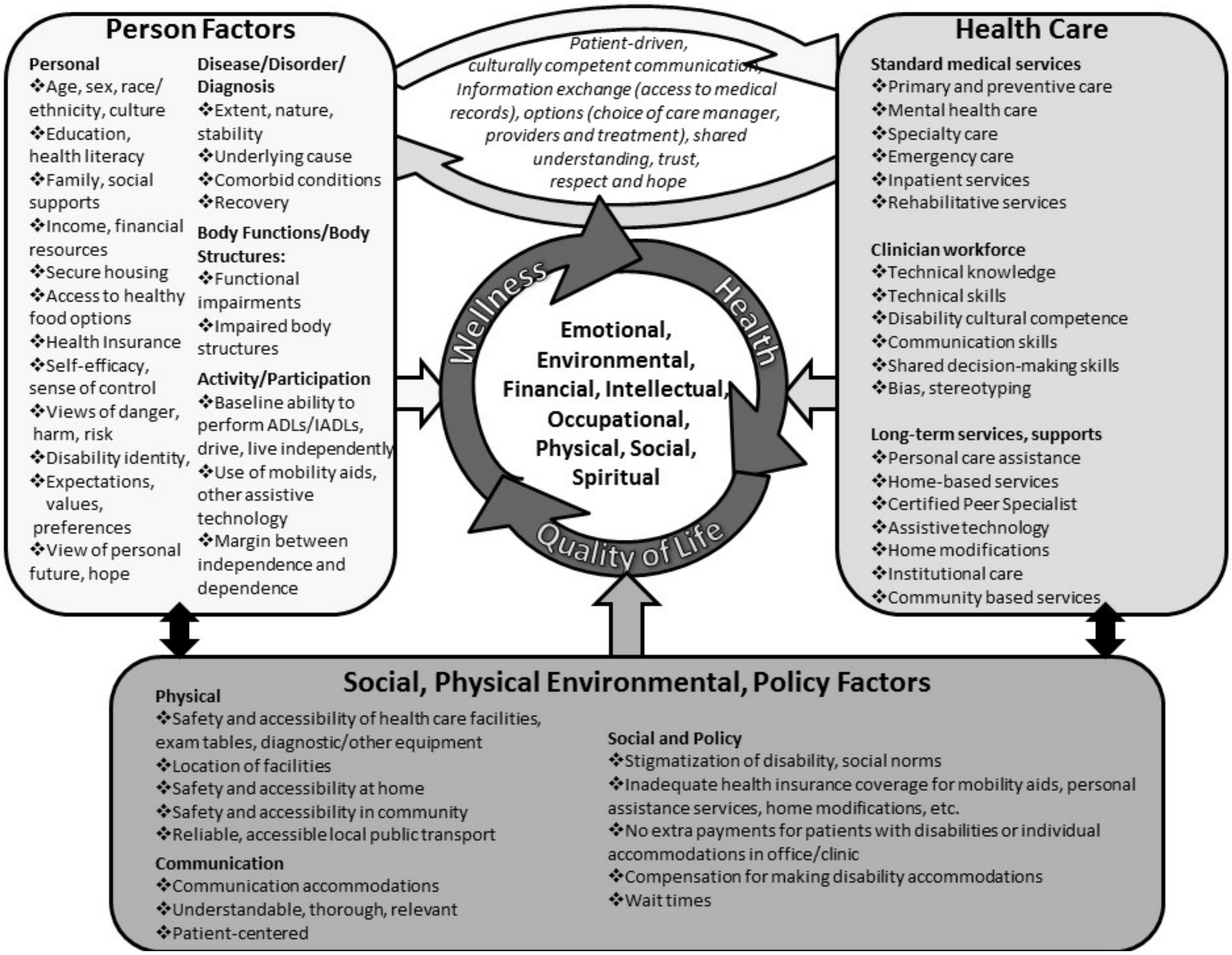
This study tested the effectiveness of consumer-driven quality information to improve One Care experiences of English- and Spanish-speaking enrollees with serious mental illness or significant physical disability (see the "Project Overview" section). This section describes 3 critical components of this study: the conceptual framework developed by disability advocates that models the relationship between health care and health, wellness, and quality of life for persons with disability (see the "Conceptual Framework Guiding Consumer-Driven Quality Assessments" section); development of the PDQ-S, used to capture baseline perceptions of One Care quality as well as intervention outcomes (see the "Designing the Persons With Disabilities Quality Survey" section); and development and description of YES Health, a consumer-led initiative to assess One Care quality that reflected priorities of One Care members with serious mental illness or significant physical disability (see "YES Health" in the Background section). As detailed in the "Study Design" section, this cluster randomized controlled trial randomly assigned 27 primary care practices with ≥50 One Care members to 3 study arms differing by information provided to practice directors and PCPs: (1) quarterly YES Health reports plus results from baseline administration of PDQ-S to 720 enrollees before YES Health implementation; (2) baseline PDQ-S results only; and (3) no study information.

Conceptual Framework Guiding Consumer-Driven Quality Assessments

As described in the "Perspectives of Massachusetts Disability Rights Advocates" section, the DHA mission statement questioned whether standard quality metrics used to measure health plan performance adequately capture concerns of persons with disability about One Care quality, especially relating to LTSS and quality of life. DHA argued that individuals with disability should assume leading roles in defining and measuring care quality, prioritizing factors related to community-based living and LTSS. Therefore, to develop our 2 informational interventions—reports about One Care quality from data gathered using PDQ-S and YES Health—we first conceptualized how persons with disability perceive the role of health care.

Two disability rights advocates codirecting the project helped formulate a conceptual model depicting how health care and other factors affect the health, wellness, and quality of life of individuals with disability (Figure 1). As described in detail elsewhere,[14] we reviewed the literature on care quality for persons with disability or with LTSS needs.

Figure 1. Conceptual Framework: How Health Care and Other Factors Affect the Health, Wellness, and Quality of Life for Individuals With Disabilities



Abbreviations: ADLs, activities of daily living; IADLs, instrumental activities of daily living.

This review convinced us not to replicate other efforts. Four major international and US initiatives had developed specific components, with mutually supportive and overlapping tenets, that we fit together to build our conceptual framework:

1. We framed our conceptual model around achieving health, recovery, and wellness. We defined wellness using the 8 dimensions specified by the US Substance Abuse and Mental Health Services Administration.[15] Focusing on health and wellness, we drew

from the 2005 Call to Action issued by US Surgeon General Richard Carmona in commemorating the 15th anniversary of the Americans With Disabilities Act.[16,17] Carmona identified aspects of the clinical workforce and health care delivery system that compromise care for persons with disability. Warning that individuals with disability can lack equal access to health care, the Call to Action demanded that health care providers attain knowledge and tools to screen, diagnose, and treat people with disability with dignity as whole persons, and that health care and related services be fully accessible to maximize these individuals' independence.[16,17]

2. We defined *disability* using the International Classification of Functioning, Disability and Health (ICF) definition, developed by the World Health Organization.[18] ICF defines *disability* as an "umbrella term for impairments, activity limitations, or participation restrictions," conceiving "a person's functioning and disability. . .as a dynamic interaction between health conditions. . .and contextual factors," including environmental and personal attributes.[18] Importantly, ICF views environmental factors expansively, including societal attitudes and the physical and built environments.

3. We informed individual components of our framework using independent living principles. The overarching tenet of independent living is that persons with disability are the experts on their lives and have the right to make all decisions that affect them. Other supporting principles include achieving equity and integration (ie, no segregation); living within communities, not institutions; eschewing "medicalizing" disability (ie, disability is not equivalent to sickness and does not necessarily require intervention from health care professionals); focusing on self-help, self-determination, and peer support; eliminating barriers of all sorts; putting the consumer in control; believing in the potential of recovery; and conducting efforts across disability types.

4. We structured our framework around the Healthy People 2020 model of social determinants of health.[19] The vision of Healthy People 2020 is "a society in which all people live long and healthy lives." Factors at multiple levels affect health and health behaviors, including personal (ie, biological, psychological), social and physical environments, and policies. Significant and dynamic interrelationships among these different levels determine health.[20]

Figure 1 pulls together these 4 overlapping components; at the center are the interrelated concepts of health, wellness, and quality of life. Personal factors of individuals with disability are grouped largely within categories from the ICF. Attributes of the health care delivery system and larger environment include physical features and health care professional workforce factors, including stigmatizing attitudes. Arrayed above interactions between individuals and the health care system, communication is broadly construed and encompasses not only culturally competent communication but also access to information, knowledge about and having options for care, shared understanding between persons and care providers, trust, and hope. This model informed our examination of the 12 surveys chosen by the Centers for Medicare & Medicaid Services (CMS) and MassHealth to evaluate One Care plan performance.[8,21-32] The surveys determined whether, from the perspective of individuals with disability, gaps existed in quality assessment.[14]

Designing the Persons With Disabilities Quality Survey

In Year 1, we designed the PDQ-S, which served 2 roles in this project: First, we reported information generated by baseline (ie, before the start of YES Health) administration of PDQ-S to primary care practice managers and PCPs as 1 of our 2 informational interventions (see the "Reports of Baseline [Wave 1] PDQ-S Findings" section); and second, we used subsequent results from administering PDQ-S after the 12-month YES Health initiative in difference-in-differences analyses to assess outcomes and effectiveness of the 2 interventions (see the "Identifying the Wave 2 PDQ-S Sample," "Study Outcomes", and "Analytical and Statistical Approaches" section). Here, we describe the development and content of PDQ-S, which is detailed elsewhere.[33] Project team members with physical disability or serious mental illness played leading roles in PDQ-S development and testing, with additional input from ROC and CAT members with disability (see the "Role of Persons With Disability in the Design and Conduct of This Study" sections), supporting its content validity.

Guided by our conceptual framework (Figure 1), we began by reviewing the content of the 12 surveys.[14] This review identified gaps in these 12 quality measures from the perspective of persons with disability. We also examined existing measures of self-efficacy, which we viewed as related to independent living principles. These reviews provided information about how existing surveys approach certain concepts, problematic phrasing of questions, and other insights into designing surveys for this population. We developed PDQ-S in 4 phases (described below).

Key Informant Interviews

We conducted fourteen 30-minute telephone or in-person interviews with key informants—namely, individuals representing major One Care stakeholders. These interviews aimed to obtain participants' views about critical quality considerations confronting One Care, particularly for enrollees with serious mental illness or significant physical disability and matters relating to LTSS. To guide these interviews, we developed an 8-item, semistructured, open-ended interview protocol based primarily on DHA mission statement observations about measuring quality in fully integrated service delivery programs for persons with disability. Three interviews involved more than 1 interviewee (18 total key informants). Key informants included 7 disability advocacy stakeholders (including persons with lived experiences of serious mental illness, significant physical disability, or substance use); 2 representatives of the local union serving personal care assistants; 3 clinical leaders of One Care plans; 4 Massachusetts officials (rehabilitation commissioner, director of MassHealth quality measurement) and local health policy experts; and 2 CMS officials (1 each from CMMI and MMCO). Details differed, but interviewees provided largely consistent messages about which quality concerns would most affect One Care members with serious mental illness or significant physical disability. We appeared to reach thematic saturation approximately halfway through our scheduled interviews. Major themes included the following:

- One Care participants must be viewed as individuals with their own values, preferences, expectations, and goals; care must be consistently and explicitly person-centered.
- Care must aim to bolster hope, including for recovery from serious mental illness or substance use.
- LTSS evaluations must assess support for One Care members living as they wish and maximizing their quality of life.
- Independent living principles must guide quality measurement. These principles include "dignity of risk" (ie, informed persons with disability being able to take risks to live as they wish even against the advice of others, such as caregivers).

Several interviewees explicitly mentioned including Maslow’s hierarchy of needs within a conceptual framework for One Care evaluation, with assessments along Maslow’s 5-level hierarchy—from physiological needs to safety, to love and belonging, to esteem, and finally to self-actualization.

Focus Group Interviews

Building on key informant findings, we sought input directly from persons with serious mental illness or significant physical disability through focus groups. We designed a semistructured focus group moderator’s guide through an iterative process, drawing on topics raised by the key informants, DHA’s mission statement, and conceptual framework perspectives. Eligibility criteria included aged 21 to 64 years, self-reported disability (serious mental illness or significant physical disability), and insurance coverage (One Care or MassHealth). Participants received a $50 gift card for participation. Collaborators with disability led focus-group recruitment and screening activities across Massachusetts. A professional moderator facilitated all 12 focus groups, while an individual representing the lived experience with concordant gender and disability status comoderated each focus group. Analyses of transcripts aimed to identify potential domains and specific themes to inform PDQ-S development. A research consultant to the collaborating advocacy organization, led in-depth analyses conducted by staff with disability and CAT members.

With 87 participants, we conducted 12 gender-concordant and disability-concordant focus groups across Massachusetts: 4 in Spanish and 8 in English. Along with potential questions within each theme, 7 broad themes emerged from the focus group analysis. The analysis generated 38 questions for persons with serious mental illness and 29 questions for persons with significant physical disability. Broad themes were similar across the 2 disability groups, although the potential questions differed somewhat. Certain themes hewed closely to concepts within Maslow’s hierarchy, such as love/belonging and self-esteem.[14]

Drafting PDQ-S

PDQ-S development involved extensive, iterative input from all members of the project team, including the investigators, community partners, ROC, and CAT. A senior survey scientist (K.D.) led efforts to draw potential survey domains from information gleaned from the reviews of surveys used by CMS and MassHealth to evaluate One Care, the key informant interviews, and focus groups. Our initial set of domains aimed to (1) assess how One Care members with serious mental illness or significant physical disability perceive core components of One Care, and (2) evaluate effects of One Care on the daily lives and well-being of its members. We sought to create a survey that would average 10 to 15 minutes to complete.

The draft PDQ-S encompassed 6 domains that cut across One Care's service delivery model, including LTSS, and participants' perceptions of their daily lives and how One Care affects them. A certified translator translated PDQ-S into Spanish. To be inclusive for the testing phase, the draft PDQ-S was substantially longer than desired for the final instrument.

Instrument Testing and Survey Revision

We tested the draft PDQ-S using cognitive interviews: a semistructured, open-ended protocol with 8 debriefing questions, in English and Spanish. The debriefing questions identified items needing revision (eg, because the topic was too sensitive, because wording was unclear). Interviewers timed the interview to determine the length of survey administration. With training and oversight from a survey scientist, 3 staff with serious mental illness or significant physical disability from the Disability Policy Consortium (DPC; Malden, MA) conducted the respondent recruitment, screening, and cognitive interviewing. The 20 participants (10 each within each disability group) each received a $50 gift card. After completing the cognitive interviews, the DPC interviewers and survey scientist analyzed responses to the debriefing questions, summarized key findings, and proposed changes to the PDQ-S. Project team members reviewed these suggested revisions and made extensive comments. PDQ-S was finalized based on iterative discussions, with ultimate choices (eg, about which questions to retain or delete) made by team members with disability.

Table 1. Main Questions Included in Final Version of the PDQ-S

No.[a]	Question	Comments
Q2	For each statement below, please check the box that shows how much you disagree, somewhat agree, or strongly agree with each one.	This question stem is followed by 6 items (a-f) about the respondent's life and self-perceptions, built on independent living principles (dignity of risk), Maslow's hierarchy of needs, quality of life trajectory, and participation in social and community life.
Q3	Are any of the following people part of a team that provides you with the support and services you need?	This question stem is followed by 5 items (a-e) listing friends or family who are paid, a certified peer specialist, personal care or other assistants, a long-term services coordinator, and a primary care provider.[b]
Q4	Do you feel these people work together as a team to provide you with the support and services you need?	
Q5	Do you have a <u>Care Team</u>?	A short definition of care team appears before this question.
Q6	Do you have a <u>Care Plan</u>?	A short definition of care plan appears before this question. If the person answers "yes," Q6a asks about whether the respondent had an "equal say" in developing the plan; Q6b asks whether the respondent has received a written copy of this plan.[c]
Q7	Since enrolling in this health plan, have you been offered <u>new</u> services or help with. . .	This question stem is followed by 6 items (a-f) relating to several levels of Maslow's hierarchy of need: physiological need and safety (eg, housing, food, utilities), setting goals for the future, and organizing life to participate in desired activities.
Q8	Since enrolling in this health plan, have you been offered <u>new</u> services or help with. . .	This question stem is followed by 4 items (a-d): getting equipment or technology; dental care; mental health recovery; and substance use or sobriety.
Q9	Which of the following best describes how you make most important decisions about your health?	This question is followed by 4 response categories: making decisions for "myself"; sharing decisions with health care providers; health care providers make decisions; don't know.

No.[a]	Question	Comments
Q10	Since enrolling in this health plan, have you felt that any health care providers had information or records about your mental health that you did not give permission for them to have?	
Q11	Since you enrolled in this health plan, about how often do you feel your primary care provider. . .	This question stem is followed by 4 items (a-d): showed respect for opinions, whether agreed with them or not; treated respondent “like a child”; cared about respondent as “whole person”; asked about sexual function and desires.
Q12	Since you enrolled in this health plan, about how often do you feel your primary care provider. . .	This question stem is followed by 4 items (a-d): refused support services or equipment needed for independence; changed treatment without discussing how it would affect life; said or did something that made respondent feel “physically unsafe”—and, separately, “emotionally unsafe.”
Q13	Since enrolling in this health plan, were there any times when you needed urgent or emergency medical care or treatment but you either put off getting it or did not get this care at all?	If respondent answers “yes,” Q13b asks for main reason for this lapse, offering 7 response categories (including an open-ended “other”). Categories represent concerns voiced by focus-group participants (eg, fear of being mistreated or misunderstood by staff, fear of losing housing or custody of a child, long wait times).
Q14	Since enrolling in your health plan, is your life now better, the same, or worse in each of the following areas:	This question stem is followed by 7 items (a-g), including hopes about the future, relationships with other people, doing things the respondent enjoys, worry or stress about life, and fear that providers are making decisions about the respondent.
Q15	Since enrolling in your health plan, is the amount of control you have over your health care. . .	Response categories are more than before, about the same, and less than before.
Q16	Since enrolling in your health plan, would you say the quality of all the health care you have received is. . .	Response categories are better than before, about the same, and worse than before. Q16a is an open-ended question: Why is that? Please give an example of how your health care is now better, about the same, or worse than before. . .

Abbreviation: PDQ-S, Persons With Disabilities Quality Survey.

[a] Question number.

[b] Doctor, nurse practitioner, or physician assistant.

[c] One Care rules require members to receive a written copy of their Care Plan.

Table 1 summarizes content of the final PDQ-S. It contains 15 substantive items in addition to an introductory item confirming respondents' enrollment in One Care, 11 sociodemographic characteristic queries, and a final item for contact information (used to mail the incentive payment).

YES Health

To operationalize the vision of the DHA mission statement—persons with disability proactively measuring their own quality of care and engaging with providers to improve care—DPC staff members developed for this study a multifaceted initiative that they called **YES Health**: **Y**our **E**xperience, **S**peak up for better health care. English- and Spanish-speaking DPC staff members, all of whom self-identify as having a physical disability or being in recovery from a psychiatric diagnosis or serious mental illness, designed and implemented YES Health. Their goal was to engage One Care enrollees with serious mental illness or significant physical disability in reporting about their care quality. DPC staff would then compile these quality assessments and communicate them directly to PCPs caring for One Care members, with the intent of improving that care. YES Health, which DPC staff members conducted over a 12-month period, was 1 of the 2 informational interventions assessed in this cluster randomized trial (study arm 1).

Conceptual Foundation of YES Health

DPC staff conceptualized YES Health on the principles of community-based participatory research (CBPR), in which activities aim ultimately to motivate change and foster empowerment and capacity within communities.[34-38] In particular, YES Health built on notions of "empowered consciousness" and "nothing about us without us."[37,39] YES Health pushed beyond usual CBPR precepts, using an "about us, by us" framework. Instead of looking outside the community to synthesize scattered ideas and implement research, YES Health sought leadership, expertise, and partnerships within diverse disability communities. DPC staff members led YES Health development and implementation, while the researchers primarily provided logistical support and technical advice as specifically requested by DPC staff for building their methodological capacity.[38]

DEVELOPMENT AND COMPONENTS OF YES HEALTH

DPC staff spent approximately 6 months designing YES Health concepts and its multiple components (Table 2). Based on responses to the request for proposals, DPC selected the Health Communication Core (HCC) at Dana-Farber Cancer Institute to support design of the intervention's communication strategies and its website. HCC personnel met at length with DPC staff to delineate details about the goals, general tone, and components of the initiative; a specific "brand image" that would be consistent across all communication modalities; and technical aspects of the website, particularly disability access. HCC proposed several naming options to brand the initiative, including YES Health, which DPC chose. DPC staff identified technical website disability accessibility standards to guide HCC programmers. DPC personnel made final decisions about all written content and appearance of YES Health materials. Resource limitations prevented us from generating new photographs and extensive graphics to illustrate the website; instead we used low-cost stock images and sought a bright, positive color scheme.

During the 3 months of YES Health website programming and testing, DPC staff focused on other aspects of YES Health (Table 2), including specifying enrollment and eligibility criteria for YES Health membership (a key criterion was being assigned to 1 of the 9 primary care practices in study arm 1); creating the membership screening process; establishing telephone, voice mail, and email procedures; designing postcards, rack cards, and flyers advertising YES Health; establishing a YES Health Facebook group; and developing procedures for data gathering using Survey Monkey (via website or telephone). The 2 lead DPC staff members wrote and appeared in an introductory video, which HCC produced and posted on the YES Health website. To educate local disability communities about YES Health—and obtain input about ways to recruit One Care enrollees to join YES Health—DPC staff visited advocacy organizations statewide near the 9 primary care practices. They also hired YES Health "ambassadors" from the community. Although limited resources prevented us from creating a parallel Spanish-language version of the website, other communication materials (except the postcards; see Table 2 footnote) were made available in Spanish. DPC staff who are native Spanish speakers reached out to advocacy organizations serving Hispanic populations, responded to all Spanish-language voice mails, and assisted Spanish speakers in answering the quarterly surveys.

Table 2. Components of the YES Health Initiative

Component	Description
Telephone number	YES Health had its own telephone number with voice mail. DPC[a] staff responded within 48 hours in either English or Spanish to voice mail messages.
Email address	YES Health had its own email address. DPC staff responded within 48 h in either English or Spanish to email messages.
Website	The website had public content, including information about YES Health and One Care–related news items and a member component including the quarterly surveys. Members had to meet eligibility criteria and sign in with a password to access surveys, news briefs, and other YES Health research–specific information.
Facebook group	The group was established for YES Health members to discuss their One Care experiences, and DPC personnel staffed the Facebook group. Because of limited use, DPC stopped the group after 8 mo.
Outreach to community advocacy organizations	DPC staff members visited 60 community organizations across Massachusetts serving persons with either serious mental illness or significant physical disability to introduce YES Health; 8 visits were conducted in Spanish, the remainder in English. DPC sent information on YES Health to 32 more agencies.
Public media and public appearances	YES Health appeared on 3 local access television shows around Massachusetts[b] and made presentations at 2 One Care Implementation Council meetings and a Department of Public Health Massachusetts Health and Disability Partnership quarterly meeting. DPC staff spoke to 2 Commonwealth Care Alliance Consumer Advisory Board meetings. It had a table at 2 NAMI statewide conventions, 2 Boston ADA[c] anniversary celebrations, and a DAAHR forum.
YES Health ambassadors	After soliciting candidates from 15 disability advocacy organizations in Boston, Merrimack Valley, and western Massachusetts, DPC hired 4 individuals to serve as regional YES Health representatives to solicit new members. Because of limited success, the ambassador program ended after 6 mo.
Mailed postcards	A postcard in English was sent in month 1 (n = 1046) of YES Health implementation to persons with serious mental illness or significant physical disability in 9 primary care practices. Given poor responses to the initial mailing, a second redesigned postcard was sent in month 5 (n = 1021); the front of the new postcard read, “Receive $10 as our thanks for joining.”[d]

Component	Description
Rack cards	Rack card text described YES Health and invited members; identical texts in English and Spanish appeared on either side of the card. DPC sent each practice 5 rack cards, which they could display in their waiting rooms or other locations. Ambassadors gave rack cards to community organizations they visited. Approximately 400 total rack cards were distributed.
Flyers	Flyers, in English and Spanish, had the same content as the rack cards. Flyers were distributed at events and during visits to organizations. Approximately 400 total flyers were distributed.
Telephone "town hall" meetings	Two meetings in English and 1 in Spanish were held over the phone for YES Health participants to discuss the quality of care they received in One Care. Members received $10 for participating.
YES Health member survey	Quarterly surveys gathered information from YES Health members on a topic—and using questions—developed by DPC. Members could answer the Survey Monkey survey either online through the YES Health website or over the telephone with a DPC staff person. Members received $10 for each survey completed.
YES Health member newsletters	DPC wrote and mailed 2-page paper newsletters at 3 intervals to YES Health members. Newsletters generally combined a member narrative with data from the recent member survey.
Outreach to primary care practices	DPC staff contacted the 9 selected primary care practices, offering to either visit or speak by telephone to describe YES Health, its participants, and its goals. DPC made efforts to contact either the practice medical director or practice manager.
Mailings to primary care clinicians	DPC wrote and mailed 2-page reports at 4 intervals to all 60 primary care clinicians (physicians and 2 nurse practitioners) and practice managers in the 9 selected primary care practices across Massachusetts. These reports generally combined a YES Health member narrative with data from the recent member survey.

Abbreviations: ADA, Americans With Disabilities Act; DAAHR, Disability Advocates Advancing Our Healthcare Rights; DPC, Disability Policy Consortium; NAMI, National Alliance on Mental Illness.

[a] The DPC is in Malden, Massachusetts. All DPC staff members self-identify as having disability.

[b] Boston: 1 speaker, in English; Worcester: 3 speakers, in English (2/3) and Spanish (1/3); and Lawrence: 2 speakers, in English (1/2) and Spanish (1/2).

[c] The ADA was signed July 26, 1990.[d] Printing of the Spanish-language postcards was delayed. Because of low yields from the English-language postcards, the project team decided not to send the Spanish postcards.

YES Health aimed to gather data quarterly about issues that especially concerned One Care members with significant physical disability or serious mental illness. DPC staff chose the quarterly topic; drafted roughly 8 to 12 questions addressing critical concerns for each topic; sought feedback from local disability advocates; programmed the final questions into Survey Monkey; conducted the survey, including helping participants answer by telephone; and used basic descriptive methods to compile and analyze the results. DPC staff summarized these findings in quarterly reports sent to PCPs (see the “Quarterly Reports of YES Health Quality Assessments” section) and YES Health members.

METHODS

Study Design

The major research question was the following: Does providing consumer-defined information about consumers' quality of care to practice managers and PCPs improve the perceptions of One Care members with serious mental illness or significant physical disability of their quality of care? A second research question was the following: Does the nature and intensity of the consumer-defined quality information affect the extent and type of quality improvements, again from consumers' perspectives? We designed our study as a cluster randomized controlled trial with the primary care practice as our unit of randomization.

We randomly assigned 27 participating primary care practices with ≥50 One Care members with significant physical disability or serious mental illness to 1 of 3 study arms, which differed by the type of information mailed to providers:

1. Nine practices (YES Health and PDQ-S): Practice managers and individual PCPs caring for at least One Care enrollee received (1) baseline (wave 1) results from surveying One Care enrollees with physical disability or serious mental illness using the PDQ-S before YES Health began; and (2) information generated quarterly by the 12-month, consumer-led initiative, YES Health.
2. Nine practices (PDQ-S only): Practice managers and individual PCPs caring for at least One Care enrollee received baseline (wave 1) PDQ-S results only.
3. Nine practices (control): Practice managers and individual PCPs received no information from the study.

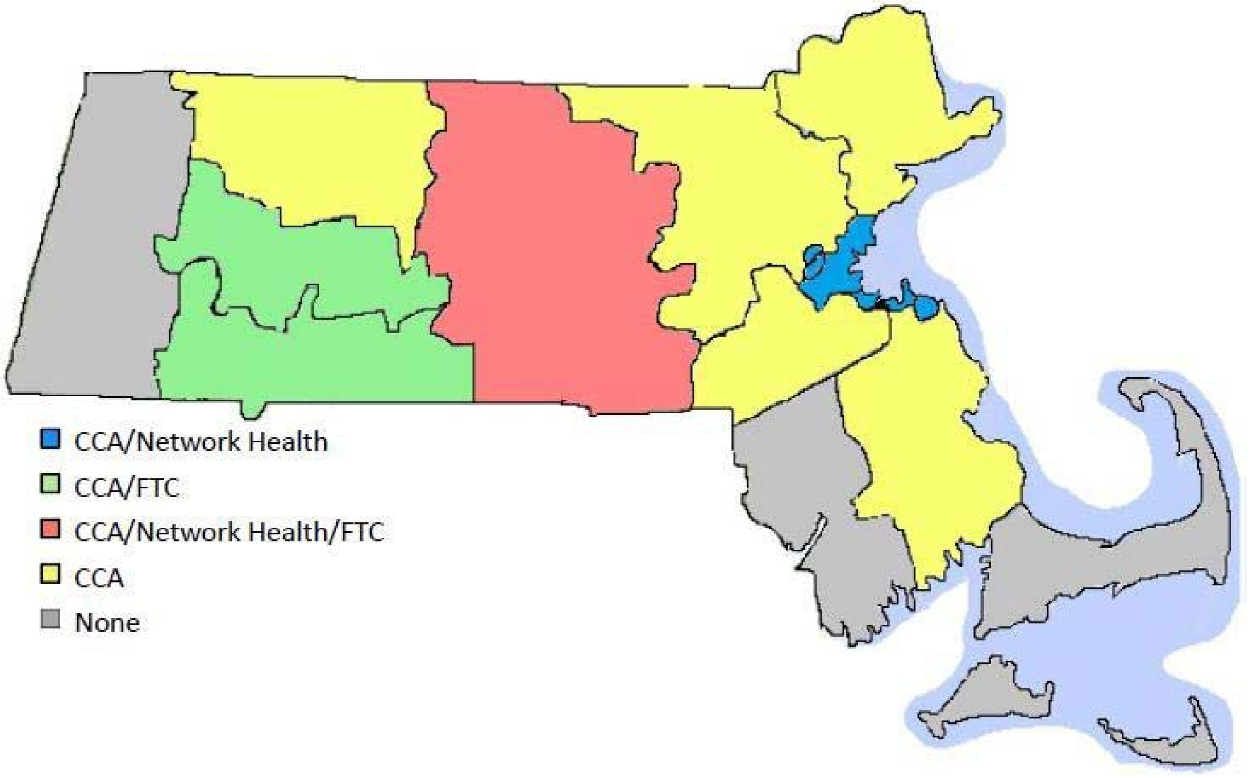
We administered PDQ-S again 1 year later (wave 2, after completion of the 12-month YES Health initiative) and used difference-in-differences analyses of PDQ-S results across the 2 waves to assess intervention outcomes.

Study Setting

As described in the "Policy Context" section, the study's setting was the Massachusetts One Care demonstration program for individuals aged 21 to 64 years who are dually eligible for

Medicare and full Medicaid (MassHealth) benefits.[4,6,8] We submitted the proposal to PCORI in August 2013. During that August, CMS, MassHealth, and the 3 selected One Care plans (which received final contracts in mid-July 2013) were urgently finalizing arrangements for One Care's launch.[6] The 3 plans—Commonwealth Care Alliance (CCA), Fallon Total Care (FTC), and Network Health— covered all Massachusetts counties except Barnstable, Berkshire, Bristol, Dukes, and Nantucket (Figure 2). All 3 plans provided letters of support indicating likely willingness to participate in the PCORI study, should it be funded.

Figure 2. Massachusetts One Care Coverage Map as of Fall 2013



Abbreviations: CCA, Commonwealth Care Alliance; FTC, Fallen Total Care.

One Care began operating on October 1, 2013. The early implementation of One Care[6,8] confronted significant logistical and financial challenges.[6,8] Network Health had other priorities and declined participation in the PCORI project. FTC participated but announced plans to leave One Care just as we were starting baseline (wave 1) PDQ-S administration (late spring 2015). Therefore, the remaining plan, CCA, was our study setting. CCA is a private, nonprofit, hybrid health plan and health care delivery system with a long history of providing fully integrated care to low-income persons with heavy burdens of disease and disability.[8,40-44] It serves the largest geographic area of all plans (Figure 2). CCA had substantially larger numbers of One Care members than did the other 2 plans. For our randomization purposes, CCA had 27 practices caring for ≥50 One Care members with significant physical disability or serious mental illness.

Identifying the Baseline (Wave 1) PDQ-S Sample

This section describes selection of participants in the wave 1 PDQ-S administration, the "Interventions" section describes the study cohort for the YES Health intervention, and the "Identifying the Wave 2 PDQ-S Sample" section describes selection of participants for wave 2 PDQ-S administration.

Wave 1 PDQ-S involved a sample of 720 community-dwelling adults with significant physical disability or serious mental illness who were enrolled in CCA's One Care program (ie, persons assigned to MassHealth rating categories C2A, C2B, C3A, and C3[*]). All eligible individuals had been enrolled in CCA's One Care for ≥90 days. Each sample member was a patient in 1 of the 27 primary care practices staffed or contracted by CCA that were eligible for our study. Eligible practices had ≥50 One Care enrollees with significant physical disability or serious mental illness. We drew the survey sample of 720 members from a universe of 3483 CCA enrollees in those 27 practices whose coverage by CCA started before May 2015. We excluded individuals from the wave 1 sample if CCA's records indicated that they spoke a language other than English, Spanish, or American Sign Language.[†] We randomly selected roughly equal numbers of enrollees (25-27) from each practice (a stratified random sample where the strata of interest were practices). We selected 50 enrollees from 1 practice because it had many more enrollees than did the other 26 practices. Although about 21% of the sample

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[*] When individuals enroll in One Care, MassHealth assigns them a "rating category" based primarily on previous MassHealth claims. This rating category determines the capitated payment level. Rating category C2 indicates community-dwelling persons with "high behavioral health need"; C2B includes persons with comorbid substance use disorders; and C2A includes all other persons in this category. Rating Category C3 indicates community-dwelling persons with substantial needs for LTSS care: 2 or more ADL limitations and 3 skilled nursing days weekly; or 4 or more ADL limitations. C3B indicates persons with selected diagnoses associated with very high costs, and C3A indicates all other persons in this category. Our sample included persons in the C2 and C3 rating categories, as indicated in the CCA documentation.

[†] People whose language preference was not known were included in the survey.

members did not have a designated PCP specified in the sampling frame, all enrollees in the universe of eligible enrollees did have a designated primary care practice among the 27 eligible practices.

Interventions

Reports of Baseline (Wave 1) PDQ-S Findings

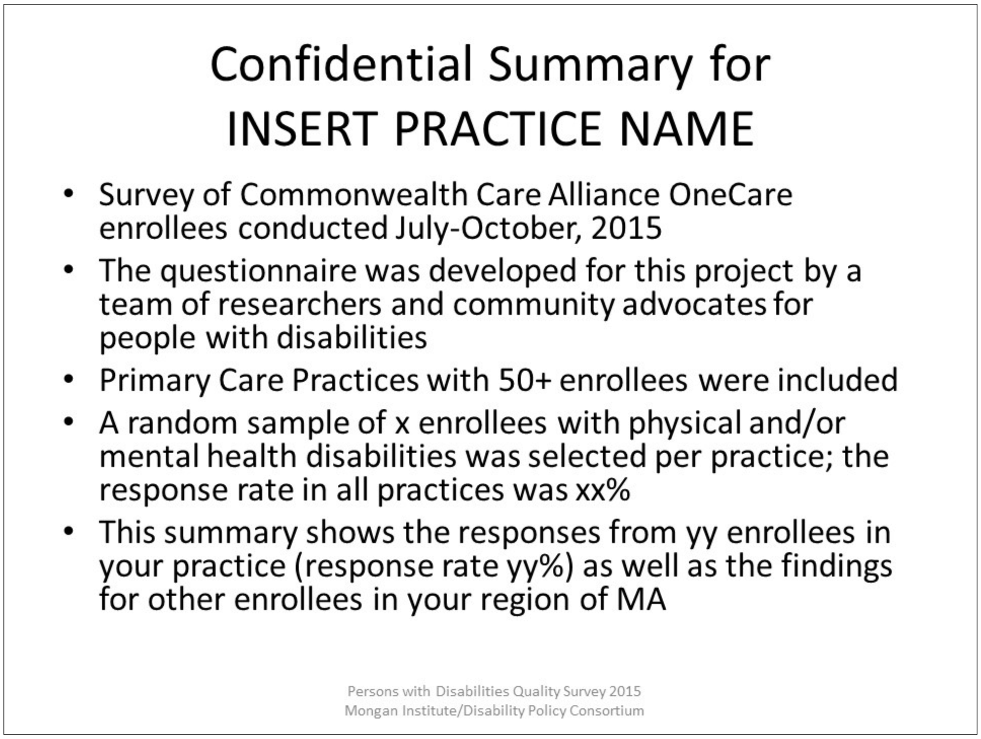
We created a practice-level report of baseline (wave 1) PDQ-S findings that included a cover letter describing the survey and a 3-page report of text and graphics showing practice-level data, as well as comparative data from a random sample of all wave 1 participants. We sent these reports to the practice manager at each of the 18 practices randomized to the 2 intervention arms (arms 1 and 2). Approximately 1 month later, we sent the same practice report to 221 PCPs that the health plan indicated served as the PCP for at least 1 individual in the wave 1 sample. One very large practice had 24 eligible PCPs; the others averaged 7 PCPs per practice (range, 4-14). Figures 3 to 8 show examples of tables and figures sent to PCPs; the Results section presents details about wave 1 PDQ-S results. We invited questions or follow-up from the practices and received only 1 anecdotal report from a provider that she had seen the data.

Quarterly Reports of YES Health Quality Assessments

To prepare for sharing quarterly YES Health quality assessment reports with practice managers and PCPs at the 9 study arm 1 primary care practices, DPC staff contacted practices and offered to describe YES Health to practice staff either in person or by telephone. DPC staff sought advice about the most effective method to provide the YES Health quality assessments to PCPs so that PCPs would engage with them and support quality improvement activities. DPC had considerable difficulty getting responses from the practices despite multiple and varied attempts at contacting different practice personnel. Without input from the PCPs or practice managers, the most efficient and straightforward approach for distributing the quarterly reports was by regular US Postal Service mail (CCA had provided PCP and practice mailing addresses but not email addresses) in the form of a 2-page report with both narrative and numerical content. DPC staff conceptualized, produced, and mailed these quarterly reports to each PCP and the practice manager. DPC staff sent similar content in written newsletters to YES Health participants.

Figures 3 to 8. Reports About Baseline PDQ-S Findings for study arms 1 and 2: Examples of Tables and Figures Sent to Practice Managers and PCPs

Figure 3. Confidential Summary

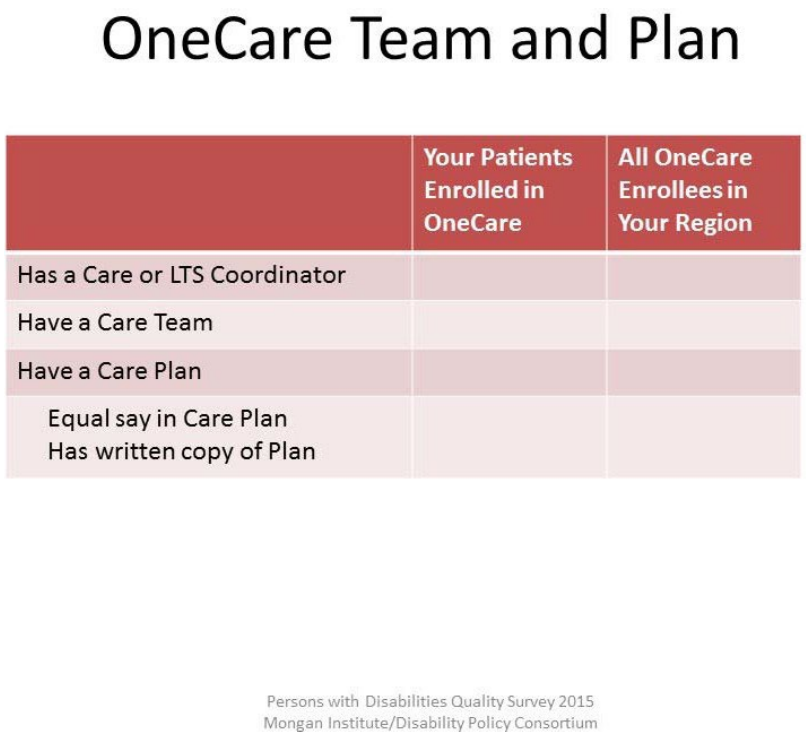


Confidential Summary for
INSERT PRACTICE NAME

- Survey of Commonwealth Care Alliance OneCare enrollees conducted July-October, 2015
- The questionnaire was developed for this project by a team of researchers and community advocates for people with disabilities
- Primary Care Practices with 50+ enrollees were included
- A random sample of x enrollees with physical and/or mental health disabilities was selected per practice; the response rate in all practices was xx%
- This summary shows the responses from yy enrollees in your practice (response rate yy%) as well as the findings for other enrollees in your region of MA

Persons with Disabilities Quality Survey 2015
Mongan Institute/Disability Policy Consortium

Figure 4. One Care Team and Plan



OneCare Team and Plan

	Your Patients Enrolled in OneCare	All OneCare Enrollees in Your Region
Has a Care or LTS Coordinator		
Have a Care Team		
Have a Care Plan		
Equal say in Care Plan Has written copy of Plan		

Persons with Disabilities Quality Survey 2015
Mongan Institute/Disability Policy Consortium

Abbreviation: LTS, long-term service.

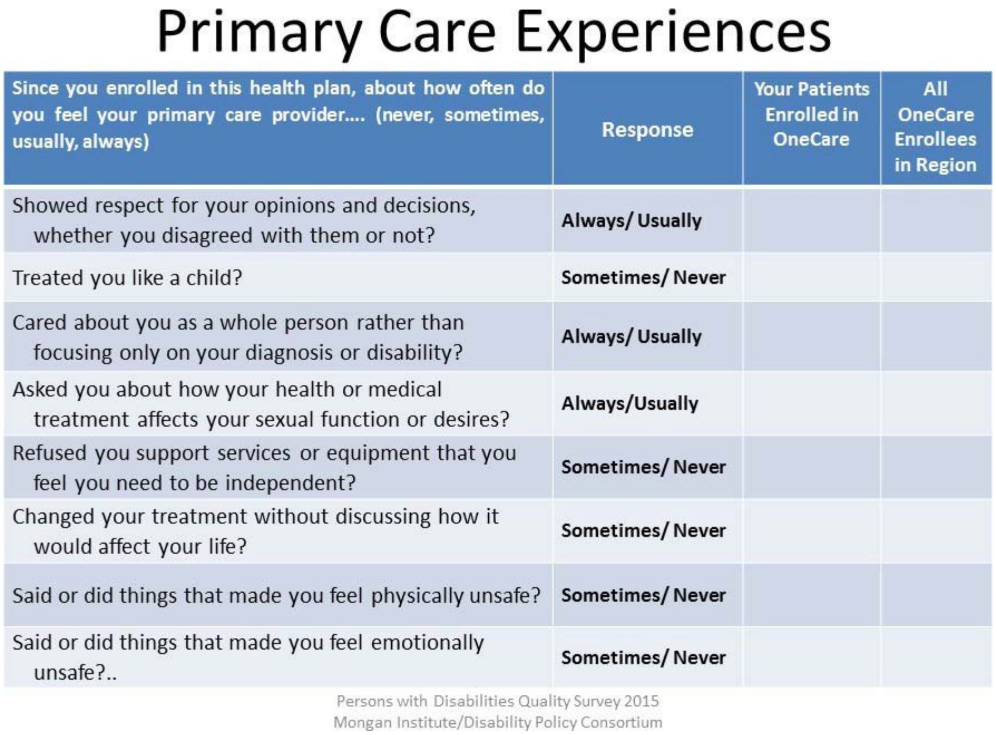
Figure 5. Independence

Independence

For each statement below, please check the box that shows how much you disagree, somewhat agree, or strongly agree with each one.	Your Patients Enrolled in OneCare who AGREE	All OneCare Enrollees in Your Region who AGREE
I decide for myself <u>what</u> I will do each day and when I will do it—for example, when I wake up, eat, or go to bed and what I do for fun at home or in my community.		
I believe my quality of life will get better in the future.		
I feel free to take risks when I want to, even if some people do not agree with my choices.		
I do things that make me feel good about myself - such as work, school, volunteer activities, or creative projects.		
I worry about keeping my housing or having a place to live.		
I am able to get together, talk with, or chat online with other people each day.		

Persons with Disabilities Quality Survey 2015
Mongan Institute/Disability Policy Consortium

Figure 6. Primary Care Experiences



Primary Care Experiences

Since you enrolled in this health plan, about how often do you feel your primary care provider…. (never, sometimes, usually, always)	Response	Your Patients Enrolled in OneCare	All OneCare Enrollees in Region
Showed respect for your opinions and decisions, whether you disagreed with them or not?	Always/ Usually		
Treated you like a child?	Sometimes/ Never		
Cared about you as a whole person rather than focusing only on your diagnosis or disability?	Always/ Usually		
Asked you about how your health or medical treatment affects your sexual function or desires?	Always/Usually		
Refused you support services or equipment that you feel you need to be independent?	Sometimes/ Never		
Changed your treatment without discussing how it would affect your life?	Sometimes/ Never		
Said or did things that made you feel physically unsafe?	Sometimes/ Never		
Said or did things that made you feel emotionally unsafe?..	Sometimes/ Never		

Persons with Disabilities Quality Survey 2015
Mongan Institute/Disability Policy Consortium

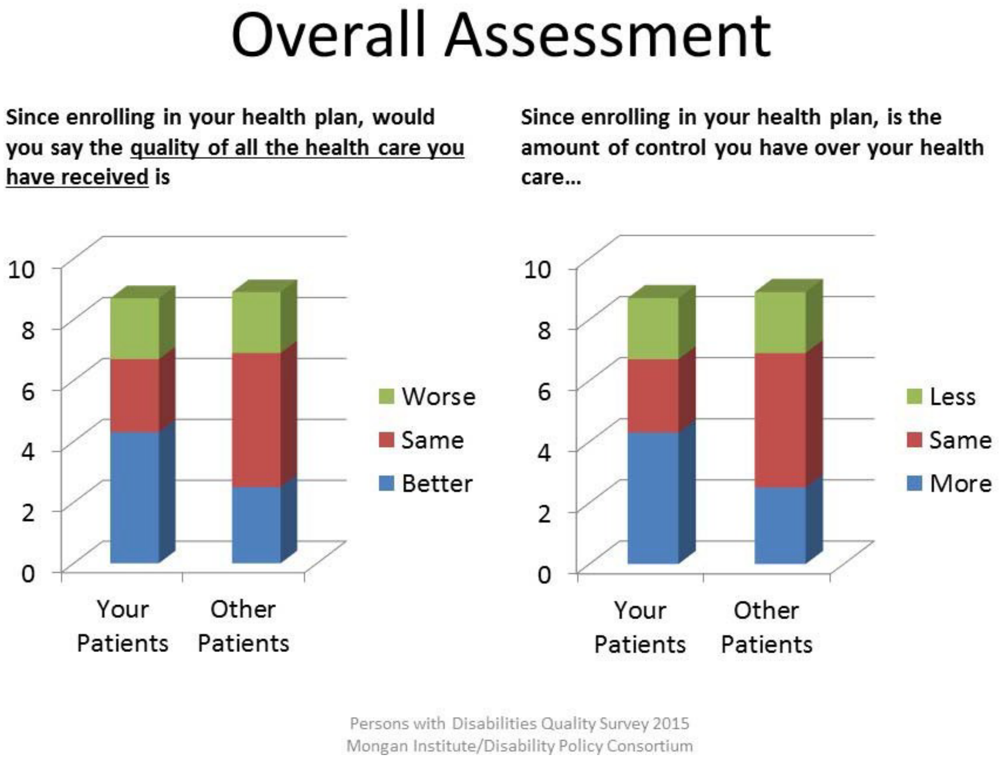
Figure 7. One Care Experiences

One Care Experiences

Since enrolling in your health plan, is <u>your life now</u> better, the same, or worse in each of the following…	Your Patients Enrolled in OneCare BETTER	All OneCare Enrollees in Your Region BETTER
My health		
My access to services or equipment I need to live as independently as I wish		
My involvement in groups, places, or activities I enjoy		
My relationships with other people		
My feelings of hope about the future		
Fears that my health care providers are making decisions about me without me		
My worry or stress about my life		

Persons with Disabilities Quality Survey 2015
Mongan Institute/Disability Policy Consortium

Figure 8. Overall Assessment



Overall Assessment

Since enrolling in your health plan, would you say the quality of all the health care you have received is

Since enrolling in your health plan, is the amount of control you have over your health care...

Persons with Disabilities Quality Survey 2015
Mongan Institute/Disability Policy Consortium

Identifying the Wave 2 PDQ-S Sample

We administered the wave 2 PDQ-S 12 months after wave 1 and as the YES Health intervention concluded. As in wave 1, the wave 2 PDQ-S included a sample of 720 community-dwelling adults with significant physical disability or serious mental illness who are enrolled in CCA One Care and are assigned to 1 of the 27 study primary care practices in the 3 study arms. In preparation for wave 2, we compared the list of all eligible One Care enrollees from which the wave 1 sample was drawn with an updated file of CCA One Care enrollees active as of April 2016 and determined that more than 600 of our wave 1 sample was still enrolled and eligible for wave 2. In consultation with study leaders and their statistical consultant, Mathematica retained wave 1 sample members who were still enrolled in CCA One Care and had no PCP change recorded or who were still enrolled in One Care but had changed to a PCP in another eligible study practice. We excluded wave 1 enrollees who changed to a PCP outside of the 27 study practices and disenrollees from CCA. We replaced excluded or disenrolled sample members with other eligible enrollees on a practice-by-practice basis consistent with the number of enrollees who had left that practice.

Study Outcomes

We hypothesized that gathering consumer-defined quality information from persons with disability and reporting this information to PCPs would motivate PCPs to improve their quality of care as perceived by One Care enrollees. Wave 2 PDQ-S results would indicate postintervention perceptions of care quality of One Care enrollees with significant physical disability or serious mental illness. The change between wave 1 and wave 2 PDQ-S results would indicate whether either or both interventions (see the "Reports of Baseline [Wave 1] PDQ-S Findings" and "Quarterly Reports of YES Health Quality Assessments" sections) affected the perceptions of One Care enrollees—and thus suggest whether PCPs had improved their care.

Data Collection and Sources

Data Collection for PDQ-S Waves 1 and 2

The "Reports of Baseline (Wave 1) PDQ-S Findings" and "Quarterly Reports of YES Health Quality Assessments" sections describe data collection and sources for the 2 informational interventions (report of baseline PDQ-S findings and quarterly YES Health reports). Here, we describe data collection for PDQ-S waves 1 and 2. We administered PDQ-S twice, 1 year apart, each during 12 to 13 weeks in June-September 2015 and 2016. Our multimodal design included self-administered web and mail modes and interviewer administration by telephone.[‡] This design gave sample members the opportunity to respond using the mode and time frame most convenient for them. In each wave, we sent all eligible participants an advance letter with information to complete PDQ-S online. Persons who completed PDQ-S in the first 10 days of the field period received a $15 gift card, while those completing it later received a $10 gift card. About 27% of survey respondents competed PDQ-S within the 10-day window. The distribution of chosen administration modes was similar in both

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[‡] We also had resources for face-to-face, in-person administration, but no participant requested that option.

waves. Of the 3 possible modes, participants preferred telephone administration (69.5%). Of the small percentage of respondents who answered by web in wave 1 (5%), only a few (10% of the 5%) also participated by web in wave 2.

We calculated response rates as 62.7% in wave 1 and 60.6% in wave 2; weighted response rates were 65.4% and 62.0%, respectively, accounting for selection probabilities. We calculated response rates using Response Rate No. 4, American Association for Public Opinion Research (AAPOR) 2016.[§] As such, both waves met our target response rate of 60%. Most importantly, we succeeded in including populations that can be difficult to reach, such as people who have experienced homelessness and those who speak only Spanish. Throughout the field period, Mathematica monitored data collection for the sample overall and by subgroup, including tracking survey completion across the 27 practices, the 3 study arms, language of survey completion, and the 2 subgroups of disability (significant physical disability and serious mental illness). At the close of the field period, response rates ranged from 37.5% to 75.0% across the 27 practices, and were 62.1%, 60.5%, and 57.2% by study arm, respectively. Final response rates were 63.8% for persons with physical disability and 54.6% for individuals with serious mental illness. Response rates among Spanish (66.7%) and English speakers (63.3%) were similar (persons with unknown language preferences had a 51.8% response rate).

Survey of Primary Care Physicians in Year 3

We had originally intended to conduct semistructured, open-ended interviews with 2 individuals at each of the anticipated 12 YES Health practices (see the “Conduct of Study” section); however, the lack of responsiveness from practice personnel (see the “YES Health Results” section) caused us to change our plans.

To elicit feedback directly from PCPs to whom we had sent reports, we developed a brief survey to be mailed to the PCPs of record for the enrollees we had sampled for PDQ-S

[§] Applying the AAPOR RR4 formula to the wave 2 data, the numerator in the response rate formula is 426, and the denominator is 426 + eligibility rate × 284, where the eligibility rate is 426/436. This assumes that all nonrespondents have unknown eligibility (ie, it is possible that they could be dead or have a language other than English, Spanish, or American Sign Language).

wave 1. Survey development proceeded in 4 phases: review of key informant interviews conducted with physician stakeholders at the start of the project; solicitation of feedback from the research team and ROC; instrument drafting by our survey research methodologist; and final review by 2 other survey researchers with expertise in clinician surveys.

Because the reports we had sent to the PCPs included PDQ-S findings, we sought to assess the value that PCPs placed on PDQ-S-type information and test their knowledge of key elements of One Care and quality reporting about One Care. Survey domains included attitudes about the integration of physical and behavioral health care for persons with disability (3 items); items about One Care plans, care teams, and new services made available to patients through One Care (identical to measures in PDQ-S; 5 questions); provision of primary care services important to persons with disability and emphasized in YES Health reports (3 items); recall of quality reports, including PDQ-S and YES Health (4 items); an overall assessment of benefits of One Care for patients (5 items); and provider characteristics (4 items). We conducted the survey by postal mail among the PCPs assigned to the enrollees sampled in wave 1 of the PDQ-S. During October to December 2016, we mailed surveys to PCPs, enclosing $50 in retail gift cards. We sent up to 2 more mailings to nonrespondents, correcting address errors or changes through outreach to practice administrators, web searches, and further updates from CCA. If we could not locate the targeted physician in Massachusetts or in one of our study practices, we excluded them from the eligible physicians for this survey.

Among the 221 PCPS listed by the health plan as the providers of record for wave 1 sample members, 19 were excluded for having subsequently left an eligible practice, and 10 refused participation. We received surveys from 110 of 202 eligible PCPs (54.4%), although 7 indicated they had no One Care patients and therefore could not answer questions about One Care enrollees. We nonetheless included them in our analyses.

Analytical and Statistical Approaches

We focus here on the analysis of the wave 1 and wave 2 PDQ-S data; the differences in results from these 2 surveys represent our main outcome measure (ie, whether enrollees' perceptions of quality of care, broadly defined, have changed across the 12-month interval between waves; see the “Study Outcomes” section). We performed descriptive analyses of cohort characteristics and cross-sectional PDQ-S results within waves, and longitudinal analyses across the 2 PDQ-S waves. We compared the change from wave 1 to wave 2 and among the 3 within each wave, using chi-square tests. We also analyzed results from the randomized trial (see the “Study Design” section) by comparing the changes from wave 1 to wave 2 among the 3 study arms by testing the wave and arm interaction in the logistic regression models. We performed a subanalysis using only results from persons who completed both wave 1 and 2 surveys. We conducted all analyses using SAS survey procedures to consider survey sampling structure and sampling weights. We report weighted percentages in the Results section to reflect the underlying populations.

We conducted primarily descriptive analyses of the PCP survey. We also ran analyses by PCP assignment to each of the 3 study arms. These analyses were affected by small numbers of PCPs in certain combinations of study arms and question response category.

Key Assumptions of Methods

As in any randomized trials with surveys, our study has 2 key assumptions: (1) The study groups are similar; and (2) there is no nonresponse bias. For the first assumption, we found some imbalances across the groups because randomization occurred at the practice level, not at the patient level. Therefore, we conducted regression analyses including these patient-level characteristics in the model to account for these imbalances. For the second assumption, we adjusted the original sampling weights assigned to each individual to account for differences between respondents and nonrespondents.

Handling of Missing Data

As stated in the “Key Assumptions of Methods” section, we accounted for nonresponse by adjusting the original sampling weights assigned to each individual. For each adjustment factor that we calculated, the goal was to increase weights of interviewed individuals who are most similar to those individuals who could not be interviewed, thereby counteracting differences between respondents and nonrespondents and reducing the potential for nonresponse bias.[**] For specific PDQ-S items, missing data ranged from 0% to 8% with a mean of 2.7%. With such small amounts of missing information, we did not attempt to impute values.

Identifying Heterogeneity of Treatment Effects in Subgroups

We examined the heterogeneity of treatment effects in subgroups identified by type of disability (significant physical disability vs serious mental illness). Our (null) hypothesis is patients with physical disability and serious mental illness will report similar overall One Care experiences and perceptions in responding to PDQ-S; however, we also hypothesize that the 2 groups will differ somewhat in responses to individual PDQ-S items.

Conduct of Study

As documented throughout this project, all aspects of the study were approved by the Partners Human Research Committee IRB. We submitted multiple amendments to the IRB as the study proceeded, addressing each upcoming activity in turn.

As described in the “Study Setting” section, the major deviation of our final study from the proposed protocol involved the participation of a single One Care plan. We originally intended to include all 3 One Care plans and to randomize 36 practices to the 3 study arms (12 practices from each One Care plan). However, with CCA as our sole participating plan, we had only 27 practices that met our criteria for participation (ie, ≥50 One Care members with either significant physical disability or serious mental illness).

The other major deviation from our proposed plans resulted from the difficulties engaging PCPs and practice managers through the YES Health initiative (see the “Survey of Primary Care Physicians in Year 3” and “YES Health Results” sections). That led us to conduct a survey of PCPs in months 32 to 33 of the project.

[**] For justification of using nonresponse adjustments to weights, see Chapter 8 in Lohr SL, *Sampling: Design and Analysis*. Brooks/Cole Publishing Company; 1999.

RESULTS

In this section, we present our results as follows: description of study population (see the "Description of Study Population" section); results from the baseline (wave 1) PDQ-S, which was sent to practice managers and PCPs in study arm 1 and 2 practices (see the "Baseline [Wave 1] PDQ-S Results" section); findings from the YES Health quarterly survey (ie, information sent to practice managers and PCPs in study arm 1; see the "YES Health Results" section); results of the randomized controlled trial (see the "Results From Cluster Randomized Controlled Trial" section); and findings from the PCP survey (see the "Physician Survey Results" section). CONSORT diagrams describing the administration of our 3 surveys, PDQ-S wave 1, PDQ-S wave 2, and the PCP survey, can be found in Figures 9, 10, and 11, respectively.

Description of Study Population

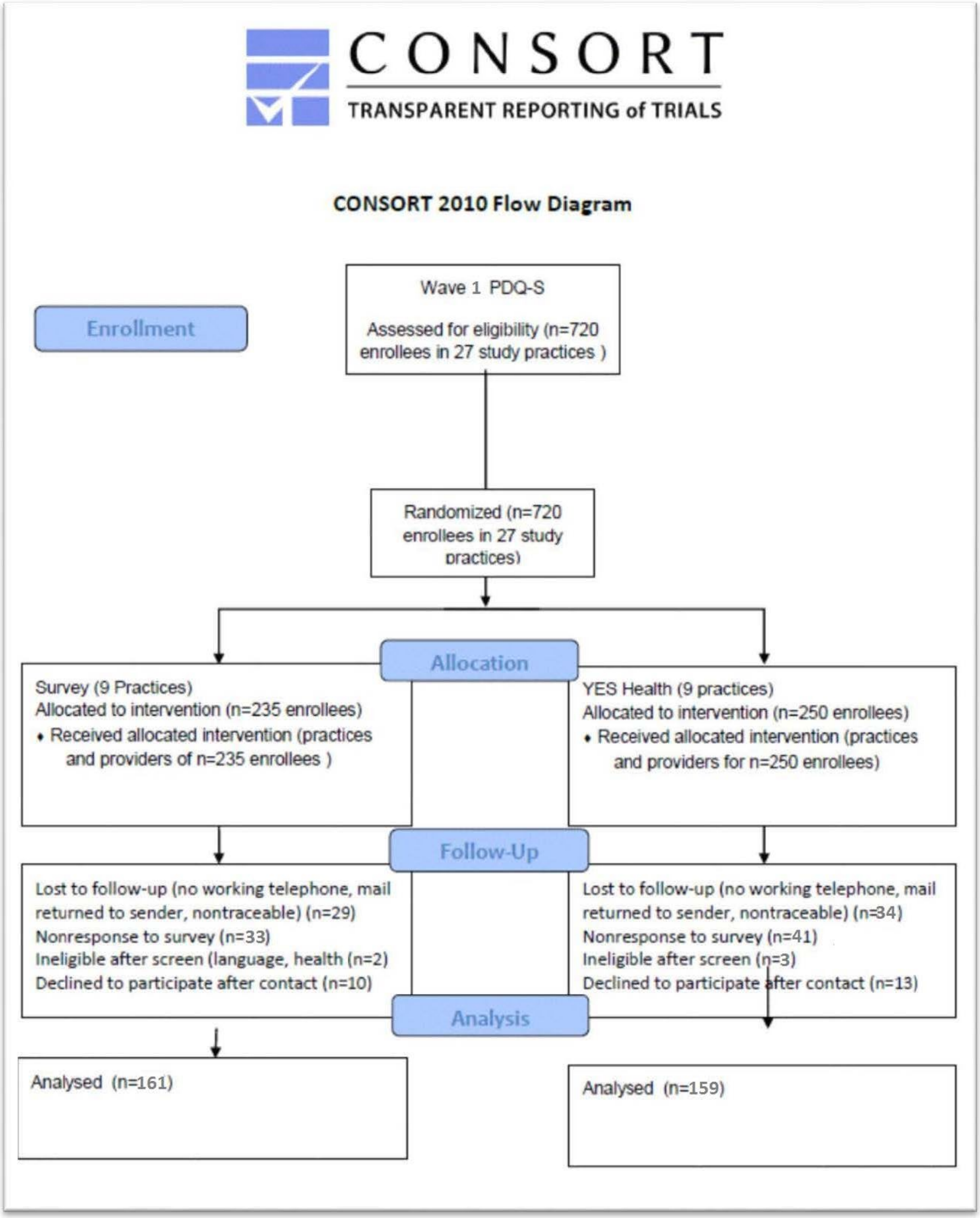
In wave 1, a total of 451 persons answered PDQ-S: 160 in the YES Health and PDQ-S arm; 156 in the PDQ-S–only arm; and 135 in the control arm. In wave 2, a total of 426 persons answered PDQ-S: 154 in the YES Health and PDQ-S arm; 141 in the PDQ-S–only arm; and 131 in the control arm. As noted in the "Key Assumptions of Methods" section, we randomized practices not participants; therefore, imbalances across study arms did occur with certain participant attributes. Table 3 shows demographic characteristics of participants in each of the 2 waves across the study arms.

In wave 1, participants across the 3 study arms were similar by age, gender, disability type, education, language of survey completion, current living arrangements, and whether persons had experienced homeless in the past 6 months. Across all 451 participants, 45.8%[††] were male, 37.8% had significant physical disability, 33.9% had less than a high school education, 83.9% completed the survey in English, 42.6% were living alone, and 10.5% had experienced homelessness in the past 6 months. In contrast, significant differences appeared across the 3 study arms in other participant characteristics. For example, overall 39.3%

[††] Percentages from PDQ-S results represent weighted percentages. We weighted percentages to ensure that the estimates provided here represent the entire underlying population, not just the sampled cases.

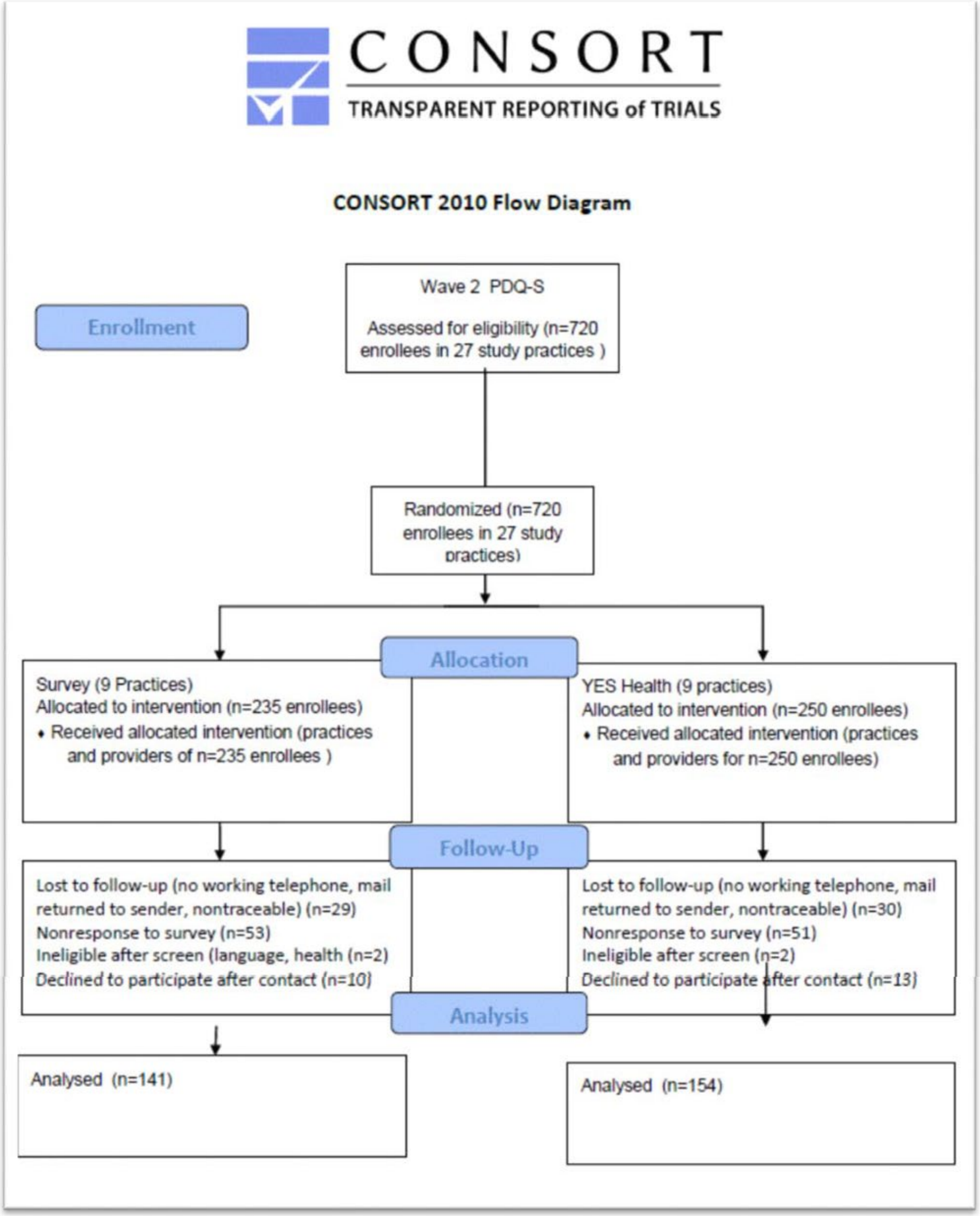
participants were White; however, 54.1% of participants in the YES Health/PDQ-S arm were White, compared with 25.2% in the PDQ-S–only arm and 37.8% in the control arm. Marital status also differed significantly: Overall, 44.9% participants were single, but 31.3% of participants in the YES Health/PDQ-S arm were single, compared with 51.4% in the PDQ-S–only arm and 53.4% in the control arm.

Figure 9. CONSORT Diagram for Wave 1



Abbreviation: PDQ-S, Persons With Disability Quality Survey.

Figure 10. CONSORT Diagram for Wave 2



Abbreviation: PDQ-S, Persons With Disability Quality Survey.

Figure 11. CONSORT Diagram for Primary Care Physician Survey

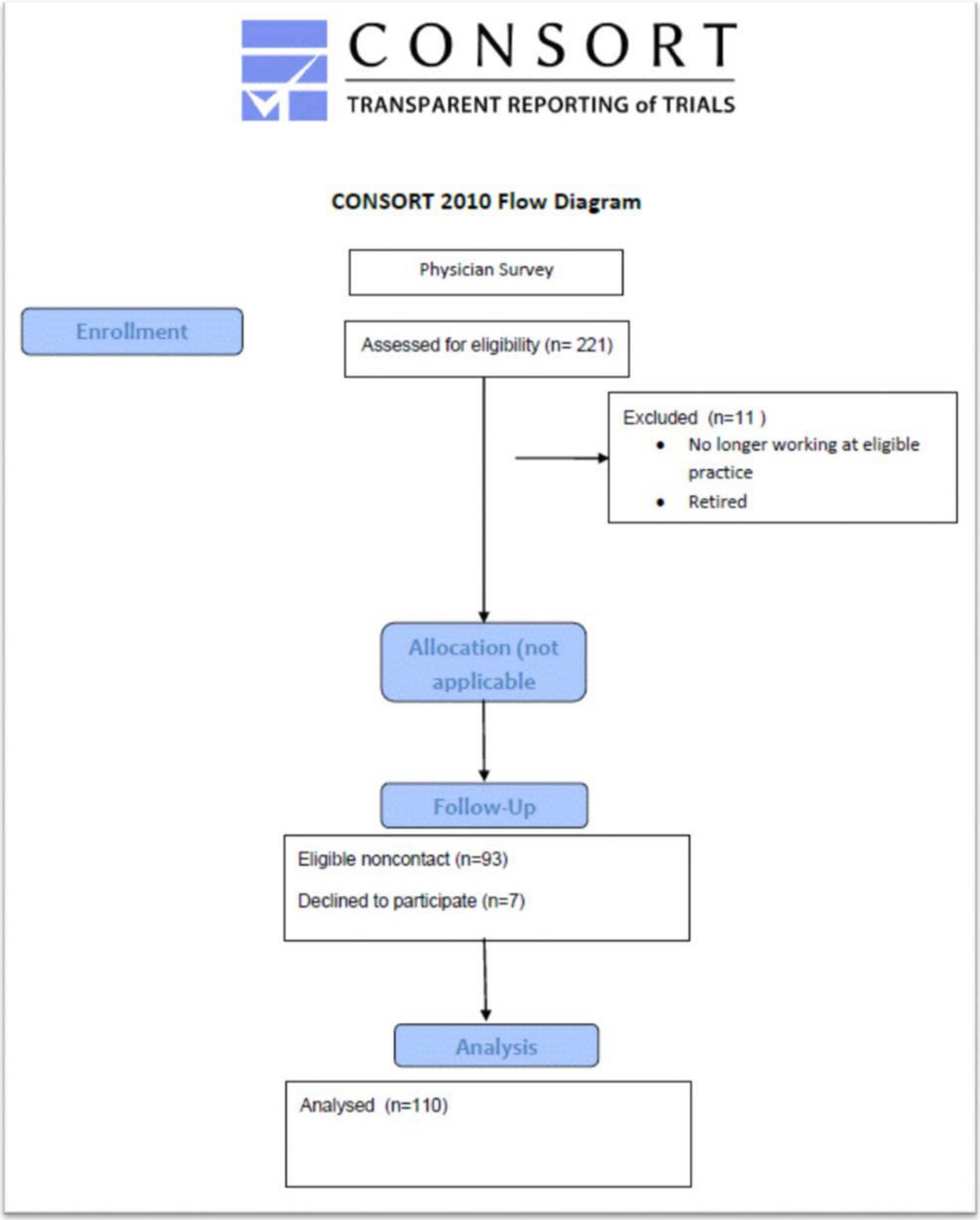


Table 3. Sociodemographic Characteristics by Study Arm and Survey Wave

	Study arm and wave															
	YES Health and PDQ-S				PDQ-S Only				Control				Total			
	Wave 1 n = 160		Wave 2 n = 154		Wave 1 n = 156		Wave 2 n = 141		Wave 1 n = 135		Wave 2 n = 131		Wave 1 N = 451		Wave 2 N = 426	
Sociodemographic characteristics	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Age																
<40 y	27	19.7	23	18.2	32	23.0	24	20.8	24	18.1	23	20.3	83	20.3	70	19.7
40-49 y	31	22.5	25	21.3	36	20.8	31	22.5	27	17.6	21	16.9	94	20.4	77	20.3
50-59 y	79	44.8	67	41.0	66	42.9	62	39.6	61	47.0	50	35.6	206	44.8	179	38.9
≥60 y	23	12.9	39	19.6	22	13.2	24	17.1	23	17.3	37	27.3	68	14.4	100	21.1
Gender																
Male	80	47.8	74	42.5	66	43.5	64	43.5	61	46.0	67	54.8	207	45.8	205	46.6
Female	80	52.2	80	57.5	90	56.5	77	56.5	74	54.0	54	45.2	244	54.2	221	53.4
Race/ethnicity[a,b]																
White	81	54.1	74	53.8	37	25.2	42	31.8	52	37.8	45	33.2	170	39.3	161	40.1
Black	12	5.5	11	6.2	58	31.2	48	28.7	26	18.7	20	13.2	96	18.2	79	15.8
Hispanic	59	33.3	59	35.1	40	32.3	35	30.0	35	29.5	46	37.2	134	31.8	140	34.0
Other	8	7.1	10	4.9	21	11.3	16	9.5	22	14.0	20	16.4	51	10.6	51	10.0

Sociodemographic characteristics	**Study arm and wave**												**Total**			
	YES Health and PDQ-S				**PDQ-S Only**				**Control**							
	Wave 1 n = 160		**Wave 2 n = 154**		**Wave 1 n = 156**		**Wave 2 n = 141**		**Wave 1 n = 135**		**Wave 2 n = 131**		**Wave 1 N = 451**		**Wave 2 N = 426**	
	No.	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**
Disability type: significant physical disability[b]	62	37.7	52	36.7	54	32.0	52	34.6	54	44.1	56	53.2	170	37.8	170	41.0
Serious mental illness	98	62.3	102	63.3	102	68.0	89	65.4	81	55.9	75	46.8	281	62.2	281	59.0
Education less than high school[b]	55	32.8	44	28.2	39	29.3	32	24.6	47	40.2	48	43.4	141	33.9	141	31.5
High school or GED	46	30.2	53	35.3	45	29.3	40	31.2	40	32.4	41	32.9	131	30.6	131	33.3
More than high school	55	37.0	53	36.4	66	41.5	63	44.1	42	27.4	34	23.7	163	35.6	163	35.2
Marital status: single[a,b]	54	31.3	69	39.0	75	51.4	75	57.7	71	53.4	68	56.3	200	44.9	200	50.4
Married or partnered	31	21.3	26	21.8	24	18.7	23	18.0	18	12.5	24	19.5	73	17.7	73	19.9
Widowed or divorced	71	47.4	56	39.2	51	29.8	39	24.3	41	34.1	33	24.2	163	37.3	163	29.8
Current living arrangement[§]																
Lives with others	92	55.4	91	60.0	95	62.2	83	56.2	75	54.6	83	67.8	262	57.4	262	61.1
Lives alone	68	44.6	63	40.0	61	37.8	58	43.8	60	45.4	48	32.2	189	42.6	189	38.9
Experienced homelessness in past 6 mo																
Yes	11	5.9	11	5.8	23	14.5	14	11.7	13	11.3	10	10.7	47	10.5	47	9.2
No	144	94.1	138	94.2	127	85.5	122	88.3	118	88.7	109	89.3	389	89.5	389	90.8

Sociodemographic characteristics	Study arm and wave												Total			
	YES Health and PDQ-S				PDQ-S Only				Control							
	Wave 1 n = 160		Wave 2 n = 154		Wave 1 n = 156		Wave 2 n = 141		Wave 1 n = 135		Wave 2 n = 131		Wave 1 N = 451		Wave 2 N = 426	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Language version of PDQ-S																
English	129	83.9	125	82.6	136	82.6	127	86.4	120	85.2	112	82.7	385	83.9	385	83.9
Spanish	31	16.1	29	17.4	20	17.4	14	13.6	15	14.8	19	17.3	66	16.1	66	16.1

Abbreviations: GED, general education degree; PDQ-S, Persons With Disability Quality Survey.

[a] Distribution differs significantly (*P* ≤ .05) among study arms in wave 1.

[b] Distribution differs significantly among study arms in wave 2.

§Distribution differs significantly between waves 1 and 2 in the control arm.

In wave 2, distributions of participants by age, gender, language of survey completion, current living arrangements, and whether persons had experienced homeless in the past 6 months did not differ statistically significantly across the 3 study arms. Across all 426 participants, 46.6% were male, 83.9% completed the survey in English, 38.9% were living alone, and 9.2% had experienced homelessness in the past 6 months. Significant differences appeared across the wave 2 study arms in other participant characteristics. Most importantly, overall, 41.0% participants had physical disability; however, 36.7% of participants in the YES Health and PDQ-S arm had physical disability, compared with 34.6% in the PDQ-S–only arm, and 53.2% in the control arm. Educational status also showed significant differences: Overall, 31.5% participants had less than a high school education, but 28.2% of participants in the YES Health and PDQ-S arm had this level of education, compared with 24.6% in the PDQ-S–only arm, and 43.4% in the control arm.

Between waves 1 and 2, the only statistically significant difference in distribution of demographic characteristics among PDQ-S participants involved living arrangements in the control group: Persons in wave 1 were much more likely to live alone (45.4%) than those in wave 2 (32.2%).

Baseline (Wave 1) PDQ-S Results

Results from wave 1 PDQ-S administration appear in Table 4 (perceptions relating to independent living principles), Table 5 (perceptions of One Care and PCP experiences), and Table 6 (perceptions of daily life). We used these results to produce the baseline reports sent to practice managers and PCPs in study arms 1 and 2 (Figures 3-8). We describe these results further—in comparison to wave 2 findings—in the “Results From Cluster Randomized Controlled Trial” section. For purposes of the randomized clinical trial, it is important to note that wave 1 findings did not vary significantly across the study arms for independent living principle questions (Table 4) and perceptions of One Care and PCP experiences (Table 5). In wave 1, the only statistically significant difference in responses across study arms involved the percentage of persons saying their relationships with other people were better now than in the past year: 25.1% in study arm 1 compared with 40.2% in arm 2 (Table 6).

Table 4. Perceptions Relating to Independent Living Principles by Study Arm and Survey Wave

“Strongly agree” response[a] to statement:	Study arm												Total			
	YES Health and PDQ-S (arm 1)				PDQ-S Only (arm 2)				Control (arm 3)							
	Wave 1 n = 160		Wave 2 n = 154		Wave 1 n = 156		Wave 2 n = 141		Wave 1 n = 135		Wave 2 n = 131		Wave 1 N = 451		Wave 2 N = 426	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
I decide for myself what I will do each day and when I will do it.	103	67.6	116	72.5	116	73.2	110	79.2[b]	89	66.5	88	65.2	308	69.2	315	72.5
I believe my quality of life will get better in the future.	68	40.1	60	33.6[c]	76	45.3	65	51.8	56	41.2	51	39.1	200	42.2	181	41.3
I feel free to take risks when I want to, even if some people do not agree with my choices.	45	30.5	53	36.8	59	39.2	63	48.6[b]	48	35.0	43	32.0	152	34.8	164	39.2
I do things that make me feel good about myself.	64	43.2	62	42.2[c]	78	48.3	48	56.6	65	51.1	63	45.6	207	47.3	175	48.0
I worry about keeping my housing or having a place to live.	39	26.9	40	28.4	31	21.5	36	25.7	26	17.1	29	20.2	96	22.1	102	25.0
I am able to get together, talk with, or chat online with other people each day.	51	31.4	61	39.9	55	40.4	59	43.9	49	35.5	56	42.4	155	35.7	169	42.0

Abbreviation: PDQ-S, PDQ-S, Persons With Disability Quality Survey.

[a] Response categories = strongly agree, somewhat agree, somewhat disagree, and strongly disagree.

[b] Result differs significantly (*P* ≤ .05) compared with the control arm within the same wave.

[c] Result differs significantly (*P* ≤ .05) compared with the PDQ-S–only arm within the same wave.

Table 5. Perceptions of One Care and PCP Experiences by Study Arm and Survey Wave

	Study arm												Total			
	YES Health and PDQ-S (arm 1)				PDQ-S only (arm 2)				Control (arm 3)							
	Wave 1 n = 160		Wave 2 n = 154		Wave 1 n = 156		Wave 2 n = 141		Wave 1 n = 135		Wave 2 n = 131		Wave 1 N = 451		Wave 2 N = 426	
Question	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**
Do you have a care team? **YES**	94	58.5	97	62.9	97	63.4	97	71.2[a]	84	61.4	73	55.9	275	61.0	278	63.5
Do you have a care plan? **YES**	92	58.5	94	58.1	78	52.1	90	66.6[a,b,c]	79	56.6	74	52.1	249	55.7	263	59.1
Did you have equal say in developing your care plan? **YES**	85	54.0	84	51.8[d]	68	44.0	80	60.1[a,b,c]	68	48.1	61	44.7	221	48.8	232	52.4
Did you receive a written copy of the care plan? **YES**	45	27.2	53	33.7	48	31.9	47	35.7	40	31.7	35	26.5	133	30.2	140	32.1
How often has your PCP showed respect for your opinions and decisions? **ALWAYS**	90	56.9	84	54.7	87	56.6	81	55.6	70	50.4	63	51.2	247	54.8	235	53.9
How often has your PCP treated you like a child? **NEVER**	131	84.7	129	84.8	131	85.1	106	77.6	108	81.7	100	81.2	370	84.0	343	81.3
How often has your PCP cared about you as a whole person? **ALWAYS**	83	49.7	85	53.8	90	57.6	78	56.1	82	60.2	66	55.6	255	55.6	245	55.1
How often has your PCP asked about how your health/medical treatment affects your sexual function or desires? **ALWAYS**	21	11.7	16	10.8	21	12.4	28	19.1	21	15.6	24	20.4	63	13.1	65	16.5
How often has your PCP refused you support service/equipment	117	75.1	118	75.7[d]	128	84.5[a]	94	67.3[b,c]	94	69.6	93	72.8	339	76.6	306	72.0

	Study arm															
	YES Health and PDQ-S (arm 1)				**PDQ-S only (arm 2)**				**Control (arm 3)**				**Total**			
	Wave 1 n = 160		**Wave 2 n = 154**		**Wave 1 n = 156**		**Wave 2 n = 141**		**Wave 1 n = 135**		**Wave 2 n = 131**		**Wave 1 N = 451**		**Wave 2 N = 426**	
Question	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**
you feel you need to be independent? **NEVER**																
How often has your PCP changed your treatment without discussing how it would affect your life? **NEVER**	132	83.9	127	80.2	128	83.8	107	77.0	103	78.6	100	80.8	363	82.2	337	79.3
How often has your PCP said or done things that made you feel physically unsafe? **NEVER**	135	85.7	137	88.0	133	85.2	117	80.9	116	87.4	111	87.1	384	86.0	370	85.4
How often has your PCP said or done things that made you feel emotionally unsafe? **NEVER**	129	81.4	135	87.4[d,e]	133	86.3	109	74.41[a,b,c]	105	78.6	111	85.6	367	82.2	349	82.5
In the past year, in your health plan, would you say the quality of all the health care that you have received is **BETTER THAN BEFORE?**	107	64.6	72	46.4§	93	59.6	80	58.7	83	64.8	65	48.0§	283	62.9	235	51.0[c]

Abbreviations: PCP, primary care provider; PDQ-S, PDQ-S, Persons With Disability Quality Survey.

[a] Result differs significantly (*P* ≤ .05) comparing the control arm within the same wave.

[b] Result differs significantly (*P* ≤ .05) comparing the change between waves to control arm.

[c] Result differs significantly (*P* ≤ .05) comparing the wave 1 within the same study arm.

[d] Result differs significantly (*P* ≤ .05) comparing the change between waves to PDQ-S–only arm.

[e] Result differs significantly (*P* ≤ .05) comparing the PDQ-S–only arm within the same wave.

Table 6. Perceptions of Daily Life by Study Arm and Survey Wave

	Study arm															
	YES Health and PDQ-S				PDQ-S only				Control				Total			
	Wave 1 n = 160		Wave 2 n = 154		Wave 1 n = 156		Wave 2 n = 141		Wave 1 n = 135		Wave 2 n = 131		Wave 1 N = 451		Wave 2 N = 426	
Question	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**
In the past year, my feelings about hope for the future have **INCREASED**.	71	41.7	44	29.2[a]	71	48.8	44	31.9[a]	53	40.5	45	38.5	195	43.7	141	33.0[a]
In the past year, my fears that my health care providers are making decisions about me without me have **DECREASED**.	7	4.2	32	22.5[a]	7	3.9	28	21.1[a]	8	5.4	28	22.6[a]	22	4.5	88	22.1[a]
In the past year, my worry or stress about my life has **DECREASED**.	27	20.4	29	17.8	32	17.0	16	12.1	23	15.6	13	10.9	82	17.8	58	13.8
In the past year, the amount of control I have over my health care has **INCREASED**.	67	36.6	36	23.9[a]	61	40.6	37	27.8[a]	48	38.6	35	27.3	176	38.6	121	26.3[a]
In the past year, in your health plan, is your life now better, the same or worse, in each of the following:																
My health: **BETTER NOW**	80	44.9	56	31.5[a]	74	50.0	51	37.3[a]	58	44.9	52	38.3[a]	212	46.6	165	35.5[a]
My access to services/equipment I need to live as independently as I wish: **BETTER NOW**	76	42.3	60	36.7	75	51.4	49	39.8	61	48.9	43	32.7	212	47.4	170	36.5[a]

	Study arm												**Total**			
	YES Health and PDQ-S				**PDQ-S only**				**Control**							
	Wave 1 n = 160		**Wave 2 n = 154**		**Wave 1 n = 156**		**Wave 2 n = 141**		**Wave 1 n = 135**		**Wave 2 n = 131**		**Wave 1 N = 451**		**Wave 2 N = 426**	
Question	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**
My involvement in groups, places, or activities I enjoy: **BETTER NOW**	50	27.9	40	24.0	54	37.0	37	29.7	36	28.0	33	24.6	140	31.0	113	26.1
My relationships with other people: **BETTER NOW**	47	25.1[b]	50	32.7[c]	53	40.2	41	29.9	40	30.1	41	30.9	140	31.7	131	31.2

Abbreviation: PDQ-S, PDQ-S, Persons With Disability Quality Survey.

[a] Result differs significantly (*P* ≤ .05) comparing the wave 1 within the same study arm.

[b] Result differs significantly (*P* ≤ .05) comparing the PDQ-S–only arm within the same wave.

[c] Result differs significantly (*P* ≤ .05) comparing the change between waves to PDQ-S–only arm.

YES Health Results

Over the 1-year implementation, DPC screened 112 individuals, and 45 (40.2%) were eligible and joined YES Health (Table 7). This represents 3.6% of 1255 potential participants in the 9 YES Health practices identified by Mathematica from the CCA database. DPC had spent considerable time and resources in developing its website and online communication approaches; however, most YES Health members (32/45 [71.1%]) preferred to receive routine communications (eg, newsletters) through regular US mail rather than online (Table 7). Similarly, most (37/45 [82.2%]) preferred to complete the Survey Monkey quarterly survey by telephone with DPC staff rather than online. Although 29 (64.4%) had used Facebook previously, only several participants joined the YES Health Facebook group discussions, which DPC stopped staffing after 8 months (Table 2).

Sequentially, the quarterly surveys of YES Health members considered (1) One Care care plans and care teams, (2) communication, (3) LTSS, and (4) transportation. DPC staff found that enrollees often did not understand even basic aspects of One Care, such as requirements for members to each have a written care plan and care team, which they participated in forming. Surveys therefore typically started by describing the topic (eg, care plans). Table 8 presents the questions and response categories from each YES Health survey, which aimed to take <15 minutes and could be completed either on the YES Health website or by telephone with English- or Spanish-speaking DPC staff. The transportation survey attracted the most respondents (36/45 [80.0%]).

Table 7. Characteristics of Persons With Disability Who Signed Up for YES Health

(n = 45)	
Characteristic	**n**
Age, y	
31-40[a]	6
41-50	9
51-63	27
≥63	3
Gender	
Male	17
Female	28
Language	
English	38
Spanish	7
Disability type	
Serious mental illness	14
Significant physical disability	18
Both	13
Communication modality preference	
Mail through US Postal Service	32
Email	12
Missing/unknown	1
Survey mode preference	
Telephone	37
Online	7
Missing/unknown	1
Has used Facebook in the past	
Yes	29
No	16
Answered quarterly YES Health survey	
First quarter	25
Second quarter	29
Third quarter	24
Fourth quarter	36

[a] No participants were younger than 30 years old.

Table 8. Quarterly YES Health Member Survey: Survey Topics, Questions, and Responses

Survey topic and questions		Selected responses
Quarter 1: Your care plan and care team		**Total n = 25**
2	Before today, has anyone explained to you what a care plan is?	Yes = 17/25
3	Before today, has anyone explained to you what a care team is?	Yes = 17/25
4	Do you know who your primary care provider is?	Yes = 25
5	Do you have a care team?	No = 4/25; not sure = 5/25
6	Did you choose your own care team?	6/20 persons with care team reported choosing care team
7	Has your whole care team ever met as a group?	10/20 persons with care team said team had met as a group
8	Did you help develop your care plan?	No = 8/24; not sure = 1/24
9	How did you help develop your care plan?[a]	
10	Do you have anything else to add about your care team or care plan?[a]	
Quarter 2: Communication		**n = 29**
2	Are you usually able to promptly reach your primary care provider, behavioral health specialist, or care coordinator when you need to speak to him or her?	Yes = 22/29
3	Do you engage in conversations with your team about recovery, lifestyle goals, or important relationships or other information that impacts the quality of your life?	Yes = 24/29
4	What qualities in a provider make it easier for you to share personal information (check all that apply)?[b]	Being a good listener (24/29) and nonjudgmental (21/29) were most important qualities
5	Do you feel safe sharing personal information about yourself with your current primary care provider or behavioral health specialist?	Yes = 26/29
6	Why don't you feel comfortable sharing information?[c]	
7a[d]	Which of these types of information do you feel comfortable sharing with them (check all that apply)?	
7b	Do you feel comfortable sharing these types of information with them?	0/11 persons felt uncomfortable sharing any of this type of information with their provider

Survey topic and questions		Selected responses
	What medication you are taking, and if you are taking it as prescribed	
	Whether you feel depressed or suicidal	
	Whether you feel manic	
	Your sexual practices	
	Your use of drugs and alcohol	
	Paranoia or intrusive thoughts	
Quarter 3: IL-LTSS		**n = 24**
2	Before reading the definition at the start of this survey, had you heard of IL-LTSS coordinator services?	Yes = 9/24; no = 14/24; not sure = 1/24
3	Have you ever been offered the opportunity to work with an IL-LTSS coordinator?	Yes = 11/24; no = 13/24
4	Were you given the information you needed to make an informed decision about whether you wanted an IL-LTSS coordinator?	Yes = 11/24; no = 11/24; not sure = 2/24
5	Are you currently working with an IL-LTSS coordinator?	Yes = 11/23; no = 10/23; not sure = 2/23; 1 person skipped this question
6	How happy are you with the IL-LTSS coordinator (or coordinators) that you have worked with?	Very happy = 6/8; neutral = 1/8; very unhappy = 1/8; 3 persons skipped this question
7	Has your IL-LTSS coordinator assisted you in getting long-term support and/or services? These could include housing resources, transportation, and assistance with employment.	Yes = 5/8; no = 3/8; 3 persons skipped this question
8	Have you ever been denied support or services that you requested through your IL-LTSS coordinator?	Yes = 2/8; no = 6/8; 3 persons skipped this question
9	What services were you denied?[a]	1 person answered a mobile health device with a fall guard; another said he or she would not say until under oath
10	Did your IL-LTSS coordinator help you try to get the services you were denied?[e]	Yes = 1/2; no = 1/2
11	Would you want to receive IL-LTSS coordinator services in the future?	Yes = 9/14; no = 1/14; not sure = 4/14; 10 persons skipped this question
12	Do you have anything else to tell us about IL-LTSS coordinators and/or services and supports (including suggestions for how the coordinator role could be improved?)[a]	3 persons were happy with it, 1 person felt a need for in-home counseling services, and 1 person said One Care should consider services on a case-by-case basis

Survey topic and questions		**Selected responses**
Quarter 4: Transportation		**n = 36**
2	What forms of transportation do you use (check all that apply)?[f]	Transportation paid by health care provider (23/35) and being driven by friends or family or a PCA (14/35) were the most common responses.
3	Which of the following do you regularly use transportation to access (check all that apply)?[g]	Doctors' appointments (31/35) and visiting friends and family (18/35) were the most common responses.
4	How reliable is your transportation?	Very reliable = 24/35; somewhat reliable = 6/35; somewhat unreliable = 4/35; very unreliable = 1/35
5	How important is access to transportation to your quality of life?	Extremely important = 27/35; quite important = 5/35; somewhat important = 2/35; not very important = 1/35
6	Are you provided transportation as part of your One Care coverage?	Yes = 24/35; no = 11/35; 1 person skipped the question
7	What is the name of the company that provides your One Care transportation? If you don't know, write "don't know."	Answers varied; 6 persons did not know; 2 used instant transportation
8	What do you use your One Care provided transportation for (check all that apply)?[h]	The main usage was to travel to and from doctors' appointments (24/24). The second main usage was to meet with their care coordinator or other members of the care team (7/24).
9	Is the transportation provided by One Care your primary or sole way of getting to medical appointments?	Yes = 19/23; no = 4/23; 13 persons skipped this question
10	How difficult is it to arrange transportation through this service?	Very easy = 11/24; fairly easy = 5/24; fairly difficult = 6/24; very difficult = 2/24; 12 persons skipped this question
11	Are the rides you receive through One Care usually on time?	Always on time = 11/23; usually on time = 9/23; sometimes on time = 2/23; rarely on time = 1/23; 13 persons skipped this question
12	Have you ever missed medical appointments because rides are late or do not arrive?	Never = 12/23; rarely = 8/23; sometimes = 2/23; often = 1/23; 13 persons skipped this question
13	How helpful are providers when you miss or are late for appointments due to transportation issues?	Not at all helpful = 2/9; somewhat helpful = 4/9; fairly helpful = 1/9; very helpful = 2/9; 27 persons skipped this question
14	Has your care coordinator been helpful when transportation is late or does not show up?	They have not been helpful = 1/12; they have been somewhat helpful 2/12; they have been very helpful 5/12; I have not discussed the issue with them = 4/12; 24 persons skipped this question
15	Have you contacted the One Care ombudsman about transportation issues?	Yes = 5/12; no = 7/12; 24 persons skipped this question

Survey topic and questions		Selected responses
16	Who makes decisions about how you can use the One Care transportation service (check all that apply)?[i]	Me = 11/24; my care coordinator = 9/24; the One Care plan itself = 9/24; 12 persons skipped this question
17	How has transportation impacted your relationship with your providers?[a]	.
18	Overall, how do you feel about the transportation service provided through One Care?[a]	
19	Were you aware transportation services were available through One Care?	Yes, but I don't want them = 6/9; yes, and I would want them but have not applied = 1/9; yes, I applied and was rejected = 1/9; no, and I would be interested in applying for these benefits = 1/9; 27 persons skipped this question
20	Do you have anything else to tell us about transportation?[a]	

Abbreviations: IL-LTSS, Independent Living–Long-term Services and Supports; PCA, personal care attendant.

[a] Open-ended response.

[b] Response categories: respect my privacy, nonjudgmental, interested in what I have to say, good listener, other (please specify).

[c] Response categories: I'm afraid I'll be judged, I do not feel emotionally safe with my provider, I don't think they will provide what I am looking for, other (please specify).

[d] Question 7a was the original phrasing of the question using the response categories shown in question 7b below. Two DPC staff members realized, while conducting the survey by telephone, that some respondents felt a particular response in the original wording did not apply to them. DCP therefore changed wording of the question (now 7b), which asks persons to answer "yes," "no," or "not applicable" to each item. Eleven persons answered this version of the question.

[e] After this question, the online survey directed respondents to go to a website for information about One Care LTSS services.

[f] Response categories: drive a vehicle that you own, drive a vehicle owned by someone else, being driven by friends and family or a PCA, subway, bus, commuter rail, walking, biking, app-based transportation services (eg, Uber, Lyft, Fasten), standard taxis (that you pay for yourself), regional paratransit service (such as The Ride, Worcester Paratransit, or PVTA Paratransit), transportation (such as vans or taxis) paid for by your health care provider, other (please specify).

[g] Response categories: work, volunteering, doctor appointments, other rehabilitation services (eg, dayhab, therapy), pharmacy trips, buying groceries, visiting friends and family, other (please specify).

[h] Response categories: travel to and from doctors' appointments, picking up medication, meeting with your care coordinator or other members of your care team, buying groceries, seeing friends or family, going to work, other (please specify).

[i] Response categories: me, my providers, my care coordinator, the One Care plan itself, the transportation company.

DPC analyses included reviews of the narrative responses, present in roughly 50% of the open- ended questions. DPC summarized messages from the 4 surveys as follows:

- Quarter 1: All respondents knew their primary care providers, but nearly 40% said they either didn't have or didn't know about their care team; 33% reported not having helped develop their care plan (a One Care requirement).
- Quarter 2: Most respondents reported conversing with their clinicians about various issues in their daily lives and felt safe sharing personal information with their practitioners; no areas for improvement were identified.
- Quarter 3: Of respondents, 62% reported never having been offered an LTSS coordinator; 83% of persons with an LTSS coordinator reported being "very happy" with this service.
- Quarter 4: Of respondents, 72% who used transportation provided through One Care had no other means of transportation; although transportation supported by One Care allowed most members to appear for their medical appointments, more than half of patients who missed appointments because of transportation problems reported that their clinicians did not always understand.

Quarter 1, 3, and 4 survey results were summarized in newsletters to YES Health members.

DPC staff tried numerous times to contact either the medical director or the practice manager at the 9 YES Health primary care practices. One practice invited DPC to visit and suggested names of One Care enrollees who might be candidates for YES Health (4 subsequently joined). Another practice had DPC staff visit, but practice personnel questioned the methodological rigor of the PCORI study instead of discussing YES Health goals. By telephone, 1 practice representative requested not to be contacted again about YES Health. We had planned originally to engage productively with medical directors and/or practice managers in ongoing discussions about YES Health members' One Care experiences; however, DPC shifted its strategy to mailing a 2-page, quarterly report to 60 primary care providers listed by CCA on its enrollment files as serving One Care members with significant physical disability or serious mental illness at the 9 practices (Figure 12 shows the Quarter 4 report). In addition to rack cards (Table 2), the first mailing contained an introductory letter and 2 narratives (about a YES Health ambassador and a One Care member). For the other 3 reports, the front side contained a personal narrative, while the back side presented several summary results from the survey

(Quarters 1, 3, or 4) and recommendations for clinicians from DPC staff based on survey findings. No clinicians or practice managers contacted DPC about these reports.

Figure 12. Fourth Quarterly Report to Primary Care Physicians From YES Health

yesHealth
Your Experience: Speak up for better health care

Lenny Somervell is DPC's new JOIN Fellow Community Organizer. She is coming from a background in museum education, volunteer coordinating, and youth work. We are glad to have Lenny on the YESHealth team.

I'm excited to join the YESHealth project as it expands its outreach in partnership with Disability Advocates Advancing Our Healthcare Rights (DAAHR), a statewide coalition of disability, elder and healthcare rights organizations. I'm looking forward to providing a platform for MassHealth members, as well as One Care enrollees, to share their experiences of healthcare reform and be a stronger voice in reducing physical, social and other barriers to medical, LTSS and recovery services.

While learning about YESHealth was eye-opening, collecting and analyzing responses to our latest transportation survey has been even more so. It was gratifying to see that when provided appropriately, coordinated transportation can improve the life of a YESHealth member. It was also important to see just how much progress needs to be made to grow the transportation system so that it can meet the expectations set out in One Care.

I'm so grateful to YESHealth members who take time to respond to our surveys and allow us to bring this information to light. In its expanding capacity, YESHealth will act not only as a way for people with disabilities to share their successes and frustrations with healthcare reform, but also give advocates and our allies a qualitative and quantitative forum to inform our healthcare advocacy. I'm honored to help share these experiences with you so that we can work to achieve better, more person-centered healthcare.

Sincerely,
Lenny Somervell

Learn more about YESHealth at www.yeshealth.org

YESHEALTH IS EXPANDING TO HEAR FROM MORE MEMBERS ABOUT THEIR HEALTH CARE EXPERIENCES. WE ALSO WANT YOUR THOUGHTS AS PROVIDERS. CONTACT KIMBERLEY WARSETT, KWARSETT@DPCMA.ORG WITH YOUR THOUGHTS ON HOW WE CAN IMPROVE OUR PROVIDER UPDATES.

DPC
11 Dartmouth St.
Suite 301 Malden, MA 02148
617-542-3822; www.dpcma.org

yesHealth
Your Experience: Speak up for better health care

Figure 12. Fourth Quarterly Report to Primary Care Physicians From YES Health (continued)

yesHealth
Your Experience: Speak up for better health care

Reliable transportation and coordination is key to appropriate care planning in support of better health outcomes and quality of life for One Care enrollees. Unique to One Care is the opportunity of providing enrollees transportation to nonemergency medical appointments and activities, and nonmedical activities, resources, and services that promote independence and participation in the community.

Inflexibility in scheduling rides and difficulty communicating with operators can lead to missed medical appointments, unnecessary emergency vehicle rides, and isolation, which can seriously undermine an enrollee's health, LTSS, and/or recovery plan. One Care users have little control over when or if their transportation arrives, and yet report being punished for missed appointments on the same level as those who drive themselves.

Results from the most recent survey of YESHealth members on transportation access in One Care indicate more work needs to be done to improve this important service.

Survey results

- **72% of respondents who use One Care transportation have no access to regular independent transportation** such as their own car or public transit.
    - ***100%*** *of those who had* ***no transportation other than One Care*** *reported being* ***homebound other than going to medical appointments.***
- 64% of respondents reported **never having missed a medical appointment due to issues with One Care transportation.** However:
    - ***62%*** *of those who did reported that* ***their provider was not particularly understanding.*** *One reported being charged for an appointment he missed because of issues with One Care.*
    - ***62%*** *said that* ***their care coordinator had been very helpful.***

"I would like more transportation to other places besides doctor's appointments-like grocery stores, food pantries, church, AA meetings"

Recommendations

Ask your patients about their transportation needs and if they are being met by One Care.

Communicate with a patient's care coordinator if a patient's transportation is not reliable.

Communicate with your patient and your patient's care coordinator if transportation is needed for an urgent appointment that will take place in less than 48 hours.

Familiarize yourself with the One Care ombudsman program and advocate with your patient.

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yesHealth
Your Experience: Speak up for better health care

Results From Cluster Randomized Controlled Trial

We analyzed changes in PDQ-S responses between waves 1 and 2 (Tables 4, 5, and 6) to assess whether providing YES Health and/or PDQ-S information to practice managers and PCPs affected perceptions of the quality of care among One Care members with significant physical disability or serious mental illness. With few exceptions, we failed to find any differences in PDQ-S responses between waves 1 and 2. Particularly, differences-in-differences analyses did not identify evidence that our interventions had improved enrollees' perceptions of their care quality. A subgroup analysis from the 315 persons who completed PDQ-S in both waves 1 and 2 (112 in study arm 1, 115 in arm 2, and 88 in arm 3) also failed to find evidence that our interventions had any effects.

Despite this disappointing outcome from the randomized controlled trial, PDQ-S, which was based largely on input from individuals with significant physical disability or serious mental illness,[33] may offer insights not available from other widely used surveys.[36] Descriptively comparing wave 1 and 2 PDQ-S results shows the absence of significant differences between the years but nonetheless highlights findings that suggest perceptions of socioeconomically disadvantaged persons with significant physical disability or serious mental illness enrolled in a highly integrated managed care program. We present findings by broad domains of PDQ-S in the "YES Health Results" section: perceptions relating to independent living principles, perceptions of One Care experiences and PCPs, and perceptions of daily life.

Independent Living Principles

Table 4 shows results of 5 questions relating to principles of independent living. We found no significant differences between responses in wave 1 compared with wave 2. Across all 3 study arms we found the following responses to PDQ-S questions:

- "I decide for myself what I will do each day and when I will do it—for example, when I wake up, eat, or go to bed and what I do for fun at home or in my community." The percentage responding "strongly agree" was 69.2% in wave 1 and 72.5% in wave 2.
- "I believe my quality of life will get better in the future." The percentage responding "strongly agree" was 42.2% in wave 1 and 41.3% in wave 2.
- "I feel free to take risks when I want to, even if some people do not agree with my choices." The percentage responding "strongly agree" was 34.8% in wave 1 and 39.2% in wave 2. When stratified by the type of disability, those with physical disability had a larger increase from wave 1 to wave 2 (31.4% to 39.2%) compared with those with

serious mental illness (36.8% to 39.3%). The difference in disability was more profound in the PDQ-S–only arm: Those with physical disability had a much larger increase from wave 1 to wave 2 (26.1% to 53.3%) compared with those with serious mental illness (45.4% to 46.2%).

- "I do things that make me feel good about myself—such as work, school, volunteer activities, or creative projects." The percentage responding "strongly agree" was 47.3% in wave 1 and 48.0% in wave 2.
- "I worry about keeping my housing or having a place to live." The percentage responding "disagree" was 22.1% in wave 1 and 25.0% in wave 2. When stratified by the type of disability, those with physical disability had an increase from wave 1 to wave 2 (14.6% to 23.0%), while those with serious mental illness stayed the same (26.6% vs 26.4%).
- "I am able to get together, talk with, or chat online with other people each day." The percentage responding "strongly agree" was 35.7% in wave 1 and 42.0% in wave 2.

One Care Experiences and Perceptions of PCPs

Table 5 shows results from several questions about key components of One Care and members' perceptions about their PCPs.

All members of One Care are required to have a care team, which the member helps identify. Across all survey respondents, 61.0% in wave 1 and 63.5% in wave 2 reported having a care team. Similarly, all One Care members are required to have care plans, which they help develop and of which they are given a copy. Overall, in wave 1, 55.7% reported having a care plan, 48.8% indicated they helped develop the plan, and 30.2% said they had a copy of the plan. In wave 2, 59.1% reported having a care plan, 52.4% indicated they helped develop the plan, and 32.1% said they had a copy of the plan. Only the PDQ-S–only study arm showed significant improvement between wave 1 and wave 2: 66.6% reported having a care plan in wave 2, compared with 52.1% in wave 1 ($P = .022$); 60.1% indicated they helped develop the plan in wave 2, compared with 44.0% in wave 1 ($P = .012$).

As shown in Table 5, we found no differences between waves 1 and 2 in how persons felt about their PCPs. Across all 3 study arms, we found the following responses to PDQ-S questions:

"Since you enrolled in this health plan, about how often do you feel your primary care provider. . ."

- "Showed respect for your opinions and decisions, whether you disagreed with them or not?" The percentage responding "always" was 54.8% in wave 1 and 53.9% in wave 2.
- "Treated you like a child?" The percentage responding "never" was 84.0% in wave 1 and 81.3% in wave 2.
- "Cared about you as a whole person rather than focusing only on your diagnosis or disability?" The percentage responding "always" was 55.6% in wave 1 and 55.1% in wave 2.
- "Asked you about how your health or medical treatment affects your sexual function or desires?" The percentage responding "always" was 13.1% in wave 1 and 16.5% in wave 2.
- "Refused you support services or equipment that you feel you need to be independent?" The percentage responding "never" was 76.6% in wave 1 and 72.0% in wave 2.
- "Changed your treatment without discussing how it would affect your life?" The percentage responding "never" was 82.2% in wave 1 and 79.3% in wave 2.
- "Said or did things that made you feel physically unsafe?" The percentage responding "never" was 86.0% in wave 1 and 85.4% in wave 2.
- "Said or did things that made you feel emotionally unsafe?" The percentage responding "never" was 82.2% in wave 1 and 82.5% in wave 2.

Respondents of neither disability type reported significant changes on experiences with PCPs between wave 1 and wave 2.

Perceptions About Daily Life

As shown in Table 6, we found few significant differences across waves in responses to the 9 questions about daily life. We found the following responses to PDQ-S questions:

"Since enrolling in your health plan, is your life now better, the same, or worse in the following areas?"

- "My feelings of hope about the future." The percentage responding "increased" was 43.7% in wave 1 and 33.0% in wave 2 (*P* = .004). When stratified by the type of disability, those with physical disability had a small increase from wave 1 to wave 2 (33.9% to 37.7%), while those with serious mental illness had a large decrease (49.6% to 29.6%).

- "Fears that my health care providers are making decisions about me without me." The percentage responding "increased" was 32.8% in wave 1 and 9.3% in wave 2 (*P* < .001). When stratified by the type of disability, those with physical disability had a smaller decrease from wave 1 to wave 2 (21.6% to 12.1%) compared with those with serious mental illness (39.5% to 7.4%).

- "My worry or stress about my life. The percentage responding "increased" was 32.0% in wave 1 and 37.9% in wave 2 (*P* = .11). When stratified by the type of disability, fewer of those with physical disability reported increased worry in wave 1 than wave 2 (37.8% vs 33.3%), while more of those with serious mental illness reported increased worry across waves (22.3% vs 44.5%).

- "The amount of control I have over my health care." The percentage responding "increased" was 38.6% in wave 1 and 26.3% in wave 2 (*P* < .001). When stratified by the type of disability, those with physical disability had a larger decrease from wave 1 to wave 2 (40.5% to 25.3%), compared with those with serious mental illness (35.5% to 27.6%).

- "My health." The percentage responding "better now" was 46.6% in wave 1 and 35.5% in wave 2 (*P* = .004).

- "My access to services or equipment I need to live as independently as I wish." The percentage responding "better now" was 47.4% in wave 1 and 36.5% in wave 2 (*P* = .005). When stratified by the type of disability, those with physical disability had a decrease from wave 1 to wave 2 (55.5% to 36.8%), while those with serious mental illness had a small increase (34.1% to 36.0%).

- “My involvement in groups, places, or activities I enjoy.” The percentage responding “better now” was 31.0% in wave 1 and 26.1% in wave 2 (*P* = .16). When stratified by the type of disability, those with physical disability had a decrease from wave 1 to wave 2 (34.4% to 24.4%), while those with serious mental illness had a small increase (25.4% to 28.4%).

- “My relationships with other people.” The percentage responding “better now” was 31.7% in wave 1 and 31.2% in wave 2 (*P* = .89). When stratified by the type of disability, those with physical disability had a decrease from wave 1 to wave 2 (38.4% to 29.8%), while those with serious mental illness had a small increase (20.6% to 33.3%).

“Would you say the quality of all the health care that you have received is better than before, about the same as before, or worse than before?”

- The percentage responding “better than before” was 62.9% in wave 1 and 51.0% in wave 2 (*P* = .002). We observed similar patterns in both disability types.

Physician Survey Results

As described in the “Survey of Primary Care Physicians in Year 3” section, the failure of YES Health to engage PCPs raised concerns that the randomized controlled trial might fail: If physicians were unaware of the intervention, how could the intervention succeed? We therefore conducted a survey of PCPs assigned to the One Care enrollees sampled in wave 1 of PDQ-S. As shown in Table 8, some respondents failed to report demographic information among the 109 responders: 12.8% with age missing, 14.7% with gender missing, 14.7% with race missing, and 15.6% with ethnicity missing. Among those who provided information, across the study arms the mean (SD) age was 49.0 (10.6) years; 45.8% were male; 79.8% were White; and 9.7% were Hispanic.

Table 9 shows responses to questions about their One Care experiences, their perceptions of the program, and exposure to study materials. Of the 48 physicians assigned to practices in the YES Health arm, only 2 indicated having seen YES Health materials, which had been mailed to them quarterly. Of these 48 physicians plus the 39 physicians assigned to practices in the PDQ-S–only arm, only 6 reported having seen the PDQ-S reports, which had been mailed to them roughly 9 months previously. Notably, 38 (34.9%) physicians were not sure whether their One Care patients had a formal care team, as designated by the program. Fifty (45.9%) said they had not worked with their patients to create a care plan, as also required by the program. Most were not sure about how One Care had affected their patients' lives.

Table 9. Characteristics of Primary Care Physicians Responding to PCP Survey

Physician characteristics		All		YES Health Only		PDQ-S only		Control	
		No.	%	No.	%	No.	%	No.	%
Total respondents		109		48		39		22	
Age	NMiss	14		7		3		4	
	Mean	145		50.7		48.7		45.6	
	SD	29.7		11. 4		10.7		7.6	
Hispanic or Latino	Yes	9	8.3	5	10.4	4	10.0	0	0.0
	No	84	77.1	36	75.0	31	77.5	17	77.3
	No response	17	15.6	7	14.6	5	12.5	5	22.7
Race	White	75	68.8	32	66.7	29	72.5	14	63.6
	Black or African American	6	5.5	2	4.2	3	7.5		14.5
	Asian	9	8.3	4	8.3	2	5.0	3	13.6
	More than 1 race	4	3.7	2	4.2	2	5.0	0	0.0
	No response	16	14. 7	8	16.7	4	10.0	4	18.2
Gender	Female	51	46.8	23	47.9	18	45.0	10	45.5
	Male	43	39.4	18	37.5	17	42.5	8	36. 4
	No response	16	14.7	7	14.6	5	12.5	4	18.2

Abbreviations: PCP, primary care provider; PDQ-S, Persons With Disability Quality Survey.

Table 10. Responses to Primary Care Physician Survey

Physician outcomes		YES Health only		PDQ-S only		Control	
		No.	%	No.	%	No.	%
Independence attitudes							
Q1a: I believe that integrating care for both physical and behavioral health needs is important	Somewhat agree	1	2.1	1	2.6	0	0.0
	Strongly agree	43	89.6	37	94.9	21	95.5
	No response	4	8.3	1	2.6	1	4.5
Q1b: It is important for PCPs to work with health plans to assure people with disabilities get services they need	Disagree	0	0.0	1	2.6	0	0.0
	Somewhat agree	12	25.0	6	15.4	3	13.6
	Strongly agree	31	64.6	31	79.5	18	81.8
	Don't know	1	2.1	0	0.0	0	0.0
	No response	4	8.3	1	2.6	1	4.5
Q1c: I believe I am compensated fairly to provide care to One Care patients	Disagree	9	18.8	6	15.4	2	9.1
	Somewhat agree	11	22.9	3	7.7	3	13.6
	Strongly agree	2	4.2	8	20.5	4	18.2
	Don't know	22	45.8	21	53.8	12	54.5
	No response	4	8.3	1	2.6	1	4.5
One Care experiences							
Q3: patients in One Care have a formally designated Care Team	Yes, All of my One Care Patients	8	16.7	13	33.3	3	13.6
	Yes, Some of my One Care Patients	11	22.9	8	20.5	8	36.4
	No, none of my One Care Patients	2	4.2	1	2.6	0	0.0
	Not sure	23	47.9	15	38.5	10	45.5
	No response	4	8.3	2	5.1	1	4.5
Q4: work with One Care patients to create a personal written Care Plan	Yes, I do	6	12.5	5	12.8	0	0.0
	Yes, another member of the staff	11	22.9	10	25.6	6	27.3
	Yes, both I and other staff	1	2.1	8	20.5	1	4.5
	No	24	50.0	12	30.8	14	63.6
	No response	6	12.5	4	7.7	1	4.5

		YES Health only		PDQ-S only		Control	
Physician outcomes		**No.**	**%**	**No.**	**%**	**No.**	**%**
Q5: work as a team to provide One Care patients with support/services	Definitely Yes	7	14.6	13	33.3	1	4.5
	Somewhat Yes	22	45.8	18	46.2	13	59.1
	Somewhat No	4	8.3	3	7.7	1	4.5
	Definitely No	1	2.1	0	0.0	1	4.5
	Not sure	9	18.8	4	10.3	4	18.2
	No response	5	10.4	1	2.6	2	9.1
Q10a: One Care patients lives change, overall health	Better now	17	35.4	15	38.5	6	27.3
	The same	10	20.8	11	28.2	4	18.2
	Not sure	14	29.2	10	25.6	7	31.8
	No response	7	14.6	3	7.7	5	22.7
Q10b: One Care patients lives change, access to services	Better now	17	35.4	23	59.0	11	50.0
	The same	13	27.1	2	5.1	2	9.1
	Not sure	11	22.9	10	25.6	4	18.2
	No response	7	14.6	5	10.3	5	22.7
Q10c: One Care patients lives change, their involvement in groups	Better now	11	22.9	16	41.0	2	9.1
	The same	10	20.8	7	17.9	5	22.7
	Not sure	20	41.7	13	33.3	10	45.5
	No response	7	14.6	3	7.7	5	22.7
Q10e: One Care patients lives change, feelings of hope	Better now	9	18.8	11	28.2	3	13.6
	The same	10	20.8	7	17.9	2	9.1
	Worse	0	0.0	0	0.0	1	4.5
	Not sure	21	43.8	18	46.2	11	50.0
	No response	8	16.7	3	7.7	5	22.7
Q10g: One Care patients lives change, overall worry or stress	Better now	11	22.9	12	30.8	5	22.7
	The same	12	25.0	9	23.1	2	9.1
	Not sure	16	33.3	15	38.5	10	45.5
	No response	9	18.8	3	7.7	5	22.7
Primary care experiences							
Q7_1: Spent time in office visits to ask about interests/values without focusing on disability	Never	5	10.4	4	10.3	3	13.6
	Sometimes	25	52.1	17	43.6	10	45.5
	Usually	10	20.8	9	23.1	4	18.2
	Always	4	8.3	5	12.8	2	9.1
	No response	4	8.3	4	10.3	3	13.6

Physician outcomes		YES Health only		PDQ-S only		Control	
		No.	%	No.	%	No.	%
Q7_2: Initiated discussions about health/medical treatment affects sexual function or desires	Never	12	25.0	6	15.4	6	27.3
	Sometimes	21	43.8	18	46.2	11	50.0
	Usually	6	12.5	3	7.7	1	4.5
	Always	0	0.0	3	7.7	1	4.5
	No response	9	18.8	9	23.1	3	13.6
Q7_3: Refused support that they requested because health plan would not cover	Never	20	41.7	16	41.0	9	40.9
	Sometimes	20	41.7	16	41.0	10	45.5
	Usually	1	2.1	1	2.6	0	0.0
	Always	1	2.1	2	5.1	0	0.0
	No response	6	12.5	4	10.3	3	13.6
Awareness of PDQ-S and YES Health							
Q8a: Seen YES Health – Your Experience	Have not seen or received	36	75.0	31	79.5	18	81.8
	Have seen or received report	2	4.2	3	7.7	0	0.0
	No response	10	20.8	5	12.8	4	18.2
Q8c: Seen PDQ-S report	Have not seen or received	37	77.1	29	74.4	18	81.8
	Have seen or received report	3	6.3	3	7.7	0	0.0
	No response	8	16.7	7	17.9	4	18.2

Abbreviations: PDQ-S, Persons with Disabilities Quality Survey.

DISCUSSION

Decisional Context

YES Health suggests that persons with disability can lead evaluations of their care quality, focusing specifically on issues that particularly concern them about improving their health and quality of daily life. However, this research highlights 2 significant challenges: (1) difficulties engaging large numbers of persons within the disability community to participate in proactive quality monitoring; and (2) problems attracting PCPs to partner with and learn from their patients with disability, with the shared goal of improving care. Overall findings from PDQ-S suggest that One Care frequently functions as intended (eg, with enrollees participating in preparing their own care plans with care teams they designated) and improving enrollees' lives. Nevertheless, considerable room for improvement remains. Having motivated individuals with disability work collaboratively with physicians could potentially inform quality improvement efforts with powerful, person-centered insights.

Study Results in Context

As noted in external assessments of the Massachusetts One Care program, disability rights advocates made important contributions to designing One Care. "State leaders were open to actively engaging in discussions and some decision-making with these community-based consumer advocacy partners."[6] Buoyed by this involvement, Disability Health Alliance members—some of whom played leading roles in this study—believed they could proactively engage providers in improving quality of care. Therefore, in this study, the disability advocates developed and led YES Health with the long-term goal of building competence and capacity within their organizations for ongoing monitoring of One Care quality. Assessing whether YES Health could engage persons with disability in their own health care and promoting care improvement were important goals. YES Health succeeded in creating a structure, conceived and built by individuals with disability, which captured the voices of their intended audience: One Care members with significant physical disability or serious mental illness.

Nevertheless, before YES Health began, even the 2 DPC project leaders had difficulty predicting how many One Care members would join. This target audience has significant disability, as judged by MassHealth rating categories; many of them also have comorbid conditions, including substance abuse disorders, further compromising their health. In addition, all are sufficiently financially impoverished to receive full Medicaid benefits. In this context, attracting 45 members, conducting and analyzing 4 surveys, and mailing reports summarizing findings to primary care practices and providers are important accomplishments. However, as perhaps should have been anticipated,[45] YES Health faced many impediments to achieving its goals, which may inform similar future efforts.

First, less than 4% of potential participants joined YES Health. We do not know why others did not. Nonetheless, we believe that making even $10 payments to members was critical to maintaining their engagement in both survey and town hall activities. We had initially aimed to attract participants by presenting this initiative as proactive collaboration between DPC staff, all of whom have disability, and community members with disability. DPC staff argued that voices of persons with disability typically go unheard or are interpreted—and thus distorted—by people outside the community. As 1 DPC staff member wrote, “Every victory for our rights and our dignity that our community has won came from people raising their voices together.” However, nearly all advocacy organizations that DPC staff visited to introduce YES Health highlighted the necessity to pay for participation. Throughout YES Health implementation, DPC staff heard from participants how they used these $10 payments (eg, to purchase milk). Providing monetary incentives for participation therefore seems necessary to motivate and continue participation among the populations like One Care enrollees.

Second, DPC staff spent considerable effort and resources creating and maintaining the YES Health website and Facebook group, yet few YES Health members used these online resources. Many participants reported not having access to computers or a way to connect online. YES Health members preferred telephone contacts, viewing personal conversations as building relationships. These calls with DPC staff generated rich information—beyond the survey—about members’ health care experiences. However, all YES Health participants were aged 31 and older. Younger persons may have had different preferences about communication mode and gravitated toward online interactions. We therefore believe that moving forward, multimodal outreach—both online and in person—is essential to attract and communicate effectively with this population.

Finally, PCPs and practice managers showed no interest in YES Health. DPC staff received no response from mailing hundreds of 1-page reports, which included One Care member narratives, brief survey results, and recommendations for improving care. Many factors could explain clinicians' disinterest, including hectic schedules, disregarding postal mail, questioning YES Health methods and/or motivations, and unequal power dynamics between patients and clinicians.[45] CCA was very supportive of this study; however, CCA wanted to limit outreach from the research team to their PCPs who were newly implementing One Care among their most complex enrollees. CCA informed PCPs about the study but did not require them to respond in any specific way. Given the resource and time constraints that squeeze many primary care practices in general, efforts to force participation among PCPs serving One Care enrollees (eg, by requiring certain quality improvement activities with community involvement) would have been unlikely to succeed—especially since there are no models for this type of consumer- directed interaction. Future efforts could focus on interactions with health plan leaders themselves rather than on their contracted or supported primary care practices.

Despite these difficulties, YES Health represents an innovative effort in which persons with disability led direct consumer evaluations of health care. YES Health activities did build capacity[38] within the Massachusetts disability community for future consumer involvement. As 1 DPC staff person wrote,

> *Ultimately, we learned that by being people with disabilities ourselves, we provided an avenue where people felt comfortable opening up to us. . .sharing their own stories. Their stories were heard by people who at times had similar issues as the participants. This allowed for deep conversation and candid discussions about what people were experiencing on a day-to-day basis.*

Some participants told DPC staff that, through YES Health, they felt more prepared to engage in their own health care. Although we cannot quantify whether those feelings improved health and wellness, this empowerment likely benefitted YES Health members through hearing and valuing their stories.

Implementation of Study Results

This was a negative study: We failed to find that providing consumer-generated data—through postal mailings of brief reports—improved care, as judged by reports from One Care members with significant physical disability or serious mental illness. However, the tools developed during this project, notably the PDQ-S and YES Health approach, might inform future quality measurement and health care advocacy for persons with disability. Through the advocacy channels of our DPC team members, we are attempting to disseminate these methods and use them for current advocacy. For example, in spring 2018, MassHealth planned to make major changes to move most members with disability into accountable care organizations. DPC is using the YES Health approach to gather information from the disability community about its members' perceptions of these changes and what advocacy activities would best assist them.

Generalizability

YES Health may have limited generalizability. The initiative involved Massachusetts One Care members with significant physical disability or serious mental illness from 1 health plan. Although DPC used multiple strategies to solicit participants, YES Health ultimately reached relatively few people, especially few young people. Study design (ie, recruitment of participants from only 9 randomly selected primary care practices) and human subjects considerations prevented DPC staff from having contact information for eligible individuals. Personal outreach to individuals might have attracted more members. Furthermore, One Care had gained considerable national attention,[1,4,6,8] and its enrollees underwent extensive surveying, including 12 quality surveys administered by CMS and MassHealth.[14] Anecdotal reports suggested "survey burnout," or fatigue, among One Care members, even about answering questions from their peers with disability. YES Health participants were all aged 30 or older, which could have contributed to their preference for telephone rather than online communication. Finally, although DPC tried intensively to contact primary care practices, different approaches might have been more productive.

Subpopulation Considerations

We involved 2 subgroups of One Care participants: persons with significant physical disability or serious mental illness. Although we recognized that members of these subgroups could prioritize different aspects of care when assessing their experiences, we chose to design a single survey (PDQ-S), which addresses shared concerns. Our cluster randomization did not treat these subgroups differently, and our study was not powered to consider differences between them. Nonetheless, in our discussion of results (see the “Results From Cluster Randomized Controlled Trial” section), we highlight some differences between these groups.

Study Limitations

The “Study Results in Context” and “Implementation of Study Results” sections review important limitations of our study, including concerns about generalizability. We were not powered to examine results by individual practice or practice type (eg, practices operated by CCA clinicians vs contracted practices). The investigators were limited by our agreement with CCA from proactive outreach efforts with the PCPs serving One Care enrollees, largely because of the challenges and time commitment of implementing a new program involving complex, high-need patients. However, the disability advocates conducting YES Health—as representatives of One Care consumers—were free to approach these clinicians. We had only postal addresses, not email addresses, limiting our ability to communicate with the PCPs. Another limitation was our reliance on the rating category assigned by MassHealth to identify persons by disability type. Based on previous MassHealth claims, these rating category assignments were often erroneous.[6]

Future Research

Two hypotheses or expectations underlying our research were that having empowered patients engage collaboratively with PCPs to inform quality improvement would be welcomed by physicians and result in better care quality. Because PCPs failed to engage with the DPC disability advocates conducting YES Health, we cannot assess whether the second hypothesis holds. We also do not know whether trying alternative means to create partnerships between health plan members and PCPs regarding quality improvement projects would generate productive dialogue. Future research should address both concerns.

CONCLUSIONS

Through YES Health, leaders in the Massachusetts disability advocacy community with significant physical disability or serious mental illness reached out via multifaceted efforts to engage their peers in evaluating the quality of their One Care services. Our project demonstrated the feasibility of individuals with disability designing and implementing this multipronged effort to gather data that were maximally meaningful to the One Care constituency. Nevertheless, over 12 months, YES Health attracted only 45 members—and their participation depended largely on $10 payments for each contribution (eg, answering the short, quarterly Survey Monkey questionnaire about care quality). Compared with going online, participants greatly preferred providing their input over the telephone by talking with YES Health staff, with whom they described a sense of ease and connection. Anecdotal reports about these conversations suggested that YES Health members found them meaningful.

Disappointingly, the cluster randomized controlled trial failed to demonstrate that YES Health—or reports to PCPs about baseline PDQ-S results—had any effect on improving care quality, as assessed through reports of One Care members with significant physical disability or serious mental illness. However, aggregate results from PDQ-S reveal that, while One Care has substantial achievements, more work is required to improve care for the particularly disadvantaged population it serves. For example, according to wave 2 PDQ-S results, only 41.3% of respondents feel their quality of life will improve in the future—not surprising given their substantial burden of chronic disease and functional impairments. Only 35.5% responded that their health was “better now” since enrolling in One Care. However, in wave 2, 51.0% said the quality of all the health care they had received was “better than before”; 59.1% reported having a care plan and 63.5% care teams, although One Care requires all members to have both care plans and teams. These findings suggest solid progress toward achieving this goal, but considerably more remains to be done.

Given the gaps between enrollees’ perceptions of their care and the requirements of One Care, the failure of PCPs to respond to repeated efforts of the YES Health team represented the greatest lost opportunity of the study. Each of the 2-page, quarterly reports

YES Health sent to PCPs contained recommendations about how identified quality problems could be remedied, in the view of these disability advocates. Whether a productive dialogue between One Care PCPs and the YES Health disability advocates could have improved care remains an unanswered question. Future research will need to assess whether direct collaborations between physicians and empowered patient representatives will improve care quality.

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