Rethinking complex care measurement: Using patient- and staff-reported measures

August 31, 2021
12:00 - 1:15 ET

Center for Health Care Strategies

The National Center for Complex Health & Social Needs
An initiative of the Camden Coalition

Agenda

Introduction

Housekeeping

Overview of measurement in complex care

Presentation:

- Karla Silverman, MS, RN, CNM, Associate Director for Complex Care Delivery, Center for Health Care Strategies
- Joslyn Levy, BSN, MPH, Principal, Joslyn Levy & Associates
- Carey Howard, MPH, Program Director, Center for the Urban Child and Healthy Family at Boston Medical Center
- Susan Foster, MSN, FNP-BC, Chief Medical Officer, Hill Country Health and Wellness Center
- Jo Campbell, ACSW, CWWS, Integrated Operations Director, Hill Country Health and Wellness Center

Q&A

Presentation:

- Rebecca Sax, MPH, Senior Program Manager, Camden Coalition of Healthcare Providers
- Janice Tufte, Public-Patient Involved Stakeholder, National Consumer Scholar, PCORI Ambassador

Q&A

Wrap-up & next steps

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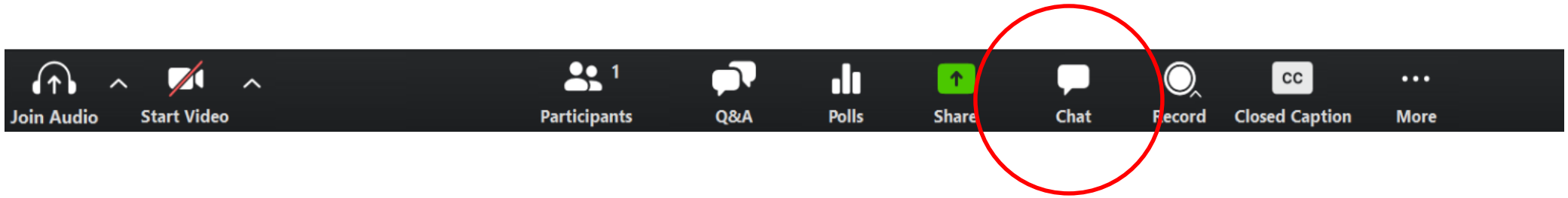
Housekeeping

- This event will be recorded
- All questions and resources should be submitted through the chat feature



Center for Health Care Strategies

The National Center for Complex Health & Social Needs
An initiative of the Camden Coalition

Overview of measurement in complex care

The National Center for Complex Health and Social Needs identifies and disseminates the most effective models, approaches, and resources for complex care.

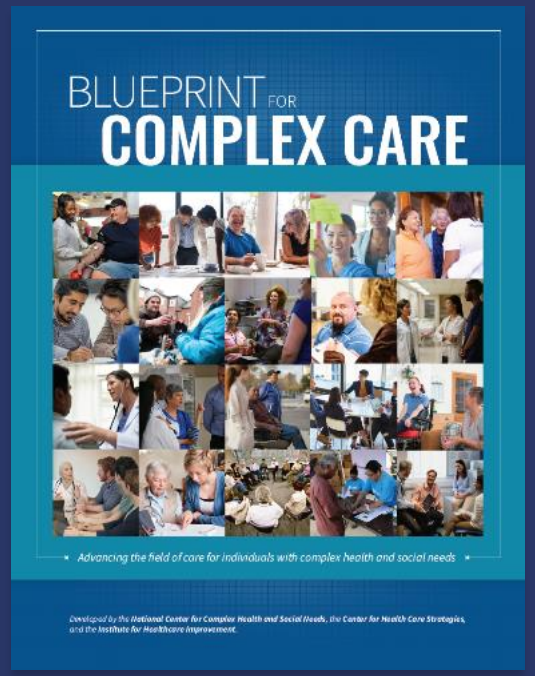
We collaborate with a diverse network of complex care practitioners, national leaders, policymakers, researchers, and consumers to:

- Convene stakeholders through meetings, working groups, and webinars
- Collaborate to build the field based on our Blueprint for Complex Care and Core Competencies
- Curate and disseminate easy-to-understand resources from across the country
- Provide technical assistance to support organizations implementing and scaling complex care programs

Complex care is a person-centered approach to address the needs of people who experience combinations of medical, behavioral health, and social challenges.

Complex care works at the individual and systemic levels: it coordinates better care for individuals while reshaping ecosystems of services and sectors

Current measures do not account for the holistic goals of complex care.



Reducing healthcare costs and hospital utilization are the most common metrics used to measure program success

However, complex care program goals often encompass other important aspects of care, including health equity, the patient and staff experience, and the individual's holistic sense of well-being.

Blueprint for Complex Care and *Measuring complexity* recommend developing a standardized set of holistic measures that better account for goals and priorities of complex care programs.

Complex care programs are are re-evaluating their approach to measurement.

An increasing number of programs are incorporating key complex care principles such as person-centeredness and team-based care into their measurement strategies.

This webinar will provide an overview of two projects that are helping complex care programs innovate across the country.

Today's webinar will include two complementary measurement approaches for complex care.

CHCS AIM Measures Library

- Set of measures for capturing patient and staff perceptions pertaining to key complex care concepts
- Description of library development and considerations for their use

National Center Patient-Reported Outcome Measures (PROMS) Report

- Discussion of the factors that support or hinder implementation of PROMS in complex care programs
- Inventory of existing PROMS instruments that are well-suited to complex care programs

Center for Health Care Strategies
Better care where it's needed most

Advancing Integrated Models

Rethinking Complex Care Measurement: Using Patient- and Staff-Reported Measures

August 31, 2021

Karla Silverman, Associate Director, Complex Care Delivery

Center for Health Care Strategies

Made possible through support from the Robert Wood Johnson Foundation

Center for Health Care Strategies

Dedicated to strengthening the U.S. health care system to ensure better, more equitable outcomes, particularly for people served by Medicaid.

Together with our partners, our work advances:

- **Effective models for prevention and care delivery** that harness the field's best thinking and practices to meet critical needs
- **Efficient solutions for policies and programs** that extend the finite resources available to improve the delivery of vital services and ensure that payment is tied to value.
- **Equitable outcomes for people** that improve the overall wellbeing of populations facing the greatest needs and health disparities.

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About the Advancing Integrated Models (AIM) Initiative

- Two-year, multi-site initiative funded by the Robert Wood Johnson Foundation
- Targeting populations with low incomes and people with complex health and social needs
- Goal of supporting health systems and providers in their efforts to strategically integrate and align person-centered approaches to care, including:
  - → Complex care management
  - → Trauma-informed care
  - → Physical and behavioral health integration
  - → Mechanisms that address health-related social needs

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AIM Pilot Sites

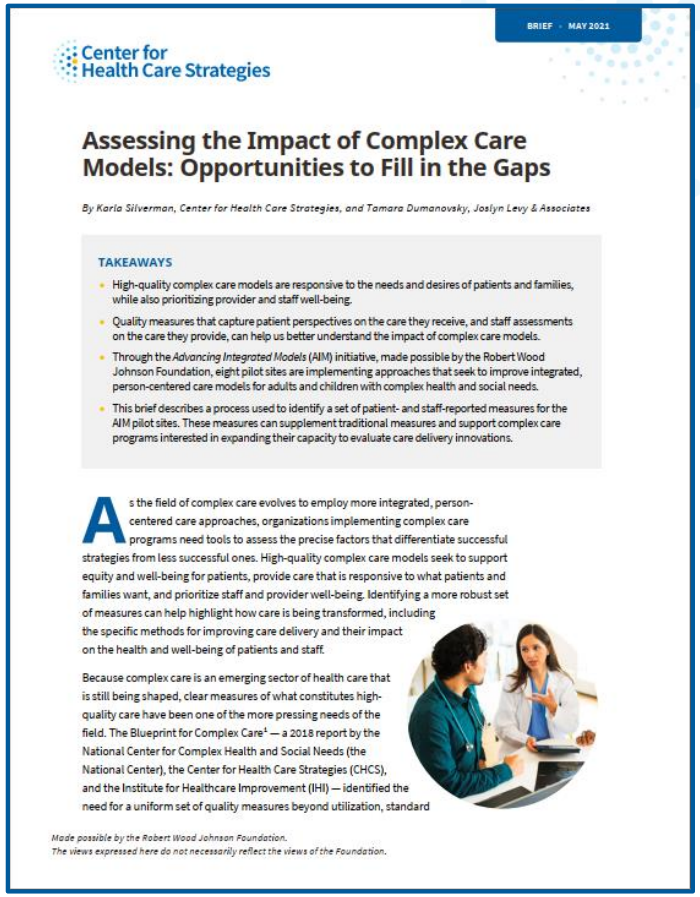
Boston Medical Center: Center for the Urban Child and Healthy Family
Johns Hopkins HealthCare
Maimonides Medical Center
Denver Health
Hill Country Health and Wellness Center
OneCare Vermont
Bread for the City
Stephen and Sandra Sheller 11th Street Family Health Services

Going Beyond Typical Complex Care Measures

- Noted gaps in the field of complex care measurement
- To help the AIM pilot sites understand the impact of the care delivery models they were implementing, wanted to expand our thinking beyond standard-measures of cost, utilization, and outcomes
- Incorporated measures that capture patient and staff perceptions of how patient-centered care is, how equitable and respectful it is, how or if overall well-being is valued and addressed, and if care is coordinated

Going Beyond Typical Complex Care Measures

- Measures are intended to be used as quality improvement tool
- Pilot sites were encouraged to use small core set of measures and choose from larger set of measures depending on what their care model focused on and what they wanted feedback on
- Patient and staff measures are available for the field to use
  - → **Brief:** Assessing the Impact of Complex Care Models: Opportunities to Fill in the Gaps



BRIEF • MAY 2021

Center for Health Care Strategies

Assessing the Impact of Complex Care Models: Opportunities to Fill in the Gaps

By Karla Silverman, Center for Health Care Strategies, and Tamara Dumanovsky, Joslyn Levy & Associates

TAKEAWAYS

- High-quality complex care models are responsive to the needs and desires of patients and families, while also prioritizing provider and staff well-being.
- Quality measures that capture patient perspectives on the care they receive, and staff assessments on the care they provide, can help us better understand the impact of complex care models.
- Through the *Advancing Integrated Models* (AIM) initiative, made possible by the Robert Wood Johnson Foundation, eight pilot sites are implementing approaches that seek to improve integrated, person-centered care models for adults and children with complex health and social needs.
- This brief describes a process used to identify a set of patient- and staff-reported measures for the AIM pilot sites. These measures can supplement traditional measures and support complex care programs interested in expanding their capacity to evaluate care delivery innovations.

As the field of complex care evolves to employ more integrated, person-centered care approaches, organizations implementing complex care programs need tools to assess the precise factors that differentiate successful strategies from less successful ones. High-quality complex care models seek to support equity and well-being for patients, provide care that is responsive to what patients and families want, and prioritize staff and provider well-being. Identifying a more robust set of measures can help highlight how care is being transformed, including the specific methods for improving care delivery and their impact on the health and well-being of patients and staff.

Because complex care is an emerging sector of health care that is still being shaped, clear measures of what constitutes high-quality care have been one of the more pressing needs of the field. The Blueprint for Complex Care[1] — a 2018 report by the National Center for Complex Health and Social Needs (the National Center), the Center for Health Care Strategies (CHCS), and the Institute for Healthcare Improvement (IHI) — identified the need for a uniform set of quality measures beyond utilization, standard

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The views expressed here do not necessarily reflect the views of the Foundation.

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AIM Measures Library

Rethinking Complex Care Measurement: Using Patient- and Staff-Reported Measures

Joslyn Levy, BSN, MPH, Principal, Joslyn Levy & Associates

August 31, 2021

AIM Measures Library Content

- 26 patient-reported and 32 staff-reported measures to support improving care for people with complex health and social needs
- Measures in the form of survey questions
- Half from existing sources/ half either modifications of existing measures or newly created for AIM

Measurement Topics

Patient perceptions of:

- Patient-centered quality of care
- Services provided to meet health-related social needs
- Integrated care (medical, physical, emotional, psychological)
- Equitable, respectful, and supportive care
- Coordination with other services and providers
- Patient well-being

Staff perceptions of:

- Equity as a primary organizational commitment
- Care integration (behavioral health, trauma-informed care, and health-related social needs)
- Supporting medical, physical, psychological, emotional, and social needs of clients
- Partnerships with outside service organizations
- Staff well-being

JL&A

Approach to Library Development

- Measures Review
- Evaluation Advisory Committee
- Delphi process

Evaluation Advisory Committee Members

David Labby	Health Share of Oregon
Danica Richards	CHCS
Diana Hartley-Kim	11th Street Family Health Services
Eliza Hallett	Boston Medical Center CUCFH
Karla Silverman	CHCS
Ken Epstein	East Bay Center for Children
Mark Humowiecki	Camden Coalition of Healthcare Providers
Meryl Schulman	CHCS
Mohini Venkatesh	National Council for Behavioral Health
Parinda Khatri	Cherokee Health Systems
Rachel Everhart	Denver Health
Renee Boynton Jarrett	Boston Medical Center
Stacy Johnson	Bread for the City
Susie Foster	Hill Country Health and Wellness Center
Tanya Tucker	The Full Frame Initiative
Therese Wetterman	Health Leads (current - World Economic Forum)

JL&A

Delphi Process for Measures Review

- Rating Criteria
  - Sensitivity to change: This measure can show change over 12 months
  - Clarity of language: The language is clear and unambiguous
  - Applicability: This measure applies across settings, situations, and populations
  - Advancing the field: This measure adds value
- Measures Revision
- New Measures

JL&A

Examples of Patient Reported Measures

Domain	Measure
Goals & Experience with Care	My care team and I regularly review my care plan so it reflects my preferences and current circumstances .
Equity	I believe my care team feels comfortable around people who look like me and/or sound like me.
Health & Well-Being	The staff truly believe in me – that I can achieve my goals.
Care Integration	My care team considers other aspects of my life when helping me make health care decisions.

Examples of Staff-Reported Measures

Domain	Measure
Goals & Quality of Care	When developing care plans, the care team here routinely collaborates with patients to co-create goals.
Equity	Our organization's leadership are committed to equity as a high priority.
Data Collection & Monitoring	We routinely collect and update data on social risk factors that are a priority to the communities we serve.
Health & Well-Being	I feel respected and included by the other members of our care team.
Care Integration	Providers and staff are well-informed about patients' current social needs (e.g., housing, transportation).
Community Partnerships	We have established relationships with community agencies to facilitate our referrals to them.

JL&A

Learnings from Delphi Process

- Update outdated language
  - Care teams and care partners vs. providers
  - Patient assets vs. deficits
- Delve into definitions
  - Complex care concepts are still evolving and are very broad in scope
  - Stakeholders bring different perspectives
  - Operationalization of the concepts differ based on local context

Considerations for Selecting and Using Measures

Involve stakeholders

- Measure what matters
- Align on definitions of value

Customize measures to enhance learning

- Balance benefits of standardization and specificity
- Use language that is familiar

Develop a data collection plan

- Determine which staff, which patients and how many
- Decide on methods and frequency
- Coordinate to minimize burden

Develop a plan for how you will use the data

- Include stakeholders in making meaning of the data
- Share learning with stakeholders

JL&A

AIM Site Experiences Using the Measures Library

Hill Country Health and Wellness Center

Boston Medical Center
Center for the Urban Child and Family Health

Hill Country Health and Wellness Center AIM Evaluation

Jo Campbell ACSW, Integrated Operations Director Hill Country

Susie Foster FNP-BC, CMO Hill Country

Welcome to Hill Country

- 1985: A group of friends, a doctor, and a frontier town without healthcare
- Integrated from the start: sole service provider
- Maintaining an integrated approach to care while treating patients with complex health and social needs in a seamless continuum of care

Results and Learnings

Results

- Confirmed our impression that participants perceive care is supportive and achieves our intent.
- Results on staff survey were overall positive
  - Some staff noted coordination challenges

Learnings

- Shorter more frequent surveys
- Surveys to capture patient and staff voice are necessary but not sufficient

Next Steps

- Go deeper with participants – develop representative advisory group & identify questions that go to the next level
- Conversations with staff on care coordination challenges as follow up to staff survey results

BOSTON MEDICAL CENTER

Center for the Urban Child and Healthy Family

Carey Howard, MPH, Program Director, Center for the Urban Child and Healthy Family



Center for the Urban Child and Healthy Family

- Testing clinical innovations to ensure all children have an equal opportunity to be **healthy** and **achieve their full potential**
- The **Pediatric Practice of the Future**, an innovative model of primary care delivery

  - Model developed using **human centered design** methods to understand families goals and priorities for their wellbeing
  - Supported by the AIM initiative, the Center launched the pilot in January 2020 of 100 BMC families

Practice of the Future Pilot Goals

- Test a model to address **health equity**
- Collect **data, iterate, and refine** components of the model
- In partnership with BMCHP, exploration of a **pediatric alternative payment model** with quality metrics linked to model elements
- **Scale** elements that are working to the larger pediatric practice

Data drives decisions about the model implementation, effectiveness, and impact

Quality Improvement Measures	▪ Collected to understand implementation of the model, how it's working, and for who ▪ Used in real time to refine, iterate, and make decisions about the models effectiveness
Outcome Measures	▪ IRB-approved study to understand long term impact of program components on family health outcomes (physical and emotional well-being, dyadic attachment, parental well-being, trust in HC)
Cost Measures	▪ Collected to understand cost associated with implementation of the new model ▪ Accountable to ACO metrics ▪ Support development of models to project ROI ▪ **Make the case for alternative payment models in partnership with BMCHP**

We are proposing a set of quality metrics that better relate to child and family well-being

Core Constructs

- Dyadic Care
- Health Equity/Trust in Healthcare
- Economic Well-Being
- School Readiness

Testing tools to measure core constructs

1. **Equity and Trust in Health Care** (AIM Measures)
2. **Economic Well-Being:** Consumer Financial Protection Bureau (CFPB) Financial Well Being Scale
3. **School Readiness:** Healthy and Ready to Learn questions (National Survey of Children's Health questions)

AIM Measures Library Administration

- From December 2020-February 2021 Research Assistants administered AIM surveys to 49 POF Families
- The staff/clinician questions were also administered via anonymized link to the POF clinical team
- Key themes from family responses:
  - **Quality improvement efforts around family perception of equity needed:** Responses to equity questions require reflection and considerations for programmatic improvement: some families have comments about not being understood because of accent or being treated differently because of their race
  - **Need for continuing to center family priorities – no one size fits all approach:** What some families identified as things they did not like, others identified as strengths of the program.
  - **Important limitation is only surveying English speaking families:** In next iteration, surveying in other languages will be an important factor.

Key Lessons & Next Steps

Lessons on Process:

- Analysis process has not been straightforward
- It is important to implement these questions but also to contextualize the responses and share back findings with families and care team members
- Families are not used to answering these types of questions, we may see more openness to answering candidly in the future

Next steps

- Finalize report of findings
- Discuss findings with families and clinical team to share and brainstorm programmatic improvements
- Administer questionnaire annually to families and care team, track responses over time
- Share with Department leadership to make the case for integration of these questions in standard practice

Questions?

Submit your questions through the chat feature

Person-centered implementation of patient-reported outcome measures (PROMS) in complex care programs

Rebecca Sax, Senior Program Manager, Field Building & Resources
National Center for Complex Health and Social Needs

August 31, 2021

Patient-reported outcome measures (PROMs)

- PROMs are a promising way to assess individuals' health and well-being in a person-centered way

- These measures consist of structured tools through which individuals assess their own health status

- There are generally two types of PROMs: disease- or condition-specific and general well-being. More general measures may be more applicable for individuals with complex needs.

Holistic patient-reported measures for complex care programs

- EuroQol-5D (EQ-5D)
- Functional Assessment of Chronic Illness Therapy—Fatigue scale
- Health Confidence Index
- Health Utilities Index Mark 3 (HUI3)
- Healthy days
- Patient Activation Measure (PAM)
- Patient Health Questionnaire (PHQ-9)
- Patient-Reported Outcomes Measurement Information System [PROMIS]- PROMIS 29
- Personal Wellness Profile
- Quality of Well-Being Scale (QWB)
- Short-Form 36 (SF-36)
- Short-Form 6D (SF- 6D or Six Dimensions)

Example questions from widely-used PROMs

PROMIS 29

- In the past 7 days…I found it hard to focus on anything other than my anxiety
  - Never-Rarely-Sometimes-Often-Always

Healthy Days

- During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?
  - Number of days-None

What Matters Index

- Do you think any of your pills are making you sick?
  - Yes-No

Implementation of PROMs in complex care programs

National Center partnered with Kaiser Permanente's Institute of Health Policy and Care Management Institute to explore the factors that support or hinder implementation of PROMs in complex care

Over the project, feedback was gathered from patients, providers, and evaluators via:

- Expert advisory committee
- Field survey
- Key informant interviews
- Expert convening

Findings

Just because a measure is patient-*reported*, doesn't mean it is patient-*centered*

While some complex care programs are using PROMs, they are overwhelmingly only using the data for direct patient care rather than quality improvement or evaluation

There are many logistical barriers to implementation of PROMs and to take full advantage of the data collected

Themes

Measurement strategy & selection

Stakeholder engagement

Logistical considerations

Recommendations: **Measurement strategy & selection**

1 Identify program goals

Should be developed in partnership with individuals with lived experience

2 Identify existing measures

Catalog all measures currently in use

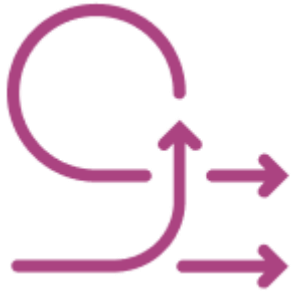
3 Map existing measures to program goals

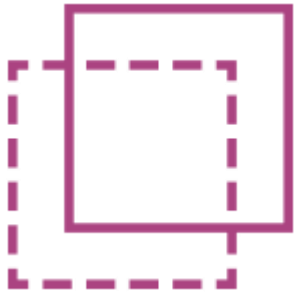
Determine if there are any redundancies or gaps in existing measures

4 Fill gaps using person-centered principles

Identify outcomes and tools that are meaningful for individuals

Recommendations: **Stakeholder engagement**





1 Embrace the roles individuals bring to the table

Stakeholders do not need formal training in measurement to provide feedback on what is important to measure

2 Be flexible about process

Recognize that patients or clinicians choose to participate on top of their existing responsibilities

3 Be transparent with language and data

Explain technical language and put data in context

Recommendations: **Logistical considerations**

1 Streamline clinical workflows that include measurement

Workflows should integrate data collection into the clinical process

2 Optimize EHRs to support PROMs

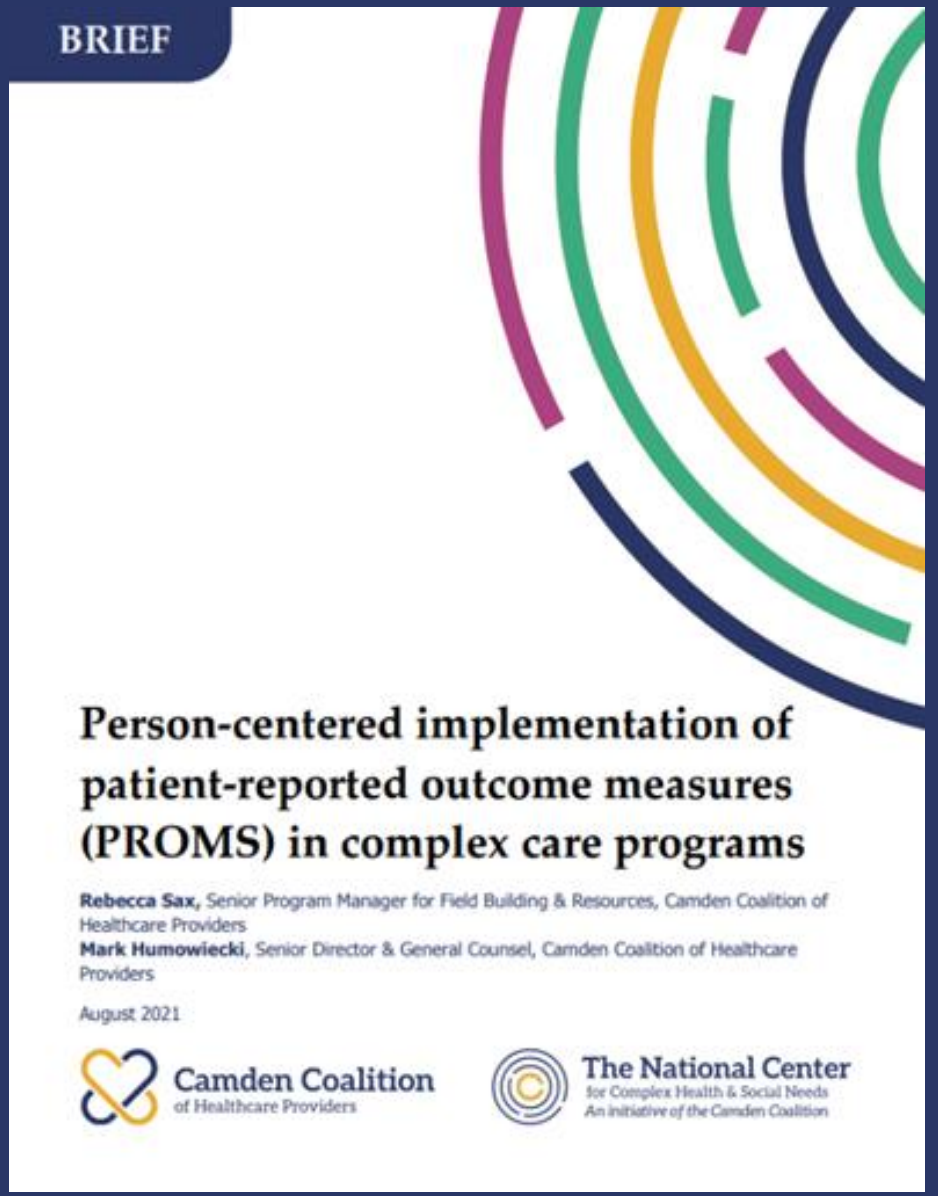
It is critical for care teams and non-clinical staff to have access to PROMs data

3 Tailor language for patient population

Consider individuals for whom English is not a first language and who might have experienced individual or historical trauma

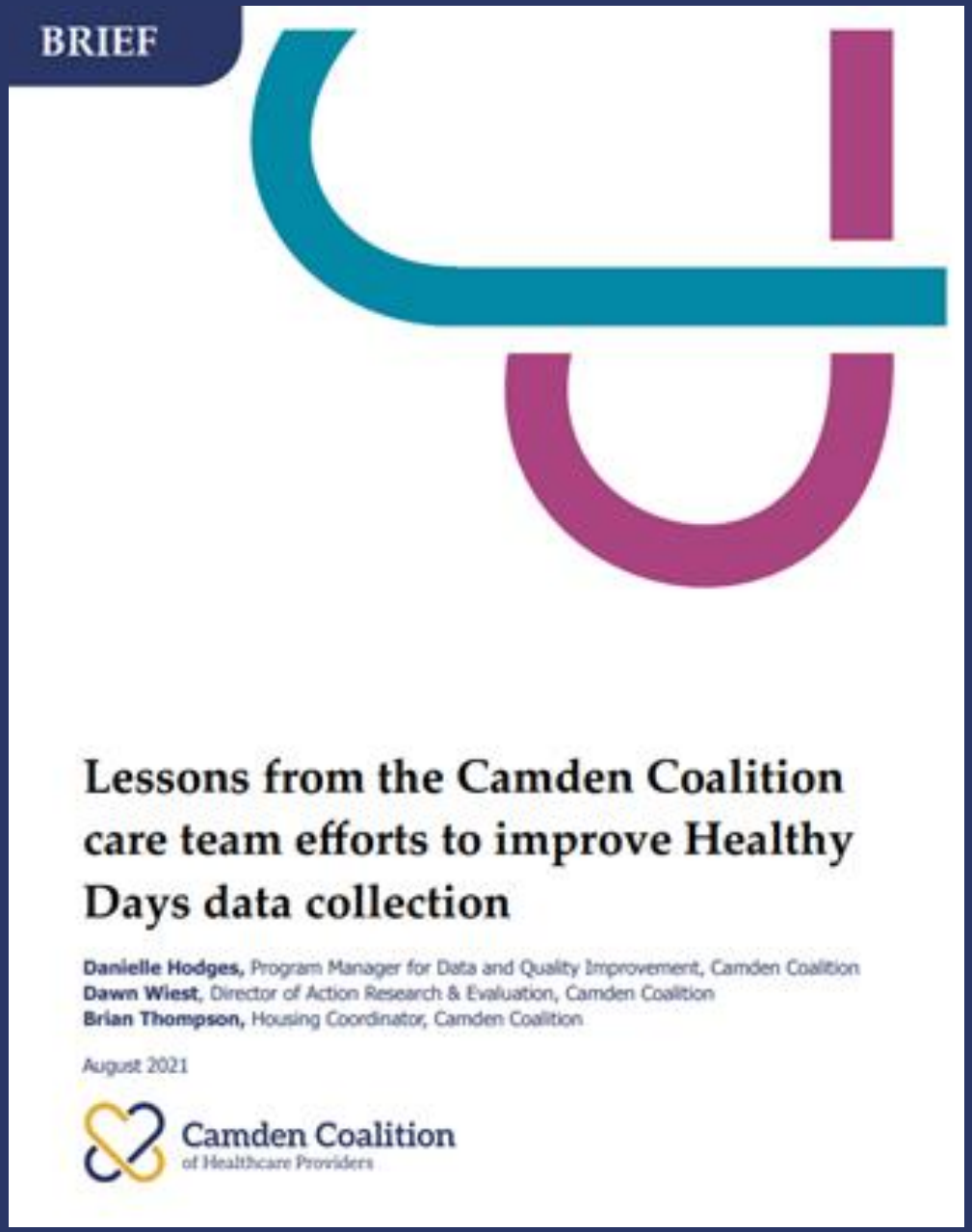
Project report available now!

Download the brief:
bit.ly/complexcarePROMs



Lessons from the Camden Coalition care team efforts to improve Healthy Days data collection

Download the brief:
bit.ly/improvinghealthydays



Stakeholder reflections

Janice Tufte, Hassanah Consulting
Public-Patient Involved Stakeholder, National Consumer Scholar,
PCORI Ambassador

August 31, 2021

Janice

- *Who Am I ?* I am an individual who lives with multiple complex conditions where the effective health and wellness management of, requires close contact with health providers coupled with access to available resources outside the health care setting.
- *Connections:* I require frequent touch points with communities I personally relate to and can ‘connect’ with.
- *Opportunities*: Working with stakeholder Subject Matter Experts / Measurement Leaders in the fields of Clinical Measurement & Measurement Guidance and I Invite patients and caregivers to participate when I see beneficial connections

Lived Experience Personal and Professional

Process: How I got involved, what the transition was like

Role: Advisor, Key Informant, Subject Matter Expert on Technical Expert Panels (TEPs) & Work Groups, Presenter, Author

Advisor Affiliations: PCORI Ambassador, Patient Advisor Kaiser Person and Family Centered Care, National Center Scholar

Major Projects:

1) Multi Stakeholder *Innovative Accelerator Project *IAP-TEP Measure set development for CMS - Substance Use Disorders/Beneficiaries of Complex Needs/Physical-Behavioral Health Integration/ Long Term Systems Services
2) PCORI Research Agenda Setting Projects including Multiple Chronic Conditions / Addressing Low Value Care / Complex Care and Social Needs
3) National Quality Forum – Work groups, endorsement and HHS Recommendation TEPs

Reflections on National Center PROMs project findings

- Project highlights:
  - Person-Centered Principles & Measurement –

    "What matters to me is very different than what matters to healthcare providers, it's my whole world"
  - Mandatory stakeholder involvement for identifying gaps in the health & delivery systems and in all aspects of PROM development and implementation
- Alignment with other measurement initiatives:
  - Recent clinical measure development focuses on equity and value
  - CMS Meaningful Measures/Sets are prioritizing 'What Matters to Patients' and social determinants of health with patient input
  - Increased recognition that evidence-based clinical performance measures help clinicians provide appropriate and necessary care, while also informing quality improvement efforts
  - Process measures are needed to ensure correct diagnosis, appropriate treatments, and overall health improvement (including preventative care)

Person-centered PROMS

Complex care programs can ensure that PROMs are person-centered by prioritizing:

- **P**references & Priorities
- **E**arly Intervention Opportunities
- **R**eflecting Patient Values
- **S**tated Goals
- **O**n-going Care
- **N**eeds

PERSON-CENTERED CARE

What Might the Future of Patient-Centered Measurement Look Like ?

Patient and caregiver involvement in multiple levels of measurement development & strategy

- *Examples: Setting research agendas, identifying gaps in current measurement, Technical Expert Panels, advancing adoption of PROMs in local health and social systems, alignment efforts, Measurement Ambassador program with outreach and mentoring opportunities.*

Implementation for continuous input and sharing, especially in the identification of gaps in care and which PROMs are appropriate

- *Social isolation and social connection are important areas for measure development*
  - *A provider noted that "successful patients were those who had at least one strong social connection."*
- ***Stress and Stigma** should be measured*
  - *Create a stress & stigma scale (like the subjective pain scale)*

Development of a patient-centered multi-stakeholder measurement advisory work group

- ***Key topics:** Validated scale for equitable care, inclusion of participants and measure developers that are representative of a community, design collaboration and patient priorities definition refinement*

Thank you !
www.janicetufte.com

For more information

- National Center for Complex Health and Social Needs: nationalcenter@camdenhealth.org
- Rebecca Sax, National Center: rsax@camdenhealth.org
- Janice Tufte, Hassanah Consulting: janicetufteconsulting@yahoo.com

Questions?

Submit your questions through the chat feature

Putting Care at the Center 2021

The annual conference on complex care

Online, October 20-22, 2021

Registration is open!

Join us virtually and register at:

www.centering.care

We want your feedback!

An evaluation survey will be sent out after this webinar

Thank you!

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