Engaging Consumers in Care Delivery:

An Implementation Framework

March 2019

Overview

Ideal person-centered, value-driven health care involves consumers in all aspects of decision-making about their health care. In practice, however, most health care delivery falls far short of achieving this goal. The Health Care Transformation Task Force ("Task Force") has created this implementation framework for engaging consumers in care delivery against which organizations can adopt, evaluate and/or refine their efforts ("Framework"). The Framework reflects a deeper dive into the first of the Task Force's six Consumer Priorities for Value-Based Care[1]:

> *Person centered, value-driven health care delivery includes patients/consumers as partners in all aspects of decision-making about their health care.*

The Framework is organized around three core elements of care that engage patients. Within each is a set of best practices that organizations can use to evaluate existing efforts and/or use to support new initiatives.[2] These best practices are accompanied by case studies of high-performing programs. The three core elements include:

A. **Coordination of Care and Systems of Care, Including Physical/Mental Health and Social Services (pg. 3)**

   Includes key elements like care planning/care team approach, integration of services, and care outside the four walls of a facility such as telehealth/digital health, home health, and other support services.

B. **Shared and Empowered Decision-Making (pg. 8)**

   Addresses shared decision-making tools, meaningful consumer guidance on provider quality/value, individual preference/goal definition, informed consent, access to personal health data, and accessibility/support such as health literacy, language support, disability support, and cultural/linguistic competency.

C. **Individual Activation for Self-Management (pg. 12)**

   Incorporates elements such as peer support models, use of social media, and other tools/technology to support personal health management.

There are other areas that warrant further research but were outside the scope of this project, specifically: the point-of-care-level interaction between provider and patient, and system-level design functions including the design of care programs and their ongoing governance. Digital health, including digital/electronic access to health information, secure provider messaging, ability to share patient-generated health data, and use of consumer-facing technologies such as mobile apps, is considered a cross-cutting theme through these three elements.

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[1] Health Care Transformation Task Force. *Value-Based Payments & Person-Centered Care: Six Guiding Principles.* Available at: https://hcttf.org/2016-8-30-addressing-consumer-priorities-in-value-based-care/

[2] The full checklist of best practices for all three core elements is included as an addendum to this resource on page 19.

A. Coordination of Care and Systems of Care

Consumer engagement in coordination of care and systems of care involves designing and delivering care that is truly patient-centered and engages consumers in meaningful, collaborative ways. Key considerations include the care planning/care team approach, integration of services, and care outside the four walls of a facility, such as telehealth, digital health, home health, and other support services.

1. **Coordinated, evidence-based care.** *Effective, coordinated care should meet the consumer's needs, coordinate across multiple providers, and should be evidence-based. This means:*

- ☐ Care meets an individual's physical and mental needs, including prevention and wellness, acute care, and chronic care;
- ☐ Treatment is evidence-based, trauma-informed, and updated as new evidence emerges;
- ☐ Individuals are risk-stratified and segmented via data-driven, clinically supported protocols and matched to appropriate programs with continuous communication from care providers;
- ☐ Care plans are created with the individual and his/her caregiver, and incorporate elements of self-management; and
- ☐ Individuals/caregivers have access to a comprehensive team of care providers, including but not limited to physicians, nurses, social workers, care coordinators, rehabilitation providers, and peers, who collaborate to advance the goals of the individual and his/her caregiver:
    - a. Each team member operates at his/her highest level of training and full scope of licensure.
    - b. Individuals/caregivers have a specific point of contact within the care team, but each care team member can facilitate the right support as needed.
    - c. Individuals/caregivers are able to spend an adequate amount of time with the care team; conversely, team members have adequate time/tools to achieve care plans goals.
    - d. All team members' voices – including the individual/caregiver – are heard and respected, and the team focuses on continuous, proactive, evidence-based patient-centered care.

2. **Collaboration.** *Successful care coordination should be built upon collaborative partnerships between individuals, caregivers, and providers, with one individual serving as the primary point of contact to the patient. This means:*

- ☐ Individuals/caregivers feel encouraged, supported, and prepared to actively participate in decision-making;
- ☐ Individuals, caregivers, clinicians, and health care leaders collaborate on program development, implementation, and evaluation; and
- ☐ Consumer governance structures, such as advisory committees comprised of patients/families/caregivers that represent the community, are effectively incorporated into care design and feedback mechanisms.

3. **Information sharing.** *Individuals should be provided with health care information that is accurate, complete, easy to access and interpret, and addresses their concerns. This means:*

☐ Health care practitioners communicate and share unbiased information with individuals and caregivers in useful ways with appropriate context;

☐ Individuals and caregivers receive timely, complete, and accurate information to effectively participate in decision-making; and

☐ Individuals are able to access, ask questions, and understand their complete clinical history (e.g., direct access to electronic medical records) and share with third-party applications as desired.

4. **Dignity and respect.** *Provider-patient relationships should be based on mutual respect, inclusivity, and choice. This means:*

☐ Clinical encounters are relationship-based and focus on the whole person, rather than just the condition or illness;

☐ Providers honor individual/caregiver perspectives and choices, and seek to incorporate those perspectives into care plans; and

☐ Individuals retain choice about whether they participate in programs, meaning an initial affirmative decision to participate (not an "opt-out" system) and the right to drop participation at any time. This includes documentation demonstrating that these rights have been conveyed to the individual and are understood.

5. **Accessibility.** *Appropriate services and resources should be readily available. For example:*

☐ Affordable, personalized, and high-value[3] services;

☐ Accessible and appropriately coordinated services with shorter waiting times for urgent needs, enhanced in-person hours, and alternative methods of electronic communication such as email and text;

☐ Access to community resources, such as food banks and transportation, to address non-clinical needs; follow-up on whether they were accessed and addressed the individual's needs; and

☐ Ready access to appropriate medications at the point of care.

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[3] "High-value services" are clinical, evidence-based services that have demonstrated value for diagnosis and/or treatment.

MENTAL HEALTH INTEGRATION PROGRAM (MHIP)

Program Description

The Washington State Mental Health Integration Program (MHIP) was created in 2007 in partnership between the Community Health Plan of Washington (CHPW, a not-for-profit health plan), Seattle-King County Department of Public Health, and the AIMS Center at the University of Washington.[4] The program was initially patterned after the IMPACT program developed by the University of Washington.

Key Attributes of the Program

- **Team-based care:** Team-based care, including use of a clinical behavioral health (BH) care manager, and use of a psychiatric caseload consultant.
- **Screening:** In addition to PHQ-9 depression screening, patients also were screened for anxiety and substance use conditions. Over time, additional screening tools have been incorporated into the care model, including symptom rating scales, functional rating scales, and important medical markers, such as glycosylated hemoglobin (hemoglobin A1C, HbA1c) and LDL cholesterol. Appropriate and eligible patients are identified via standardized screening (such as the PHQ-9) or via referral by the primary care physician.
- **"Warm handoff"**: Whenever possible, "warm handoff" referrals are utilized, connecting the behavioral care manager immediately to the patient. The care manager also has a primary role of coordination of referrals and care transitions – including referral to specialty mental health when indicated, once patients are enrolled in the MHIP program.
- **Psychiatrist consultant**: The psychiatric consultant provides regular (usually weekly) caseload reviews with the care manager for the purpose of ensuring population review for the assigned caseload. During the consultations, the psychiatrist assists with diagnosis and formulation and makes recommendations regarding medications, psychotherapy, and patient management. Recommendations are documented in a caseload review note that is forwarded to the primary care physician. The consultant remains available throughout the week by telephone to assist the care team in the event of additional questions. Psychiatric consultants are often available either in-person or by telepsychiatry for direct patient care consultations or for more complex clinical questions or concerns.

Challenges and Opportunities for Improvement

- **Incorporating processes and outcomes measures into clinicians' workflows.**
- **Ongoing workforce development, training, and support:** For such a large program, it was a challenge to find and train a clinical workforce of more than 100 behavioral health care managers and approximately 20 part-time psychiatric consultants. Once the initial roll-out process was complete, the challenge of program sustainability became apparent. Use of recorded web-based training helped, but training needs remain an ongoing challenge. Furthermore, as the program expands, it continues to draw clinicians from an already-strained mental health clinician resource pool.

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[4] Advancing Integrated Mental Health Solutions Center. Washington State's Mental Health Integration Program (MHIP); 2018. https://aims.uw.edu/washington-states-mental-health-integration-program-mhip. Accessed November 22, 2018.

Program Description

The TEAMcare Study was conducted through the Group Health (GH) Cooperative, a large health maintenance organization in Washington State that is now owned by Kaiser Permanente. The TEAMcare intervention was based in 14 GH primary care clinics in Western Washington.

This 12-month intervention aimed to improve disease control for both medical and psychological illnesses by focusing on patients with poor glycemic, blood pressure, or lipid control, and coexisting depression. This multi-condition collaborative care management intervention was developed by synthesizing collaborative care for depression with a chronic care model, and added a treat-to-target strategy initially developed for diabetes.[5]

This patient-centered intervention was integrated into primary care by applying one treatment approach across three chronic illnesses (congenital heart disease, diabetes, and depression). Disease-specific treatment recommendations combined Group Health evidence-based guidelines with the treat-to-target program for diabetes from the Kaiser Care Management Institute.

Key Attributes of the Program

- **Team-based care coordinated by nurse care managers.**
- **Clinician consultants:** Consultants included psychiatrists, an internist, a family medicine physician, and a psychologist. Specialty consultations with a diabetes expert and a cardiologist were available when patients had complex insulin management regimes or when patients had complicated cardiac presentations.
- **Depression screening.**
- **Identified care plans** that reflected patient control and choices.
- **Collaboration:** Treatment was determined by the primary care physician, the psychiatric consultant and the patient.
- **Behavioral activation:** Behavioral activation aimed to motivate patients, enhance disease self-management activities, increase social contacts and pleasurable activities, and facilitate decision-making.
- **Self-care strategies:** Patients who were working to improve their blood pressure were given a blood pressure monitor and optimum blood pressure measurement techniques and strategies for monitoring were discussed. Patients who were in an active phase of titration of antihypertensive medications often chose to check their blood pressure every morning. Patients could also email their providers with the home blood pressure readings and receive treatment adjustments.
- **Patient and provider education.**
- **Relapse prevention plan.**

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[5] McGregor M, Lin EH, Katon WJ. TEAMcare: An Integrated Multicondition Collaborative Care Program for Chronic Illnesses and Depression. J Ambul Care Manage. 2011 Apr-Jun; 34(2): 152-162. doi: 10.1097/JAC.0b013e31820ef6a4.

Challenges and Opportunities for Improvement

- **Staff training and experience:** When the intervention began, care managers were concerned about their knowledge and skills related to depression. Initially, they were overwhelmed by the number and variety of antidepressants, the indications, and the side effects of each. In the first few months after the initial training and supervision sessions, each care manager gained a familiarity with the medications and focused on the several medications that were most commonly recommended. Other concerns about depression treatment were lack of confidence about motivational interviewing and behavior change techniques. With practice and weekly supervision discussions, the care managers became more facile with therapeutic communication and behavioral activation skills.
- **Clinical documentation:** Clinical documentation was another challenge for the care managers. All were capable users of the EMR. However, because the EMR did not include a tracking system that captured all outcome criteria and did not include a care plan, multiple systems had to be used. Although the care managers became faster at using multiple documentation systems, it remained a time-intensive process.

B. Shared and Empowered Decision-Making

Shared and empowered decision-making which means enabling consumers to be active and informed participants in their care. This element addresses topics such as shared decision-making tools, meaningful consumer guidance on provider quality/value/out-of-pocket cost, individual preference/goal definition, informed consent, and accessibility/support, including a focus on health literacy, language support, disability support, and cultural competency.

1. **Collaboration.** *Providers collaborate with individuals to facilitate informed decision-making. For example:*

   - ☐ Individuals and caregivers are encouraged and supported to actively participate in care and decision-making;
   - ☐ Consumers have culturally and linguistically appropriate and relevant resources, such as online comparison tools, to support informed decision-making on physicians that will best meet their clinical and financial needs; and
   - ☐ Individuals and clinicians work together to make decisions and define goals that are informed by the individual's needs, desires, financial constraints, socioeconomic background, and realistic outcome expectations.

2. **Consumer-centricity and empowerment.** *Decision-support tools and programs are designed to help empower consumers shape their own care paths. This means:*

   - ☐ Tools and programs incorporate learnings from other sectors (i.e., retail and technology) to help engage and educate consumers;
   - ☐ Providers actively and consistently engage consumers in goal definition and refinement conversations; and
   - ☐ Consumers are provided with the most current evidence (including the latest clinical research, personal health information, and cost structures) needed to make informed decisions, in easily understandable terms.

3. **Accessibility.** *Consumers have direct access to on-demand resources through a variety of channels. Thus:*

   - ☐ Decision-making support tools accommodate variances in literacy, culture, languages, and visual/auditory/cognitive impairments;
   - ☐ Materials are accessible to individuals before, during or after a visit, in multiple formats; and
   - ☐ Resources are provided through multiple channels of electronic communication, considering security and accessibility concerns such as limited cellular and internet access; live support is available on an as-needed basis.

4. **Scalability.** *Programs and resources can be scaled across multiple sites and populations. This means:*
   - ☐ Resources and tools are easily adaptable and translatable in content and structure;
   - ☐ Substantive training and education are available for providers; and
   - ☐ The cost of program and/or support tools is not a barrier to implementation.

Shared and Empowered Decision-Making Case Study | ONE KEY QUESTION

Program Description

One Key Question (OKQ) is a program developed by the Oregon Foundation for Reproductive Health. It proposes that all women of reproductive age should be asked, "Would you like to become pregnant in the next year?" on a routine basis in primary care. The screening also incorporates four patient response categories (Yes, No, Ok either way, Unsure) to better reflect the spectrum of intention. Through this approach, providers can respond or refer women to family planning counselors based on their responses. Women who reply with "No," "I'm not sure," or "I'm fine either way" are redirected to a conversation about contraceptive options tailored to their specific needs. Women who reply "Yes" are engaged in well-woman and preventative care programs immediately.

OKQ is designed to proactively address the root causes of unintended pregnancies, poor birth outcomes, and disparities in maternal and infant health. The program is focused on understanding women's family planning intentions and providing follow-up care. It is intended to be non-judgmental and equally supportive of women who want to become pregnant, those who do not, and those who are unsure or would be open to pregnancy. OKQ is used in a variety of settings, from home visiting, to primary care, to other locations such as food assistance programs and dental offices. Results from a 2015 report on the screening tool show that of the 70% who indicated that they did not want to become pregnant, 30% were not using contraception at the time.[6]

Key Attributes of the Program

- The screening tool is designed to be **simple** and conversational to open the dialogue for further discussion on prevention and care options.
- It can be **employed in various localities** – such as health clinics and food assistance offices.
- It addresses a **basic but under-screened** question around unintended pregnancy.
- It **prompts individual engagement** by asking about desire and actions.
- The program is **scalable and provides extended training** for screening and appropriate follow-up.

Challenges and Opportunities for Improvement

- There is still limited data on the efficacy of the program. While initial data reveals significant opportunities to improve family planning, more research needs to be done on the efficacy of the program with regard to follow-up care.

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[6] Wood S, Beeson T, Goldberg DG, Mead K, Shin P, Abdul-Wakil A, Rui A, Sahgal B, Shimony M, Stevens H, Rosenbaum S. Patient Experiences With Family Planning in Community Health Centers; July 2015. https://publichealth.gwu.edu/sites/default/files/Geiger_Gibson_Family_Planning_Report_2015.pdf. Accessed on March 22, 2019.

MGH SHARED DECISION-MAKING PROGRAM

Program Description

The Shared Decision Making (SDM) Program at Mass General Hospital (MGH) launched in 2005.[7] The program was developed with the goal of ensuring that patients receive the right care at the right time, based on their unique preferences and values. The program offers decision aids – e.g., problem-specific information including treatment options and expected outcomes – that cover 40 different topics to patients at all 18 of MGH's adult primary care practices, as well as its specialty practices in orthopedics, oncology, cardiology, men's health, geriatrics, mental health and obstetrics-gynecology.

During an office visit, clinicians can discuss the SDM program with eligible patients who need to consider routine screening options or health care treatment decisions. If the patient is interested, clinicians are able to electronically "prescribe" decision aids. The decision aids can also be ordered directly by health educators and staff, as well as by patients themselves.

When an order is placed, a note is automatically put in the patient's electronic health record and the order is fulfilled by staff. The decision aids are available in several formats. Patients can receive an e-mail through their patient portal with a link that allows them to access the decision aid online; others can receive a DVD and brochure by mail.

Topics include cancer screening, diabetes, orthopedics, heart disease, depression, general health, prostate conditions and women's health, among many others. Most of the aids are available in Spanish. The video component includes interviews with physicians, as well as patients who have chosen different treatments, and their experiences are shared candidly.

Other examples of decision aids are worksheets that cover different medication or treatment options; for example, medications to lower blood sugar in patients with diabetes. These worksheets are intended to be used during consultations to prompt and guide a discussion about patient preferences, values, and concerns. Strong support from leadership has played an integral role in establishing a culture at MGH that's receptive to shared decision-making. The program also offers training sessions for all clinicians, physicians, nurses, residents and medical students that explain the benefits of shared decision making, best practices for using these decision aids, and tips for how best to elicit patients' goals and preferences. Assessment is also an ongoing part of the SDM program.

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[7] Sepucha KR, Simmons LH, Barry MJ, Edgman-Levitan S, Licurse AM, Chaguturu SK. Ten Years, Forty Decision Aids, And Thousands Of Patient Uses: Shared Decision Making At Massachusetts General Hospital. Health Affairs. 2018 Apr; 35(4): 630-636.

Key Attributes of the Program

The shared decision-making program is important in engaging individuals because:

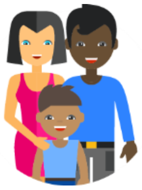
- It provides patients with **evidence-based decision aids** to help them learn more about their care options.
- The aids are **accessible** to patients before, during, or after a visit, in multiple formats.
- It allows patients to use the aids from the **comfort of their own home, and with family or other caregivers.**
- Patients are able to place an order themselves and **self-select topics of their interest.**
- It engages the **entire care team.**
- The tools are **easy to understand** and offered in both English and Spanish.
- It facilitates a **collaborative approach** for clinical decision making.
- It trains clinicians on how to elicit patient **preferences, values, and concerns.**

Challenges and Opportunities for Improvement

While this tool currently produces great value to consumers, opportunities for improvement include:

- Offering decision aids in additional languages.
- Ensuring that patients going in for a new surgical consultation visit for are able to receive decision support prior to consultation.
- Better tracking of patient feedback and responses, which is currently done manually.
- Further analysis of data to look at the correlation between use of decision aids and patient-reported experience.

C. Individual Activation for Self-Management



Individual activation for consumer's self-management involves providing resources, education, and support to encourage consumers to actively manage their own care. It incorporates elements such as peer support models, use of social media, and other tools/technology to support personal health management.

1. **Information.** *To be engaged in their health care, individuals need actionable information about how to help manage their own health condition. This includes:*

- ☐ Relevant background on their health condition;
- ☐ Simple instructions on actions they should take;
- ☐ An explanation of how and why those actions are important;
- ☐ An FAQ style list of answers to common questions;
- ☐ Instructions for emergency situations;
- ☐ Information on how to address social needs that directly and indirectly impact health status;
- ☐ Information on how to obtain more resources, both specific to self-management activities (ex. diabetic testing programs) and also for related broader wellness topics (ex. nutrition for individuals with diabetes);
- ☐ Information on the out-of-pocket cost of services; and
- ☐ A point of contact for in-person follow up (see #4 below).

2. **Accessibility.** *To be effective, self-management tools must be accessible to the individuals that will use them. This means:*

- ☐ All materials should be written at a level that will work for varying levels of functional literacy;
- ☐ All materials should be available in multiple languages;
- ☐ All materials should be accessible to individuals with disabilities and functional impairments, including visual or auditory impairments;
- ☐ Self-management protocols should consider the role of family and caregivers, who – in some cases – may be an important part of self-management; and
- ☐ Accessibility planning should consider varying and sometimes inconsistent individual access to internet, smartphones, cell phones, etc.

3. **Training.** *To the extent a self-management program uses equipment (testing supplies, needles, etc.), consumers should receive training on how to use that equipment. This means:*

☐ A description of what the equipment is used for;

☐ Training on equipment use; and

☐ Instructions for replacing equipment, repeating training, and getting help.

4. **Point of contact**. *To ensure continuous self-management, individuals must have a reliable point of contact within the health care system for follow up. This means:*

☐ The individual should be provided with the name and contact information of their point of contact;

☐ The (primary) point of contact should be one named person that is regularly available at established times;

☐ During all off hours – even weekends, the individual should be diverted to another point of contact; and

☐ All points of contacts should be trained in the self-management techniques and have real-time access to the EHR so they are prepared and able to answer questions.

5. **Choice and control.** *Consumers should always feel safe and empowered in self-management programs. This means:*

☐ Individuals should always retain choice about whether they participate in programs, meaning an initial affirmative decision to participate (not an “opt-out” system) and the right to drop participation at any time;

☐ Within the choice framework, information and incentives should be aligned with high-value care. However, incentives should never come in the form of penalties or punishments;

☐ Individuals should have access to their EHRs and be encouraged to interact with those EHRs to support their own on-going care; and

☐ EHR platforms used in self-management programs should be integrated with all relevant provider offices per consumer consent, but otherwise maintain high standards for confidentiality.

6. **Care coordination**. *Self-management activities should not be siloed from broader care coordination activities.*

☐ Self-management should be a part of an individual’s care plan that is regularly discussed with care teams; and

☐ Clinical visits should draw out connections between overarching patient goals and the contribution of self-management activities.

REMOTE BLOOD PRESSURE MONITORING

Program Description

Massachusetts-based Partners Healthcare is piloting a population-based remote blood pressure monitoring program in four sites, including Massachusetts General Hospital, Brigham Health, Newton Wellesley Hospital, and North Shore Medical Center. Primary care providers are involved in all locations, with cardiologists also engaged at two of the four sites. To be considered for participation, a provider group must express interest and fall below the system's designated threshold for hypertension management. Patients must also satisfy specific clinical criteria including an age range of 18 to 80, not pregnant, and a documented diagnosis of hypertension. Additionally, enrollees must have a personal smartphone or tablet and access to the iPhone App Store or Android Google Play. Prior to program initiation, patients sign terms and conditions and register their device.

Eligible patients receive a blood pressure device that they do not have to return (Omron 10 Series) and are invited to join the program via a secure patient portal. Data from the device is directly uploaded to the electronic health record (EHR) – in this case EPIC – through a unique cloud-based program called the Connected Health Integration Pathway (CHIP). Providers are able to access timely and accurate patient data in the EHR, creating an environment that facilitates collaborative care. Patients have access to their own data via the patient portal. Partners offers enrollment assistance through its Center for Population Health Patient Engagement team.

This collaboration allows patients to share personal health data with their providers seamlessly and securely using their own consumer devices. It effectively pushes care coordination and management out of the hospital or clinic and into the home. Additionally, the platform provides consumers an instant connection to health and wellness opportunities that improve outcomes and prevent medical emergencies.

Key Attributes of the Program

The remote blood pressure monitoring program is important in engaging individuals because:

- It provides consumers with **ongoing information to help manage their condition** in the place they live and work.
- It is **accessible** to most individuals.
- Patients have a known **point of contact** throughout the process.
- It facilitates **collaborative** decision-making.
- It **provides choice to both the patient and provider** through the ability to stop the flow of data at any time. They can determine how much data to collect/transmit, how long, and the overall purpose.
- The format is **standardized, actionable, and HIPAA-compliant**.
- The program uses CHIP – a **custom-built platform** – to share the blood pressure record with the EHR.
- All participating **providers must use a specific EHR** – in this case EPIC.

Key Attributes of the Program *(continued)*

- Patient **data is integrated in the EHR** in such a way that it's both useful to clinicians and accurate enough to be trusted. Integration to the EHR is unique to this system.
- It **can be used jointly** with other monitoring and care services.
- It **enables clinicians to access streaming data from devices in near real-time** and set guidelines to determine which data requires immediate attention.
- It provides a **one-stop shop,** eliminating the need to go external. The CHIP platform allows data to flow securely to the electronic medical record.

Patients and providers are eager to leverage personal health technologies to enhance care coordination, patient engagement and collaboration to improve care delivery and clinical outcomes.

Challenges and Opportunities for Improvement

While this tool produces great value for consumers and providers, possible improvements or challenges include:

- Identifying the most efficacious way to enroll patients who could benefit from the service.
- Providing assistance with technical aspects, particularly to the older population most impacted by hypertension.
- Eligible patients must have a personal device and access to apps. This may exclude some low income or elderly populations.
- Patient and provider workflow requirements must be considered and satisfied for the program to be successful.
- Finding the balance: Determining how patient-generated health data can be integrated into the clinical system in such a way that it helps providers rather than inundating them with unneeded or unverified information.

Individual Activation for Self-Management Case Study

CHRONIC DISEASE SELF- MANAGEMENT

Program Description

The Chronic Disease Self-Management Program (CDSMP) is one of 15 different programs under the Self-Management Resource Center (SMRC).[8] Initially established by Stanford University in 1979 to help individuals self-manage the effects of arthritis, the program evolved and expanded over the course of the next several decades to focus on issues such as comorbid conditions, workplace chronic disease, diabetes, chronic pain, cancer, HIV, and support for caregivers. The SMRC is now a standalone organization that licenses its program curriculum to providers, insurers, public health departments, Area Agencies on Aging, and other public/private organizations. Altogether, the SMRC's programs have upward of 700 licensees around the world who are attached to approximately 12,000 different organizations.

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[8] Self-Management Resource Center. Chronic Disease Self-Management (CDSMP); 2018. https://www.selfmanagementresource.com/programs/small-group/chronic-disease-self-management/. Accessed November 21, 2018.

Program Description *(continued)*

The CDSMP is geared primarily toward older individuals with chronic illness. The program is designed around small group workshops administered by two trained leaders, one or both of whom are non-health professionals with chronic disease themselves. The program sessions are 2.5 hours in duration and occur once per week for six weeks in community settings such as senior centers, churches, libraries, and hospitals. The program is also available online through Canary Health.

Participants make weekly action plans, share experiences, and help each other solve problems they encounter in living with one or more chronic conditions. They also receive training on topics such as techniques to manage pain, fatigue, and isolation; appropriate exercise regimes; effective communication; nutrition; decision-making; problem-solving; and evaluation of new treatments. The curriculum has been reviewed by clinicians and various health professionals at Stanford and other institutions around the world. Participation in the program is voluntary. Materials available to participants include a workbook and relaxation CD. The program is also taught in Spanish, with translations available in 11 other languages.

Research studies have shown that CDSMP participants achieve significant improvements in exercise, cognitive symptom management, physician communication, self-reported health, disability, fatigue, and social limitations. They have fewer inpatient admissions, reduced length of stay, and reduced outpatient visits, which correspond to a cost savings ratio of 1:4 that may persist up to three years.[9]

Key Attributes of the Program

The CDSMP is effective at engaging individuals because:

- It is directly **accessible** for most individuals – no prescription is needed, and individuals can access content in a variety of languages.
- Patients have a known **point of contact** throughout the process.
- Courses are generally **peer-taught** by trainers with personal chronic illness experience.
- The material is **evidence-based, clinically reviewed, and time-tested.**
- Training is **participatory and action-oriented.**
- The format and content are **standardized and replicable.**
- The **barriers to participation** are low; participants are not required to undergo concurrent medical treatment, etc.
- It emphasizes and encourages **individual agency** over health care decisions.
- It **can be used jointly** with other care services.

Challenges and Opportunities for Improvement

Although the CDSMP is a highly successful and optimized program, the primary challenge is:

- Funding, particularly for broader adoption. Licensing fees start at $500 for three years and run upward, with a separate training cost. Although some states – including Massachusetts, Florida, Wisconsin, South Dakota, and New Mexico – have a number of programs available, other states are stretched thin. The Administration for Community Living provides a limited amount of annual funding to help states implement and sustain the program, but broader roll-out depends on funding and commitment from private organizations.

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[9] Evidence-Based Leadership Council. Chronic Disease Self-Management Program (CDSMP). http://www.eblcprograms.org/evidence-based/recommended-programs/cdsmp. Accessed November 21, 2018.

Conclusion

True person-centered care is the cornerstone of a value-driven health care system. In the absence of care delivery that engages and empowers consumers to become partners in their own health narrative, the meaning of "value" is reduced to little more than cost and utilization control – neither of which, on their own, best serve patients or support a healthier population.

The Framework encapsulates the work of organizations at the vanguard of person-centered care – those that have dedicated significant time, energy, and resources to providing the support that consumers need to be fully engaged in their care decisions. While there is more work yet to be done on this front, the Framework and sample case studies are intended to serve as a guidepost for organizations as they develop, expand, and refine their patient engagement capabilities.

About Us

The Health Care Transformation Task Force is an industry consortium that brings together patients, payers, providers, and purchasers to align private and public sector efforts to clear the way for a sweeping transformation of the U.S. health care system. The Task Force is committed to rapid, measurable change, both for itself and the country. It aspires to have 75% of its member businesses operating under value-based payment arrangements by 2020.

Additional Resources

A. *Coordination of Care and Systems of Care*

- American Psychiatric Association Academy of Psychosomatic Medicine. Dissemination of Integrated Care Within Adult Primary Care Settings: The Collaborative Care Model 2016. https://www.integration.samhsa.gov/integrated-care-models/APA-APM-Dissemination-Integrated-Care-Report.pdf. Accessed March 22, 2019
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B. *Shared and Empowered Decision-Making*

- Ganos E. The Robert Wood Johnson Foundation. Costs of Care: Getting the Patient-Provider Conversation Right; June 2016. https://www.commonwealthfund.org/publications/journal-article/2016/feb/engaging-patients-through-opennotes-evaluation-using-mixed. Accessed March 22, 2019.
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- The Commonwealth Fund. Helping Patients Make Better Treatment Choices with Decision Aids. https://www.commonwealthfund.org/publications/newsletter/helping-patients-make-better-treatment-choices-decision-aids. Accessed March 22, 2019.
- The Commonwealth Fund. How to Develop Breakthrough Technologies for Patient Engagement; July 2015. https://www.commonwealthfund.org/event/2015/how-develop-breakthrough-technologies-patient-engagement. Accessed March 22, 2019.

C. *Individual Activation for Self-Management*

- Evidence-Based Leadership Council; 2018. http://www.eblcprograms.org/evidence-based/recommended-programs/. Accessed March 22, 2019.
- Agency for Healthcare Research and Quality. Self-Management Support. https://www.ahrq.gov/professionals/prevention-chronic-care/improve/self-mgmt/index.html. Accessed March 22, 2019.

Addendum: *Checklist of best practices*

This checklist includes the best practices for all three core elements of the Framework. This checklist can be used as a standalone resource or in combination with remainder of the Framework serving as a "how to" guide.

A. Coordination of Care and Systems of Care

Key elements include care planning/care team approach, integration of services, and care outside the four walls of a facility, such as telehealth, digital health, home health, and other support services).

1. **Coordinated, evidence-based care.** *Effective, coordinated care should meet the consumer's needs, coordinate across multiple providers, and should be evidence-based. This means:*

- ☐ Care meets an individual's physical and mental needs, including prevention and wellness, acute care, and chronic care;
- ☐ Treatment is evidence-based, trauma-informed, and updated as new evidence emerges;
- ☐ Individuals are risk-stratified and segmented via data-driven, clinically supported protocols and matched to appropriate programs with continuous communication from care providers;
- ☐ Care plans are created with the individual and his/her caregiver, and incorporate elements of self-management; and
- ☐ Individuals/caregivers have access to a comprehensive team of care providers, including but not limited to physicians, nurses, social workers, care coordinators, rehabilitation providers, and peers, who collaborate to advance the goals of the individual and his/her caregiver:
  a. Each team member operates at his/her highest level of training and full scope of licensure.
  b. Individuals/caregivers have a specific point of contact within the care team, but each care team member can facilitate the right support as needed.
  c. Individuals/caregivers are able to spend an adequate amount of time with the care team; conversely, team members have adequate time/tools to achieve care plans goals.
  d. All team members' voices – including the individual/caregiver – are heard and respected, and the team focuses on continuous, proactive, evidence-based patient-centered care.

2. **Collaboration.** *Successful care coordination should be built upon collaborative partnerships between individuals, caregivers, and providers, with one individual serving as the primary point of contact to the patient. This means:*

- ☐ Individuals/caregivers feel encouraged, supported, and prepared to actively participate in decision-making;

- Individuals, caregivers, clinicians, and health care leaders collaborate on program development, implementation, and evaluation; and
- Consumer governance structures, such as advisory committees comprised of patients/families/caregivers that represent the community, are effectively incorporated into care design and feedback mechanisms.

3. **Information sharing.** *Individuals should be provided with health care information that is accurate, complete, easy to access and interpret, and addresses their concerns. This means:*

- Health care practitioners communicate and share unbiased information with individuals and caregivers in useful ways with appropriate context;
- Individuals and caregivers receive timely, complete, and accurate information to effectively participate in decision-making; and
- Individuals are able to access, ask questions, and understand their complete clinical history (e.g., direct access to electronic medical records) and share with third-party applications as desired.

4. **Dignity and respect.** *Provider-patient relationships should be based on mutual respect, inclusivity, and choice. This means:*

- Clinical encounters are relationship-based and focus on the whole person, rather than just the condition or illness;
- Providers honor individual/caregiver perspectives and choices, and seek to incorporate those perspectives into care plans; and
- Individuals retain choice about whether they participate in programs, meaning an initial affirmative decision to participate (not an "opt-out" system) and the right to drop participation at any time. This includes documentation demonstrating that these rights have been conveyed to the individual and are understood.

5. **Accessibility.** *Appropriate services and resources should be readily available. For example:*

- Affordable, personalized, and high-value[10] services;
- Accessible and appropriately coordinated services with shorter waiting times for urgent needs, enhanced in-person hours, and alternative methods of electronic communication such as email and text;
- Access to community resources, such as food banks and transportation, to address non-clinical needs; follow-up on whether they were accessed and addressed the individual's needs; and
- Ready access to appropriate medications at the point of care.

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[10] "High-value services" are clinical, evidence-based services that have demonstrated value for diagnosis and/or treatment.

B. Shared and Empowered Decision-Making

Addresses shared decision-making tools, meaningful consumer guidance on provider quality/value/out-of-pocket cost, individual preference/goal definition, informed consent, and accessibility/support, such as health literacy, language support, disability support, and cultural competency.

1. **Collaboration.** *Providers collaborate with individuals to facilitate informed decision-making. For example:*

   - ☐ Individuals and caregivers are encouraged and supported to actively participate in care and decision-making;
   - ☐ Consumers have culturally and linguistically appropriate and relevant resources, such as online comparison tools, to support informed decision-making on physicians that will best meet their clinical and financial needs; and
   - ☐ Individuals and clinicians work together to make decisions and define goals that are informed by the individual's needs, desires, financial constraints, socioeconomic background, and realistic outcome expectations.

2. **Consumer-centricity and empowerment.** *Decision-support tools and programs are designed to help empower consumers shape their own care paths. This means:*

   - ☐ Tools and programs incorporate learnings from other sectors (i.e., retail and technology) to help engage and educate consumers;
   - ☐ Providers actively and consistently engage consumers in goal definition and refinement conversations; and
   - ☐ Consumers are provided with the most current evidence (including the latest clinical research, personal health information, and cost structures) needed to make informed decisions, in easily understandable terms.

3. **Accessibility.** *Consumers have direct access to on-demand resources through a variety of channels. Thus:*

   - ☐ Decision-making support tools accommodate variances in literacy, culture, languages, and visual/auditory/cognitive impairments;
   - ☐ Materials are accessible to individuals before, during or after a visit, in multiple formats; and
   - ☐ Resources are provided through multiple channels of electronic communication, considering security and accessibility concerns such as limited cellular and internet access; live support is available on an as-needed basis.

4. **Scalability.** *Programs and resources can be scaled across multiple sites and populations. This means:*

   - ☐ Resources and tools are easily adaptable and translatable in content and structure;
   - ☐ Substantive training and education is available for providers; and
   - ☐ The cost of program and/or support tools is not a barrier to implementation.

C. Individual Activation for Self-Management

Incorporates elements such as peer support models, use of social media, and other tools/technology to support personal health management.

1. **Information.** *To be engaged in their health care, individuals need actionable information about how to help manage their own health condition. This includes:*

- ☐ Relevant background on their health condition;
- ☐ Simple instructions on actions they should take;
- ☐ An explanation of how and why those actions are important;
- ☐ An FAQ style list of answers to common questions;
- ☐ Instructions for emergency situations;
- ☐ Information on how to address social needs that directly and indirectly impact health status;
- ☐ Information on how to obtain more resources, both specific to self-management activities (ex. diabetic testing programs) and also for related broader wellness topics (ex. nutrition for individuals with diabetes);
- ☐ Information on the out-of-pocket cost of services; and
- ☐ A point of contact for in-person follow up (see below).

2. **Accessibility.** *To be effective, self-management tools must be accessible to the individuals that will use them. This means:*

- ☐ All materials should be written at a level that will work for varying levels of functional literacy;
- ☐ All materials should be available in multiple languages;
- ☐ All materials should be accessible to individuals with disabilities and functional impairments, including visual or auditory impairments;
- ☐ Self-management protocols should consider the role of family and caregivers, who – in some cases – may be an important part of self-management; and
- ☐ Accessibility planning should consider varying and sometimes inconsistent individual access to internet, smartphones, cell phones, etc.

3. **Training.** *To the extent a self-management program uses equipment (testing supplies, needles, etc.), consumers should receive training on how to use that equipment. This means:*

- ☐ A description of what the equipment is used for;
- ☐ Training on equipment use; and
- ☐ Instructions for replacing equipment, repeating training, and getting help.

4. **Point of contact**. *To ensure continuous self-management, individuals must have a reliable point of contact within the health care system for follow up. This means:*
   - The individual should be provided with the name and contact information of their point of contact;
   - The (primary) point of contact should be one named person that is regularly available at established times;
   - During all off hours – even weekends, the individual should be diverted to another point of contact; and
   - All points of contacts should be trained in the self-management techniques and have real-time access to the EHR so they are prepared and able to answer questions.
5. **Choice and control.** *Consumers should always feel safe and empowered in self-management programs. This means:*
   - Individuals should always retain choice about whether they participate in programs, meaning an initial affirmative decision to participate (not an "opt-out" system) and the right to drop participation at any time;
   - Within the choice framework, information and incentives should be aligned with high-value care. However, incentives should never come in the form of penalties or punishments;
   - Individuals should have access to their EHRs and be encouraged to interact with those EHRs to support their own on-going care; and
   - EHR platforms used in self-management programs should be integrated with all relevant provider offices per consumer consent, but otherwise maintain high standards for confidentiality.
6. **Care coordination**. *Self-management activities should not be siloed from broader care coordination activities.*
   - Self-management should be a part of an individual's care plan that is regularly discussed with care teams; and
   - Clinical visits should draw out connections between overarching patient goals and the contribution of self-management activities.