

Exhibit 6.1: The Four Levels of Patient Activation

Level (% of General Population)			
1 (10%–15%)	2 (20%–25%)	3 (25%–30%)	4 (20%–25%)
<p>Predisposed to be passive</p> <p>Patients lack the confidence to play an active role in their health.</p> <p><i>“My doctor is in charge of my health.”</i></p>	<p>Building knowledge and confidence</p> <p>Patients have some knowledge but gaps remain. They can set simple goals.</p> <p><i>“I could be doing more.”</i></p>	<p>Taking action</p> <p>Patients have the key facts and are building skills. They are goal oriented.</p> <p><i>“I’m part of my primary care team.”</i></p>	<p>Maintaining behaviors, pushing further</p> <p>Patients have adopted new behaviors but may struggle in times of stress or change. Healthy lifestyle is a key focus.</p> <p><i>“I am my own advocate.”</i></p>

Source: Adapted from Greene et al. (2015).

Well-being is defined as having opportunity, being happy, and experiencing no stress. Patients with high well-being are more likely to engage in healthy behaviors, develop social connections, and build strong support systems.

Exhibit 6.2 describes the key elements of the SDOH.

Exhibit 6.2: Social Determinants of Health

Economic Stability	Environment	Education	Food	Community Social Context	Healthcare System
Employment	Housing	Literacy	Hunger	Social education	Health coverage
Income	Transportation	Language	Access to healthy options	Support systems	Provider availability
Debt	Safety	Childhood education		Community engagement	Provider language
Medical bills	Parks	Vocational training		Discrimination	Provider cultural competency
Support	Playgrounds	Higher education			Quality of care

Source: Data from Office of Disease Prevention and Health Promotion (2020).

The following community-assessment-gap solutions that address specific SDOH can be added to the list in the “Engagement and the Population Health Model section:

- Relaxed traffic
- Walkable neighborhoods
- Mixed-use land
- Bike shares
- Rail trails

When a whole community comes together to raise the health status of its members, the options are endless.

How do individual clinics integrate the SDOH in their practices? Here are a few examples:

- Creating a Spanish-language video describing the benefits of colon cancer screening in a clinic serving a large Hispanic population
- Using cartoons as a way to initiate difficult conversations with victims of sexual trauma
- Language interpretation services
- Clothing and food drives to support patients in poorer areas
- Purposefully siting clinics on a bus route
- Providing integrative medicine options, such as yoga and tai chi, in remote areas through the use of technology
- Free parking

Whole Health

In 1948, the World Health Organization (2020) defined *health* as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.” We have come full circle to appreciate that our patients are not simply a set of presenting symptoms to treat. They are unique individuals with unique stories.

To be effective healthcare partners, we need to know our patients’ stories. What matters most to them? What are their goals for their healthcare? What are their preferences in how they receive care? These are all important questions to consider as we nurture the human being—body, mind, and spirit—beneath the diagnosis and look at our systems through their eyes.

Organizations are becoming increasingly sophisticated in their approaches to patient and family engagement. The Veterans Health Administration

(VHA; Bokhour et al. 2020) has developed a Whole Health model designed to create a strong partnership between the patient and the primary care team. The VHA defines *Whole Health* as “Personalized, Proactive, Patient-driven care, an approach to healthcare that empowers and equips people to take charge of their health and well-being and live life to the fullest.” It takes us beyond the presenting symptoms to focus on the patient’s values, aspirations and goals for well-being. Getting to know the patient’s story, needs, and expectations of care is key.

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The primary care team’s conversation with the patient includes a discussion of what matters most in the patient’s life. Given these stated priorities, is the patient doing everything they can to achieve the goals? Together, the patient and the primary care team set goals and build the health plan to achieve those goals, identifying resources within the healthcare system and the community to support the plan. The use of appreciative inquiry to ask meaningful, open-ended questions helps the team understand the patient’s needs in order to meet their goals.

The patient also completes a Personal Health Inventory, which becomes part of the medical record. As the patient progresses through this tool, they rate how they feel about their physical and mental/emotional well-being as well as their day-to-day life.

Next the patient describes their purpose. What do you live for? What matters most to you? They rate themselves on various aspects of self-care: moving the body, nutrition, personal development, spirituality, recharging, professional care, and more. The answers help the patient and primary care team formulate their healthcare goals with regard to these aspects:

- Movement and physical activities
- Sleep and relaxation
- Learning, work, and community involvement
- Relationships
- Spirituality and resilience
- Physical environment
- Mindfulness
- Healthcare and prevention

This approach provides fully integrated care, focused on the whole person. Partnership and shared responsibility, together with access to supportive resources, are the critical success factors. No longer is it enough to focus on and treat only the patient’s complaints—indeed, that was never enough. We would wonder why

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patients weren't compliant with their treatment plan. Without engagement, without knowing the patient's story and expectations, treatment cannot succeed.

Mindfulness

Fully integrated care, focused on the whole person, moves our expectation as healthcare providers from "patient compliance" to patient engagement. The Whole Health approach promotes mindfulness of the primary care team and the patient to improve the experience.

Training and mindfulness tools are available to staff, particularly those in high-stress areas and during high-stress events such as the COVID-19 pandemic.

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The aim is to optimize staff health, well-being, and performance while empowering patients to be more active in their health. (And of course, there's an app for that! Via their mobile devices, patients and staff can have mindfulness at their fingertips to use any time they need a short break.)

The VHA is using this mindfulness approach for patients with chronic pain, mental health conditions, and chronic disease diagnoses, including complementary and integrative health therapies such as health coaching, acupuncture, pain management groups, dietitian appointments, and a peer-led course aimed at goal creation. Early results are displayed in exhibit 6.3.

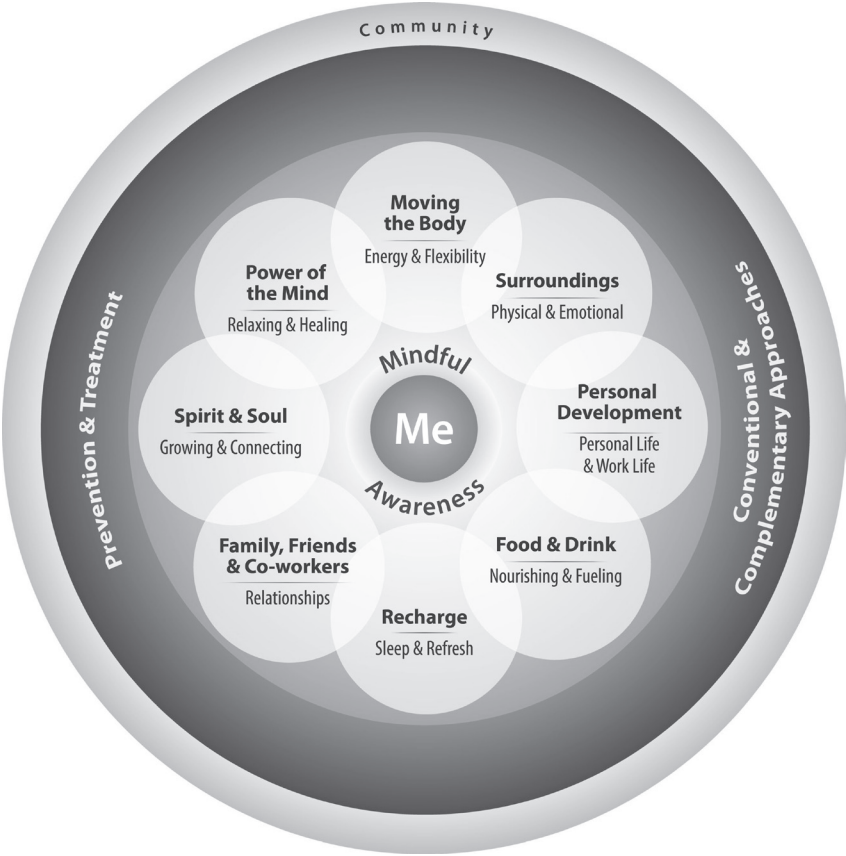
Patients and employees both appear to benefit from the implementation of a Whole Health approach to care; see exhibit 6.4.

Exhibit 6.3: Early Results of Efforts to Promote Veteran Mindfulness

- Greater improvements in the perceptions of the care received as being more person centered
- Greater improvements in engagement in healthcare and self-care
- Greater improvements in perceived stress, indicating improvement in overall well-being
- Reduction in opioid use
- Reduction in pharmacy costs

Source: Data from Bokhour et al. (2020).

Exhibit 6.4: Circle of Health: Me + Self-Care + Professional Care + Community



Source: Data from Bokhour et al. (2020).

CULTURAL COMPETENCE AND DIVERSITY

Do the composition of your staff and the nature of your care practices reflect those whom you serve? An analysis of your patient demographic will help identify the racial and ethnic cultures you need to consider when hiring staff and designing culturally competent services. The goal is to contribute to the elimination of racial and ethnic health disparities while improving health outcomes and quality of care.

What can you do to meet this goal? Here are a few approaches:

- Provide staff training on cultural competency and cross-cultural issues.

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- Include a diverse group of patients, reflecting your patient population, on your patient/family advisory council.
- Ensure, through the patient assessment and treatment processes, that patients' cultural, religious, or spiritual beliefs are accommodated.
- Mitigate language and communication barriers.

Understanding how diversity influences the patient's perception of their care and treatment will provide a better platform for the care process. Diversity goes beyond race to involve family, age, religion, nationality, gender, disability status, and socioeconomic backgrounds.

If we are not working together to provide culturally competent care, patients will be at higher risk of negative health consequences, poor-quality care, or dissatisfaction.

HEALTH LITERACY

Key to partnering with our patients is understanding and addressing health literacy. *Health literacy* is defined as reading, writing, listening, speaking, math skills, and conceptual knowledge. It's the capacity to process basic information to make

Half of all American adults have difficulty understanding and using healthcare information.

decisions. Low literacy may affect patients' ability to read and understand instructions on medicine bottles, health educational materials, and insurance forms, and their competence to make decisions and set their own goals.

Half of all American adults have difficulty understanding and using healthcare information (Office of Disease Prevention and Health Promotion 2020). I was surprised that this number was

so high. In the face of illness and stress, even excellent readers may struggle with health information. Let's review some tools and strategies to address health literacy:

- Universal precautions, in this context, means always offering assistance. For example, at check-in, the medical assistant would ask the patient if they need help in filling out the forms.
- Teach-back is giving information and asking the patient to repeat it back.
- Chunk and Check is providing information in digestible chunks and checking understanding as you go.
- Language interpreting and translation services.

The primary care team should identify the patient's oral and written communication needs, including the patient's preferred language for discussing healthcare.

We should always use simple, understandable language and visuals to promote understanding.

Patient Education

Let’s explore this topic further. Using the tools to address health literacy, every member of the patient-centered medical home team is part of the patient education process. Effective educators determine patients’ needs, treat patients as individuals and partners, and offer clear explanations, using the following steps:

- **Assess:** Define needs, concerns, and readiness.
- **Plan:** Set learning objectives and identify materials.
- **Implement:** Execute the plan.
- **Document:** Ensure effective communication with the rest of the team.

Creating bridges between patients’ needs and concerns through effective education can lead to realistic patient goals. Exhibit 6.5 illustrates this concept.

Don’t forget to include family members and caregivers in the education process. They can act as invaluable supports to the treatment plan and the patient’s goals.

Patient/Family Advisory Councils

Yet another approach to engaging our patients is the patient/family advisory council (PFAC), a formal group that meets regularly with leaders and staff to discuss and give input on policy and program decisions. This is a great way to get the voice of the customer on topics such as new construction, the Patient’s Handbook, food and parking—all usually areas of concern and complaints from our patients.

Exhibit 6.5: Example Bridges to Help Patients Set Goals

Patient Need	Patient Concern	Bridge
Healthy eating to manage cholesterol and diabetes	Not being able to eat favorite foods	Offer a nutrition consult and recipes for tasty meals.
Increasing movement through exercise	Thinking that all exercise hurts	Start slow with low-impact options.
Smoking cessation	It’s hard to quit	Offer classes and support groups.

Here is an outline of the scope of the PFAC:

- Serves as a communication channel and improves relationships among patients, families, and staff
- Provides a way for patients and families to assist in evaluating and providing input on the delivery of patient services
- Collaborates in partnership with staff, providers, and leadership in the planning and operation of programs to enhance care and services
- Provides a forum for staff to listen to their customers
- Establishes a link between the healthcare organization and the community

Fifteen to twenty members, with an executive as champion, and a patient as a co-leader, make for a manageable group. Typical members include the patient advocate, a nursing representative, and the chaplain. Department heads and front-line staff can be members or make presentations on an ad hoc basis.

How do you identify your patient members? Through complaint letters, surveys, the patient advocate, and other staff. They often know good candidates.

I have recently heard of an organization that had difficulty getting members to the table because of busy schedules and driving distances. So, they hold virtual meetings and it works well for them.

Taking it a step further, some of these patients can also act as “advisors,” conducting mystery shops, presenting at staff onboarding, serving on hospital committees, presenting their story at town hall meetings, and advocating for the organization in the community.

I know of an organization that invites a patient to address all new hires during onboarding. This patient shares his experiences at various healthcare facilities across the country: the good, the bad, and the ugly. He holds nothing back as he communicates his expectations for the staff.

Potential barriers to a successful PFAC include:

1. Leadership and culture that are top-down
2. Fear that patients’ and their families’ suggestions might be unreasonable
3. Concern about confidentiality
4. Lack of guidance and support

If these barriers are successfully mitigated through careful design and rollout, and respectful interactions, the PFAC presents a win-win for the patient and the healthcare organization. Patients and families gain a better understanding of the healthcare system, appreciate being listened to, understand how to become active participants in their care, and develop close relationships with other members on the council.

The PFAC provides a venue for receiving and responding to patient or family input, resulting in better-informed planning. It leads to increased understanding and partnerships among patients, families, and staff while transforming the culture toward patient-centered care.

See appendix H for a sample PFAC charter.

High Reliability Organization

We discussed the high-reliability organization framework for safety in chapter 4 as it related to staff engagement. What's in it for our patients? With zero preventable harm as the aim, systems and processes are designed, monitored, evaluated, and improved relentlessly to provide a safe environment for our patients.

We can include patients on process improvement teams and invite them to safety forums to share their stories. There is nothing like hearing directly from those who experience adverse events to get staff's attention. This direct conduit to the voice of the customer informs problem solving and solution creation.

In turn, our patients learn that we are committed to their safety and value their involvement in continuous process improvement. We take it to the next step by including a patient as a member on our quality council.

Full Disclosure

What happens when an adverse patient event occurs? How we handle these incidents can have a significant impact on the patient-provider-organization relationship. Transparency and inclusion are important. Informing the patient and the family about the incident, keeping them in the loop, and including them in the improvement process are key.

To inform patients and families of adverse events, acknowledge what happened, apologize, demonstrate empathy and concern, and improve processes to prevent further occurrences. Invite them to share their story at a town hall or safety forum. Openness sets the stage for reflection, learning, and continuous improvement.

Don't forget the staff during this time. They are often the second victims of an adverse event who need your support.

What are the ramifications of not being highly reliable?

- Increased costs of care and administration
- Increased external oversight
- Decreased reimbursement
- Decreased patient satisfaction
- Increased potential for healthcare-acquired conditions
- Time away from the core function

We must partner with patients' caregivers to create better health outcomes for our patients.

SUPPORTING THE CAREGIVER

Let's widen the circle of patient experience by extending the concepts of Whole Health to patients' family and friends, who are often their caregivers. By providing support and completing health-related tasks between clinic visits, these caregivers can have a great impact on the patient's health and

well-being. We must partner with them to create better health outcomes for our patients.

To begin with a look at the caregiver role, review this list of functions, which is comprehensive but not all-inclusive:

- Provide transportation to appointments
- Assist with patient goals
- Assist with activities of daily living
- Prepare meals and handle the shopping
- Remind patients to take medications
- Offer love and encouragement
- Act as advocate and liaison with the primary care team

This list indeed could go on. The point is that caregivers play a critical, irreplaceable role in the health of their loved ones.

So how do we take care of the caregivers? By connecting them to some of the same wellness activities that we provide to our patients. Caregivers do a superb job of taking care of others, often at the expense of their own well-being. Through self-care, caregivers can restore their energy, gather strength, and get a short respite from their responsibilities.

Many healthcare organizations have recognized the need to provide this support and have acted on it by creating resources to enhance caregiver well-being. The team social worker is often the go-to person for these supports. Exhibit 6.6 lists and describes approaches and tools for caregiver support.

Share these self-care tips with your patients' caregivers. Your staff can benefit from them as well.

- **Physical:** Take some time out of your day today to soak in a candlelit tub, get a haircut or massage, take a quiet walk, or relax with a cup of tea. Renew your body with some kindness and care and see how it changes your day.
- **Mental:** Wake up your mind by taking a risk, learning a new word, writing a poem, playing a memory game, or reading.

Exhibit 6.6: Approaches and Tools for Caregiver Support

Resource	Description
Self-care courses	Topics include “Taking Care of Yourself,” “Managing Stress,” “Utilizing Technology,” “Problem Solving,” and “Effective Communication”
Caregiver support line	Available to address immediate needs and provider education
Journaling	Daily self-care reflections as a means of connecting with one’s well-being
Support groups and networks	Provide discussion platforms and the chance to share the lived experience while connecting with others who provide care to loved ones
Respite programs	Temporary relief to a primary caregiver from the continuous support and care of a family member
Peer mentoring	Provides guidance to caregivers through sharing experiences and skill building with other caregivers
Mental health counseling	Professional support for the caregiver
Wellness activities	Yoga, mindfulness, and breathing exercises
Self-care techniques	See “Self-Care Tips for Caregivers,” this chapter

Source: Data from Bokhour et al. (2020).

- **Emotional:** Notice and name feelings; identify your unmet needs.
- **Behavioral:** Start a new, small habit or let go of an old one.
- **Social:** Reach out, write a letter, call a friend. Connection has the power to heal.
- **Nature:** Awaken the senses through bird watching, stargazing, or walking in the woods.
- **Visualization:** Listen to recordings to help visualize calm scenes and settings. Try guided-imagery exercises to help you relax.

Breathing exercises, healthy eating, physical exercise, and adequate sleep round out the list.

VOLUNTEERS

Let’s not forget another important part of the care team: our volunteers. A valuable resource, volunteers support patients, families, and staff in the primary care setting. Careful screening, orientation, ongoing evaluation, and matching interests

to opportunities ensure a good fit for both the organization and the volunteer. Volunteer duties include the following:

- Escorting patients
- Ensuring adequate supplies of wheelchairs at the clinic entrance as well as refreshments and reading materials in the waiting room
- Administrative tasks
- Providing and gathering information
- Participating in a pet therapy program (see chapter 7)
- Emotional support; just being there to listen

We need to be purposeful about nurturing and providing support and recognition to this group of dedicated caregivers.

IMPROVING PATIENT ACCESS

Patient feedback indicates that, in addition to caring relationships with the primary care team, patients value timely access to all aspects of their care.

Enhancing Access to Care

Enhanced access allows patients and families more flexibility to attend appointments. Same-day appointments, expanded hours (including evenings and weekends), 24-hour coverage, and telehealth are becoming commonplace in the primary care space. Acting as the hub of the patient's healthcare experience, the primary care provider facilitates access to acute care, oral health services, urgent and emergent care, preventive services, rehabilitative equipment, substance abuse treatment, eye care and behavioral health needs. Coordination of these transitions ensures the continuity of care.

Enhancing Access to Information

Critical to engaging our patients is ensuring that they have access to the information that they need to be an active partner in their healthcare. Here's what doesn't work: filing a request with the medical records department, paying a fee, waiting days or even weeks to have your request filled. Then you may receive a CD that you can't access or you are forced to review your record with the clerk looking over your shoulder.

Now let's talk about what does work. Enter the open notes movement, initiated by Thomas Delbanco, MD, in 2010. This experiment provided secure portals for patients to read their medical records and enter notes of their own.

Patients became better educated about and more engaged in their care, and even identified errors. Their family members and caregivers also became more engaged (Delbanco 2016).

Although open notes aren't for everyone, two out of three patients liked reading their physician's notes. They felt that they could better remember instructions they were given during their office visit or at discharge. They had quicker access to their test results and appreciated the opportunity to help improve the accuracy of the record. A year after initiating the practice, not one physician stopped sharing notes. Full transparency promotes better provider–patient partnership.

The Role of Technology

In chapters 2 and 3 we discussed the use of telehealth and telemedicine to provide patients remote access to services. These strategies are becoming more commonplace as the COVID-19 pandemic catalyzes change. Our patients are acclimating to these tools and, indeed, have come to expect them in the primary care space.

Many healthcare organizations leveraged apps and social media during the pandemic to remain connected to patients, who then became aware of such resources for mental and physical health. The VHA (Bokhour et al. 2020) disseminated 16,000 laptops and more than 7,500 phones to veterans in rural areas as a means of continuing healthcare, especially mental health services. Similarly, when community clinics and practices were forced to shut their doors to routine care at the onset of the pandemic, telehealth became the means for providers and patients to stay connected. As COVID-19 surged, so did the number of telehealth visits. The result: Telehealth is here to stay.

The challenge lies in nurturing the patient–provider relationship via this platform to ensure that the patient feels cared for and heard. Patients report that their providers are more focused on them as clinicians leverage their communication skills to overcome the loss of subtle body language cues. The unexpected benefit to providers of seeing inside patients' homes gives them insight into living conditions and helps them offer in-home supports.

Exhibit 6.7 displays an array of telehealth services.

Taking full advantage of these technology-based solutions can increase patient engagement and partnership while meeting the needs of older, sicker, and poorer populations. Addressing their needs with telehealth is the core of a successful population health strategy.

As we design these services, we need to include the patient and their family members so we can understand the impact and the challenges inherent in new technology. This would be a good topic for your PFAC: How do technology-driven services affect the consumer experience?

Exhibit 6.7: Telehealth Services

- Remote monitoring of vital signs
 - Remote provider–patient consultations
 - Access to specialty services: dermatology, cardiology, behavioral health
 - Retinal exams
 - Yoga and tai chi classes
 - Life coaching
 - Social work support
 - Nutrition class
 - Disease-specific educational services
 - Access to patient records for test results, scheduling appointments, and communicating with the primary care team
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Secure patient portals provide access to test results, medication refills, appointments, education, and communication with the primary care team. Additionally, the VHA (Bokhour et al. 2020) has created “Annie,” a text-messaging service that promotes self-care for patients and caregivers. Annie texts stress-management tips to caregivers three times per week. Messages may be educational or motivational, or may describe a stress-management activity.

ANOTHER PATIENT ENGAGEMENT STORY

Let me finish this chapter with another story—Mrs. Rooney’s story.

Mrs. Rooney is 62 years old, has heart failure and diabetes, and recently moved to a new town to be near her daughter. She calls a local doctor’s office to make an appointment. The scheduler reminds her to bring in all of her medicines and supplements.

When she arrives for her first visit, she finds parking easily and notices that there are plenty of accessible spaces in the lot. She enters the building through an automatic door and sees wheelchairs placed nearby for those who need them. There is a pleasing mural on the wall just inside the entranceway.

As she enters the waiting room, she observes natural light and wall hangings with relaxing images. Current magazines and up-to-date educational materials are available as well as coffee and tea. Comfortable chairs are placed in conversational arrangements.

At the first visit, the receptionist asks whether she would like help in filling out forms. Mrs. Rooney notes that the forms are simple and understandable and is able to proceed without help.

Next a medical assistant reviews all of the medicines Mrs. Rooney brought and enters relevant information into an electronic health record. Then the doctor reviews with Mrs. Rooney the medical history form she has completed and asks her what she understands about her conditions. After discussing her current symptoms, the doctor explains the treatment options, and together they create a care plan. The doctor asks Mrs. Rooney to explain in her own words how she will take her medicines and the complications she might anticipate. The doctor clarifies any confusion and then asks her again to share her understanding.

When the doctor leaves, a nurse enters the room, asks Mrs. Rooney about any remaining questions, and reviews with her a one-page handout on key points about medicines and the treatment plan.

The nurse or another health educator then gives Mrs. Rooney a copy of her medicine schedule to keep on her refrigerator and guides her through an easy-to-use personal health record. This includes her health information in plain language and simple interactive tutorials. The nurse also refers Mrs. Rooney to a diabetes education program.

Before Mrs. Rooney leaves, a scheduling assistant makes an appointment for her to return in three months. The following week, a member of the patient support team calls Mrs. Rooney to confirm the referral and appointment, to ensure that she is taking her medicines properly, and to verify that she was able to use her personal health record.

Between visits Mrs. Rooney takes her medicines regularly, undertakes the personal health record's interactive learning activities related to nutrition and physical activity, and participates in a diabetes peer support group offered by her neighborhood YWCA. When Mrs. Rooney returns for her annual wellness visit, she is confident in her ability to manage her conditions and ready to engage further with providers to improve her health.

This simple story encompasses the key components of patient engagement, summarized in the following Key Points. It also touches on the healing environment, the subject of chapter 7.

KEY POINTS

- Population health management is a key patient engagement strategy.
- SDOH can be used to identify nonmedical gaps in community services that impact health and well-being.
- Treat the whole person: mind, body, and spirit.
- Meet patients where they are through health literacy techniques.
- Understanding how diversity influences the patient's perception of their care and treatment will provide a better platform for the care process.

- Include patients in advisory councils, process improvement teams, and safety forums.
- Patients with chronic pain, mental health conditions, and chronic disease can benefit from a Whole Health approach.
- We must partner with family and friends who act as caregivers to create better health for our patients.
- Critical to engaging our patients is ensuring that they have access to the information that they need to be active partners in their healthcare.
- Use technology to open up avenues of engagement.

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