

ENGAGING DISADVANTAGED OLDER PEOPLE
IN THEIR HEALTH AND HEALTH CARE:

STRATEGIES TO ENGAGE OLDER PATIENTS
IN THEIR HEALTH THROUGH THE
PATIENT-CENTERED PRIMARY CARE MEDICAL HOME

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SUMMARY

The willingness and capacity of older people to assume new responsibilities for their health and health care must grow if they are to fully benefit from recent scientific and technical advances in health and medical care. The increasing fragmentation, conflicting priorities and complexity of health care in the U.S. today demand that older people perform a challenging set of actions if they are to avoid needless suffering and successfully manage the growing burden of chronic disease.

The Center for the Advancement of Health envisions a nation in which older people — alone or with support from a caregiver — actively engage in their health and health care. Realizing this vision will require creating the conditions for older people to be informed, active participants in managing their health and health care. Older people who become "engaged" in their health and health care are those who become more:

- Active in preserving their own functioning.
- Informed patients and consumers of health services.
- Active advocates for effective health care.

The result will be improvements in the health and quality of life of older Americans. Achieving such major changes require the development and implementation of an integrated set of strategies. The mobilization to reach these goals must focus on at-risk and disadvantaged populations that bear a disproportionate burden of ill health.

One strategy with the potential to have a national impact on older people's abilities to engage in their health and health care is to weave the engagement of older people — and the very specific behavioral components that it constitutes — into the reform of primary care.

In an effort to respond to the crisis in primary care in the U.S., there is considerable interest in the patient-centered medical home as a vehicle to achieving patient-centered primary care, moderating care costs, and improving outcomes through improved coordination and comprehensive care for complex conditions.

This initiative proposes to capitalize on the relationships of the nation's leading advocate for patient-centered care, the John D. Stoeckle Center for Primary Care Innovation, located at Massachusetts General Hospital, in this reform effort. The Stoeckle Center is a member of the advisory and governing bodies working for this change. In addition, the Center participates in the "Ambulatory Practice of the Future" program at the Mass General, which provides a laboratory in which to test new approaches.

The Stoeckle Center proposes to inject a concern for patient engagement into its work with various coalitions and groups as they plan for the patient-centered medical home, using the Engagement Framework as its guide.

In addition, the Center would take on the following:

1. Development of a shared patient / care team compact that would clarify mutual expectations, role and responsibilities.
2. Expansion of the pre-visit packet with focus on medication reconciliation in order to create routine and easy communication between doctors and patient about current medication use. This project would add to an existing initiative to help patients prepare for a primary care visit.
3. Packaging and dissemination of recommendations about how to build and support patient and family partnerships as part of primary care.

The Engagement Challenge for Older People

Conventional wisdom within the health industry (which is not yet shared by the general public) is that cost reductions and improvements in quality of care will occur when patients behave more responsibly by practicing health promotion; getting screened properly at the right time; choosing the right doctors, hospital and treatments; and managing their chronic conditions effectively.

And so getting good care and making good use of health information increasingly requires that individuals take effective action. Thus, the stakes of not participating in their health and health care increase: there is greater potential for patient and provider error and poor adherence to treatment, both of which lead to poorer health outcomes. The inefficient use of health care resources is costly to individuals, clinicians, health plans and payers. People who are educated and wealthy are more likely to be able to assume this new role as an active participant in health and health care and thus benefit more from the knowledge, technology and skills available. The converse is also likely that those who do not participate — for whatever reason — will benefit less.

But many older people are not taking on their new role and the attendant responsibilities active participation in their health and health care — and they probably will not do so long as long as they are unaware of what they are expected to do in order to stay well and actively manage their health care when they are ill.

In a recent series of interviews, the Center for the Advancement of Health (the Center) found that most older people are surprised, not only that they need to learn about the emerging details of a new diagnosis, but also by the tasks they and their families were expected to take on in order to get good care. Many older people didn't realize that they were expected to find and evaluate the qualifications of specialists to give them second opinions. Others were shocked when they realized that their own doctor might not have the expertise to treat their condition.

Some were taken aback by the need to maintain their own medical record as a back-up to ensure that information was not lost among doctors and hospitals. And others believed — until proven wrong — that there was no need to ask questions because the doctor would tell them everything they needed to know.¹

Whatever the level of discourse, health care now uses the language of "personal responsibility" and the notion of individuals as "consumers" as shorthand to describe people who exert "choice" and who are "empowered," "activated" patients.

Unfortunately, even older people who have had a lot of experience with illness and who know what it means to negotiate the health system as a patient these days often lack a basic understanding about what must be done to get the best possible care.

¹ Gruman, J. (2007). *AfterShock: What to do when the doctor gives you — or someone you love — a devastating diagnosis*. New York: Walker Publishing Company, Inc.

Doctors, labs and hospitals have clear expectations about what patients must do. Some expectations (such as refraining from smoking, getting regular exercise and losing excess weight) are so obvious that many health professionals do not mention them. Sometimes expectations have changed, but older people have not received any news about the change (such as always check about making sure a specialist takes your insurance and Medicare). Finally, some expectations develop as a result of communication gaps among doctors and hospitals (such as obtaining test results and sending them to all relevant physicians).

These expectations present a challenge to well-educated, sophisticated, wealthy older people. But they are particularly daunting to those who lack the wherewithal — the knowledge, the skills, the resources, the confidence or the access — to effectively take on this new, unfamiliar role.

In the belief that older people's engagement in health and health care is necessary to achieve acceptable outcomes and containing costs, CMS and Medicare Advantage Plans have developed and tested interventions to help beneficiaries adopt healthier behaviors (by providing smoking cessation assistance), obtain clinical preventive services, (by covering vaccines and cancer detection tests) take care of their diseases at home (by producing materials and Websites and supporting demonstration projects to support chronic disease self-management) and implement community-based support programs to help Medicare beneficiaries sign up for their benefits (State Health Insurance Assistance Program — SHIPS).

But the belief that *all* older people will be equally able to be good consumers — to seek information, make good choices and then act wisely on those choices in their daily lives for good health care is one that will further magnify existing disparities in health outcomes.²

Known difficulties about involving older people in their own health care include;

- That discarding their traditional passive role and becoming an active participant in their care is a difficult transition for most older people.
- That many older people prefer to be informed by their physician about their illness and to have him or her in charge of the major decisions about their treatments and care.
- That even if given sufficient information, many older people are not confident that they can make the right decisions for themselves about their health and health care.

² R Thomson, M Murtagh and F-M Khaw. Tensions in public health policy: patient engagement, evidence-based public health and health inequalities *Qual. Saf. Health Care* 2005;14;398-400.

- That information on the Internet, the go-to health information source for patients, will be difficult for older people to access and use to be able to effectively participate in their own care because as a group, they tend to have less experience with computers.
- That most older people are not comfortable asking questions when they are confused about their disease and its treatment and finding a new a doctor when they are treated poorly.
- That many older people do not have access to a caregiver who is willing and able to take an active role to help them overcome these difficulties.

The behavioral and social science research literature that documents these flaws is substantial.³ Thus, efforts to ensure that all older people — and particularly those who lack skills and resources, are frail or who are ill — are able to engage positively in their health and health care will not succeed as long as their difficulties in effectively participating are not addressed.

Only by identifying the full range of behaviors that are expected of older adults in order to get decent care, understanding the barriers and facilitators that influence whether people perform them, and then strategically delivering effective targeted communication, support and guidance will *all* older people be able to fully benefit from the health care available to them.

The Engagement Framework

What are the behaviors that the health system expects all people who are seeking care to perform? The Center compiled the Engagement Framework of behaviors that constitute "positive participation" in health and health care (see Appendix A). This list comes from the Center's review of the scientific literature, consultation with experts and extensive interviews with a large sample of individuals.

But there has thus far been scant recognition of the magnitude and scope of the change in attitude and behavior that is expected of older people to respond to health care as it is delivered today.

In order for older people to become positive participants in their health and health care, they — and their caregivers — need to know what these expectations are and be willing and able to act on them. If they are unwilling or unable to perform these behaviors, they will need to find support — information, resources, guidance and services — that will enable them to get help doing so.

³ <http://www.pickereurope.org/Filestore/Downloads/QEI-Review-intro.pdf>

The Role of Primary Care in Supporting the Engagement of Older People in Their Health Care

Efforts to improve the patient's experience of care and patient engagement come at a time when primary care is beleaguered by misaligned incentives that promote specialty care and huge morale issues that contribute to the low numbers of healthcare professionals choosing primary care as a profession. Despite the evidence from cross-national comparisons illustrating that nations with a greater orientation to primary care are more likely to experience better health outcomes and lower health care expenditures, there is no national plan to emphasize primary care. In response to this situation, there is much interest in the patient-centered medical home as a vehicle to achieving patient-centered primary care, lowering health care costs, and improving outcomes through improved coordination and comprehensive care for complex patients. These outcomes will result from building and maintaining long-term relationships between provider and patient with the aim of better communication, care coordination and support for people to manage their illnesses and maintain their health.

Because older people are likely to have more than two chronic conditions and tend to be the most complex patients, this development is highly relevant to their abilities to take an active role with regard to their care. However, little is known about patient-centered care primary care practices and the factors associated with high performance for older people generally and disadvantaged older people specifically.

As groups like the Centers for Medicare and Medicaid Services, professional societies, major employers, and commercial insurers prepare to launch medical home demonstrations, more information and practical guidance is needed about the factors that constitute patient-centered primary care, as well as effective models to engage older patients and their caregivers in maintaining and improving the health of the older person.⁴ Over the past two decades, various conceptual frameworks have been developed for describing patient- and family-centered care,⁵ but these frameworks have seldom been translated into specific patient-centered quality improvement models relevant to older people, curricula, educational programs, or resources to help build these competencies into practices across the country.

The Patient Centered Medical Home (PCMH) is an approach to providing comprehensive primary care. The PCMH is a health care setting that facilitates partnerships between individual patients and their personal physicians, and when appropriate, the patient's family.

⁴ Davies E, Cleary D. Hearing the patient's voice? Factors affecting the use of patient survey data in quality improvement. *Quality and Safety in Health Care* 2005; 14: 428-432.

⁵ Conway J, Johnson B, Edgman-Levitan S, Schlucter J, Ford D, Sodomka P, Simmons L. Partnering with Patients and Families to Design a Patient- and Family-Centered Health Care System: A Roadmap for the Future. A Work in Progress. Submitted for publication.

Principles of the Patient-Centered Medical Home

The American Academy of Pediatrics (AAP), American Association of Family Physicians (AAFP), American College of Physicians (ACP), Society of General Internal Medicine (SGIM), and American Osteopathic Association (AOA), representing approximately 333,000 physicians, have developed the following joint principles and terms to describe the characteristics of the PCMH.⁶

- *Personal physician* — each patient has an ongoing relationship with a personal physician trained to provide first contact, continuous, and comprehensive care.
- *Physician-directed medical practice* — the personal physician leads a team of individuals at the practice level who collectively take responsibility for the ongoing care of patients.
- *Whole-person orientation* — the personal physician is responsible for providing for all the patient's health care needs or taking responsibility for appropriately arranging care with other qualified professionals. This includes care for all stages of life: acute care, chronic care, preventive services, and end-of-life care.
- *Care is coordinated and/or integrated* across all elements of the complex health care system (e.g., subspecialty care, hospitals, home health agencies, nursing homes) and the patient's community (e.g., family, public and private community-based services). Care is facilitated by registries, information technology, health information exchange and other means to assure that patients get the indicated care when and where they need and want it, in a culturally and linguistically appropriate manner.
- *Quality and safety* are hallmarks of the medical home:
 - Practices advocate for their patients to support the attainment of optimal, outcomes that are defined by a care planning process driven by a compassionate, robust partnership between physicians, patients, and patients' families.
 - Evidence-based medicine and clinical decision-support tools guide decision making
 - Physicians in the practice accept accountability for continuous quality improvement through voluntary engagement in performance measurement and improvement.
 - Patients actively participate in decision-making, and feedback is sought to ensure patients' expectations are being met.
 - Information technology is utilized to support optimal patient care, performance measurement, patient education, and enhanced communication
- *Enhanced access* to care is available through systems such as open scheduling, expanded hours, and other new options for communication between patients, their personal physician, and practice staff.

⁶ "Joint Principles of a Patient-Centered Medical Home Released by Organizations Representing More Than 300,000 Physicians: Principles Call for Changes at the Physician Practice Level to Improve Outcomes." March 5, 2007. Accessed January 8, 2007. Available at <http://www.acponline.org/college/pressroom/pcmh.htm>

- *Payment* appropriately recognizes the added value provided to patients who have a patient-centered medical home. The payment structure should be based on the following framework:
 1. It should reflect the value of physician and non-physician staff patient-centered care management work that falls outside of the face-to-face visit.
 2. It should pay for services associated with coordination of care both within a given practice and between consultants, ancillary providers, and community resources.
 3. It should support adoption and use of health information technology for quality improvement;
 4. It should support provision of enhanced communication access such as secure e-mail and telephone consultation;
 5. It should recognize the value of physician work associated with remote monitoring of clinical data using technology.
 6. It should allow for separate fee-for-service payments for face-to-face visits. (Payments for care management services that fall outside of the face-to-face visit, as described above, should not result in a reduction in the payments for face-to-face visits).
 7. It should recognize case mix differences in the patient population being treated within the practice.
 8. It should allow physicians to share in savings from reduced hospitalizations associated with physician-guided care management in the office setting.
 9. It should allow for additional payments for achieving measurable and continuous quality improvements.

The Opportunity to Influence National Initiatives

Because of the crisis in primary care, several national efforts are underway to reshape primary care in the US — both its delivery and the profession as a whole. The mission of The Stoeckle Center for Primary Care Innovation, based at the Massachusetts General Hospital (The Mass General), is to: 1) redesign and revitalize primary care in order to effectively meet the needs of patients and their families, doctors, and other professionals who deliver primary care; 2) provide an extraordinary experience of care for patients and their families; and 3) create an exciting and fulfilling professional life for current and future generations of primary care practitioners. We are working with health care systems across the country and are deeply involved with all of the initiatives described below to create new models of primary care.

Several national initiatives are underway to demonstrate the effectiveness of the patient-centered medical home and to implement new models of primary care that incorporate its principles; however, these principles are not easy to put into practice, especially in existing practices that have to transform themselves into this new practice model while delivering care. Some of the larger initiatives include:

- *The Patient-Centered Primary Care Collaborative*: a coalition of major employers, consumer groups, and organizations representing primary care physicians and other stakeholders who have joined to advance the patient-centered medical home. (www.pcpcc.net)
- *TransforMED*: a demonstration project led by the American Academy of Family Physicians (AAFP), which is focused on practice redesign. TransforMED is studying and implementing transformed models of high-performance practices that meet the principles of a medical home. (www.transformed.com)
- *The Trust for Healthcare Excellence*: a non-profit initiative to promote the collective efforts and conditions necessary for health and healthcare excellence through a strong primary care system. (www.trustforhealth.org)

Patient Engagement

Despite strong interest in these new models of primary care, few people have integrated effective and practical methods of patient engagement into these patient-centered medical home practices. As practices go through this transformation, they are particularly interested in tested models of care that allow them to maintain the trust of their patients and clinicians. There is growing evidence that the engaged patient takes a more active role in self-management of chronic illness.^{7, 8} Practical patient engagement strategies are especially critical for older patients who have complex medical problems that require ongoing coordination of care and a deep understanding of how to navigate our complex healthcare system— this is the most important population to engage in their own care and to equip with the tools needed to manage their ongoing health problems. This is also a critical time to design and implement patient engagement strategies because of the demographics of the U.S. population and the enormous demand for chronic disease management and self-management approaches in a growing elderly population.

Models to improve patient engagement within the context of the patient-centered medical home are particularly timely. Since the patient-centered medical home is designed to create a system oriented to finding ways to support patients in improving their health, clinicians should be uniquely receptive to patient engagement initiatives. Payers, employers, consumers, and physicians agree that the patient-centered medical home must reward value, and compensation should be linked to outcomes. For this reason, creating systems to support patients in using health care effectively should contribute substantially to the success of the system.

Compensation under the patient-centered medical home model will pay for enhanced access and communication, improved coordination of care, rewards for higher value, expanded administrative and quality innovations, and promotion of active patient and

⁷ Hibbard JH, Mahoney EH, Stock R, and Tusler M. Do increases in patient activation result in improved self-management behaviors? *Health Services Research*. 2007; 42: 1443-63.

⁸ Hibbard JH and Tusler M. Assessing activation stage and employing a "next steps" approach to supporting patient self-management. *J Ambulatory Care Management*. 2007; 30: 2-8.

family involvement. The patient-centered medical home model will also engage patients and their families in positive ongoing relationships with their physicians. An aim of the patient-centered medical home is to improve the quality of care delivered and help control the unsustainable rising costs of healthcare for both individuals and plan-sponsors.

As these models become more widespread, the patient-centered strategies must be an intrinsic part of the design so that they can be effectively evaluated in the national demonstration programs and can become part of the core cultures of these practice models. To quote Dr. Terry McGeeney, CEO of AAFP's TransforMED initiative: "We have also learned that implementing new processes and making changes in order to check off components of the model as having been completed — *without a plan to put the patient at the center* — does not create a medical home."

The Approach: Working Toward a Patient-Centered Medical Home That Supports the Active Participation of Older Patients

In order for the patient-centered medical home to actively engage patients, four major features need to be present:

- Effective patient-clinician/care team communication
- Support of patients to find and use medical information and self-management tools
- "Personalized" health care and treatment that is customized to the ability of the patient for engagement in care
- Positive feedback for participatory behaviors.

Effective patient-clinician/care team communication is the cornerstone on which the patient-centered medical home must rest. Providers must be knowledgeable in behavior modification, motivational interviewing, and assessment of patients' understanding of their medical issues. Furthermore, patients must be encouraged to participate in improving communication through visit preparation and involvement in decision making with their clinician/care team. Patients and the clinical care team must develop better methods and tools to allow everyone involved in the care to communicate clearly about their roles and their comfort with different levels of patient engagement.

Providing support and guidance to patients in their use of medical information and self-management tools is a key aspect to patient engagement. Helping disadvantaged older people who may not be Web-savvy or health literate to access information allows improved self-management and more efficient use of medical services. This information not only includes traditional patient education material, but also patient access to medical record information, and if desired, decision support tools and peer communities.

"Personalized" care allows patients to develop trust in their patient-centered medical home. Patients are more likely to be engaged when they perceive the system as "user-friendly" to their own needs. Methods to identify patient preferences for communication and involvement in health decisions, their preferred learning style, and their health care goals are all necessary. In addition, infrastructure that supports patient feedback to

providers, such as patient-family advisory councils, should be actively supported in the patient-centered medical home.

In order for any behavior to be continued, *positive feedback* must occur to reinforce the behavior. In the patient-centered medical home, patient engagement should lead to improved access to providers (mostly through non-visit-based interactions) and improved experiences of care with the medical system. Health outcomes, such as lower blood pressure and better glucose control, are not easily appreciated by patients. Therefore, feedback on these measures may need to emphasize other incentives, such as reduced fees, health promotion classes, and an emphasis on helping patients achieve their personal goals related to quality of life.

What would an initiative to achieve this look like?

The John D. Stoeckle Center for Primary Care Innovation at The Mass General has developed a number of innovative practices to help clinicians provide patient-centered care that also will help achieve the principles of the patient-centered medical home. All of these initiatives can be shared with other organizations and have been designed to be exported from The Mass General across the U.S. as part of our mission.

We propose to make a clear case for the need for clinicians who treat disadvantaged older people to make use of the programs that have already been tested and propose an outreach and education effort to disseminate them. And we propose to develop new programs tailored to the needs of older disadvantaged patients and their caregivers that can be tested in patient-centered medical home demonstration projects.

Existing Programs and Strategies

➤ *Shared decision making prescriptions*

Shared decision making focuses on utilizing patient preferences and values to inform a medically complex decision. This process can be time-consuming and confusing for providers. We have incorporated an "electronic prescription" into our medical record that allows providers to quickly incorporate shared decision making into a visit. A library of shared decision making videos, provided by the Foundation for Informed Medical Decision Making (www.fimdm.org), is stored at our hospital's patient education center. During a visit, a provider is given reminders on the problem list (through video icons) as well as links to the entire menu of shared decision making videos. With one click, the provider can print a description of the video and automatically request a copy be mailed to the patient's home. An electronic note documenting the prescription is recorded. To date, we have distributed over 1,350 videos in our practices. We have 150 clinicians participating in ordering videos and have surveyed patients and providers about its value which is quite high from both perspectives.

➤ *Pre-visit preparation*

We have also piloted the use of pre-visit packages to inform patients about annual preventive health visits. Using a computer algorithm based on the scheduling system, patients who appeared to be due for the preventive measures at age 50 were mailed

packets. These packets were piloted tested with feedback from patients, and then automatically included in reminder mailings for the appointments. In addition, a pre-visit form was included that prompted patients to identify health concerns in advance, reconcile medication lists, and update preventive health records. This form was successfully used in several practices, and is now being modified for use in all of our primary care practices.

➤ *Ambulatory Practice of the Future*

The Stoeckle Center for Primary Care Innovation has been actively involved in the creation of an "Ambulatory Practice of the Future" at The Mass General, a primary care practice for hospital employees and their families. This multi-disciplinary effort is focused on the creation of the patient-centered medical home as well as a laboratory for continuous innovation and quality improvement efforts. Planned innovations for the practice include utilization of a "Health and Life Balance" coach, remote physiologic monitoring, virtual visits, and shared health plans. In addition, use of group visits, a web-based patient portal, and same-day scheduling will all be incorporated. The practice is expected to open in 2009.

In all of these projects, The Stoeckle Center has successfully engaged physicians, nurses, administrative staff, patients and families in the design and implementation process. Our underlying principle has always involved "making the right decision easier," and eliciting feedback from the front lines to improve the project. The concept of increasing patient engagement in the patient-centered medical home is synergistic with the above projects as well as our future efforts.

PROGRAMS AND STRATEGIES TO BE DEVELOPED

➤ *Development of a Shared Patient/Care Team Compact*

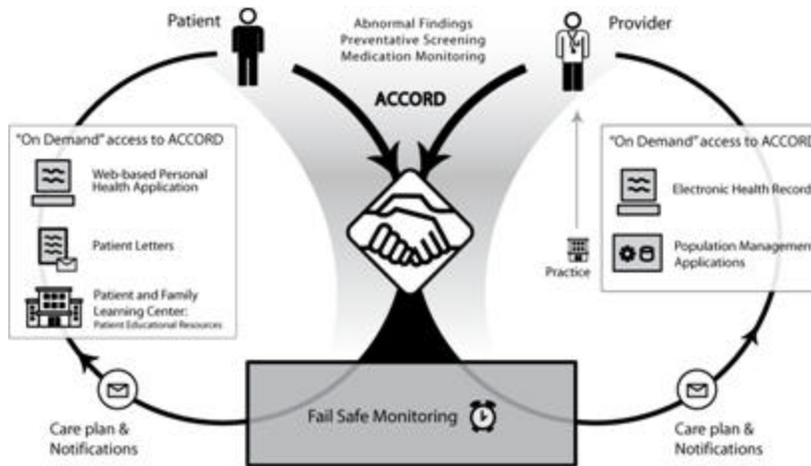
Although shared care plans have been successfully implemented in some settings, little is known about how older individuals respond to this concept or about the effectiveness of these plans. There is evidence that some patients prefer a less active role in their care,⁹ and a truly patient-centered medical home would allow this option

Currently, The Stoeckle Center is working with the Lab of Computer Science at The Mass General to develop a written and computerized patient record tool called the Ambulatory Care Compact to Organize Risk and Decision-making (ACCORD). This ACCORD will support shared decision making and creates a formal "compact" between patients and their care team. This is an innovative model of care delivery that enables patients and primary care providers (PCPs) to agree upon shared care plans that incorporate patient and provider preferences. This "compact" between a patient and his or her own PCP will be supported by an information architecture and software designed to facilitate the creation, initiation, and longitudinal tracking of these preferred care plans. This compact also allows for inclusion of a patient proxy so it is

⁹ Levinson W, Kao A, Kuby A, Thisted RA. Not all patients want to participate in decision making: A national study of public preferences. *J General Internal Medicine* 2005; 20: 531-5.

feasible that the information contained in the compact could also be shared with adult children of older patients or other caregivers. We propose to pilot test versions of this compact with patients over the age of 65. We will obtain qualitative feedback about the format, and then pilot a revised format in one of our practices.

Ambulatory Care Compact to Organize Risk and Decision-Making: The ACCORD Model



- *Expansion of the pre-visit packet with focus on medication reconciliation*
Currently, there is great effort to develop better methods to accurately identify the medications older individuals are taking. Methods such as the often-recommended "brown bag" visit are not practical for busy clinicians. By combining our pre-visit project with our electronic medication records, we propose developing a system to engage patients in medication reconciliation, and improve their knowledge of medications. Our proposal would aim to develop the tool and to examine its use in a primary care clinic. Patient satisfaction and acceptance would be measured as well.
- *Patient and Family Partnerships*
As health care organizations strive to improve the quality and safety of care, many are welcoming patients and families as partners in these efforts. These partnerships encompass not only the delivery of care but also program planning, quality improvement, patient safety, education, facility design, and evaluation. The partnerships are grounded in the principles of patient- and family-centered care, which acknowledge that families are essential to patients' well-being and are allies for health care quality and safety. Improving the safety and quality of health care is a goal so challenging that it cannot afford to ignore a key source of expertise — the wisdom and experience of patients and families themselves.

Involving patients and families in the design of effective and practical patient engagement strategies for primary care practices will be essential for the success of

these efforts. Patients and families can play an invaluable role in helping practices design and implement these strategies. There are several roles they can play:

- Reviewing educational materials to ensure that they are understandable and cover relevant topics
- Identifying knowledge gaps in areas that may fall outside of the care team's expertise but that are critical to patient engagement, such as care coordination, arranging and managing home health services, managing prescription drug benefits
- Recommending marketing strategies that promote patient engagement tools and techniques
- Keeping clinicians and administrators sensitive to the day to day needs of their patients.

Implementing patient and family advisory councils and faculty programs is becoming more common in hospitals but strategies to enable busy and resource-strapped primary care practices to partner effectively with patients and their families need development and testing. Practices need advice about how to select patients and families with whom to partner, how to address confidentiality issues, and how to overcome clinician and staff concerns that patient expectations are impossible to achieve. The Stoeckle Center has a wealth of experience partnering with patients and families and can help others address these concerns by working with our practice and national partners to strengthen these strategies and integrate them into the new models of care.

Considerations

In summary, The Stoeckle Center is well positioned to serve as a dissemination arm for existing patient engagement strategies as well as a laboratory to develop new methods of patient engagement locally and with our national collaborators. We also are working at a national policy level to ensure that these methods become embedded in the day to day operations of the new models of primary care delivery, including the patient-centered medical home demonstration projects.

Susan Edgman-Levitan, Executive Director, Michael Barry, MD, Medical Director, Bill Kormos, MD, Director of Education, and Beth Rider MD, MSW, Director of Programs for Communication Skills are working closely with the national initiatives mentioned above and have been asked to serve as advisors to help integrate patient engagement and practice redesign strategies into these new models of care. Ms. Edgman-Levitan serves on the board of the Trust for Healthcare Excellence and has been invited to serve on the national board of the AAFP's TransforMED initiative.

The Stoeckle Center is one of the clinical members of the national Patient-Centered Primary Care Collaborative and is also an invited member of the Group Practice Improvement Network (GPIN). All of these relationships and leadership roles will be leveraged to achieve our goal of increasing patient engagement in primary care in a way

that meets the needs of patients and their families and improves the quality of care overall for our patients.

Attachment A

The Engagement Framework

A growing consensus within the health care industry holds that cost escalation will be restrained and quality of care and outcomes improved if people become more actively engaged in protecting their health and managing their health care. This is particularly true for older people, who are more likely to have at least one chronic condition and thus use more health care. However, there is little consensus about exactly what engagement means. While the idea is appealing, it frequently lacks the precision necessary to achieve its potential. Embedded in the rhetoric about consumer engagement is a set of expectations that place substantial new demands on Americans seeking and using health care. The purpose of this framework is to explicitly lay out what actions are required of competent patients in an era of Consumer Engagement.

If health care delivery predicated on the notion of responsible individual behavior is to become a reality, our nation will require a dramatic change in the awareness, willingness and capacity of most older people to assume the wide range of personal responsibilities expected of them.

The following behaviors constitute engagement in health and health care and set the conditions under which — based on the best available evidence — individuals are more likely to receive the optimal benefits of medical science and practice.

I. Active Engagement in Managing Health

A. Healthy behaviors

Individuals and their caregivers will continuously

1. *Acquire and use information to:*

- a. Assess their risks for poor health, disease and injury
- b. Set priorities for changing behavior to prevent disease and maintain health
- c. Identify and locate services to support changing behavior and maintaining those changes over a lifetime

2. *Take action to:*

- a. Exercise regularly
- b. Eat a balanced diet
- c. Maintain recommended body weight
- d. Not use tobacco products and not abuse alcohol or other substances
- e. Act to prevent injuries at work, home, play and in transit

B. Chronic disease self-management behaviors

Individuals and their caregivers will

1. *Acquire and use information to:*

- a. Understand their disease and what can be gained by medication use and behavior change
- b. Evaluate their treatment options
- c. Identify and locate services to support changes in their behavior and maintaining those behaviors over time

2. *Take action to:*

- a. Follow treatment regimens, including diet, exercise, and substance use agreed upon by them and their provider
- b. Monitor symptoms/condition (for diabetes—regular glucose monitoring, checking feet; for depression—medication and/or counseling and monitoring symptoms; for hypertension—regular measurement of blood pressure; blood pressure diary)
- c. Manage symptoms
- d. Know what their targets and danger signs are (what one's blood pressure should be) and act to meet those targets

II. Active Engagement in Managing Health Care

A. Medical encounter behaviors

Individuals and their caregivers will

1. *Acquire and use information to:*

- a. Prepare a list of questions/issues for discussion in visit
- b. Learn about the possible side effects or complications of new prescription medications

2. *Take action to:*

- a. Report accurately on the history and current status of physical and mental symptoms
- b. Ask about the evidence for the efficacy of different treatments (risks and benefits)
- c. Evaluate options in discussion with health care provider
- d. Negotiate the treatment plan and follow-through.
- e. Ask questions when explanations are not clear
- f. Bring a list of medications when visiting a health care provider
- g. Check if insurance covers the medications and tests the provider ordered
- h. Bring another person to assist them if they are frail, confused, unable to move around or unable to remember the conversation with the provider
- i. Bring a summary of medical history, current health status and recent tests to all visits
- j. Obtain all test results and appointment records and maintain personal health record at home

B. Consumer Behaviors

Individuals and their caregivers will

1. Acquire and use information to:

- a. Gather additional expert opinions on any serious diagnosis prior to beginning any course of treatment
- b. Compare coverage options when selecting health plans, and match to their own values, needs and preferences and select affordable quality care
- c. Use comparative performance data to select high performing providers and facilities
- d. Learn what services and programs they qualify for

2. Take action to:

- a. Establish a relationship with a trusted health care professional or group
- b. Pay all bills in a timely manner or arrange an alternate plan

C. Interact with healthcare institutions (primary care provider, specialist, nursing home, assisted living, hospital, ER).

Individuals and their caregivers will

1. Acquire and use information to:

- a. Self-triage to the appropriate setting when a problem requires professional attention

2. Take action to:

- a. Obtain referrals and then get recommended screenings (e.g. breast cancer, prostate cancer, colon cancer, cervical cancer)
- b. Get an annual flu shot and other vaccines as recommended
- c. Make appointments; inquire about no-show policies; arrive on time; stay until the encounter is completed
- d. Physically navigate the health facility or obtain assistance to do so
- e. Inquire about pre-authorization / pre-certification for all out-of-office tests
- f. Maintain all receipts for drugs, devices and services
- g. Complete advance directives and medical power of attorney, file with appropriate physicians and produce them for medical authorities when appropriate.
- h. Talk with medical providers to ensure that relevant medical information is conveyed between providers and institutions (e.g., discharge plans)