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ENGAGING DISADVANTAGED OLDER PEOPLE
IN THEIR HEALTH AND HEALTH CARE:

TRAINING OLDER PATIENTS TO INTERACT WITH
HEALTH CARE CLINICIANS AND INSTITUTIONS

*Prepared for The Atlantic Philanthropies
December 2007*

Summary	2
The Challenge	4
The Engagement Framework	6
The Approach: Training Older Patients to Interact with Health Care Providers and Institutions	7
Considerations	10
Appendix	
Engagement Framework	12

SUMMARY

People are increasingly urged to be informed and engaged consumers of health services and information in order to be able to participate effectively in their care. Unfortunately, even older people who have had experience with illness and with negotiating the health system are likely to lack a basic understanding about what's required to get the best possible care.

Doctors, labs and hospitals have expectations about what patients must do, though they rarely state those explicitly. When the system fails to perform right, many people do not have the confidence or skills to correct problems. This presents a challenge even to well-educated, sophisticated, wealthy older people. But such fixes 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 role.

Getting good care and making good use of health information increasingly depends on individuals' active engagement. 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 intervene on behalf of individual patients, many patient navigator and patient advocate programs have been introduced. However, the expansion of these programs to reach all who need them is limited by resource constraints. It is important to provide experience and hands-on understanding of how the health care system works, both when it works well and when it does not. For patients with limited language and interaction skills, and limited health literacy, the problem of managing health and health care is especially daunting.

To date, there has been little public demand for education on how to interact effectively with health care providers and institutions. Having "the right information at the right time" is an ideal. But stories about the difficulty of actually doing so are becoming more frequent and the consequences are increasingly vivid. With appropriate sponsorship and messages, it is possible to increase the demand for instruction.

By targeting older adults with low literacy skills and their caregivers, training to interact effectively with doctors, nurses and administrators, it may be possible to mitigate the relative disadvantage they experience in their ability to meet the challenge of participating in their health care.

A collaboration of interested organizations and experts should be convened to develop strategies and models to step up engagement behaviors. Representative patients and caregivers, professional societies, advocacy organizations, experts in health literacy, and leaders from the aging network, CMS, Medicare Advantage plans and existing patient training efforts should be invited to advise an initiative that undertakes the following tasks:

1. Survey the field of patient interaction skills to summarize the approaches currently being taken to teach people to get the most from their health care encounters.
2. Propose a series of best practices, both in approach and content, to teaching health care interaction skills to low income older people with limited literacy skills and their caregivers.
3. Identify potential program homes that are already training and supporting disadvantaged older adults and their caregivers to manage their health, their chronic conditions and their health care into which best practices can be integrated.
4. Pilot test / feasibility test the implementation of the best practices.

Training older adults with multiple chronic conditions and limited literacy skills to interact effectively with health care clinicians and administrators is not likely to be easy. The initiative proposed intends to explore what it will take to support those who are disadvantaged by the requirement that they actively participate in order to get decent health care and thus to minimize their risk.

This initiative will produce a robust set of best practices based on evidence, experience and feasibility. These best practices should *not* serve as the basis of free-standing training or education programs, but rather, should be integrated into existing efforts, thus filling an important gap in the skills required to engage in health and health care.

The Challenge

Contemporary wisdom within the health industry is that cost reductions and improvements in quality of care will occur when patients behave more responsibly. They can do this by practicing health promotion, getting appropriate screening, interacting effectively with their doctors and clinical staff, and managing their chronic conditions effectively. However, frail older adults, in particular, do not expect or know how to be engaged and informed patients. Most older adults assume their job is to show up at the doctor's office when they are ill. Neither preparing for doctor or hospital visits, nor aggressively taking over management after leaving is what they think is "their job" as consumers of health care.

Getting good care and making good use of health information now 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.

Older adults are often painfully aware of the ways in which their attempts to manage their own health and health care go wrong, especially as they age, develop more chronic conditions and experience the hazards of hospitalization. However, even those who have had a lot of experience with illness and who know the demands of negotiating the health system as a patient may lack sufficient understanding and skills to get the best possible care.

Doctors, labs and hospitals require a great deal care coordination from patients. They often have expectations that seem so obvious that many health professionals do not mention them (such as refraining from smoking, getting regular exercise and losing excess weight). Sometimes expectations have changed, but an elderly patient has not received any messages about the change (such as always check about getting insurance pre-authorization for procedures and tests, read package inserts for medications). Some expectations develop as a side effect of communication gaps among doctors and hospitals (such as send test results to all relevant physicians). Doctors and patients alike have been slow to recognize that the push for patients to become active participants in care requires changes in how people interact with health care providers when they meet. Especially for frail older adults, speaking up in an encounter with a doctor is often challenging. Taking on the necessary self-management tasks and informed decision-making tasks is unlikely if the patient never speaks up, or — sometimes worse — waits for an adult child or other caregiver to take over the conversation.

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 think 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 — there was no need to ask questions because the doctor would tell them everything they needed to know.¹

In the belief that older people's engagement in health and health care is necessary to achieving 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), and to take care of their diseases at home (by producing materials and websites, and supporting chronic disease self-management demonstrations). They have also implemented community-based support programs to help Medicare beneficiaries sign up for their benefits (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 their 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.
- 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

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.

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.

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 the flaws in these assumptions is substantial.³ Thus, efforts to ensure that all older people — and particularly those who lack skills and resources, or who are frail or ill — are able to engage in their health and health care will not succeed as long as these assumptions remain implicit, but unaddressed, in the communication, support and guidance that is offered to increase older people's abilities to engage with their health and health care.

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 may 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

It is important to understand, from the older adult's perspective, what behaviors 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). 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 if they are 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 Coulter A, Ellins J. *Patient-focused interventions: A review of the evidence*. Picker Institute Europe, August, 2006. http://www.pickereurope.org/Filestore/Publications/QEI_Review_AB.pdf

The Approach: Training Older Patients to Interact with Health Care Clinicians and Institutions

Many older adults fail to understand the need to interact more forcefully with health care clinicians and institutions. Further, they believe that, as has historically been the case, those institutions will perform in their stead many of the engagement behaviors listed in the Appendix. They expect health professionals to remember to sort out fact from fiction, relevant from irrelevant. They expect providers to give them sufficient basic information about their disease(s) and their treatment to care for themselves on a day-to-day basis without asking for it. Some patients may be very well informed about what they think is their condition and seek out information about their diagnosed or undiagnosed condition and symptoms. Other patients do not seek out information either about their condition or about what they must do to follow through on the tests, drugs and behaviors their clinician has recommended, feeling that is the doctor's job to tell them if they need to know.

Clinicians rarely ask about what patients know about their condition and its treatment: this is not usually addressed in clinical interactions. Whether consumers are over-informed or under-informed, they rarely speak up, being usually reluctant to reveal their level of knowledge. Checking with their doctor to see if their understanding is corresponds with the doctor's is taboo for many patients. Knowing what to do to follow through on medical recommendations, or to manage the care system is frequently a mystery.

Older people's lack of assertiveness with their physicians can be traced to the long-standing pattern of medical paternalism described by Talcott Parsons in 1951⁴, wherein people who are sick are exempt from their work and social responsibilities in exchange for trying to get well and following their doctor's directives. This passive "sick role" accurately reflected the expectations of both doctors and patients of the time and was reflected in the training of physicians, the organization of health care services and the manner in which health care services were delivered. For generations, American patients placed their lives in the hands of their doctors — they ceded control of their disease — in the belief that this professional had superior knowledge, vast experience and could be trusted to act on their behalf and in their best interest.

For many older people who grew up with health care that required and reinforced these attitudes and behaviors, the transition to active, questioning patient presents considerable challenges. But not overcoming those challenges leads to confusion, poor adherence, unnecessary suffering and poor use of patients' and providers' resources.

Some consumer advocates and health care professionals have begun to recognize the need to explicitly train older people and their caregivers to interact more effectively with their doctors, nurses and administrators. To lift the veil of professional secrecy

⁴ Parsons, T. *The Social System*. The Free Press 1951

surrounding what is supposed to happen in an outpatient encounter, some courses in patient communication skills are taught in community colleges and other venues. Because professional jargon clouds people's ability to understand medical problems, treatment plans and medication labels, pioneering projects in health literacy have begun.⁵ Innovators in adult literacy classes have begun to incorporate field trips to hospitals to teach people to navigate competently for themselves through the health care system. These programs teach both how the health care system works, and how people can interact with health professionals to acquire the information and skills to get the most from their encounters. Courses in chronic disease self-management have successfully addressed the behaviors in the "Managing Chronic Conditions" section of the Engagement Framework in multiple session training courses using standardized curricula.⁶

By targeting older adults with low literacy skills and their caregivers training to interact effectively with doctors, nurses and administrators, it may be possible to mitigate the relative disadvantage they experience in their abilities to meet the challenge of participating fully in their health care.

A collaboration of interested organizations and experts should be convened. Representative patients and caregivers, professional societies, advocacy organizations, experts in health literacy, and leaders from the aging network, CMS, Medicare Advantage plans and existing patient training efforts should be invited to advise an initiative that undertakes the following tasks:

1. Survey the field of patient interaction skills training to identify and summarize the approaches currently being taken to teach people to get the most from their health care encounters. Search specifically for efforts targeted toward older people and people with low literacy skills.
2. Propose a series of best practices — both approach and content — for teaching health care interaction skills to older people with limited literacy skills and their caregivers. It is clear that older people who have limited mobility, who do not use computers and who have limited health literacy will require different approaches if these people's health is not to be further disadvantaged by their inability to perform these behaviors because of their circumstances and abilities. Approaches that are classroom based with field trips to health care institutions, Web-based instruction and networking approaches are some of the formats currently in use. These approaches will meet the needs of only a part of this population. A few efforts have been undertaken to address a subset of these concerns via the Visiting Nurse Society, for example, that would also shed light on the feasibility and parameters of such an effort.

⁵ *Improving Prescription Drug Container Labeling in the United States: A Health Literacy and Medication Safety Initiative*. Presented to the Institute of Medicine roundtable on Health Literacy, October 12, 2007. <http://foundation.acponline.org/hl/hcc2007.htm>

⁶ Holman H, Lorig K. Patient Self-management: a key to effectiveness and Efficiency in care of chronic disease. *Public Health Rep.* 2004;119:239.

3. Identify potential program homes that are already training and supporting disadvantaged older adults and their caregivers to manage their health, their chronic conditions and their health care into which best practices can be integrated.

As people become more sophisticated and as the health care system evolves under cost and quality pressures, more programs and services will be available to older adults and their caregivers who need support and guidance. This evidence-based set of skills should complement and deepen existing efforts.

For example, community-based agencies and organizations that provide services and support for disadvantaged older people may find opportunities to integrate these best practices into existing training efforts. Similarly, they may be able to integrate them into services targeted to the unique needs of each person. It is also possible that a Medicare Advantage plan would integrate the best practices as a specific service it offered to members or that community health clinics might see a place for such a program.

4. Pilot test / feasibility test the implementation of the best practices.

Tests should be conducted in at least three settings over time, each of which represents a different role and kind of authority in patients' lives. For example, one test site might be in a faith-based institution, another in a community clinic and another in a senior services organization. Adequate resources should be allocated to raise interest and demand of older people and their caregivers to participate.

Best practices should be revised, models developed for use and further testing, and advocacy for their adoption should be supported if this approach proves useful and feasible.

Establishing the initiative's advisory group is a large and complex task. Not only must the group become invested and be informed, it must also be included in decision-making and offer a venue for critique and improvement of existing efforts. The management of advisory group — from deciding about its composition through its management over time — must be thought of as an integral part of raising the visibility and priority of patient engagement generally and the productive involvement of each individual member in this initiative as one of the outcomes.

Training older adults with multiple chronic conditions and limited literacy skills to interact effectively with health care clinicians and administrators will not be easy. The initiative proposed intends to explore what it will take to support those who are disadvantaged by the requirement that they actively participate in order to get decent health care and thus to minimize their risk. At the end of the initiative, advisory group members should have a better understanding of the challenge of mounting an effort to accomplish this aim.

Considerations

1. Isn't this already being done through chronic disease self-management interventions and patient education?

Our extensive review of privately and publicly funded efforts found that this modest but critically important set of skills was often either missing or addressed obliquely or only addressed in the context of a specific condition.

We believe that an important gap would be filled by clearly defining these skills, collecting the research evidence and best practices and then working to get them integrated in existing interventions targeted toward older adults with low literacy skills.

2. Will technology make up for consumer deficits in interaction and navigation skills?

New web-based tools for patient information and education are as frequent as mortgage defaults these days. However, these developments have limited potential to reach older adults who are frail or poor, who lack access to the Internet, and don't possess the search skills required to make use of a computer for this purpose. While older adults are one of the fastest growing groups of internet users,⁷ the rapid evolution in information technology and the expectations for its use highlight the need for health literacy and interaction skill training for those who are unlikely to make use of this asset. Prototype training based on best practices with this population — the elderly disadvantaged patient — will invite incorporation of new technologies and adaptive approaches as the imperative to explicitly address the need for older people to engage in their health care takes root. More community-based approaches will undoubtedly be needed.

3. How can instruction in interaction skills and health literacy address the special needs of the older people with limited literacy skills and their caregivers?

Only with great care. Experts in delivering information about health and social services to relevant populations of older will be invaluable members of the development group, as will representative patients and caregivers. Graduates of successful programs with different foci (e.g., chronic disease self-management) can provide early feedback to improve existing efforts. Information alone does not change behavior.

4. What are the criteria for an organization to be funded to undertake this comprehensive set of activities?

The organization should:

- a. Have a mission that is consistent with this perspective and the specific message: a) the engagement of older people in health and health care is critical to maintaining health outcomes and preventing and increase in health disparities; b) many older people

⁷ Campbell RJ. Consumer informatics: elderly persons and the internet. *Perspect.Health Inf.Manag.* 2005;2(2):2

need considerable support and guidance if they are going to be able to take on these new responsibilities.

- b. Employ spokespersons and leaders who see older people's engagement with health and health care as instrumental to achieving their aims and thus be willing to talk about it with passion and confidence and be willing to feature this initiative in organizational and advocacy communications.
- c. Have a track record of serving as a neutral convener of diverse voices and interests for the purpose of achieving a shared goal.

APPENDIX

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).