

Putting Patients First: Developing and Maintaining Patient-Centered Medical Practices

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Focus groups of low-income Washington, DC residents conducted by the DCPCA Medical Homes DC project identified a number of barriers to accessing health care and problems within the health care system. These include low levels of health literacy, problems navigating the health care system, poor communication with health care providers and staff, frustration with how services are delivered, fear of medical problems, distrust of the medical system, and problems with language and documentation among foreign-born residents. The identified barriers are common across the country, especially among low-income and minority populations, but possible solutions are neither easy nor quick-fix.

Underlying many of the focus group comments was dissatisfaction with the patient experience. Focus group discussions also made it clear that relatively few participants had the information, regular access to health care, and ability to communicate with providers necessary to engage more fully in their own health care. These problems are generally attributable to faults in the systems to deliver health care, not to faults of the individual providers and staff working in the system. Providers and other health care staff are also dissatisfied with many elements of the health care system. An increasing number of medical practices are explicitly examining their processes and systems from the patient's point of view and changing their internal operations accordingly. In addition to benefiting patients, these changes also benefit providers, typically by creating more streamlined and efficient operations. This report highlights some promising practices to create more patient-centered systems.

I. Introduction

Washington, DC, has a relatively strong medical safety net for its low-income and uninsured residents. The city is home to an active and committed group of community health centers with a mission to provide medical care regardless of ability to pay. Medicaid and the locally funded DC Healthcare Alliance programs fund health care services for more than 180,000 residents, or about 30 percent of the city's population. The Medical Homes DC project, launched in 2003 by the DC Primary Care Association with several partners, focuses explicitly on helping health centers improve their physical facilities, internal practice management, and financial and clinical systems.

Nonetheless, low-income District residents have poorer health outcomes and less access to health care than more affluent residents.² In an effort to find out more about the barriers to health care faced by low-income residents, Medical Homes DC organized a series of focus groups. A primary goal was to learn more about how uninsured and publicly insured residents experience the medical system, and whether and how they see it as meeting their health care needs.

“Health care providers and staff are typically motivated by a desire to help people. The challenge is to convert those desires into institutional practices centered on meeting patient needs.”

Although focus group participants discussed many issues, two themes dominated. First, most participants were dissatisfied with some element of their experience as a patient and reported instances when they believed that providers or staff did not respect or listen to them. In addition, relatively few focus group participants appeared to have the regular access to health care, health-related information, and ability to communicate with providers necessary to be a full participant in their own health care. The promising practices that are featured in the report are examples of initiatives or organizational changes that community health centers can make to improve the patient experience and assist residents in becoming more informed about their health and more engaged with providers.

II. Methodology

Brookings Greater Washington Research, one of the partners in the Medical Homes DC project, contracted with Lake Research Partners to conduct five focus groups in winter 2006. Focus group participants were low-income, working-age adults who were uninsured or publicly insured, although a handful had private health insurance. Two of the focus groups comprised African-American residents of neighborhoods east of the Anacostia River, a third group included a mix of African-American and Latino residents, and the fourth and fifth groups included Spanish-speaking Latinos and were conducted in Spanish.³ A total of 45 residents participated in the focus groups, including 12 African-American males, 11 African-American females, 10 Latinos, and 12 Latinas. The focus groups took approximately two hours, and all participants received a stipend of \$100.⁴

Research on the promising practices included in the report was driven by topics discussed in the focus groups. Research focused on organizational changes or initiatives that community health centers could undertake to address issues raised in the focus groups—specifically, actions that could improve the patient experience and help patients improve their health literacy and engage more fully in their own health care. The promising practices cited in the report are drawn from literature reviews of health literacy, patient-provider communication, patient-centered care, and personal health records as well as research on community health workers conducted for a 2006 Medical Homes paper. The promising practices in the report have not been rigorously evaluated as to their effectiveness and most are still evolving. Specific practices were selected for inclusion based on their responsiveness to concerns from the group groups and a judgement as to whether they have momentum in the health care field.

III. Findings from the Focus Groups

Focus group participants discussed their experiences in multiple health care settings, including community health centers, private doctors' offices, emergency rooms, and hospitals, although moderators made a special effort to focus the discussion on community health centers. Participants also discussed private and public insurance plans. Participants generally had positive and negative comments about all of the health care settings and their insurance plans. When a participant discussed a specific experience, it was not always possible to identify whether he or she was referring to a private doctor, community health center, hospital, or emergency department, or the type of insurance (or lack of it). Consequently, the report does not attempt to sort out whether experiences differ by insurance status or health care setting.

The focus groups identified several key barriers to quality health care. These include health literacy, problems navigating the health care system, poor communication with health care providers and staff, frustration with how services are delivered, fear of medical problems, distrust of the medical system, and for immigrants and those whose first language is not English, issues of language and documentation. Beyond access, these issues also have a profound effect on the quality of their experiences with the health care system. Although some of the problems identified in the focus groups are more likely to be experienced by low-income or minority individuals, other concerns, such as rushed interactions with providers or long waits to see a doctor, are also experienced by middle-class and upper-income individuals.

Because the project conducted focus group of residents and health care consumers, and not of health care professionals, we cannot comment on how local providers and staff perceive the health care system and its successes and challenges in providing health care to low-income and uninsured residents. However, on the basis of informal discussions with local providers and a review of the literature on improving access to and quality of care, it is clear that many providers and staff are equally frustrated with many of the problems identified by the focus group participants.

A. Health Literacy and Navigating the Health Care System

Underlying many of the themes raised in the focus groups is inadequate health literacy. In a recent report, the Institute of Medicine describes health literacy as a major problem across the health care system. The report defined health literacy as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.”⁵ Health literacy includes a variety of skills, including reading, writing, numeracy, listening, and speaking. Although a direct causal relationship has not yet been established between low health literacy and health outcomes, it is not surprising that research consistently suggests such a relationship. Health literacy tends to be lower among older adults, and those with low incomes, limited education, or limited English proficiency.

More than 300 studies show that health information is not understood by its intended audience.⁶ A focus group participant illustrated this problem, saying, “I found myself asking the nurse to explain to me what was just explained to me.”⁷

Additional studies show that all patients, not just low-income patients, remember as little as half of what they are told by their physicians.⁸ However, focus group participants also gave examples of providers who took care to explain relevant health issues. As one participant said, “My doctor...sits down and he explains everything to me...I think I have a very good doctor.”⁹

The health care setting is a challenging environment in which to comprehend information. Patients often have an underlying level of stress or fear, and the environment is characterized by specialized vocabulary, legal forms, and unfamiliar medical technology and procedures. Patients have less power and less access to information than do providers and staff. To make appropriate health decisions, patients must obtain and analyze a considerable amount of information, often with limited time with providers. People of all incomes and education levels commonly experience difficulty in understanding or navigating the health care system, but the challenges are multiplied for patients with low reading and math skills. In its report on health literacy, the Institute of Medicine did not mince words in describing the problem: “It is increasingly apparent that the healthcare system has not evolved to serve those with limited health literacy.”¹⁰ And yet health literacy is critical in a market-based health care system that depends on informed consumers.

One focus group participant described her frustration at not receiving the kind of information she wanted, or in a form that made sense to her: “[Doctors] give you possibilities. I don’t want possibilities. I know the possibilities before I got here. You know, I want straight answers.”¹¹ The participant did not describe the particular situation, but it is possible that the provider was giving appropriate information regarding diagnosis or treatment. However, there was clearly a disconnect between the patient’s expectations and the information or services provided.

Another area of confusion is in navigating the health care system; that is, knowing whom, for what, and when to call for medical assistance. The Institute of Medicine noted this is a particular problem for people with limited health literacy.¹² This difficulty with navigating the system was borne out in the focus groups.

At the most basic level, some focus group participants did not have much or any information about where they could seek care. This problem was most pronounced among men, especially Latinos. African-American women were most likely to know about public insurance programs, be covered by Medicaid or the DC Healthcare Alliance, and know where they could seek care. Participants appeared to have limited knowledge of the importance of preventive and primary care. With some exceptions, they did not seem to understand the value of undergoing screenings for health conditions, especially in the absence of an obvious health problem, nor did they seem to understand how patients

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can work with their providers to manage chronic diseases.

One focus group participant gave an example of going to the emergency room when her toddler had a croup cough. She was frustrated and angered when the emergency room staff said her son's case was not an emergency and she and her son had to wait for treatment. Although the specifics of the case are unknown, it is possible that the woman's child had a condition that could have been treated more effectively and efficiently in a primary care setting than in a hospital, assuming, however, that the mother had a regular pediatrician and would have been able to make an appointment in a timely manner. Access to and use of non-emergency, primary care health services are key components in successfully navigating the health care system.

B. Quality of Communication with Providers and Staff

Effective communication surfaced as a key issue in participants' satisfaction with their care, health care providers and staff, and with the health care system as a whole. Several focus group participants spoke glowingly of their doctors and other health care staff. Specifically, they highlighted that doctors and other staff listened to them, carefully explained relevant issues, gave them personal attention, and helped them fill out the appropriate insurance forms to enroll in Medicaid or the Alliance. One participant said, "I feel like family when I'm with my doctor because...I can talk about anything with [her]...she counsels me...I told her if you go anywhere, I'm going with you."¹³ Not surprisingly, individuals reporting positive relationships with their providers were the most satisfied with their health care.

A more common sentiment, however, was that health care professionals do not listen to patients and that staff treat them rudely and impersonally. One focus group participant, after hearing another speak about the personal attention she receives from her doctor, responded, "And I haven't had a doctor like that. That's what made me stop going to doctors."¹⁴ Several complained that they came to the doctor with a specific question or problem and felt their concerns were ignored or disregarded, even when the participant was trying to relay important background information that would directly affect diagnosis and treatment. One participant said, "They really do get on my nerves, those doctors. They don't listen."¹⁵ In several instances, patients became so frustrated that their interaction with a doctor escalated into direct conflict and a complete breakdown of communication. Poor personal service by non-medical support staff was another common complaint. Participants described themselves as being treated "like cattle" or "like a number" by staff, especially by receptionists or other staff who answered the phone.

C. Dissatisfaction with How Services Are Delivered

Several participants described long waits in the waiting room when they had an appointment, difficulty scheduling appointments in a timely manner, and their frustration that they were not always able to see the same doctor. Some also spoke of rushed interactions with providers, their dissatisfaction that they could only discuss one health issue per visit, and an overall sense that they are being churned through an impersonal system. Related to the communications issues discussed above, some participants believed they were not taken seriously and that they did not receive personal attention.

D. Fear of Medical Problems

For some focus group participants, especially African-American men and women, fear of bad news prevents them from seeking medical care. As one participant said, "I wouldn't even want to know if I had cancer, cause through my experience everybody that found out they got cancer, once they go get that operation they die anyway, so I wouldn't want to know."¹⁶ His statement succinctly illustrates several related problems: the failure of health education to convey the importance and value of early diagnosis and treatment; lack of access to or use of primary care, which would hopefully prevent a late-stage diagnosis; and the possibility that information passed along via informal social networks can be incomplete or misleading. Although family and friends are a common source of health information for most people, such personal stories may be particularly influential among people with limited health literacy. Individuals with low health literacy often obtain information about cancer from friends and others who experienced a late-stage diagnosis.¹⁷ If such diagnoses then deter others from seeking medical care because of a feeling of futility, the cycle of late-stage diagnoses, with fewer treatment options, will continue.

E. Distrust of the Medical System

Some participants mistrust the medical community. Some, especially African-American participants, questioned the intentions of health care providers. Some participants believe that health professionals are only after the money they will get by billing insurance companies, individuals, or Medicaid. Many believe that providers routinely order multiple tests that may not be necessary to inflate their billing. “All they care about is your money,” said one woman, “taking tests and giving you medicine that you don’t even need.” A male participant described the medical establishment as not being trustworthy, especially with black men.¹⁸ The distrust can be profound. One woman described why she is reluctant to go to the doctor: “‘cause you know deep inside your little head that they [are] not trying to help you.”¹⁹

F. Language and Documentation Issues

Latino participants raised specific issues about legal status and language. They noted that residency, documentation, and lack of social security numbers are all barriers to accessing programs and services. Some Latino participants thought that undocumented immigrants would be afraid to make use of any service that is government-sponsored.

Some Latino participants say they have hard time finding doctors with whom they feel comfortable. “Sometimes it seems if they do not want to attend to you.” said one participant. “If you can’t speak English well, they just don’t treat you well.” Some reported they cannot locate Spanish-speaking doctors and prefer to see doctors in their home country. They did not always feel comfortable using interpreters (whether a staff person from the doctor’s office, family, or friends) because they believed they were unable to communicate as effectively as when both doctor and patient spoke Spanish. Therefore, in addition to the broader patient-provider communication problems raised in the focus groups, language issues raise an additional complication about being understood.

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IV. Patient-Centered Care

In short, the focus group discussions revealed serious levels of dissatisfaction with numerous aspects of the health care system. Underlying much of the criticism is the sense that health care providers do not place a priority on meeting patients’ needs and answering their questions in an efficient, timely, and pleasant manner. Many of the problems cited by focus group participants stem from systems and practices that presumably serve the needs of providers and medical practices, or that have simply evolved over time by chance and happenstance. Scheduling systems are designed with physicians’ time in mind and based on particular ideas about how to manage patient demand. Facilities are compartmentalized and centered on the operations of various functional provider units, rather than being designed to improve patient experiences as they receive various services.

However, providers and staff also find that they are not well served by many current operational practices. In the journal *Family Practice Management*, two doctors wrote: “If there’s one certainty in health today, it is this: Almost no one is happy with the current system—not doctors, not patients, not staff members, no one. There is a clear, existing need for the fundamental redesign of all aspects of clinical practice.”²⁰ They noted problems with constant phone calls, managing paperwork, inefficiency in office operations, and the need to make extra efforts to provide good patient care. Others in the field also note that current practices and systems are causing low morale and job dissatisfaction in medical offices.²¹ One physician described the current scheduling system as “set up for combat, not for the development of personal relationships between doctors and patients. . . .Our offices expend huge amounts of energy trying to keep patients away from their doctors. In turn, patients must use enormous amounts of energy to break through the system to receive even the simplest of services.”²²

Multiple initiatives have been launched to reorganize and improve the delivery of health care. At their core, most of the approaches focus on creating a more patient-centered system within a given health care practice. For instance, open-access or same-day scheduling has become one of the major components of a patient-centered approach. This system emerged from a focus on the key health care

product: the doctor-patient relationship. The scheduling system was organized to support that relationship and remove barriers to doctor-patient interactions.²³

There is no one standard definition of patient-centered care, although certain themes are evident in all the various definitions. The Institute of Medicine defined patient-centered care as care that is “respectful of and responsive to individual patient preferences, needs, and values, and [that ensures] patient values guide all clinical decisions.”²⁴ Clinicians’ decisions are informed by an understanding of the patient’s environment, including home life, family situation, cultural background, and employment. Clinicians act in partnership with patients and work to develop patients’ knowledge and skills to manage and improve their own health.

Although the drive to create more patient-centered care is gaining momentum in the health care field, the notion that practices must change in order to provide such care seems incongruous to some clinicians and health care professionals. However, proponents of a patient-centered approach note that typically, doctors and other clinicians have defined what patients’ needs are rather than incorporating the patients’ perspective.²⁵ In general, patient-centered care seeks to expand medical care beyond a biomedical, disease-focused approach to incorporate other aspects of the patients’ life and experience that affect medical decisions, and to recast the patient-physician relationship to be less paternalistic and more of a partnership.

A 2006 report by the Economic and Social Research Institute, building on previous research by the Pickering Institute, identified the following core components of a comprehensive patient-centered care approach for underserved populations:²⁶

- Welcoming environment
- Respect for patients’ values and expressed needs
- Patient empowerment or “activation” (educate and encourage patients to expand their role in decisionmaking, health-related behaviors, and self-management)
- Sociocultural competence
- Coordination and integration of care, including team-based care and care management
- Comfort and support (emphasize physical comfort, privacy, emotional support, and involvement of family and friends)
- Access and navigation (provide a “medical home,” minimal waiting times and convenient hours, promote access and patient flow, help patient attain skills to better navigate the health care system)
- Community outreach

A shift to patient-centered practices would go a long way toward addressing most of the major issues identified by the focus groups. Making the successful transition to patient-centered practice and addressing the concerns from the focus groups requires attention to three major elements of practice.

A. Provider Systems

The systems and processes in medical offices that shape the patient visit have a major impact on the patient’s experience. Difficulty in scheduling timely appointments, long waits at the doctor’s office before or during an appointment, not always being able to see the same provider, rushed interactions with providers or the inability to raise more than one medical issue in a single visit—all of these issues cause tremendous frustration among patients and can often cause them to delay addressing health care needs.

Improving the systems that govern the patient visit is critical, although not easy. The Institute of Medicine noted, “Health care has safety and quality problems because it relies on outmoded systems of work. Poor designs set the workforce up to fail, regardless of how hard they try. If we want safer, higher-quality care, we will need to have redesigned systems of care. . . care must be delivered by systems that are carefully and consciously designed to provide care that is safe, effective, patient-centered, timely, efficient and equitable.”²⁷

B. Communication That Conveys Respect and Caring

The quality of the communication between patients, health care providers, and staff emerged as a central issue in the focus groups. As noted above, patients reported both positive and negative interactions, although unfortunately, the positive stories were less common. In the positive interactions, focus group participants believed that providers and staff gave them personalized attention, treated

them with respect, took care to explain relevant information, and answered their questions. In the negative interactions, participants reported that providers and staff treated them discourteously, did not listen to their concerns, did not take seriously the information that patients presented, and did not ensure that their questions were answered.

The focus group findings and past research indicate that patients place a high priority on being treated with respect and courtesy, and although many medical practices succeed in providing such treatment, others do not. Administrators, providers, and staff can take specific actions in how their offices are organized and staffed to prioritize and support good communication and customer service within their organizations.

C. Managing, Using, and Communicating Information with Patients

The substance of patient-provider communication—how patients and providers discuss and address specific health issues and concerns—also emerged as a major issue in the focus groups.

Patients should be able to understand and use relevant health information. Individual providers and staff and the health care system as a whole must take responsibility to clearly communicate and provide sufficient information to patients in a form that is readily understandable. In short, patients, health care professionals, and the health care system overall must take action to support health literacy.

V. Examples of Promising Practices

Many innovations have been developed and tested across the country and have formed the basis of a genuine movement toward patient-centered care. There are several examples of best practices in each of these areas, and they can have the effect of improving patient, provider and staff satisfaction. However, none of examples represent a quick or easy fix. They can involve major changes in how a medical practice is organized and led, and require committed leadership from the top and involvement throughout the organization. Transforming health center practices involves changing individual and collective work behaviors and how people are held accountable. The headline of one article about practice redesign is telling: “Nothing this good can be easy.”²⁸

A. Provider Systems

The ultimate test of a medical practice is what its patients experience. Patients and their families are the eyewitnesses to the processes of health care delivery.²⁹ The goal is to create efficient clinical and administrative systems to best serve patient needs. Underlying system redesign is the assumption that poor performance stems from faulty systems. No amount of hard work, initiative, or good will on the part of providers and staff can make up for inefficient or disjointed systems that guide the patient visit.³⁰

In addition to the interventions described below, which aim at major operational overhauls of a given medical practice, practices can also take a more targeted approach, using the Plan-Do-Study-Act (PDSA) framework. In partnership with the DC Primary Care Association, local health centers have been using PDSA to assess specific operational processes. For example, by mapping its process of obtaining, reviewing, and communicating lab results, a health care center realized that if a particular staff person did not pick up test results from the fax machine, the results were not reviewed. Consequently, the health center changed the process for obtaining and reviewing lab results. Health centers are also reviewing other processes, such as referrals, patient flow, and childhood immunization.

1. Open Access Scheduling

Provider organizations in a wide range of settings are adopting open access scheduling, also called advanced access, including small private practice offices, community health centers, managed care organizations, and academic medical practices. With open access scheduling, doctors see patients on the day the patient calls for an appointment, regardless of the reason for the visit. Within the District, several community health centers have implemented an open-access system.

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A growing body of research and success stories documents the positive effects of open access. Mark Murray and Catherine Tantau, pioneers in the field, note that after implementing open access in the 1990s, their practice reduced the appointment wait time from 55 days to one day, improved the odds of patients seeing their own physician, and increased satisfaction.³¹

Numerous other reports document success in reducing wait times, strengthening the patient-provider relationship, creating more productive visits in which more health concerns are addressed, and creating more efficient operations (with fewer no-shows and providers spending less time reviewing unfamiliar medical histories because they are more likely to see their own patients). In addition, both patient and provider satisfaction increases, and in some cases, provider productivity and revenue increase.³²

A clinician at a health center that adopted the open access system said that under the old system, “clerical staff was always protecting the doctors’ time and patients were always battling an over-booked schedule.” Afterwards, serving the patient replaced the goal of protecting the doctor.³³

Implementing open access requires a significant organizational commitment. One of the most important factors to address is the belief that providers will be overwhelmed by demand. Therefore, as a first step, a practice should measure demand by tracking average next-available appointment times, no-show rates, appointment requests, and average number of walk-ins and urgent care appointments per day. Although demand appears to be limitless, medical practices have found it to be fairly predictable.³⁴

Practices must also work through their scheduled appointments (backlog), which can be a significant amount of work. Practitioners also recommend making scheduling easier by making all appointments, regardless of type, a uniform length of 15-20 minutes (and scheduling patients for two consecutive appointments if more time is needed). They also advise developing contingency plans for times when demand exceeds prediction. See Appendix A for more detailed information on implementing an open-access system.

2. Patient Visit Redesign

Patient visit redesign focuses on decreasing patients’ waiting time in a medical office. The redesign typically begins with a small group of staff across departments analyzing several patient visits from beginning to end, including patient check-in, taking vital signs, the clinician-patient encounter, the flow of paperwork and information among staff, making follow-up appointments and referrals, and patient payment. Staff track the average patient cycle time (length of time from when patients walk in the front door to the moment they exit the facility), number of patients seen per provider over the day or tracking session, and number of hand-offs per visit (that is, from front desk staff to medical assistant to clinician and back to front desk staff). Staff then design a more efficient patient visit, one that is centered on the patient’s needs. They then chart the work flow and processes accordingly, and test it. After reviewing and learning from the implementation of alternative work processes (usually making several trial runs), the redesign team works with the staff to implement the changes in work flow and processes throughout the organization.³⁵

Jerome Belson Health Center in New York City launched a patient visit redesign effort to address long patient waiting times and staff frustration. Clinicians and clerical staff knew that patient flow was inefficient, but nobody knew the exact length of a patient visit or how their work affected their colleagues’ jobs and the quality of care. After tracking patient flow, the redesign team made a number of changes to streamline to the process.

To encourage teamwork and accountability, clinicians and staff now start each day with a 10 minute morning “huddle” to plan the day’s work. In the redesigned system, patients make three stops per visit instead of five. Patients formerly moved from one exam room, where the nurse took vital signs, to another to meet their provider. Now, patients settle in one exam room and the nurse and provider come to them. The redesign created more communication between clerical and clinical staff, better enabling clerical staff to notify clinical staff when patients arrive and again if patients are waiting for more than 10 minutes. Nurses assume certain clerical responsibilities such as scheduling patients for appointments and making copies of materials needed for charts. As a result of these and other changes, patient cycle time decreased from 68 minutes to 41 minutes, and productivity increased from 2.85 to 4.5 patients per hour.³⁶

The Southeast Health Center in Indianapolis, Indiana also experienced dramatic improvements after redesign. Their average waiting room time dropped from 28 minutes to 12 minutes, the average total visit time declined from 81 minutes to 44 minutes, the share of visits with missing charts dropped from 15 percent to less than 1 percent, and data entry backlogs were eliminated entirely. In addition, staff morale improved, with the previous “it’s not my job” syndrome replaced by a strong sense of teamwork in the service of a shared mission. Patient satisfaction improved dramatically, and patient feedback indicated a wholehearted endorsement of the specific improvements in the patient experience. One patient summed it up by saying, “Keep this up...it is a miracle!”³⁷ See Appendix B for a list of principles for patient visit redesign developed by Coleman Associates, and Appendix C for a detailed description of the redesigned visit at Southeast Health Center.

Nevertheless, in both organizations, participants are also candid about the difficulty in making and sustaining the changes. Providers and staff are often resistant to change and cynical about the redesign process. The implementers described collecting data for the patient tracking exercise as “grueling.”³⁸ Overall, the redesign process is time-consuming and demanding. Ultimately, the process involves changing more than workflow. It also changes organizational culture to emphasize teamwork, communication, and an explicit patient-centered focus.

B. Successful Communication between Patients, Providers, and Other Health Care Staff

1. Conveying Respect and Caring

The communication styles of doctors, nurses, other medical and non-medical staff such as receptionists all contribute to the overall patient experience. The importance of systems and practices that support and promote respect, compassion, and empathy in all interactions with patients cannot be overemphasized. When focus group participants spoke positively about their experiences, they focused on these qualities.

Research on what drives patient satisfaction in hospitals and other medical settings suggests that courtesy, respect, and good communication skills among providers and staff top the list, not necessarily technical competence, which is assumed.³⁹ A study on how patients rated their hospital experience found that they prioritized whether doctors, nurses, and staff listened carefully to them and explained things so they could understand. Lower on the list were issues such as pain management and avoiding medication problems.⁴⁰

Communication is a core skill for physicians and other clinicians. One article described spoken language as “the most important diagnostic and therapeutic tool in medicine.”⁴¹ And yet physicians’ communication skills are frequently judged to be inadequate.⁴² Effective communication between clinicians and patients is especially important in managing chronic diseases, which typically involve regular office visits and changes in health-related behavior such as diet or exercise habits. When patients are informed and involved in decisionmaking, they are more likely to follow treatment recommendations.⁴³ A growing body of research suggests that a patient-centered or participatory communication has a host of benefits: doctors obtain more accurate information, patient adherence and satisfaction is increased, and the stage is set for a more effective patient-physician relationship.⁴⁴

Race and ethnicity also affect communication in the health care encounter. Minority patients generally report lower-quality interactions with physicians than do whites.⁴⁵ They are more likely to believe they have been treated with disrespect by doctors or other medical staff, and they are less likely to trust their physician than whites.⁴⁶ Minority patients’ dissatisfaction with providers, however, can often be mitigated by “generic” or race-neutral physician behaviors, such as spending adequate time with and showing respect for patients.⁴⁷

Effective communication skills include asking open-ended questions, not interrupting patients (research shows that patients typically have an average of 23 seconds to explain the reason for their visit before the physician redirects them⁴⁸), and providing explanations and information in clear, nontechnical language.

However, technical mastery of certain types of communication skills is no substitute for genuine human feeling and a truly attentive and responsive focus on the patient. Numerous studies have documented the benefits of empathy in the medical encounter.⁴⁹ Patient-centered care calls for a

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communication approach that goes beyond biomedical issues. Clinicians seek to identify and respond to the patients' ideas and emotions regarding their illness and expand patients' involvement in understanding their illnesses and decisions that affect their health.⁵⁰ One study found that being treated with dignity contributed to positive outcomes independently of being involved in medical decisionmaking. Positive outcomes included patient satisfaction, adherence to therapy, and receipt of optimal prevention services.⁵¹

In a similar vein, hospital executive Fred Lee observes that patients generally assess the quality of a health care experience by how they are treated as a person, and less by how they are treated for their specific medical condition. Lee envisions three levels of care: competence, courtesy, and compassion. Patients expect competence as a *minimum* standard from providers. They also expect courtesy, and because they often do not receive it, they may remark on any courtesy that goes beyond a basic level.

It is the presence or absence of compassion, however, that overwhelmingly determines the patient's impression of his or her experience with a provider. Compassion goes beyond common courtesy; it means service to the patient that demonstrates genuine concern. Authentic compassion and caring about each patient on a personal level are highly valued by patients and translate into patient loyalty.⁵²

Lee promotes a focus on the patient *experience* at every point in the provider-patient interaction. Lee also notes that a similar approach should be taken by every staff member who comes into contact with the patient, not just the direct care providers. Interactions with receptionists, housekeeping staff, and others are equally important in creating a positive experience for the patient. For example, front office staff not only should have the skills to handle the technical aspects of their job, but also the talent and skills to make patients feel welcome, cared about, and reassured. This gets patients off to a friendly start, engenders trust in the health care system, and helps them find their way around an unfamiliar place.

Developing strong communication skills and practices among providers and staff is not simply a question of offering training in phone etiquette or reminding doctors to ask their patients if they have any questions, although these elements are important. A focus on providing services with respect and attentiveness must be part of the job description and hiring and evaluation processes. Patient-centered communication must be an institutional priority and an expression of organizational culture.

C. Managing, Using, and Communicating Information with Patients

A patient's ability to understand and act on health information is one of the most pressing issues in health care today. There is a serious mismatch between patients' skills and expectations and the information and services that the health care system provides.⁵³ The need for health literacy is growing, as health professionals and the health care system expect patients to assume more responsibility for self-care at a time when the health care system is increasingly fragmented, complex, specialized, and technologically sophisticated.⁵⁴

The American Medical Association gives a striking example of the complex information demands associated with a diagnosis of asthma, a common chronic disease: “Twenty-five years ago, patients with newly diagnosed asthma were instructed to take theophylline. Today, patients are asked to monitor asthma with a peak flow meter, select and correctly use inhalers, sometimes augment therapy with tapering dosages of steroids, and avoid triggers that exacerbate their asthma.”⁵⁵ Not surprisingly, a growing body of research demonstrates that self-management practices and clinical outcomes among people with chronic disease vary by patients' health literacy.⁵⁶

There is a consistent communication gap between patients and health care professionals, with the result that patients often do not know or understand what providers think they have communicated. Clinicians can inadvertently hinder communication in a number of ways. In general, language and words that physicians perceive to be commonly understood may not be clearly understood by the general population.⁵⁷ Medical terminology can be confusing, and lead to inadequate communication from the patient's point of view. Clinicians can also create confusion by providing more background information about a health condition than patients need to know to care for themselves. For example, a patient newly diagnosed with diabetes does not need to know the pathophysiology of the condition.

More helpful is information on the recommended dietary changes and how to check blood glucose levels.⁵⁸

True access to health care requires more than a patient's physical presence in an exam room. The patient must be able to fully engage in the process of care, which means he or she must understand and act on the relevant health information.⁵⁹ The Institute of Medicine's vision of a health-literate society is built on a foundation of successful communication of health information: "We envision a society in which people have the skills that they need to obtain, interpret, and use health information effectively, and within which a wide variety of health systems and institutions take responsibility for providing clear communication and adequate support to facilitate health-promoting actions."⁶⁰

To provide high-quality care, the health care system has a responsibility to reduce the gap between the literacy demands of the system and the literacy skills of the patients it serves. Health care providers must foster more effective and productive clinician-patient interactions by focusing on the nature, quality, and extent of communication.⁶¹

There is no gold standard to measure health literacy, and it would be impractical and undesirable for medical practices to administer a formal reading or writing assessment. However, signs that often indicate a literacy problem include: a patient declines to read or fill out a form because he or she "left their glasses at home," forms are filled out incorrectly or survey forms are filled out with identical responses. Medical practices should not assume that their patients have adequate literacy. For example, clinicians and support staff should routinely offer to help patients fill out forms. Providers and staff can assume the burden of communication. Instead of asking, Do you understand? they should say, Have I explained it clearly?

Research and suggestions also exist on developing written educational materials that are accessible to low-literacy patients. For example, materials should be targeted to the fifth or sixth grade reading level or below, rather than the tenth or eleventh grade levels, at which many patient materials are written.⁶² Resources and guidelines to develop more accessible written materials are available from multiple sources, including the Partnership for Clear Health Communication (<http://www.askme3.org/PFCHC/>) and the Health Literacy Studies program at the Harvard School of Public Health (<http://www.hsph.harvard.edu/healthliteracy/index.html>).

The following communication techniques designed to improve understanding between clinicians and patients with low literacy levels would benefit all patients.

- The "teach back" or "show me" approach, in which a provider demonstrates a particular skill, such as reading a blood glucose level or using an inhaler, rather than asking the patient to read about it in patient education materials. Provider then ask patients to demonstrate the skill, explaining that they need to ensure that they explained it clearly.⁶³
- "Closing the loop." When clinicians introduce a new health concept to patients, such as a change in medication or that high blood pressure in combination with diabetes can cause kidney damage, they ask patients to restate the information in their own words. Patients who correctly restate the concepts are more likely to retain the information because of the interaction. If patients do not correctly restate the concepts, the clinician has another opportunity to tailor the information so it is understandable. The interaction can also uncover health beliefs or differing priorities that could interfere with successful treatment.⁶⁴
- The "Ask Me 3" campaign has been introduced by a coalition of health-focused organizations called the Partnership for Clear Health Communication. The Ask Me 3 campaign provides simple advice for patients to manage their own care, and encourages providers to encourage their patients to ask and understand the answers to three questions: 1) What is my main problem? (focused on the diagnosis), 2) What do I need to do? (treatment), and 3) Why is it important for me to do this? (context). The campaign provides brochures and posters designed to educate both providers and patients. Posters and brochures for patients are designed to be displayed in waiting rooms or waiting areas, and are meant to motivate patients to ask the three questions. Materials for providers provide information on health literacy and offer communication tips.⁶⁵

1. Personal Health Records

The personal health record (PHR) offers opportunities to improve patient knowledge and engagement in their own health care. A PHR is an “electronic application through which individuals can access, manage and share their health information, and that of others for whom they are authorized, in a private, secure and confidential environment.”⁶⁶ PHRs are distinct from electronic health records (EHRs). PHRs are designed to be used by patients to increase their health-related knowledge and involve them more in their own health care, while EHRs are electronic information systems used by health care providers to record and manage information about their patients, designed to replace paper patient charts.⁶⁷

The technology supporting PHRs is still evolving, and PHRs are still only modestly distributed in the United States. However, if designed and implemented correctly, they have the potential to create a host of benefits by putting information directly into patients’ hands and placing patients at the center of their care. PHRs include a variety of health-related information, such as a list of significant illnesses and surgical procedures, current medications and dosages, immunizations and their dates, allergies or sensitivities, test results, family medical history, eye and dental information, and information a doctor might not ordinarily have, such as exercise routines, dietary habits, health-related goals, and whether the patient lives alone or with others. The goal is to provide both patients and providers with relevant information that is not always available to them.

PHRs are most likely to be useful and used by both patients and providers when they are connected to or integrated with EHRs, so that data from the PHR is available to physicians (assuming patients provide permission) and patients have a “portal” into the data from their EHR.⁶⁸ PHRs can also include applications such as the ability to make appointments, renew prescriptions, check test results, and email clinicians.⁶⁹ In addition, PHRs can help patients sort through the universe of health information by providing tailored health information. However, the presentation of data is not an end in itself.

To be transformative, PHRs must make it easier for individuals to understand relevant information and engage more actively in their own care. For example, PHRs can include tools designed to help patients’ manage their chronic disease by providing easy access to test results and customized health information, a format for patients to track their daily symptoms and data from home monitoring devices, a format to set goals and monitor their progress, and the ability to set appointments and ask questions of their providers via email. The overall goal is to support the shift from episodic and acute medical care toward a continuous healing relationship between patients and health care professionals.⁷⁰ Preliminary evidence suggests that PHRs have the potential to empower patients and their families, improve the patient-clinician relationship, increase patient safety, improve the quality of care, improve efficiency and convenience, improve privacy safeguards, and save money.⁷¹

However, PHRs will not achieve their full potential until the information technology infrastructure of the health care field evolves so that data from different providers and sources are interoperable and information can be exchanged across different systems. With networked PHRs, however, come concerns about privacy and security of data. As the health care information technology field evolves, it should develop common standards for security, privacy, and interoperability.⁷²

Lastly, given the low literacy and health literacy of many patients, PHRs must be easy to use, with simplicity in language and user interface. Consumers must be able to understand information that is presented to them if they are to be active participants in their own care.⁷³

Several organizations have developed PHRs. For example, a consortium of provider organizations in Whatcom County, WA, including a hospital and a community health center, developed a PHR called the Shared Care Plan. The Shared Care Plan is a web-based tool that connects the electronic medical system of participating providers. Although the Shared Care Plan is optimally used online, it also is available in printable versions. For participants who lack access to a computer or who need assistance, providers offer computer labs with staff assistance. Patients and their families worked with providers in designing the Shared Care Plan.⁷⁴ A sample of the plan can be viewed at <http://www.sharedcareplan.org>.

The Shared Care Plan is accessible to all members of a participating patient’s health care team at the discretion of the patient, including medical providers, pharmacies, family members, or social workers. The Shared Care Plan is also intended to function as a self-management care tool, allowing patients to manage chronic conditions, coordinate the care of others, and improve their own health. It includes a set of personal planning tools to track health issues, set goals, and plan next steps to achieve those goals.⁷⁶ One user of the Shared Care Plan noted that the plan was useful because it

provided a tool for her to keep track of all her medications and a format to set health-related goals and measure her progress.⁷⁷

Another user said the Shared Care Plan made her parents feel safer and more comfortable about handling her father's complicated health care needs because all the relevant information, especially information about medications, was readily available.⁷⁸ A physician commented that patients gravitated toward the hard-copy version and used it to stimulate and structure discussion in their doctor's visits: "In the doctor's office, a paper copy is used to help the physician or nurse understand where the patient is in their goals and understanding. Likewise this piece of paper helps the patient learn from the physician or nurse. They can write down and discuss medical concepts, diagnoses, medications, goals and plans. [Patients said] that without this piece of paper the 15 minutes of an office visit is often confusing and less valuable."⁷⁹

Another organization, the Palo Alto Medical Foundation (PAMF), a large multi-specialty group practice in Palo Alto, CA, operates a PHR system called PAMFOnline (www.pamfonline.org). Patients said that PAMFOnline makes them feel like "a team member in [their] own care" and that it helps them "understand the whole picture of [their] health better." Patients particularly liked having access to test results. Some reported that the information galvanized them to take a more active role in managing their own health, for example by altering their diet.⁸⁰

2. Community Health Workers

In addition to the "high-tech" personal health record, another strategy to improve patients' engagement in their health care, especially patients with low health literacy, is the "high-touch" approach of community health workers. Community health workers (CHWs) can go by many names, such as health educators, promotoras, and peer health promoters, but they share some basic characteristics: they provide health education and outreach to individuals in low-income and medically underserved communities and link them to medical care and other services. CHWs typically are members of the community they serve and receive training to develop their communication skills, leadership, and health-related knowledge.

The core competencies of CHWs are communication and relationship building, which allow them to build trust among patients who tend to be unfamiliar with or mistrustful of the formal health care system. They are well positioned to explain health issues in ways that are relevant to patients' interests and needs, to help patients navigate the health care system, and to help patients take a more active role in their own care.

CHWs have the potential to improve patients' health literacy and alleviate many of the barriers low-income residents experience in accessing health care. CHWs can provide information on health issues, including chronic diseases and the importance of primary care; help individuals sign up for Medicaid and other public programs; provide information on where people can go for health care; promote continuity of care by helping individuals keep their appointments, receive lab results and secure referrals; provide informal counseling and support; and communicate with providers about the needs and circumstances of neighborhood residents.⁸¹

In the focus groups, participants were very receptive to the idea of CHWs and of having a community-based person as a resource on health-related information and access. When discussing potential roles for CHWs, participants stressed the importance of strong communication skills, just as they did with other providers. Participants believed that CHWs must be personable, caring, and committed.⁸²

The District is already home to several CHW programs (or programs with outreach and education workers who carry out CHW-like activities), operated by community health centers, community-based organizations, the Department of Health, and the DC Area Health Education Center. The DC Primary Care Association recently launched a Community Health Worker initiative aimed at strengthening the training and preparation of CHWs in the District. The first cohort of 20 CHWs graduated in July 2007.

"Community health workers have the potential to improve patients' health literacy and alleviate many of the barriers low-income residents experience in accessing health care."

VI. Conclusion

The focus group findings paint a complex picture of access to health care in the District. Participants related both positive and negative experiences. Their views of the health care system can be described variously as appreciative, satisfied (sometimes very satisfied), angry, resentful, distrustful, and wary. Some participants believed their health care provider listened to them, explained relevant issues carefully, and had their best interest at heart. Others felt disrespected and poorly served.

Review of the literature on the current health care system indicates that dissatisfaction with the status quo is not limited to patients alone. Providers are increasingly frustrated with financial, administrative, and other pressures that sidetrack them from their core business of interacting with patients to help improve their health and alleviate suffering.

Numerous initiatives in the health care field aim to improve the accessibility and quality of health care, with a strong focus on ensuring that health care is “patient-centered.” The clinical, administrative, and managerial operations of medical practices must stay focused on the primary goal of serving patients and incorporate patients’ perspectives, interests, and needs into the delivery of care. It is harder than it sounds.

This report outlined several promising practices to improve the organization and delivery of health care to ensure better patients care. Although the strategies can provide significant benefits, they are also challenging to implement, and improvements can be difficult to sustain without continued attention. That said, most people enter the health care field, whether as a medical assistant, administrator, or physician, because of a basic desire to help people. The challenge is to convert these good intentions into institutional practices. The move to patient-centered care can proceed along many possible paths. We hope this report will start a conversation about the problems identified in the focus groups and the many possible paths to more patient-centered care.

Appendix A. Ten Tips for Successfully Implementing Open-Access Scheduling

1. Move toward advanced access by working down your backlog of appointments.
2. Roll out the new system by showing, not telling, patients how it works. When we try to explain our systems, we often make them overly complicated.
3. Begin offering all patients an appointment on the day they call your office, regardless of the reason for the visit.
4. If patients do not want to be seen on the day they call, schedule an appointment of their choosing. Do not tell them to call back on the day they want to be seen.
5. Allow physicians to pre-schedule patients when it is clinically necessary (“good backlog”).
6. Reduce the complexity of your scheduling system to just three types of appointments (personal, team, and non-established) and one standard length of time.
7. Make sure each physician has a panel size that is manageable, based on his or her scope of practice, patient mix, and time spent in the office.
8. Encourage efficiency and continuity by protecting physicians’ schedules from their colleagues’ overflow.
9. Develop plans for how your practice will handle times of extreme demand or physician absence.
10. Reduce future demand by maximizing today’s visit.

Source: Mark Murray and Catherine Tantau, “Same-Day Appointments: Exploding the Access Paradigm,” *Family Practice Management* 7 (8) (2000): 45-50

Appendix B. Key Principles of Patient Visit Redesign

Principles used by Southeast Health Center to redesign their patient visits in collaboration with Coleman Associates

- **Focus on the Patient!** Work is organized around the patient's needs, and those policies that are not patient-focused are discarded. For example, patients are weighed and money collected in exam-room privacy.
- **Patient Waiting Time Is Minimal and Delightful.** Front desk is eliminated, waiting time is minimized, refreshments are made available, as are toys and videos for children, and waiting patients are kept informed.
- **Clinicians Are Well Supported.** Each clinician works with two medical assistants and three exam rooms. The MAs and provider form a Core Care Team.
- **Teamwork Abounds.** Care Teams huddle every morning to review the patient schedule and strategize about patient care. Team members anticipate one another's needs in the context of delivering care. All work is intensely patient-focused.
- **Clinician is Freed from Paperwork.** The medical assistant records notes, drafts prescriptions, helps complete pre-encounter paperwork.
- **Clinical Charting is Completed During the Visit.** No piling up the charts for end-of-day updates. Everyone goes home on time.
- **Clinical Support Staff Are Cross-Trained in All Functions.** This eliminates handoffs. Medical assistants are cross-trained in all support functions. A medical assistant can follow a patient from the beginning to the end of a visit.
- **The Environment Is Attentive, Professional, Warm, and Friendly.** Facility is clean and orderly, staff professionally attired, and a patient-first attitude prevalent.
- **Patient Care Teams Are Self-Managing.** All team players adopt the philosophy "It is my job." Shared ownership fosters shared responsibility and accountability. Site-based team (all Care Teams combined) sets goals and monitors its performance.
- **Results Are Measured Continually. Charts are audited for quality of care.** Outcomes are measured as are patient satisfaction, patient visit cycle times, staff satisfaction, and productivity.

Source: Coleman Associates, "Redesign: A Catalyst for Transformation: The Apollo 11 Case Study," http://www.patientvisitredesign.com/coleman_associates/cs_apollo_11.html (accessed June 22, 2007).

Appendix C. A Detailed Description of the Southeast Health Center Redesigned Patient Visit

On entering the building, the patient is immediately greeted by a staff member stationed just inside the clinic entrance who welcomes her and asks if she has an appointment. There is no counter or desk between the greeter and the patient.

The greeter invites the patient to help herself to refreshments and have a seat in the waiting room, assuring her that a medical assistant will be calling her shortly.

The waiting room is exceptionally clean and has been recently painted and decorated. There are toys and videos for kids.

The greeter has informed the medical assistant via walkie-talkie that the patient has arrived for her two o'clock appointment. *[This eliminates two typical delays in patient visits: an unresponsive front desk and paper-based communication that depends on staff checking for processed paperwork before a patient can proceed to the next step.]*

A medical assistant (MA) comes to the waiting room, greets the patient, and leads her directly to an exam room. It is in the exam room that the MA takes the patient's weight—in privacy—and her vital signs. The MA also asks the patient if her address, phone number, or insurance coverage has changed. The phone number has changed, so the MA writes the new number on the encounter form. She will key it into the computer after the visit concludes.

[If the patient's insurance had changed, the MA would summon the cashier to the exam room to do the necessary paperwork. The cashier would work to complete this change before the provider arrived but would complete the paperwork at the conclusion of the visit should the provider interrupt the process. The principle: Nothing interferes with the encounter between patient and provider.]

When the doctor enters the exam room, the MA remains to serve as vital support to the doctor. The MA focuses on the paperwork and logistics, while the doctor focuses exclusively on the patient. While the doctor examines and treats the patient, the MA is making entries—at the doctor's direction—on a specially engineered notes form. Towards the end of the encounter, the MA drafts a prescription as requested by the doctor and hands it to the doctor for review before she, in turn, gives it to the patient.

[During this encounter, medical record entries were completed at the time of visit—so records will not accumulate into a depressing stack on the provider's desk to be updated at the end of day. Also, please note that medical record entries reflect what was communicated to the patient. Typically the provider reviews entries at the close of the visit.]

The doctor asks the MA to set up a follow-up appointment for the patient in two weeks and makes sure she understands her medication schedule. The doctor moves on to see another patient while the MA carries out the doctor's instructions without the patient having to leave the exam room. The MA has noted that the patient's new insurance status necessitates a co-payment so she informs the cashier that the encounter has concluded. The cashier then enters the exam room to tell the patient she will not need to go to the cashier's window because all collections now take place in the privacy of the exam room.

As the patient is leaving, several staff ask if she has everything she needs, and once assured that she does, say goodbye. Only 40 minutes have elapsed since she arrived at the health center.

Source: Coleman Associates, "Redesign: A Catalyst for Transformation: The Apollo 11 Case Study," http://www.patientvisitredesign.com/coleman_associates/cs_apollo_11.html (accessed June 22, 2007).

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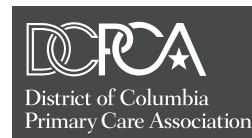
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