

# Supporting Patients' Engagement in Their Health and Health Care

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## Supporting Patients' Engagement in Their Health and Health Care

Providing more patient-centered health care has attracted interest from a wide range of stakeholders. Principles that characterize such patient-centered care often describe the responsibilities and attributes of the professionals and institutions that deliver such care. Included in these principles are general accounts of how patients should be treated: that their preferences should be respected, their emotional needs attended to, their autonomy supported and their decisions shared with families and the care team.

What is often lacking from the descriptions of patient-centered care is the recognition that patients are not merely the objects of care, but rather that they are full-fledged participants in it – and that unless that participation is active and informed, the beneficial impact of health care, whether services, drugs, surgery or devices, is severely muted. People who are unable to seek care when they need it, who don't fill their prescriptions, who delay their colonoscopies indefinitely or who keep smoking – regardless of the reason – place their own health at risk, waste human and material resources and incur unnecessary expense to themselves and others.

Full participation of every patient in finding and using safe, decent health care is vital to the success of the health care enterprise in improving the health of individuals and the population. We know that some patients will only partly meet this aim and that many never will. But we also know that those who are able to a) manage complex drug regimens, b) care for themselves after surgery, and c) consider complex information when finding the providers and treatments that meet their needs are more likely to reach the promise of increased length and improved quality of life that advances in medicine offers.

Current disparities in health outcomes will only increase unless the central role patients now play in the success of their care is recognized and addressed. What opportunities does delivering more patient-centered care present to enable all patients to benefit optimally from the care available to them?

The enthusiasm surrounding patient-centered care also signals readiness on the part of many professional health stakeholders to modify their own behavior in response to the current demands of health care delivery. This transformation sets specific new expectations for professionals and it is only seemly, that in explicitly patient-centered settings, patients -- the ultimate stakeholders in health care -- understand what they can now expect from their health care providers. But the transition from standard issue health care to more patient-centered care also requires setting in place practices and services that will enable patients to positively participate in their health and health care to the extent they are able.

Given the current interest in patient-centered health care, we offer providers and policy makers two modest approaches to ensure that their efforts to deliver more patient-centered care also supports patients' ability to participate actively in their own care.

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## What are the RULES of engagement?

Each practice and clinic has unique ways of doing business: how to make an appointment, how to contact the doctor or the team, who to discuss financial matters with, whom to call for problems in the middle of the night, how referrals are handled. Why not develop and distribute a **short guide** that spells this out?

It is frustrating both for patients to have to guess what the rules might be and for staff that spend their days correcting those who guess wrong. Attachment A provides a list of information that patients need to in order to interact effectively with a clinic or practice. A concerted effort to provide this information early and often to every patient in the form of a pamphlet provided at every visit, available in the waiting room and posted on practice Websites would be welcomed by most patients.

## What are the TERMS of engagement?

The change from current models of health care services to care that is purposefully patient-centered offers an opportunity to make explicit previously assumed expectations about responsibilities of both providers and patients. Rather than develop a contract, which smacks of legal obligation and litigation, consider developing a **pact**. A pact is an agreement about roles and responsibilities that recognizes the mutual interdependence of the parties: neither can solve the problem without the other. A pact is also entered into with a sense of moral and social obligation which expresses the intent of all parties to work together toward a shared aim.

So, for example, a pact might include patients agreeing to behaviors such as “I will discuss all my current medications, non-prescription medication products, vitamins or herbs as well as all of my current and past problems with providers, recognizing how important this information is in guiding my care and making me safer.” (Casale, AS. 2007) Or, “Before leaving my appointment, I will ask questions when any explanations and next steps are not clear.” On its end, the care team would agree to such behaviors as “We will ask specifically what the patient’s concerns and questions are for the visit. We will respond to concerns and answer questions.” Or, “We will help you understand your treatment options by discussing the pros and cons and possible outcomes with you because there is often more than one possible response to your symptom or disease.”

Many patients are not used to querying their clinicians when they don’t understand a recommendation, nor are they always aware of the impact of their specific behaviors on the course of their disease. Outlining the expectations of the clinicians about how and about what they hope to communicate is a good starting point. In all cases, the refusal of patients or providers to agree with the intent of the proposed pact behaviors/roles (see Attachment B), the statements would make for very interesting conversations indeed.

Attachment B consists of a list of ten sets of patient and clinician behaviors that are aligned to support active engagement and promote transparency by both the patient and their clinician team. The sets are also organized by three types of activities: *Sharing Information, Shared Decision Making and Responsibility for Care.*

Moving from traditional passivity to active, informed engagement is an unexpected challenge for many patients. One critical contribution of patient-centered care is to ensure that every patient and every caregiver has the knowledge, skills and opportunity to take effective action.

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## Attachment A

### Short Guide for Patients\*

A basic “how to benefit from and use our medical services” guide for patients should include:

- Guidance about when to seek and where to go for after-hours and emergency care.
- How to make appointments, along with a description of no-show policies and expectations for timely arrival with reasonable estimates of waiting times (both for an appointment and when waiting to see the clinician after arriving).
- If and how the provider can accommodate unique needs (physical navigation, hearing or visual impairments, translation services, etc.) and how to arrange for assistance if needed.
- The health insurance documentation and/or payment process required for receiving care.
- Guidance about bringing another person to assist the patient if he or she is frail, confused, unable to move around without assistance, unable to remember the conversation with the provider or simply needs support.
- Instructions for bringing a summary of their medical history, current health status and recent test results or referral documentation as appropriate.
- What type of diagnostic tests are commonly conducted in the practice, what tests or treatment follow-up is commonly provided by an external provider (with name of various providers, e.g., radiologists ) and how patients or caregivers will be notified of test results.
- Instructions for securing prescription refills, reporting adverse side effects and decisions to discontinue medication or change agreed upon treatment plan.

(\*Adapted from the Center for Advancing Health’s Engagement Behavior Framework)

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## Attachment B

### Patient-Clinician PACT \*

*Just as patients are supported by family members and caregivers, clinicians function as part of a medical practice, with an invaluable support team. The roles of Patient and Clinician, as described in the following responsibilities/behaviors, depend on these care networks to assist with meeting expectations.*

#### Sharing Information

- Patient:** Before each medical visit, write down a list of concerns and questions to talk about with your clinician.

**Clinician:** Ask specifically what the patient's concerns and questions are for the visit. Respond to concerns and answer questions..
- Patient:** Report accurately on the problem: How long has it been going on? How severe is it? How does it affect you?

**Clinician:** Provide a safe setting for talking about confidential concerns. Inquire about mental and physical symptoms, any substance use, changes since last visit and progress in previous treatment plan.
- Patient:** Bring a list of all current medications and their doses, including vitamins, supplements and alternative products and be ready to let your clinician know if they are helping you or if you are having any problems with them. Bring all reports and clinical notes from other doctors to your visit.

**Clinicians:** Review the list of medications and how they are working. Make a plan for refills, substitutions and discontinuation.
- Patient:** Before leaving your appointment, ask questions when explanations and next steps are not clear.

**Clinician:** Ask your patients to describe their understanding of what you have talked about and what each of you will be doing next.
- Patient:** Tell your clinician when you get care somewhere else; for example, if you go to the emergency room or see a specialist your clinician didn't refer you to. Authorize those doctors to share this information with your clinician.

**Clinician:** Ask the patient about whether he or she has consulted other clinicians. Be sure that medical information is shared with other appropriate providers and institutions.

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## Shared Decision Making

6. **Patient:** Ask about and consider information about how different treatments or tests might affect you.  
**Clinicians:** Describe the benefits and risks of treatments and tests.
7. **Patient:** Agree on a care plan with your clinician. Follow-through on referrals for treatment and testing. Track any success or problems with following your care plan.  
**Clinician:** Agree on a care plan with your patient; explain your reasons for advising any treatments and tests. Provide or prescribe sources for additional information and support. Make and record referrals and provide contact information for them. Discuss how you will monitor and revise the plan together.
8. **Patient:** If you are told that you have a serious illness, ask your clinician to help you get other expert opinions on your condition and care plan before starting treatment.  
**Clinician:** Provide guidance and referral about getting other opinions about serious diagnoses prior to beginning treatment. Meet to talk about what to do if you get different expert opinions.

## Responsibility for Care

9. **Patient:** Fill or refill prescriptions on time. Use medications or devices as directed. Monitor whether they are working and any side effects. Consult with your clinician before you stop taking any prescribed drug or change the way you are taking them, stop any therapy or stop using prescribed devices.  
**Clinician:** Use electronic prescribing or some form of medical record checklists to make sure that your patient receives the right drugs at the right dose and that any new drugs don't conflict with the patient's current medications. Ask the patient about the effectiveness and side-effects of the drugs you previously prescribed.
10. **Patient:** Discuss with your clinician about whether you should get shots (e.g., flu shots) and tests (e.g., Pap, mammogram and colonoscopy).  
**Clinician:** Discuss your patient's health and family history; modify standard recommendations for shots, screening and early detection tests as needed. Assist by providing shots and tests or make referrals for screening or early detection.

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The Center for Advancing Health (CFAH) is committed to creating an America where everyone is equipped to live a healthy life and make informed choices about health care. For more than 15 years, CFAH has worked to translate complex scientific evidence into information, policies and programs that will ensure that each person can make wise decisions about their health and interact effectively with their health care providers. CFAH is an independent non-profit organization that is supported by a number of foundations (principally the Annenberg Foundation and the W.K. Kellogg Foundation) and individuals.