Patients and Health Care Teams: Building Successful Partnerships

PRESENTER MANUAL
The National Partnership for Women & Families is dedicated to promoting public policies and business practices that expand opportunities for women and improve the well-being of our nation’s families. We believe that actions speak louder than words, and for more than 40 years we have played a critical role in enacting landmark policy from prohibiting pregnancy discrimination to giving 60 million Americans family and medical leave.

Today, we promote fairness in the workplace, access to quality and affordable health care, and policies that help women and men meet the dual demands of work and family.

Through education, outreach, and public policy, the National Partnership is an effective advocate for millions of women and families.

Founded in 1971, the National Partnership is a nonprofit, nonpartisan 501(c)3 organization located in Washington, D.C.
### Introduction for Presenter

The Patient Empowerment Training Module is designed to be an interactive presentation between a presenter and a single patient or group of patients, families and caregivers. These sessions ideally last about 45 minutes to an hour and should include discussion.

Attendees should be given manuals, which are similar to this one, but have dedicated space to take notes, which should be encouraged.

The goal of the Patient Empowerment Training Module (PETM) is to empower patients to identify quality care, seek quality care, and partner with their providers to improve their health. In preparation for the session, presenters should review the materials and become comfortable with the content. The most successful presenters:

- Are consumer or patient advocates with strong knowledge of the health care system.
- Include local and supplemental materials. These may include health passports, medication cards, fact sheets or any other materials produced for consumers by consumer and community groups or governmental organizations.
- Keep the session interactive and specific to the patients and caregivers in attendance. Sessions should include several opportunities for attendees to tell their stories and ask questions.
- Understand the importance of quality health care and how to find it locally.

The additional information offered in this manual should be used as guidance for your sessions as a presenter, not a script. Each session should be unique and presenters should remember above all to be yourself!
Talking Points for Patient Empowerment

- **You** are the most important member of your health care team.
- Understand what it means to get **quality health care**, and how to find it.
- **Partner** with your health care team.
- **Take action** if you are not getting the right care.

This manual was created to help you and your family find ways to get the best health care results. By best results, we mean quality health care. This is getting the right care, at the right time, for the right reason.

Patient empowerment is about how you are the most important person on your health care team, and how being an engaged patient is an important step in getting better care. This tool will also highlight ways for you to know you are getting the best possible care and your options if you don’t think you are getting the best possible care.

**Who Is The Most Important Person On Your Health Care Team? You!**

A health care team is anyone that is part of your health care experience. Your team may include physicians, nurses, medical assistants, pharmacists, lab professionals, physical therapists, family members, or mental health professionals. Of all of the people on your health care team, YOU are the most important person. You CAN make a difference in the kind of health care you receive. There isn’t a “one size fits all” approach to medicine. We all depend on our health care providers for information and treatment. We may not think about whether we are getting the right care, at the right time, for the right reason. But receiving quality care will help us and our loved ones live full lives with as few problems as possible.

**What is an Empowered Patient?**

Empowered patients are individuals who recognize that they are the most important member of their health care team. They partner with their health care teams to determine the best choices and decisions for their health and understand what quality care looks like. They ask questions, come to appointments prepared, choose their doctors based on quality, and communicate with their health care providers if they feel they aren’t getting the best care. Empowered patients know that quality care is possible and partner with their health care providers to achieve it.
Can You Relate To Feeling This Way When Interacting With Your Health Care Provider?

- Weak
- Dependent
- Not in Control
- Scared
- Confused
- Ignored
- Rushed

Can you relate to feeling this way when interacting with your health care provider? How do you feel? Has anyone in your family told you that he or she feels this way?

Most of us have felt some, maybe even all these emotions when getting medical care. Even people who are in control in every other part of their lives may not feel in control when it comes to interacting with the health care system. Instead, many of us feel rushed, unable to understand what the doctor is telling us, or uncertain about how to take care of ourselves.

Here are some explanations of how a patient or caregiver might feel during a visit to a health care provider.

**Weak**
When you are sick or concerned about your health, it is natural to feel vulnerable, tired or low on energy. In this state some patients may find it hard to focus.

**Rushed**
Many health care providers typically have busy schedules and try to see many patients over the course of a day. This pace can result in patients feeling like they don’t have enough time with their doctor.

**With few options**
It is easy to feel frustrated by the lack of information available to you when deciding what doctor to visit. At the same time, the amount of information available to you when researching a condition or disease can be overwhelming.

**Not in control**
The traditional notions of “the doctor knows best” and “the doctor knows more” are hard to shift. Even if your doctor supports you getting more involved in your own care, the perceived authority of the white coat can be intimidating.

**Scared**
When faced with an illness, you may be fearful about how the illness will impact your health and lifestyle. You may also be worried about the financial impact to you and your family because of medical bills and missed time at work.

**Confused**
Even if English is your primary language, medical jargon is unfamiliar to many of us and can leave you feeling confused and overwhelmed.
Can You Relate To Facing These Challenges When Interacting With Your Health Care Team?

- Time
- Emotions
- Culture and Language
- Health Care System Design
- Finances

We just addressed some of the emotional barriers to actively engaging in your health and health care—feeling confused, rushed, not in control, etc. There can be other barriers as well. Some of these can be the result of personal circumstances, like finances or cultural differences. Some are larger, like the way our health care system is currently designed to deliver care. What are some other barriers to being engaged patients?

**Time**

It takes time and effort to be an active partner and collaborate with your health care team. The time you take to prepare for your visit—researching your condition, preparing questions to ask, creating a current list of medications—will be well worth it in the end. Think of it as an investment in your health or the health of a loved one. This investment includes not only the time you use preparing for your visit and while at your appointment, but time spent following through with your recommended health plan. This plan might include time spent visiting another provider, exercising, or other life changes.

**Emotions**

Growing into the role of empowered patient or caregiver can feel intimidating and overwhelming—change isn’t easy! This manual is designed to give you a starting point and to help you find local and national resources to help support you in partnering with your health care team.

**Culture and Language**

In addition to the traditional patient-health care team relationship described earlier, there are many cultures where it is customary for people to follow advice and instructions from those in positions of authority, like physicians, without question or input. If you don’t think you can follow some of the steps in this manual, start small and with those changes that cause you the least discomfort. They can improve the health care you receive. You may also have difficulties if you or a family member speaks a different language than your health care team. Hospitals and doctor’s offices are required to provide translation services for non-English speakers. A medical translator is preferred to using a family member as a translator and provides greater privacy for the patient. Request a translator when you are making your next appointment.
Health Care System Design

There are important local and national efforts underway to improve our health care system, but we have a ways to go and empowered patients play a key role. Our health care system was not originally designed to support patients’ efforts to seek out information and take an active role in ensuring that they receive quality care. In the past, patients reported that they left appointments with unanswered questions, and were rarely asked by providers about their own preferences or didn’t feel as involved in decisions about their care as they wanted; however, this is changing. More and more often, health care teams are ensuring that patients and families are at the center of care.

Finances

It can be costly to take care of ourselves. Doctor visits, transportation to/from appointments, medications, exams, etc. can be financial burdens. It is very important to communicate with your health care team if you are unable to follow through with any part of your health care plan because of financial reasons. It might be embarrassing to share this information with someone, especially a new provider, but your health is at stake and he or she may be aware of resources in your community to help you.
Rethinking Your Health Care Journey

Find a Workable Plan, Be Part of a Team, Get Involved, Feel Powerful

Getting the care you need, want, and deserve is possible. You can go from feeling confused, alone, rushed, and scared to having a workable plan, feeling like you are part of your health care team, more in control of your health, and getting the best care possible.

While these goals are very possible, they can take time to achieve. Small wins, like feeling confident enough to ask questions, should be celebrated.

What Does it Take to Get There?

- Active patients.
- Health care team that works together.

Both you and your doctor play important roles in achieving your health care goals.

What does ideal care look like?

- Health care team – A patient’s care team consists of his/her primary care doctor, any and all specialty doctors, and of course the patient, as well as any caregivers or loved ones involved in the patient’s care. All of these parties should communicate and share relevant information with each other, such as new medications or changes in one’s health.
- Patients and providers work together – Discussions between patients and their care team should be multi-sided, with providers expressing clinical options and patients sharing information and expressing their preferences.
- A clear plan with goals – Patients and their care team should talk about the patient’s options and work together to share decisions related to care and to achieve goals.

What do you think of these ideas? How does this compare with the care you currently receive?
Become an Activated Patient

- Learn about your condition and how to care for yourself to live your best life.
- Look for information on what you should expect from your health care team.
- Choose a health care team that provides good care using resources available to you.
- Partner with your health care team to get good care.

Let’s take a look at your role in your health care. Listed above are some of the things you need to do to be an empowered patient and to get the best care possible. Have you done any of these things? Which ones are easiest to do? Which ones are more difficult? Why?

Finding Patient Information

American Diabetes Association
www.diabetes.org

American Stroke Association
www.strokeassociation.org

American Heart Association
www.americanheart.org

Mental Health America
www.nmha.org

Asthma and Allergy Foundation of America
www.aafa.org

Almost every disease has a national or local association working to share information with patients and families. Find the association, ask your doctor if he or she knows of any patient groups for patients like you, look online for organized groups of patients, or ask your local librarian for assistance finding resources and reference materials.

These websites sometimes have information on the best kinds of care for certain conditions. Did you know that there are certain guidelines that doctors, nurses and other health care providers are expected to follow to give you the best care possible? They are based on the idea that patients need the right care, at the right time, for the right reason and they are determined by research. This information is known as clinical care guidelines, or evidence-based care. These guidelines may include tests, physical exams, or information that your doctor should share with you.

For example, the American Diabetes Association (ADA) has a diverse group of highly trained health care providers who look at research on treatments and then decide on a set of care guidelines. The ADA executive committee approves them and publishes them in its newsletter. Patients with diabetes then have a trusted source for the most current and well-researched care guidelines and know what to expect from their doctors.
Annual Diabetes Care

Your health care team should:

**At every visit**
Check your weight, BMI (body mass index) and blood pressure.
Give you a foot exam.

**Every 3–6 months**
Give you an A1C test.

**Every year**
Give you a flu shot.

**At least every year**
Check your blood fat levels & triglycerides.
Check your cholesterol, LDL & HDL.
Check your kidney function.
Give you a dilated eye exam.
Check your feet to make sure they have feeling.

*Above is information about the care a person with diabetes should expect.*

We may not think to ask if we are getting the right care. But the right care will help us live full lives with as few problems as possible. So we should expect certain things from our health care teams—at every visit. The clinical care guidelines may be more extensive, but with this checklist, the patient can be assured that he or she is getting the most important tests and treatments.

Diabetes is not the only condition with a clinical care checklist like the one above. For example, a pregnant woman’s first visit with her provider should include:

- A complete medical history
- Urine and blood tests
- Tests for sexually transmitted diseases
- Complete physical and pelvic exams
- A review of any medications and vitamins the woman is taking
- A discussion of how to stay healthy while pregnant and
- A determination of the expected delivery date

Searching the websites of associations like those listed on the next page can help you find information relevant to your health. You can also ask your local health department or your health care team if they know of an organization that supports patients like yourself or if they have any materials available on clinical care guidelines.
Finding Quality Health Care - National Resources

Nursing Home Compare
www.medicare.gov/NHCompare

Home Health Compare
www.medicare.gov/homehealthcompare

Hospital Compare
www.hospitalcompare.hhs.gov

Leapfrog Group
www.leapfroggroup.org

Physician Compare
www.medicare.gov/find-a-doctor/provider-search.aspx

It’s important to be familiar with your condition and the kind of care that is most appropriate for it. Equally important is to know how well your doctors and hospitals provide care.

Did you know these sources of information are available? Have you ever used any? Will you use any in the future? Why or why not?

For explanation if needed:

Nursing Home Compare includes information on nursing homes that are Medicare or Medicaid certified and provide skilled care. There are many types of facilities that provide various levels of health care and assistance, some of them are not found in Nursing Home Compare because they are only licensed on the state level or choose not to participate in Medicare or Medicaid.

Hospital Compare provides information on how well the hospitals in your area care for all their adult patients with certain medical conditions. Information submitted is on a voluntary basis, and while most hospitals participate on the site, some do not. [NOTE: Presenter should research which local hospitals participate with the site before presentation]

Physician Compare is a professional directory of physicians and other health care providers. Currently, users can search for a provider using criteria including specialty, location, languages spoken, education, and hospital affiliation. Medicare beneficiaries can also identify participating providers.

Home Health Compare provides information on agencies in your area that provide home health services such as physical therapy, occupational therapy or home health aide services. Users can see information on how well agencies score on measurements of quality care compared to state and national averages.

The Leapfrog Group works to improve the transparency, quality and safety of our health care system. A useful resource offered by the organization is their Hospital Ratings tool which allows users to view and compare quality data for over one thousand hospitals.

All of these tools are valuable even if your nursing home, hospital, or physician does not participate because you can learn what information you may want to ask about when making a decision on where to get care.
The Informed Patient Institute allows users to search by state for websites that rate doctors, hospitals and nursing homes, and more importantly, grades these websites according to their usefulness to consumers. Websites include those that provide information on the performance of providers and are graded on a basis of A (outstanding) to F (not worth your time).

Aligning Forces for Quality is the official website of the AF4Q project. Here users can find links to reports on the performance of providers in many of the AF4Q communities.
Steps You Can Take To Get The Best Care

- Prepare for appointments.
- List your visit goals with the most important ones first.
- Bring a friend or family member to appointments.
- Bring a list of all your medications.

These are examples of important actions patients can take to improve the likelihood of receiving the care they deserve. These are ideal steps and you may already do one or two of these things, but the goal is to work towards as many as possible over time. The more steps you take from this list, the better your chance of receiving quality care.

You really do make a difference!

I. Be prepared for your appointments. Why are you seeing your health care team? If it is due to illness, record the symptoms and anything you are taking for them. For example, if it is for the flu, record your symptoms, such as fever or vomiting, and any over-the-counter flu medication you have taken.

II. Keep a running list of things you would like to discuss with your health care team. If this list is long, you may want to call the office and ask to schedule your appointment during the slowest part of the day. The night before, prioritize the points that you would most like to discuss with the doctor. If you don’t get to everything on your list during your appointment, ask if you can either speak with someone on the team who has more time that day, email your concerns to the doctor, schedule a time to speak on the phone with the doctor or other member of the team, or address these issues at an already-scheduled follow up appointment.

III. Bring a friend or loved one with you to your appointment. They will be able to help you take notes and absorb the information presented by your health care team. This can be especially true when you are receiving a diagnosis. You may want to tell someone in the office when you make or arrive at your appointment that a friend or family member will accompany you for your doctor’s visit. If no one is available, bring a pen and paper. When you take notes, make sure you get things down as exactly as possible and repeat them to the doctor if you are uncertain or think you may have missed something.

IV. Bring a list of all the medications you are currently taking—prescription and over-the-counter. Remember to write down the strength or dosage of the medications in addition to their names and the frequency with which you take them. Include any vitamins or supplements that you take regularly as well.
Steps You Can Take To Get The Best Care

- Share preferences, needs, medical history and other information.
- Actively listen to what the doctor or other medical staff tells you.
- Ask questions.
- Follow through on treatment.

I. Don’t be embarrassed to share things about your health. While it is difficult to share private symptoms, it is important that you do so. Sharing this type of information includes letting your team know if health treatment may be difficult for you, and the barriers you may be facing. For instance, if the doctor tells you to get more exercise, but you can’t afford either the time or the money to join a health club, talk with him or her and ask for suggestions of things you can do at home to increase your activity and achieve the same results. No one knows better than you how your treatment plan fits into your life. For example, do you have the time, financial resources, emotional support, etc. to successfully follow the plan your health care team is recommending? If not, let someone know.

II. Medical appointments can be stressful, which makes it hard to listen and remember. To make sure you are staying focused and understand what your health care provider is saying, it can be helpful to repeat back important points in your own words, using phrases like “what I am hearing is...” or “Just to make sure I understand, you are telling me...”. If your health care provider uses a computer to record your visit, ask if you can have a copy of the summary. It will include important information for you to review and it may also help you prepare for future appointments. Some patients who have trouble taking notes physically or have a particularly important appointment have found it helpful to bring a recording device to record important information from the health care team.

III. Ask questions. Not only about things that confuse you but if your doctor is suggesting further tests, ask why. Will the tests confirm your diagnosis or only eliminate a possible disease? If the doctor prescribes medicine, make sure you understand its purpose, possible side effects, and what other options may be available. Don’t be afraid to ask questions if you don’t understand something or if your health care team is using medical language that you don’t understand. You can ask, “Could you put that in plain language, please?” At the end of a visit, ask for clarification, repeat back what the doctor has told you, and confirm that you have understood it correctly. For example, “So I won’t see the effects of this new medicine for two weeks, and it might make it harder to sleep for the first few days. Is that what you said?”

IV. It can be helpful to do some research before your appointment both to formulate questions you may want to ask and to understand more of what you will talk about with your health care team. BUT do not print out an entire website and expect your doctor to have time to read through the information during your appointment. Instead, summarize or highlight important sections.

V. If there are things you need to do after your appointment, do your best to follow through. For example, fill and take your prescriptions. Start measuring your blood sugar or blood pressure. Start exercising. While the health care team can help you achieve good health, ultimately it is up to you.
Partnering With A Health Care Team: What You Should Expect

- Respect.
- Collaborative Relationship.
- Active Listening.

We’ve spent a great deal of time on ways that you can take control of your health and get the best care possible. Now, we’ll spend some time on what you should expect from your health care team.

**Respect**

Patients should expect their health care team to show respect by not keeping patients waiting for long periods of time at appointments, allowing time for questions, and sharing information during the appointment. This also includes accounting for an individual’s preferences and values when making decisions about care plans, using patient-friendly language, and addressing any cultural barriers.

**Collaborative relationship**

You, not your health care team, do most of the work to manage your condition, and you deserve support. Working together to change for the better is a long-term process. Working together means you, your family members, and your care team respect each other’s expertise, share information, build a mutual understanding of your goals, and together create a plan that everyone can use to guide care at home and in the doctor’s office or hospital.

**Active listening and encouraging input and feedback from patients**

The next two items are closely related. You and your family bring information to your health care team that no one else can provide, which is essential when forming a care plan that works for the patient. You should feel confident expressing your needs, concerns and goals and that your health care team has heard and understands them. Ideally your health care team will send out surveys to their patients about their experiences with care and make adjustments as necessary.
Partnering With A Health Care Team: What You Should Expect

- Clinical Care Guidelines.
- Timeliness.
- Follow through.

**Clinical Care Guidelines**
Clinical care guidelines, discussed earlier on pages 9 and 10, apply the best available scientific evidence to clinical decision making about a patient’s care. Physicians and other members of your health care team use these guidelines to make sure that everyone gets the highest standard of care and help prevent errors. Patients should be able to go to any hospital in their community and receive the same standard of care for the same condition.

**Timeliness**
You should be able to schedule an appointment in a reasonable amount of time based on the reason for your visit. It may take a few weeks or even a month or more to schedule a routine physical, but it should not take very long to see or speak to someone on your health care team if you are concerned about symptoms of your condition, side-effects of medicine, etc. We already talked about patients not having to wait for long periods of time on the day of their appointments. In addition, patients who prepare for their appointments should be given time to talk about concerns and get information on how to follow-up with additional questions after their appointment, whether that be by scheduling another appointment, phoning or emailing the office at a later time, or speaking with someone else on the team at the time of their appointment.

**Follow through**
Your relationship with your health care provider isn’t over at the end of your appointment. Your provider may need to send you test results, give you a referral, help you find another doctor or get back to you after consulting with another provider. This ongoing communication between patient and provider is a fundamental part of coordinating your care. Well-coordinated care—communication between a primary care provider, specialists, labs, patients/caregivers—can help avoid over-, under-, or misuse of care and conflicting plans of care. Many health care settings offer opportunities to receive test/lab results or communicate with your care team using health information technology. Ask your provider if that is something available in your office.
What To Do If Your Relationship With Your Health Care Provider Is Not What You Want It To Be

- Work to improve relationship.
- Find a new health care provider.

Sometimes even though you may be trying your hardest to be an engaged patient, your relationship with your physician isn’t what you want it to be.

What are your options if you face this situation?

**Option A: Improving relationship with current provider**

If you must remain with your health care provider because of insurance coverage, where you live, or because you want to continue to work with her or him, there are things you can do to try and improve your relationship.

If you feel that your provider has left out important information, be direct and ask for a more detailed explanation. For example, “Can you tell me about possible side effects of this medication?” or “Should I schedule a follow up appointment?” Be candid with any concerns you may have, but not accusatory. List your concerns and then ask your doctor’s opinion.

Other approaches can also be effective. For example, if you have diabetes and your health care provider hasn’t done a foot exam (refer back to clinical guidelines on page 10), at your next appointment take off your shoes. If that doesn’t work, ask a specific question, like, “Will I be getting a foot exam today?”

Sometimes, you may be happy with some members of your care team and not others. These concerns can often be addressed with a nurse manager, or other clinical manager in the office or hospital.

**Option B: Switching providers**

Depending on your situation, you may need to find a new health care provider. I know it can be hard to find a new doctor, but don’t make that the hurdle to receiving the care you need and deserve.

If you are able to change doctors, use the resources mentioned previously—measures of quality care (refer back to page 9) as well as patient information networks available through consumer or patient advocacy groups like the American Diabetes Association—to find referrals and ask your friends and family about their health care providers.
Today’s Conversation

- You are the most important member of your health care team.
- Understand what it means to get quality health care, and how to find it.
- Partner with your health care team.
- Take action if you are not getting the right care.

We just discussed how you are the most important person in your health care journey, ways to tell if you are getting the best health care, and some options if you don’t believe you are getting the best care. If there are any parts of this discussion that you would like to talk through further, please let me know.

Active Patients And Health Care Teams Working Together

Change takes time, but you can start today!

Reinforce the following ideas/concepts:

- Importance of being involved in their health care and their family’s care
- Not feeling overwhelmed (start somewhere)
- Change takes time
- There are resources to help!