Forming a Patient and Family Advisory Council

Patient and family perspectives can help achieve higher quality care in your practice

AMA IN PARTNERSHIP WITH

Martin J. Hatlie, JD
CEO, Project Patient Care

Knitasha Washington, DHA, MHA, FACHE
Executive Director, Consumers Advancing Patient Safety

How will this module help me form a Patient and Family Advisory Council?

1. Eight STEPS to form a Patient and Family Advisory Council (PFAC)
2. Answers to frequently asked questions about PFACs
3. Tools and resources to help you and your team advance patient and family engagement strategies
Introduction

Patient-centered care is vital for the success of any patient care initiative. Understanding patient and caregiver perspectives is key to achieving desired results for all involved: patients, practice staff, providers and the community. A Patient and Family Advisory Council (PFAC) is future-oriented, bi-directional, and intended to play an active partnership role in how your practice prioritizes and designs changes that will affect the patient community. Strengthening the partnership with your patients and communities will help your practice better navigate change and increase the likelihood that you will be successful in implementing value-based care and payment transformation.

Q&A

How can creating strong partnerships with patients and families improve my practice?

A PFAC is a structured program that can:

- Work in partnership with the care team to continuously improve overall quality, safety and patient experience
- Help achieve recognition or accreditation of a practice as a Patient Centered Medical Home (PCMH)
- Ensure that patient, family and community perspectives and needs are represented in business development and program implementation and evaluation
- Provide meaningful feedback on office practice policies and operations from the patient’s point of view
- Offer insightful contributions to decision-making, especially when PFAC members reflect the diversity of populations your practice serves
- Optimize educational materials and strategies that advance effective patient and family engagement (PFE), support patient self-management, improve treatment results and increase satisfaction
- Support care team and practice staff morale by contributing to the joy and meaning health care workers experience when patients feel respected and have optimal treatment results

What defines a PFAC “advisor”?

Individuals who volunteer their time and work in collaboration with the care team on a regular basis are considered advisors. People who participate in a one-time project or focus group are not advisors.

What is the difference between patient and family engagement (PFE) and a patient and family advisory council (PFAC)?

Establishing a PFAC is one of many strategies for engaging patients and family members as true partners. The figure below depicts a widely cited framework for classifying the types of engagement of patients and families at three health care system levels: in a partnership at the point of care (green); in governing or operating health care delivery
Sometimes I hear colleagues talk about “person and family” when discussing engagement. How is this different from “patient and family”?

In 2015, the Centers for Medicare & Medicaid Services (CMS) signaled a shift in language from using “patient” to using “person” in recognition that health providers are in relationships with “whole persons.” This acknowledges that the patient’s role is not just as a user of care, but as an individual whose ideas and insights often draw on personal and professional skills and life experiences. PFACs exemplify the importance of this refinement in language because
PFAC members work as advisors to the care team and practice staff, not just as patients at the point of care. PFAC is now an acronym used interchangeably to abbreviate both “person” or “patient” and family advisory council.

Eight STEPS to form and get to work with your patient (or person) and family advisory council (PFAC)

1. Develop your practice’s business case for the PFAC and ensure leadership support
2. Create a PFAC planning committee
3. Develop an action plan, charter and budget
4. Invite, interview and select PFAC members
5. Launch the PFAC and support the members in their work as effective advisors
6. Initiate improvement projects in partnership with PFAC members
7. Track the results of PFAC work
8. Celebrate PFAC successes

Develop your practice’s business case for the PFAC and ensure leadership support

Experience shows that it is essential for practice leaders to be on board and supportive of the PFAC if it is to succeed and be sustainable. Building the business case for your PFAC will help you demonstrate value to patients, staff and leadership. It will also aid in action planning later in this process.

Advancing the practice of patient and family centered care in hospitals (PDF, 542 KB)

The first step to building a business case is a PFE self-assessment. Take a comprehensive look at your program infrastructure to determine where you can utilize a PFAC to its full potential. Consider these items when performing your self-assessment to identify opportunities for integrating PFAC input:

- The value and importance you and your team place on patient and family perspectives
- The anticipated role and responsibilities of PFAC advisors
- The expected contribution advisors will make in programs and/or improvement projects
- Existing policies

The following items are also important when performing the self-assessment:

- Loyalty/patient turnover
- Evidence that patients’ needs are being met
• Input from staff as to whether connections are being made with the patients served

The assessment will also serve as a baseline measurement that can be used to track results as you implement meaningful PFE in your practice.

If your practice has just one location, it probably makes sense to start with a PFAC that advises on multiple, and perhaps all, aspects of the practice. However, some practices prefer a more service-line approach; this will depend on the goals of the PFAC. Examples include PFACs that are focused on diabetes care, management of HIV, or the well being of seniors.

If your practice has more than one location, consider developing a PFAC for each location that have a common set of goals and a similar structure. You might also consider a regional PFAC whose membership is made up of patients from a county or other geographic area that is defined by a common sense of community or set of interests.

Q&A

What is the business case for forming a PFAC?

Forming a PFAC has resulted in the following business benefits for practices:

• Better outcomes, including fewer treatment complications and hospital admissions and safer, more effective medication use
• Alignment with performance-based reimbursement, alternative payment models and other “volume to value” transformation efforts
• Alignment with the core components of and recognition/accreditation criteria for a PCMH
• Improvements in patient satisfaction ratings, including “likeliness to return” and “willingness to recommend”
• Improved staff satisfaction
• Differentiation from practices that do not utilize a patient-centered approach to care
• Improved market share
• Improved image and preference
• Potential reduction in malpractice claims
• Low cost and “low tech” to implement because no new equipment is needed

Can you share examples of different ways to structure and staff a PFAC?

The Vidant Health system, which extends across eastern North Carolina, is implementing regional PFACs that meet at convenient locations spread across the area. The Aurora Health Care system in Wisconsin implemented a county-level PFAC focused on safe medication use by seniors; this PFAC meets at a county building and other community venues already used by seniors.

If your practice is affiliated with a larger system, you may wish to consider coordinating your practice PFAC with a larger system initiative. MedStar Health, a Washington, DC- and Maryland-based system, has a system-level PFAC, at least one (sometimes more) local-level PFAC in each of its 10 hospitals, and other PFACs that are organized by its affiliated physician groups across the area. All have similar charters and the same reporting relationship to MedStar Health's safety and quality committees.*
Additionally, some state privacy and confidentiality laws may go beyond HIPAA; these criteria will depend on the state in which you reside.

There are also multiple ways to structure staff involvement in PFACs, two of which are shown here:

<table>
<thead>
<tr>
<th>Healthcare Patient Partnership Institute (H2Pi model)</th>
<th>All-patient model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Includes practice staff as members of PFAC</td>
<td>Membership of PFAC consists solely of patients, family members or other members of the community.</td>
</tr>
<tr>
<td>Patients and staff co-lead the PFAC</td>
<td>Practice leaders and staff provide support for the PFAC but do not co-lead.</td>
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### 2 Create a PFAC planning committee

When building your PFAC, designate a planning committee consisting of administrative and clinical staff. This committee will identify potential advisors, be involved in the interviewing and selection process, and develop the PFAC charter, which lays out the council’s purposes and rules. The H2Pi toolkit includes a guidance tool for forming a PFAC Planning Committee.

**Q&A**

**How do I prepare my colleagues to begin partnering with patients if they have doubts about a PFAC’s value?**

One way to generate buy-in is to ask skeptics to participate on the planning committee. They are often pleasantly surprised when brought along and their attitudes change, usually as they review applications for PFAC membership and interview applicants. Once you have selected your PFAC members, hold a meet-and-greet session as one of your first PFAC meetings.

**Is the planning committee dissolved once the PFAC is in place?**

Once the PFAC is established, some planning committee members may transition to be involved in staffing PFAC meetings or serving as members of the PFAC itself (see models above).

### 3 Develop an action plan, charter and budget

Your action plan should include goals, measures of success and a timeline. The PFAC may advise your practice on the following areas:

- Patient experience
- Patient safety
- Policy and program development
- Quality improvement
- Health care delivery redesign
- Patient education
- Patient/family communications
- Marketing
Council compact
(MS WORD, 45 KB)

Advancing the practice of patient and family centered care in hospitals
(PDF, 542 KB)

Your PFAC charter will serve as a guide for your practice and the council. Your charter should include:

- Clear purposes for the PFAC that reflect the business case you developed
- Guiding principles for the group, such as a covenant for how members should interact respectfully with one another and practice staff

Q&A

Should the PFAC have decision-making authority?

Typically, the role of a PFAC is to generate ideas and advise, not decide. This should be made clear in the PFAC charter.

Should there be term limits for PFAC members?

Many councils find that new and fresh perspectives help sustain PFAC energy and productivity over time. A typical model uses two-year terms that can be renewed twice, for a total of six years. Consider staggered terms so that not all members rotate off the council at once. Your charter should include a procedure for filling vacancies when members must leave before their term expires.

What should the budget for the PFAC contain?

Transportation. Most practices reimburse parking or transportation costs of attending the council meetings; some provide transportation where lack of transportation is a barrier to attendance.

Meals. Depending on the time of day, offering a meal or snacks and beverages during or before a PFAC meeting is appreciated.

Other compensation. Some offer modest monetary compensation, gift cards or honoraria for attendance to express appreciation for the members’ time and effort.
Invite, interview and select PFAC members

Open recruitment methods to select and retain people to serve on your PFAC include:

- Outreach to the community via mailings, email blasts, or messages posted to your patient portal
- Use of your practice’s monthly mailing, your website or other marketing materials
- Holding a town meeting-type event to invite questions
- Other community events

Interviews and use of short applications are important opportunities to make sure applicants understand the purpose of the PFAC and their role as members. These approaches also help practice leaders and staff understand what is motivating applicants to participate and if they have any personal agendas that could conflict with the goals of the PFAC.

From your applicant pool, select people who reflect the community and patient population your practice serves. Patients should come from a variety of neighborhoods and socioeconomic backgrounds. Warmly thank everyone who applies and keep a record of applicants you might want to invite back for other PFE opportunities beyond serving on the PFAC (for example, for special quality improvement initiatives such as reviewing a patient educational brochure).

Q&A

What does the interview and selection process look like for care team or practice staff members who want to participate on the PFAC?

Application and interview templates may differ slightly from those developed for community member applicants. Under the H2Pi model, any staff member passionate about PFE is encouraged to apply, regardless of their job description.

Who should be involved in recruiting patients and/or family members to apply?

Any care team member may recommend candidates for the council. Reaching out to patients and family members for their recommendations is also beneficial. You may also rely on your health coaches, community health workers or community groups to identify prospective participants.

What are some characteristics of great advisors?

Patients and family members who make great advisors exhibit the following characteristics:

- They can see beyond their personal experiences to consider others’ points of view
- They are respectful listeners
- They have served on teams where they had to collaborate with others to achieve a goal

Advisors need to be able to articulate their experiences with candor and comfort within a group. You may also choose patients and family members based on other characteristics, such as their age, gender or medical history. For example, if you know that one of the goals of the PFAC will be to seek input on diabetes education materials, you may want to look for advisors who have diabetes or who have a family member with diabetes.

As you interview potential advisors, consider their life circumstances, personalities and skills. During the process, reflect on each individual’s leadership style and personality.
What criteria should be used to screen applicants?

If your organization has a policy for volunteers, it should be used to pre-qualify applicants. Typically, volunteers need to agree to get vaccinations and complete Health Insurance Portability and Accountability Act (HIPAA) training, as well as undergo a basic security screening. During the application process, confirm whether the person is able to commit to attend scheduled meetings. Consistent presence at meetings is key to success of the PFAC.

Who ultimately has the authority to confirm or deny potential advisors?

Your practice leadership should be part of making decisions about who to appoint. The PFAC planning committee usually makes recommendations to leadership.

Are patients and families receptive to being asked to serve on advisory councils or task forces?

Experience has found that people are receptive and welcome the opportunity to help their care team and have their voices heard. In your messaging, present PFAC membership as an opportunity for meaningful volunteer work.

“Improve care by including patients in the discussion #STEPSforward”

Launch the PFAC and support the members in their work as effective advisors

The PFAC members need to understand your organization’s mission and goals, the need for confidentiality and their advisory role. When these core elements are clear, you will be able to forge an effective partnership.

At the launch meeting, begin with introductions of each member and start with the question, “What brings us here?” Orientation to the practice and the role of the PFAC can be achieved with a short overview of the practice mission and PFAC purposes. You may also cover logistics of parking, future meeting dates and times and so on. Other common practices include taking a group picture to celebrate the event. As members join the PFAC in the future, plan for time to orient them as well.

Q&A

How often should the PFAC meet to discuss and complete projects?

Most PFACs meet once a month, with some exceptions during summer vacation or winter holiday months. If your PFAC takes on specific projects, they may have different timelines. It is good to start with at least one project where progress can be made over a few months.

Do all meetings need to take place in person?

In-person meetings are the optimal format to maintain engagement and momentum, especially at the beginning as members get to know each other. PFACs increasingly are experimenting with accommodating members who need to participate remotely by telephone or webinar.

As a practice leader, what’s my role in the PFAC’s work?

An important role of physicians or other practice leaders is to visibly show support and enthusiasm for the PFAC. Clinicians and other practice staff will also have expertise that differs from community members.
Physician engagement is deeply respected and appreciated by the patients, who know how hard their physicians work and how limited their time can be.

How do I make the PFAC aware of our budget constraints so that we don’t end up with unwieldy projects?

Be honest about time or resource limitations. You can do so without sharing private business information. Remember that this is a journey you are taking with your PFAC partners. When PFAC members are aware of and understand limitations, they will adjust their recommendations as long as they feel their work still has value to the practice.

How do I make sure that the advisors respect confidentiality?

Respecting confidentiality should be part of the PFAC rules, expressed as a covenant that members have with one another. We also recommend that you have all participants sign a confidentiality agreement to emphasize its importance, regardless of whether you intend to share clinical information as part of their work. This will also be discussed in the HIPAA training, as well as the potential inclusion of Business Associate Agreements.

6

Initiate improvement projects in partnership with PFAC members

Practice leadership or the PFAC planning committee can identify issues or challenges they want to explore further with the advisors. Early meetings may benefit from presentations such as getting to know practice leadership, an overview of a process, or bringing the council a question or material to review. These presentations help to build a sense of community.

Brainstorming once the PFAC is formed is also a good idea and will help direct the group work towards a common purpose. Be aware that there may not be an agreement or bandwidth to work on all the suggestions.

Q&A

How do I initiate this brainstorming session?

Here are three ways to kick off your discussion:

- Use appreciative inquiry techniques, which ask positive, future-oriented questions to generate excitement and creativity. Asking “What works well here?” or “What should we be doing more of?” are nice ways to break the ice and approach the subject of improvement.
- Use Lean methodologies, such as “go and see” or “walk about” approaches to look at your practice from the perspective of the patients and their families.
- Review patient satisfaction surveys together. Find positive comments and ask the team “How do we get more patients to give responses like this after visiting our practice?” With negative feedback, ask for suggestions about what could be done better in the future.

What are some good starter projects?

Consider at least one project that could be a quick win to build group momentum. Popular choices include:

- Refining patient education or informational materials
- Asking about user experience with your electronic patient portal
- Asking about wait times in your office or other waiting room issues
- Considering how to design a new service or location
Probing communication issues between patients, families, providers or office staff

Bigger issues that you may wish to consider—because these concerns are familiar to most and understanding patient views on these topics is crucial to improvement—include improving medication adherence, preventing infections and preventing falls.

7 Track the results of PFAC work

Most PFACs find it easier to qualitatively measure impact at the beginning, using simple survey techniques to assess perspectives on the value of the PFAC. As you move forward, review patient satisfaction surveys to see if changes made with PFAC input show up in patient comments or if you can see them reflected in changed scores. If your initial PFE self-assessment revealed specific gaps that PFAC work helped to fill, that is a result that should be captured.

Q&A

What are some measures I can use to determine impact and success?

One simple qualitative measure you might consider is periodic evaluation of the opinions of leadership, care team members, staff and the PFAC members themselves about whether they think they are adding value. Examples of simple quantitative measures can be the number of meetings you had, meeting attendance, the number of ideas generated by the PFAC, the number of projects in which the PFAC was involved and the number of changes the PFAC helped your practice achieve.

8 Celebrate PFAC successes

Be sure to acknowledge your PFAC’s contributions by reviewing the results of its work together and then sharing your successes with your practice and your community. PFAC members can also help spread the word beyond the practice through their own networking in the community.

AMA Pearls

Give some attention to how you will measure the results of your PFAC’s work.

Even in hospital-based PFACs, measurement has historically been an afterthought. Measurements can evolve as your partnership strengthens.
Conclusion

PFAC participation can be incredibly rewarding for everyone. Acknowledging the unique perspectives of your patients and encouraging them to contribute to improving your practice can enhance the provider experience, bring joy back to work, and ultimately result in more efficient, effective and higher quality care.

STEPS in practice

1. Forming a Patient and Family Advisory Council in Salida, CO: A Case Study

First Street Family Health is a small, rural primary care practice in Salida, CO. In 2014, they received funding to redesign their practice structure as part of the Comprehensive Primary Care Initiative. One of the objectives of this redesign was to improve patient and family engagement in order to make patients and their families more involved in decision-making processes. As a small practice, it was often easy to feel that they knew the patients well and were doing everything to make them happy and keep them satisfied. They were surprised to find out how much improving engagement with patients could also improve the performance of their practice.

The practice first attempted to engage patients with patient satisfaction surveys. But without experience in survey design to glean appropriate data or interpret responses, they didn't find the surveys very useful. In many instances, surveys were incomplete and it was obvious that patients were not giving them much thought. Few patients used the surveys as a venue for delivering constructive criticism. So the practice decided to try something totally new—create a Patient and Family Advisory Council (PFAC).

Under the tutelage of a consultant from The National Partnership for Women and Families, First Street Family Health began building their PFAC. First, they assembled a team of staff members including the nurse care coordinator, a physician, a physician's assistant, front desk staff, medical assistants and back office staff. Next, they asked each of the four clinicians to list 10 people who they felt would be interested in participating in the PFAC and would do a good job as an advisor. They selected patients from each clinician's panel who best represented their community's demographics. They included patients and family members who were retired, parents, young, old, male and female.

Many patients thought it was unusual for the medical practice to ask their advice on how to be a better business, but they were receptive and excited about the potential to contribute. They commented on how they were honored that their doctor or nurse recommended them for this responsibility. It helped that Salida is a small community. The connection between practice members and the patient and family advisors is often personal—the advisor may be the bagger at the local grocery, the baseball coach for a practice member’s child or the realtor who sold a practice member their first house.

At the first PFAC meeting, the group covered the concept and goals of the council, established ground rules and discussed privacy issues. The next several meetings still felt like a warm-up and the work was slow to build. Patients were initially hesitant to do anything other than compliment the practice during the meeting. Because of this reluctance, the initial agenda topics were guided by the patient satisfaction surveys. Once the patients felt they had permission to give criticism, they were more candid and the meetings became more productive.
“What we think they want or what we think will be helpful is not always what they want. Patients need to understand what’s going on behind the scenes, what goals we have and why, and what restrictions a practice faces that they can’t change. This is eye-opening on both sides,” says Dr. Meggan Grant-Nierman, who serves on the PFAC as physician advisor.

The First Street Family Health PFAC has tackled problems big and small. These have included small things like whether the front desk staff should wear a uniform, such as a polo shirt or scrubs, as opposed to business casual attire; or big things like the design of a new office space. Two projects that stand out as particularly successful were revamping the phone triage system and guiding the design of the new office space.

The phone triage system was something that the practice had been working on improving for years. They didn't want to put patients on hold, but there were times they couldn't get to every call. Over the years, they tried adding more phone lines, hiring more front desk staff and introducing standard scripts. They even experimented with an automated answering system. The PFAC tackled this issue with enthusiasm and came up with a hybrid solution. When a patient calls, they hear an automated message where the first option is to press a digit to speak with a person. Clinicians and front desk staff were thrilled with the outcome. This early success instilled confidence in the PFAC's ability to contribute in a meaningful way. Now, when challenges come up during practice leadership meetings, the solution is often to “ask the PFAC.”

The PFAC also made a difference in the redesign of the office space. When the building was designed, the practice believed it would be appropriate to install a glass partition between the lobby and the reception desk. They thought that this separation would make patients feel more comfortable because their privacy was being respected. But when the PFAC toured the new layout their reaction was quite unexpected. They found the glass to be “rude”—it was a physical barrier that kept them closed off from the practice staff. In addition, they noticed the glass gave staff a false sense of privacy, making the staff think that patients in the waiting area couldn't hear them. Several PFAC members overheard staff having private conversations, some of which made patients feel uncomfortable. The glass was subsequently taken down and the open layout is now working well for everyone. Had the practice hired a consultant to work on the design of the space, they could have received the same feedback but spent hundreds of thousands of dollars in the process. In fact, the practice probably could have saved more money had they consulted the PFAC earlier in the design process.

Momentum can be difficult to maintain. To keep the PFAC engaged, the practice has taken innovative approaches and selected novel projects. For example, they had a PFAC member pretend to be a new patient. The “patient” evaluated every step along the way: finding a parking spot, entering the building, filling out the forms, etc. This triggered a project to recreate the new patient paperwork in a way that made it more useful for the practice and easier for the patients to understand. The practice also recently tasked the PFAC with redesigning the practice website to make it more user-friendly and appealing to patients. The PFAC has been able to evolve as progress is made and the focus shifts to other elements of the practice that can improve.

Although the practice requested that advisors commit to a one-year term for the PFAC, the term varied based on what people were able to commit. Some people drop off when they’ve completed their term, while others stay on. Fortunately, the turnover has been staggered, which has helped ensure continuity in the work. As people drop off the PFAC, First Street Family Health continues to keep balance in mind. In the PFAC's next iteration, the practice is trying to find ways to engage single parents, members from the Hispanic population and Medicaid patients to more accurately reflect the diversity in their community.

Patients, clinicians and staff have all been pleasantly surprised with the impact the PFAC has had on practice improvements. Having a PFAC is less complicated than they anticipated, and it has not been difficult to run the council or engage patients. “The patients have spoken and this is what is meaningful for them. This carries a different weight and changes are well-received because they’re not just coming from the doctors.” They strive to convey how valuable the PFAC's contributions are to their business and recognize them as a powerful collaborative force. First Street Family Health is now involving the PFAC in some of the more serious work of the practice, including quality improvement initiatives related to payment reform.
Learning Objectives:
At the end of this activity, you will be able to:
1. Describe what a Patient and Family Advisory Council (PFAC) is and how this partnership can improve one's practice
2. Discover the importance of developing a business case for PFAC and engaging the appropriate individuals to serve on the planning committee
3. Explain the purpose of an action plan and the areas the PFAC may advise you
4. Identify how to initiate improvement projects with PFAC members and track the results of PFAC work

Introduction:
Increasing administrative responsibilities—due to regulatory pressures and evolving payment and care delivery models—reduce the amount of time physicians spend delivering direct patient care. Understanding patient and caregiver perspectives is key to achieving desired results. When patients and families are engaged in practice-improvement decisions, practices are able to ensure that community perspectives and needs are represented in business operations.

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Designation Statement: The American Medical Association designates this enduring material activity for a maximum of .50 AMA PRA Category 1 Credit™. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

Target Audience: This activity is designed to meet the educational needs of practicing physicians.

*Disclaimer: Note: Hospital-based PFACs may benefit from state and federal confidentiality provisions. Practice-based PFACs can benefit from federal protection from discovery if your practice participates as a member of a federally certified Patient Safety Organization. This can be helpful to promote complete and thoughtful discussions.

†Some state privacy and confidentiality laws may go beyond HIPAA, so these criteria will depend on the state in which you reside.

Statement of Competency: This activity is designed to address the following ABMS/ACGME competencies: practice-based learning and improvement, interpersonal and communications skills, professionalism, systems-based practice and also address interdisciplinary teamwork and quality improvement.

Planning Committee:

Alejandro Aparicio, MD, Director, Medical Education Programs, AMA
Rita LePard, CME, Program Committee, AMA
Author Affiliations:

Martin J. Hatlie, JD, Project Patient Care; Knitasha Washington, DHA, MHA, FACHE, Consumers Advancing Patient Safety

Faculty:

Cynthia Barnard, MBA, MSJS, CPHQ, Vice President, Quality, Northwestern Memorial HealthCare; Becca Moran, MPH, Program Administrator, Professional Satisfaction and Practice Sustainability, AMA; Christine Sinsky, MD, Vice President, Professional Satisfaction, AMA; Allison Winkler, MPH, Senior Practice Development Specialist, Professional Satisfaction and Practice Sustainability, AMA

About the Professional Satisfaction, Practice Sustainability Group: The AMA Professional Satisfaction and Practice Sustainability group has been tasked with developing and promoting innovative strategies that create sustainable practices. Leveraging findings from the 2013 AMA/RAND Health study, “Factors affecting physician professional satisfaction and their implications for patient care, health systems and health policy,” and other research sources, the group developed a series of practice transformation strategies. Each has the potential to reduce or eliminate inefficiency in broader office-based physician practices and improve health outcomes, increase operational productivity and reduce health care costs.

Glossary Terms

**business case:** Investment of time and perception of value

**Business Associate Agreements:** According to Health and Human Services, HIPAA guidelines typically require that entities and business associates covered by HIPAA enter into contracts or agreements with their business associates to “ensure that the business associates will appropriately safeguard protected health information.”

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References


