



JOHNS HOPKINS  
MEDICINE



## IMPROVING HEALTH OUTCOMES: BLOOD PRESSURE (IHO: BP)

# PATIENT AND FAMILY ADVISOR RECRUITMENT GUIDE AND ONBOARDING TOOLKIT

**VERSION 1.0**

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## 1. Background and purpose of this guide and toolkit

This guide and toolkit, created by Johns Hopkins Medicine in collaboration with the American Medical Association's "Improving Health Outcomes: Blood Pressure" (IHO: BP) initiative, are intended to help facilitate the recruitment and orientation process for engaging patients and families as advisors in the planning, delivery and evaluation of care in your practice. Engaging patient and family members as advisors is worth considering if your practice can devote time to organizing their involvement.

We've created this guide and toolkit to be adapted to meet the needs of your practice/health center. Most of the examples in this guide and toolkit use blood pressure or hypertension as an example; however, the information and materials can be adapted for other chronic diseases and/or used for other initiatives.

### ***Patient engagement for ambulatory practices***

Ambulatory practices may find it helpful to engage patients in their quality improvement (QI) work.<sup>1</sup> Here are two ways you can engage patients and families:

- Partner with patients and families in self-management
- Engage patients and families in your QI work as advisors

Hospitals and health systems have long recognized the benefits and importance of patient and family advisory councils.<sup>2</sup> As a result there are many resources available for inpatient-based patient and family advisory groups. Ambulatory practices interested in engaging patient and family advisors (PFAs) may find that few resources exist to provide guidance on how they can recruit and work with PFAs. This guide and toolkit are intended to help fill that gap.

## 2. Benefits and importance of patient and family advisors

Evidence is growing that meaningful patient and family engagement can help achieve the triple aim of better quality, better outcomes and lower health care costs, and can also substantially reduce preventable harm. Patient and family engagement is associated with improved patient quality and safety and better health outcomes.<sup>3</sup>

Partnering with patients and families helps "patients make more informed choices about their care, use medications more safely, practice more effective self-management, contribute to infection-control initiatives and help reduce medical errors—all translating into measurable improvements in the quality and safety of care." Engaged patients also have better management of chronic conditions and overall improved functioning.<sup>3</sup>

## 3. Roles and responsibilities of practices and patient and family advisors

In order for practices and PFAs to work together effectively, it is critical to establish and communicate roles, responsibilities and expectations. These responsibilities should be outlined in the participation considerations letter and discussed at the in-person orientation meeting (see No. 7 below, "Patient and family advisors orientation session"). This guide includes a sample "Participation considerations letter" document that can be used as a template (see [Appendix 8](#)).

PFAs may serve in multiple roles and multiple terms may also be used to describe their role. Three of the common roles for PFAs are:

- **Advisor:** Enables patients and families to have direct input and influence on the policies, programs and practices that affect the care and services individuals and families receive<sup>4</sup>
- **Advocate:** Promotes patient-centeredness, patient safety and the patient voice in the health care system<sup>5</sup>
- **Ambassador:** Builds positive relationships with the health care community and works in partnership with other ambassadors and health care professionals to promote the perspectives of patients and other stakeholders<sup>6</sup>

If you will be compensating your PFAs for their work, this should also be specified in the participation considerations letter. Hourly stipends or honoraria can typically range from \$12 to \$25 per meeting.<sup>7</sup> At a minimum, PFAs should be reimbursed for any expenses incurred to attend meetings (e.g., transportation, child care, etc.). You may also provide gift cards, vouchers or other types of incentives.

#### 4. Selection criteria for patient and family advisors

While there is no single definition of an ideal candidate to serve as a PFA, “experience from existing programs suggests that important considerations are the patients’ . . . abilities to work with the health care team, their breadth of experience with the health care setting, their ability and willingness to communicate concerns, and [their] ability to represent patients and families broadly rather than focus narrowly on a particular issue.”<sup>8</sup>

##### Individuals selected as patient and family advisors should:

- Show passion for patient-centered care and for individuals and populations with chronic conditions (such as hypertension)
- Have experience working in teams, with a strong preference for those with prior positive experiences serving as PFAs in health care settings
- Have experience in managing chronic conditions, either in themselves or a loved one
- Reflect demographic diversity (e.g., race/ethnicity, age and sex)

#### 5. Recruitment strategy for patient and family advisors

The number of patient and family advisors your practice chooses to work with will be based on the needs, size and resources of your practice. Recruiting at least two PFAs is strongly encouraged. Experience from other patient and family advisory groups has shown that working with two or more PFAs can produce robust engagement.<sup>9</sup>

You may choose to recommend individuals who are patients within your practice who might be well-suited to serve as a PFA (See No. 4 above, “Selection criteria for patient and family advisors”) or you may partner with local hospital and/or health plan patient/family advisory councils to help identify candidates.

#### 6. Patient and family advisor recruitment and resources

##### Figure 1. Patient and family advisors recruitment process

The graphic below provides an overview of the major activities that are involved in the PFA recruitment process. (See next page for checklist of tasks to complete these activities.)



We recommend that your entire practice team get involved. Physicians can help to identify patients, and practice staff (e.g., office manager, front desk staff, and/or medical assistants) can manage other steps for PFA recruitment and orientation, since they may also interact with patients and their families. Feel free to modify the steps and roles depending on your workflow and practice resources.

## Patient and family advisor recruitment checklist

### Outreach

- Develop recruitment criteria
- Ask practice staff and physicians for referrals
- Partner with local hospital and/or health plan patient/family advisory councils to help identify candidates
- Use recruitment handouts, fliers, etc. (see appendices [1](#), [2](#) and [3](#))

### Identify

- Identify candidates
- Create application process
- Use application form (see [Appendix 4](#))

### Interview

- Conduct interviews with candidates
- Use interview protocol (see [Appendix 5](#))

### Select

- Select advisors (number determined by your practice)
- Use sample offer/regret letters (see [Appendix 6](#) and [Appendix 7](#))
- Use participation considerations letter (see [Appendix 8](#))

### Onboard

- Conduct an orientation session
- Use orientation agenda and other resources

## 7. Patient and family advisors orientation session

After you have selected your PFAs and received signed participation considerations letter, you may want to schedule an in-person orientation session with your team members and your PFAs, lasting 45–60 minutes. The orientation provides you with an opportunity to discuss roles, responsibilities and expectations for both your practice site and PFAs. Refer to the appendices for resources that you can use to help guide this meeting.

## 8. Ongoing patient and family advisor engagement

When considering different ways to create and maintain patient and family advisor engagement, it may be helpful to think of the patient and family advisor engagement in terms of informal engagement and formal engagement:

- Formal engagement refers to ongoing participation of PFAs in teams, working groups, committees, task forces and panels as equal members. This way they will be fully engaged throughout the process of developing, implementing and evaluating policies and programs where their advice and perspectives need to be incorporated (e.g., engage them in issue identification, research, consultation, development, implementation and evaluation of policies and programs).
- Informal engagement refers to one-time or ad hoc participation of PFAs, including:
  - Casual consultation with PFAs on developing new, or changing existing, policies/programs that may potentially affect patients and families (consultation can be in the form of meetings or phone conversations)
  - Occasional participation in meetings where perspectives of patients and families are needed for decision making (e.g., senior leadership team meetings, branch meetings, etc.)
  - Participation in focus groups and surveys
  - Development and review of audiovisual or written materials (e.g., brochures and pamphlets developed to provide information to patients and families or public)
  - Sharing their stories at meetings, conferences and events<sup>10</sup>

### **Some of the suggestions below can also help ensure PFAs are engaged in your QI work:**

- Devote time to planning and evaluation of council efforts
- Set priorities and focus efforts on meaningful, collaborative projects
- Set and achieve measurable goals
- Track accomplishments and provide positive feedback
- Create a variety of ways for PFAs to participate in the consideration of issues (e.g., conference calls, written review of materials)<sup>11</sup>
- Ask for the opinions of PFAs during discussions, encouraging their participation and validating their role
- Keep them informed about how their feedback and ideas contribute to changes and improvements

## Overview of appendices

The following is an overview of the tools you can use to recruit and onboard PFAs, help orient them to their roles and responsibilities, and help your practice site staff make the best use of PFAs.

Feel free to use all or just a few of these resources, depending on the objectives of your practice. Where possible and/or applicable, we have included placeholders and prompts to help you customize these materials for your practice.

Materials for PFAs can be distributed during an initial, in-person onboarding meeting (see No. 7 above, “Patient and family advisors orientation session”). Distribute materials for relevant practice site staff during the PFA recruitment and selection process.

**To receive customizable versions of the below tools, or if you have any feedback about this toolkit, please contact Sara Alafogianis at [sara.alafogianis@ama-assn.org](mailto:sara.alafogianis@ama-assn.org).**

## List of recruitment and onboarding tools for patient and family advisors

Resource	Use this to ...	Description	Appendix
<a href="#">Recruitment handout</a>	Provide potential candidates with detailed information about patient and family advisors (PFA) roles and benefits	Two-sided handout for potential PFAs, includes description of who is eligible to apply to be a PFA and how they can learn more	1
<a href="#">Recruitment flier</a>	Provide potential candidates with an overview of PFA roles and benefits	One-page sheet for potential PFAs with information about being a PFA, including who is eligible to apply and how they can learn more	2
<a href="#">Recruitment letter</a>	Reach out to potential candidates	Letter to potential PFAs on roles, responsibilities, benefits; who is eligible to apply, how they can learn more (to be sent with handout or flier above)	3
<a href="#">Application form</a>	Screen potential PFA candidates	Interested PFA candidates complete this three-page document or online survey, collects basic demographic information—i.e., why the individual wants to be an advisor, what experiences he/she has had as a patient, family member and/or volunteer	4
<a href="#">Interview protocol</a>	Screen potential PFA candidates	One-page, semi-structured interview protocol to obtain qualitative information and help determine if candidate will be an effective and engaged PFA	5
<a href="#">Sample offer and regret letters</a>	Notify PFA candidates of selection decisions	One-page letters to PFA candidates who have or have not been selected to serve as PFAs (note: selection letters should be accompanied by a phone call to confirm acceptance)	6 (Offer letter)
			7 (Regret letter)
<a href="#">Participation considerations letter</a>	Create an agreement between the practice and PFA	A one to two-page participation considerations letter formally establishes each PFA's acceptance of terms for participation as a patient and family advisor	8
<a href="#">PFA orientation session slide deck</a>	Provide information for new PFAs. (The IHO: BP initiative is used as an example).	Overview of expected PFA roles and responsibilities based on examples from the IHO: BP initiative  PowerPoint® presentation available	9

Resource	Use this to ...	Description	Appendix
<a href="#"><u>Talking about your experience: Questionnaire</u></a>	Help PFAs talk about their experiences	One-page handout facilitates sharing of relevant health care experiences that can be used for an interactive exercise during the PFA orientation	10
<a href="#"><u>Messaging guide</u></a>	Help PFAs effectively and consistently communicate with external audiences	Brief talking points that can be provided to PFAs for standard messaging about their role	11

# Recruitment handout

## BECOME A PATIENT AND FAMILY ADVISOR FOR <<PRACTICE NAME>>

### What is a patient and family advisor?

A patient and family advisor is someone who:

- Helps improve the patient experience and quality of care for those with chronic conditions
- Gives feedback based on his or her own experiences as a patient or family member of someone with a chronic condition
- Works with the practice team for either short or long-term commitments, depending on the project
- Volunteers his or her time (usually at least one hour and not more than four hours per month)

### Who can be a patient and family advisor?

**You do not need any special qualifications to be an advisor.**

What's most important is your experience as a patient or family member. We will provide you with any other training you need.

### Why should you become a patient and family advisor?

Patient and family advisors provide a voice that advocates for providing health care services centered on patient- and family-identified needs, rather than the assumptions of what patients and families want.

For example:

- When you or your family member visited a doctor's office, did you think there were things that could have been done better?
- Do you have ideas about how to make sure other patients and families get the best care possible?

If yes, we are looking for patient and family advisors like you to give us feedback and ideas to help us improve the quality of care for patients with chronic conditions.

### What do patient and family advisors do?

[NOTE: Personalize this section for your practice as appropriate.]

- Talk about your experience. Advisors help by talking about their health care experiences with doctors, staff and other

patients.

- Review or help create educational or informational materials. Advisors provide a patient perspective and help us make forms or educational handouts easier for all patients and family members to understand and use.
- Partner with community. Discuss what programs or resources could be offered in the community to help support patient self-management of chronic conditions
- Work on short-term projects.

We sometimes ask advisors to help us make improvements. For example, helping to design a patient self-management plan.

### Is being a patient and family advisor right for you?

Being a patient and family advisor may be a good match with your skills and experiences if you can:

- Speak up and share suggestions and potential solutions to help improve chronic condition care for others
- Talk about your experiences as a patient or family member—but also think beyond your own personal experiences
- Talk about both positive and negative care experiences and share your thoughts on what went well and how things could have been done differently
- Work with people who may be different from you
- Listen to and think about what others say, even when you disagree
- Bring a positive attitude to discussions
- Keep any information you may hear as an advisor private and confidential

For more information about being a patient and family advisor, including how to apply:

Call: <<Insert contact name and phone number>>

Email: <<Insert contact name and email address>>

This piece was adapted from the "Become a Patient and Family Advisor" brochure for hospitals. Strategy 1: Working With Patients and Families as Advisors. June 2013. Agency for Healthcare Research and Quality, Rockville, Md. [www.ahrq.gov/professionals/systems/hospital/engagingfamilies/strategy1/index.html](http://www.ahrq.gov/professionals/systems/hospital/engagingfamilies/strategy1/index.html)

# Recruitment flier



Do you have ideas to help improve care for patients at this practice?

## BECOME A PATIENT AND FAMILY ADVISOR

<<Modify flier to fit your practice/health center needs>>

### What is a patient and family advisor?

- A patient and family advisor is someone who helps improve the quality of the treatment experience for patients with chronic conditions such as high blood pressure.

### What do patient and family advisors do?

- Talk about your experience. Advisors help by talking about their health care experiences with doctors, staff and other patients.
- Participate in discussion groups. Advisors tell us what it's like to be a patient and how we can improve the care we provide.
- Review or help create patient education materials. Advisors help review or create materials like forms and educational handouts. Advisors provide a patient perspective and help us make these materials easier for all patients and family members to understand and use.
- Partner with the community. Discuss what programs or resources could be offered in the community to help support patient self-management.

### Why should YOU become a patient and family advisor?

- If you or a family member has received treatment for a chronic condition such as high blood pressure, you could help to bridge the gap between how patients experience treatment and how their physicians perceive the care they provide.

### For more information about becoming a patient and family advisor, contact:

<<Insert your practice logo here>>

Call: <<INSERT contact name and phone number>>

Email: <<INSERT contact name and email address>>

For more information about the AMA's strategic focus to improve health outcomes, visit: [ama-assn.org/go/hypertension](http://ama-assn.org/go/hypertension)

**Join us! Together we can work to improve patients' care experiences!**

## Appendix 3

# Recruitment letter

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<<Date>>

Dear <<Name>>,

Your name came to us by way of <<INSERT referral source>>, and we would like to formally invite you to considering becoming a “patient and family advisor” for <<INSERT practice/health center name>>’s efforts to help patients who have high blood pressure <<OR other condition (specify)>>.

The <<INSERT practice/health center name>> team is committed to creating an environment where the needs of patients and families drive the healthcare experience. Patient and family advisors will:

- Provide a patient perspective for providing health care services that are centered on patient- and family-identified needs, rather than assumptions about what patients and families may want.
- Offer suggestions on tools and techniques that will help patients self-manage their chronic conditions, such as high blood pressure.
- Receive a <<INSERT \$ amount>> for attending meetings and participating in telephone calls and reimbursement for any approved travel-related expenses needed to attend in-person meetings, in appreciation of their time and unique expertise <<DELETE this text if not applicable>>.

I’ve attached two documents for you to read:

1. A brochure with more information about becoming a patient and family advisor
2. An application for you to fill out if you are interested in becoming a patient and family advisor

I’ve also attached an application form. Please complete it and return it to us by <<INSERT date>> if you are interested in joining us in our efforts to making our practice/health center more patient-focused.

I hope you will consider becoming a patient and family advisor for <<INSERT practice/health center name>>. Please feel free to contact me if you have any questions.

Sincerely,

<<Practice Contact for Patient and Family Advisors>>

<<Position/Title>>

<<Additional information (if applicable)>>

<<Practice/Health Center>>

<<Address Line 1>>

<<Address Line 2>>

<<City, State ZIP code>>

P: <<Phone number>>

F: <<Fax number>>

<<email address>>

## Appendix 4

# Application form

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<<Insert practice logo or information here>>

### Patient and family advisor application form

Name: \_\_\_\_\_

Street address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ ZIP code: \_\_\_\_\_

Preferred contact:  Home  Office  Mobile  Email  Other (please specify): \_\_\_\_\_

Home phone: \_\_\_\_\_ Office phone: \_\_\_\_\_ Mobile phone: \_\_\_\_\_

Email: \_\_\_\_\_

**Please take a few minutes to complete the following questions that will help us get to know you better.**

**1. Are you a ...**

- Patient
- Family member of a patient

**2. We recognize that our patient and family advisors have busy lives. How much time are you able to commit to being a patient and family advisor each month? (check one)**

- Less than one hour per month
- One to two hours per month
- Three to four hours per month
- More than four hours per month

**3. Would you be available to participate in two or three in-person meetings a year? (You can still be an advisor if you answer "No.")**

- Yes  No
- If yes, what times would work best for you (select all that apply)?
- Morning  Afternoon  Evening  Other (please specify):

**4. Would you be available to participate in a monthly phone call for 30 to 60 minutes? (You can still be an advisor if you answer "No.")**

- Yes  No
- If yes, what times would work best for you (select all that apply)?
- Morning  Afternoon  Evening  Other (please specify):

**5. How do you want to help? I want to: (check all of your interest areas)**

- Help develop or review informational materials for patients and family members
- Help improve the patient and family role in care decision-making
- Review procedures and provide input to improve patient care experience
- Other areas of interest (please describe):

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**Please tell us about yourself.**

**6. Why would you like to serve as a patient and family advisor?**

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**7. Do you know other individuals or families who might be interested in serving as advisors?  
If so, please provide us their contact information.**

Name: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Name: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Name: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

**Please return this form by mail, fax or email (preferred method) to:**  
<<Add practice address here>>

**Attention:** <<Practice contact for patient and family advisors>>

**Phone:** <<add phone>> **Fax:** <<add fax>>

**Email:** <<add email>>

## Appendix 5

# Interview protocol

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### Patient and family advisor candidate interview guide and questions

Hello, my name is <<state name>>. Thank you for taking time to speak with me. I am <<state position and describe role>>. We are working with the American Medical Association and Johns Hopkins Medicine, who are partners in leading an initiative called "Improving Health Outcomes: Blood Pressure." The goal of the initiative, which we call "IHO: BP," is to improve blood pressure control for patients with uncontrolled high blood pressure, also known as hypertension. <<Or INSERT your practice/health center initiative information here>>

Before we begin, I'd like to go over a few things. First, our interview should take <<30 minutes>>. There are no right or wrong answers, so please feel open to share your thoughts and experiences when responding to any questions. To be sensitive to time, if we find ourselves going off track or topic, I may interrupt you to steer us back to the question. We have a fair amount to discuss and I am eager to hear your thoughts as well as give you some time to ask me questions. <<State who is taking notes>> will be taking notes just to capture the details of this interview.

Potential interview questions: <<Modify as needed for your practice/health center initiative>>

1. We ask this of all candidates: do you or your family have any financial relationships, like stocks or other investments, with health care organizations, such as pharmaceutical companies, hospitals or health plans? <<This question is to identify any conflict of interest. Delete if not applicable>>.

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2. Help us understand a bit more about your background. Please tell us about yourself.  
(Prompt with examples, such as: Tell us about your educational background, professional experience, family and hobbies, etc.)

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3. We're going to shift gears a bit and spend a little time talking about your past experiences as an advisor or an active volunteer committee member for other programs or organizations. Can you tell us about some of these? (Prompt with examples: assisting to plan an event for a local food bank, school, etc.; working with an advocacy committee for a health organization; how long have you been involved in these activities?)

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- How comfortable are you expressing your opinions in a group based on your previous experiences? What sort of group dynamics, in your previous experience, contribute to you feeling comfortable expressing your opinions? (*Prompt: How many people in the group, etc.*)

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- Tell us about a time when you've been in a group situation and someone had a different opinion than you. How did you handle this? Was there anything you did that was helpful to resolve the situation?

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4. Now, we are going to focus on conditions like heart disease. We would like to ask you about your experiences with managing high blood pressure, or other diagnosed condition, either for yourself or others.

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- Using your experience with managing (*hypertension or other diagnosed condition in response to Question #4*) either for yourself or others, please describe any specific things that doctors or staff have done or said with you or your family that you found to be especially helpful?

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- What about things with your health care that you've experienced where you thought, "That could have been done better"?

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5. If you could change one thing about the health care you and your family received for (*high blood pressure or other diagnosed condition in response to Question #4*), what would it be? (*Prompts: These could be related to health insurance, reimbursement issues, care coordination, lack of time with your physician, providing additional resources after being put on hypertension medication.*)

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6. Do you have any questions for us?

(*Interview note: Briefly describe next steps and that we're still in the process of interviewing candidates, but will be reaching out to them with a decision over the next few weeks.*)

Thank you for your time. It was pleasure speaking to you.

**Table 1. Selection criteria for patient and family advisor candidates**

(*This table can be modified to fit the needs of your practice.*)

This table provides an overview of important criteria to consider when selecting PFAs, as well as examples of requirements/qualifications you can use to assess candidates.

Selection criteria domains	Requirements/qualifications
<p><b>Availability</b> (Refer to candidate's application for this information)</p>	<ul style="list-style-type: none"> <li>• Duration of commitment: One year</li> <li>• In person meetings: Two or three in 12-month period</li> <li>• Monthly calls (30–60 minutes in length)</li> </ul>
<p><b>Level of interest</b> (Refer to candidate's application for this information)</p>	<ul style="list-style-type: none"> <li>• Help develop or review informational/educational materials for patients and family members</li> <li>• Recommend community-based products and programs, and assist with developing relationships throughout communities</li> <li>• Identify practice resource needs that could be developed as potential products and programs</li> <li>• Help improve the patient and family role in care decision-making</li> <li>• Other issues of interest</li> </ul>
<p><b>Selection criteria</b> (Rating scale of 1 – 5)</p> <p><b>(Rating scale of 1 – 5)</b>            Poor = 1;            Fair = 2;            Average = 3;            Good = 4;            Excellent = 5</p>	<ul style="list-style-type: none"> <li>• Good first impression</li> <li>• Friendly</li> <li>• Knowledge of their own/others medical condition</li> <li>• Enthusiastic</li> <li>• Passionate</li> <li>• Answered questions and communicates well</li> <li>• Experience working collaboratively in groups</li> <li>• Average rating of above criteria</li> <li>• Overall impressions</li> </ul>

## Appendix 6

# Sample offer letter

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<<Date>>

Dear <<Patient/Family Advisor Name>>:

Congratulations! I am pleased to invite you to serve as a patient and family advisor for <<INSERT practice/health center name/information>>. We are excited about the opportunity to work together to help improve patient care. <<INSERT brief information on your current initiative or project>>.

- Our first meeting will be held on <<INSERT day and date>>.
- The meeting will begin at <<INSERT time>> and end at <<INSERT time>>.
- We will meet in the <<INSERT room number or name and building number or name>>.

<<Our contact person>> will be sending you some materials for your review prior to our first meeting, such as a participation considerations letter and a W-9 tax form that will need to be completed, so that we can compensate you for your time spent participating in phone calls and attending any in-person meetings. <<Delete this section if W-9 not applicable or if you are not providing any compensation to the advisor>>

Please send a signed copy of your participation considerations letter <<and a completed W-9 form if applicable>> by email to <<email address>> by <<date>>.

Please don't hesitate to contact me if you have any questions about the participation considerations letter, the orientation session, or if you need assistance emailing any of the documentation.

Our practice team looks forward to learning together how to assist patients and families.

Sincerely,

Practice contact for patient and family advisors  
Position/Title  
Additional information (if applicable)

Practice/Health center  
Address line 1  
Address line 2  
City, State, ZIP code  
P: <<Phone number>>  
F: <<Fax number>>  
<<email address>>

## Appendix 7

# Sample regret letter

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<<Date>>

Dear <<INSERT name>>,

Thank you for your interest in becoming a patient and family advisor for <<INSERT practice/health center name/information>>. Due to the limited number of openings for patient and family advisors, we will not be able to offer you a position at this time.

We will keep your name and contact information in our database, in case an opening for a patient and family advisor becomes available in the future.

In the meantime, I would be pleased to speak with you about other opportunities to serve as an advisor or volunteer at <<INSERT practice/health center name/information>>. If you are interested, please contact me. <<Delete this section if unable to refer candidate to other opportunities>>

Again, thank you for your interest in serving as an advisor for <<INSERT practice/health center name/information>>. We appreciate your desire to improve the care experience for our patients and families.

Sincerely,

<<Insert staff liaison or key contact name, position title and contact information>>

## Appendix 8

# Participation considerations letter

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The following topics/provisions are being provided by the AMA and The Johns Hopkins University as examples of topics/provisions to be considered for use in a participation considerations letter. These are not recommended for use by a specific practice. We recommend that you confer with your legal advisors to determine what is needed in any agreement for your practice and that any agreement is up to date with the law.

<<INSERT DATE>>

Dear <<INSERT Patient and family advisor name>>,

You have decided to participate as a patient and family advisor (PFA) for <<INSERT practice/health center name>>. By sharing your experiences and perspective, you can help us make important changes to improve health care services for other patients and families. In the process, you will have the opportunity to learn new information that can enhance your awareness and understanding of high blood pressure <<INSERT other chronic disease, initiative or project of your practice/health center>>.

### **We will:**

- Provide you with training to help you be an engaged advisor.
- Listen and respond to your ideas and suggestions, and keep private/confidential the details of your experiences and insights unless we have your permission to share them.
- Provide a stipend of \$<amount> per hour for your time attending meetings and participating in telephone calls arranged by us, and reimburse you for prior-approved, travel-related expenses needed to attend any in-person meetings. We will pay you for your time within thirty (30) days of each meeting or call. We will reimburse you for your travel expenses within thirty (30) days of you providing us with documentation of those expenses <<Delete this section if you are not providing any compensation to the advisor>>.

### **You will have the opportunity to:**

- Share your valuable insights and opinions, provide feedback, offer recommendations and participate in short-term projects or activities (such as assisting in creating and testing patient and family engagement tools and materials).
- Talk about your experience about what it's like to be a patient or family member of someone with a chronic condition, to help doctors and care teams improve how they care for patients with this information.
- Attend meetings to support your engagement as a PFA and our efforts to improve patient care.

The <<INSERT practice/health center name>> team is excited to work with you to help improve care for patients and families! Please contact <<practice/health center contact person>> if you have any questions at <<INSERT Phone Number>> or <<INSERT email>>.

### **Term and Termination:**

You will be an engaged advisor for <<INSERT time frame>> beginning on the day of the last signature by you or us. We each may terminate this agreement on <<Insert number of days>> prior notice to each other.

Confidentiality statement<sup>12</sup>: (Sample provision to be considered/adapted/reviewed with your legal advisor)

As a patient and family advisor (PFA), you may be exposed to other individuals' information, which must remain private. A simple way to understand your responsibilities under the law is to remember the saying, "What you hear and see here must remain here." We require your cooperation in following these rules. Confidentiality requirements are explained in more detail below, and you will receive additional instruction on confidentiality requirements during your orientation meeting.

Health Insurance Portability and Accountability Act (Sample clause to review with counsel)

A federal law called the Health Insurance Portability and Accountability Act, commonly known as “HIPAA,” regulates how health care providers and others must safeguard protected health information of patients. This provides guidelines for how we will handle information for the patient and family advisors (PFA).

As a PFA, you may come across protected health information. It is important for you to know that protected health information can only be used and disclosed as permitted by law. This means that protected health information cannot be shared in any written, verbal or email communications with anyone, including friends and family, unless specifically permitted by law.

Protected health information includes any information that could help personally identify any particular patient. This information includes any information that identifies an individual, but is not limited to, a patient’s name, address, phone number, date of birth or financial information. Protected health information also includes details about a patient’s experiences during visits with health care professionals, including information related to the patient’s diagnosis and treatment, payments for health care, and details about the patient’s care experience in general, and any other personal information.

**Miscellaneous**

You acknowledge you are not an employee of <<name of practice>> and are not directly or indirectly practicing medicine in connection with this agreement. During the course of meetings and telephone calls, you will let us know if you have any personal or financial interests or affiliations that others may consider related to the evaluation of your comments.

**Add other clauses as applicable to your practice**

Please sign below to let us know that you have reviewed this information, understand it, and agree to it. Signing your name means that you have read and understand the information above, that you have had a chance to ask questions and that you agree not to share protected health information in any written, verbal or email communications.

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Signature

\_\_\_\_\_  
Printed name

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Address

\_\_\_\_\_  
Date

## Appendix 9

# Orientation session slide deck

Instructions to practice/health center

Please feel free to customize with you practice/health center information any slides in this presentation. For example, you may add your own logo or photos. You should also feel free to delete slides or information that does not apply to your practice/health center.

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How will we help you succeed as a PFA?

- Provide education and training to help orient you
- Create an open and courteous environment
- Listen and respond to your ideas and suggestions
- Keep you informed about how your feedback and ideas shape our work
- Provide a stipend for your time attending meetings and participating in telephone calls <<Delete if not applicable>>
  - Reimburse you for prior-approved, travel-related expenses needed to attend any in-person meetings <<Delete if not applicable>>

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Example projects

- Provide us with feedback on how tools and resources can meet the needs of patients and families
- Review patient and family advisor orientation materials
- Recommend additional tools and resources
- Provide recommendations for community-based products and programs, and assist with developing relationships throughout communities
- Participate in calls and meetings
- Other <<TBD by practice/health center>>

Since our work together is new, things may naturally evolve ... so we welcome your ideas and feedback!

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# Talking about your experience

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# “Talking about your experience”

*(This flier can be modified to fit the needs of your practice.)*

As a patient and family advisor who is part of the American Medical Association and Johns Hopkins Medicine “Improving Health Outcomes: Blood Pressure” (IHO: BP) initiative <<Or INSERT your practice/health center name here>>, you may be asked to talk about your experience, to help others understand your health care experiences and how these experiences have affected you and your family. Doing so can be a powerful way to show the need for specific changes and improvements.

As an advisor, you may be asked to help educate doctors, nurses and other medical office staff about why it is important to involve patients and families in quality improvement efforts. You may be asked to speak to a group of patients and family members about becoming advisors, or other opportunities may arise.

<<INSERT your practice/health center name here>> will provide you with training and support for each of these opportunities. You should accept invitations to speak only if you are comfortable with the request.

## Before you agree to talk about your experience

Before agreeing to speak or talk about your experience in a training, meeting or presentation, get information about what is expected of you and what you can expect. Ask the following questions:

- When, where and for how long do you want me to speak?
- What do you hope will happen as a result of me talking about my experience?
- Who is the audience? How many people will be there?

- Who else will be speaking?
- Will I be answering audience questions?
- Will the session be audio or videotaped?
- Is there reimbursement for transportation and/or child-care?

## Preparing to talk about your experience

If you have decided to talk about your experience, think about what you want to say and how you want to say it. Some people write down their main points to keep them focused. You can use the questionnaire called “Talking about your experience” to help organize your thoughts.

Before you speak in a meeting or to a group, it also helps to practice. Time yourself and see if you are staying within the requested time frame.

As you are preparing what you want to say, think about the following questions:

- Why was I asked to talk about my experience?
- What are the key messages I want to share?
- What are the two or three specific points I want the audience to remember?
- What am I willing to share? What is too private to share?
- What examples can I give of when a health care experience went well?
- What examples can I give of things that might have gone better?
- What ideas do I have about how my health care experience could have been improved?

Also keep in mind the following tips:

- **Only share what you want to share.** If you still feel angry about a certain situation or event and do not think you can talk about it in a helpful manner, it may be best not to share that part. You can also talk about it with someone you trust. Ask for ideas about how to share that part of your experience in a way in which people will listen.
- **Focus on experiences rather than individuals.** Avoid using the names of doctors, nurses and other staff. If you talk about another facility where you have received care, please do not mention it by name.
- **Be prepared for emotional reactions.** Expect that some people who hear about your experience may be deeply moved. Remember, you may feel emotional when you talk about your experience, and it's okay to show that emotion.
- **Remember you are in control.** If people ask you questions and you do not know the answers, it is okay to say so. If you do not want to answer a question, it is okay to say that as well.

This worksheet was adapted from "Strategy 1: Working With Patients and Families as Advisors." June 2013. Agency for Healthcare Research and Quality, Rockville, Md. <http://www.ahrq.gov/professionals/systems/hospital/engagingfamilies/strategy1/index.html>. Accessed May 22, 2015.

# “Talking about your experience”

## Questionnaire

Use this questionnaire to help prepare you to share your health care experience.

**What went well during your experience? What things did people say or do that were helpful?**

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**What did not go well during your experience? What things did people say or do (or NOT say or do) that made your experience less than fully positive?**

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**What improvements would you suggest? What would you rather have happened?**

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## Appendix 11

# Messaging guide

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### **Messaging guide for patient and family advisors: Communicating about your role as a patient and family advisor in the community**

#### **Background and purpose**

This guide will help you communicate with confidence about your role as a patient and family advisor (PFA) for <<INSERT practice/health center name>>. Once you are comfortable with its language, use it to communicate how <<INSERT practice/health center name>> is involving patient and family advisors.

These are some of the questions you may be asked as well as answers that you can use when talking about your role as a PFA.

#### **What is the role of patient and family advisors?**

- <<INSERT practice/health center name>> is involving PFAs to help ensure that the experiences and needs of patients and families are represented.

#### **What do patient and family advisors do?**

PFAs:

- Participate in meetings and events with project staff and clinical care teams (During these meetings we can share our ideas for how to better meet the needs of patients and families.)
- Tell our experience about what it's like to be a patient with a chronic condition or a family member of someone who has a chronic condition (Doctors and care teams use this information to improve how they care for patients.)
- Review or help create patient educational materials (Advisors provide a patient perspective that practices can use to help make these materials easier for all patients and family members to understand and use.)
- Recommend community-based programs and resources, assist with developing relationships throughout communities
- Identify resources doctors and practices need, and that could be developed as potential tools and programs

#### **How can I learn more about being a patient and family advisor?**

If you need help answering any additional questions about being a PFA, please contact <<INSERT practice/health center name and point person contact information>>.

# References

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