Including the patient voice

A guide to engaging the public in programs and policy development

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COMMONWEALTH OF MASSACHUSETTS

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INTRODUCTION

What is this guide and who is it for?

Nihil de nobis, sine nobis is a Latin phrase meaning "Nothing about us, without us."

A growing body of evidence suggests that patient and family engagement can improve the safety and quality of care. We now know that effective engagement leads to better health outcomes and increased patient satisfaction.

And yet many organizations committed to including patients in their work – health care providers, government agencies, and others – find it challenging to do so consistently and successfully. Many health care systems have committed to patient engagement in the doctor's office, but are unsure how to incorporate it into program and policy development.

What follows is a guide to help your organization include the voices of those who use the health care system into your work and advisory groups including:

- expert panels,
- quality improvement committees,
- task forces, and
- Patient and Family Advisory Councils.

Decisions made by health care organizations affect more than just the patients and staff within their four walls which is why it is important to involve not just current patients, but also family members and members of the general public. In this guide use the words "patients," "community members," or "members of the public" interchangeably as a reminder to include a variety of voices.

The Six Essential Elements were gleaned from a number of reputable sources, as well as from recent experiences by the Betsy Lehman Center including members of the public in our expert panels and other convening activities.

We continue to learn from each community adviser with whom we are privileged to work and expect this guide will grow as a knowledge-base and resource over time. For now, we wish to share it more broadly in the hope that it will help you and other organizations expand and refine your capacity to include these essential voices in the important work that you do.

ESSENTIAL ELEMENT 1

Set Goals for Engagement

Start by articulating to leadership and staff how and why the voices of those who use the health care system will be included in your organization's project. Be clear about the work that needs to be accomplished, conceptualize the roles of these members of the team, and be prepared to discuss how this engagement aligns with your organization's mission and the objectives of the task at hand.

WHY DO THIS

Four key reasons:

1. Goals form the foundation for any group project. Articulating the purpose of involving members of the public in the work will help get – and keep – everyone on the same page.
2. Alignment of your commitment to involving members of the public with the overall mission of your organization or the specific aims of the project frames the rationale in the strongest terms possible.
3. If engaging members of the public in your work is something new for your organization, goal-setting helps normalize this practice.
4. Spotlighting goals helps your organization keep the longer-term value of community member inclusion top of mind, which can help balance concerns about any short-term costs.

HOW TO GET STARTED

A few pointers:

- Be sure the goals are attainable. Is this the first time your organization is involving community members? Set your sights on achievements that are realistic so that both organizational and community participants can feel successful.
- Depending on the tasks at hand, you may need to prioritize and/or sequence the goals. For example, you may want a community member to co-chair the workgroup, but it might make sense to have that as a goal for the second phase of the work rather than the first if your team has limited or no experience with including members of the public in this type of project or work.
- Get feedback from your organization's leadership and other participants in the project so that there is general buy-in on the goals of this engagement. (See Element 2)

> *As the health care system evolves and user engagement matures, it creates opportunities to dramatically improve health care delivery. Many promising technologies and practices are being tested and many are yet to be discovered.*
>
> – American Hospital Association

TROUBLESHOOTING

You might meet with some resistance to this work in your organization. Here are some common barriers and suggestions for overcoming them.

"This takes time and we just don't have extra staff time for recruiting and including patients, families or members of the community."

Anticipate the potential for 'wasted' time if members of the community are not included. For example, a task force on improving a pharmacy's ability to communicate with non-English speakers might decide to develop a list of staff members who speak other languages to act as translators. But if patients aren't comfortable with that approach, the task force will need to do its work over again.

"We're concerned about privacy and confidentiality when including people who aren't part of our organization in our work."

Other organizations have addressed this problem by asking all members of a work group to sign confidentiality agreements (see Appendix A).

"The last time we tried this, something went wrong."

Institutional memory can be difficult to overcome. Goal-setting is a very good strategy for combatting this type of resistance. Keep the emphasis on the current project, what needs to be done and how it can't be done well without the involvement of those who use the health care system.

"People without health care backgrounds won't understand our work."

Remind your team that people from other disciplines can provide a wealth of learning for all involved. More and more organizations are reaching across industries to see how they can tackle persistent issues. Teachers, engineers, bankers, artists, lawyers, community organizers, all bring the perspective of their professional paradigm. The rules, regulations, cultures they have experienced will offer a fresh perspective and creative approaches to the problem(s) your committee or task force is trying to address.

| SOURCES AND RESOURCES

Carman KL, Dardess P, Maurer M, Sofaer S, Adams K, Bechtel C, et al. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. Health Aff (Millwood). 2013 Feb;32(2):223–31.

American Hospital Association. (2013, January). Engaging Health Care Users: A Framework for Healthy Individuals and Communities. Chicago: American Hospital Association, 2012 Committee on Research, Benjamin K. Chu and John G. O'Brien, co-chairs. www.aha.org/engaging-healthcare-users

Guide to Patient and Family Engagement in Hospital Quality and Safety. Content last reviewed December 2017. Agency for Healthcare Research and Quality, Rockville, MD. www.ahrq.gov/professionals/systems/hospital/engagingfamilies/guide.html

ESSENTIAL ELEMENT 2

Gain Support and Prepare

Support from internal constituencies for involving members of the public in your work is an essential element for success. Prepare your organization's leadership, professionals and other staff. Be sure they understand the value of this input and help them see the positive benefits, even if it seems unfamiliar or is viewed as burdensome.

WHY DO THIS

Three key reasons:

1. Leadership support ensures that the work done by your committee, task force, or other group will be valued across the organization and recommendations stemming from the work are more likely to be enacted and enforced.
2. Community members can be more effective if there is support for their perspective. It's not helpful to the work that needs to be done if they are seen as window dressing.
3. By preparing everyone involved – leadership, staff, and the members of the public you are engaging in your work– people will have a common understanding of expectations. This generally makes group work go more smoothly and maximizes the value of everyone's time and efforts.

HOW TO GET STARTED

Every organization has its own unique environment. You know yours best. Adapt these strategies to your organization's operational culture.

- Articulate to senior leadership the ways in which engaging patients, families and community members aligns with the organization's mission and the project's goals.
- Try to find a 'champion' from among senior leaders who can help you communicate more effectively with the organization's governance.
- Host a mini-workshop for members of your organization who will be working with the community advisers. Provide them with training and/or materials that answer these three questions:
  - What does community member input look like?
  - Why is the organization committed to including members of the public on this project?
  - What is my role?

A LEADER'S CHECKLIST

Developing a Clear Vision of Community Engagement

- ☐ Ensure your organization has a clear definition of community engagement.
- ☐ Discuss community engagement with your senior leadership team so that they understand it matters to you and the organization.
- ☐ Elicit input from your board, your staff and members of the public about what your organization will look like if it is successfully engaging community members.
- ☐ Make improving community engagement an organizational goal.
- ☐ Allocate time in meetings with senior leadership, staff and the board to hear and tell stories about successes and shortcomings when engaging members of the public in your work.

- Invite questions and respond with clear and timely explanations.
- Designate yourself or another key contact so that concerns can be raised before, rather than during, meetings about the project with community members at the table. Better yet, proactively set up meetings with staff individually and in groups, such as brown bag lunches, to discuss what it means to work with members of the public.
- Ideally, inclusion of community members on any one task will be discussed as part of a deep-rooted, long-term commitment to evolve the system of care within a provider organization, a geographic area, for serving a targeted population, etc.

TROUBLESHOOTING

Here are some common challenges faced when trying to gain buy-in and prepare members of an organization to welcome input from patients, families and community members.

"We don't have the staff capacity to do this work well."

It's not necessary to make a major investment to effectively engage community members in your work and it needn't be a full-time job. But time will need to be allocated to recruit, select, and train them to serve as advisers, as well as prepare the organization's staff to integrate these advisers into their work. Keep the goals of the work top of mind, and set a realistic time frame for the work based on your staff capacity.

"It's hard to get the attention of senior leaders in my organization to support and staff this work."

Find an executive sponsor if at all possible. Also, many organizations have key staff members at the operational level who help translate the leadership's vision into programs. Frequently, these individuals are existing professional staff who are well-respected and who have institutional memory and the necessary connections at both the administrative and front-line levels to get things done.

"Our organization is very hierarchical. I don't think it's realistic that people will want to hear and include the voices of those who use the health care system."

If you work in a clinical environment, it's likely that partnering with members of the public is not a familiar role for many on your team. Clinicians, administrators and others may feel that their expertise will not be validated, that community advisers will disclose private information to others outside of the organizations, or that they will make unreasonable or impractical suggestions. Address each of these concerns as part of your work in preparing the organization to accept this valuable input.

SAMPLE VISION STATEMENT

We aspire to be an organization in which:

- Members of the public are fully engaged in our efforts to provide safe, high-quality services for every patient.
- Every staff member is equipped and empowered to support community engagement.
- We have systems and processes in place to engage patients where they receive services, in our training activities and in organization planning and oversight.
- Our culture continuously reinforces the necessity for fully engaging the community.

“The staff members I’ve talked with so far actually think this is a good idea, but worry about how to do it well.”

That’s a great start! See Essential Element 5 for tips on how to welcome and support community input on your project.

SOURCES AND RESOURCES

Agency for Healthcare Research and Quality. Guide to Patient & Family Engagement: Tool 11. Working with Patient & Family Advisers. AHRQ. 2013. pp. 1–41.

Agency for Healthcare Research and Quality. Guide to Patient & Family Engagement: Tool 12. Working with Patient and Family Advisers. AHRQ. 2013. pp. 1–2.

A Leadership Resource for Patient and Family Engagement Strategies. Health Research & Educational Trust, Chicago: July 2013. Accessed at www.hpoe.org

> *When [the CEO] first came, he really tagged the phrase, ‘Patients first.’ You’ll hear employees talk about that all the time. That really focused the organization—remember, that’s why we are here. It’s not about the nurses or the physicians, it’s about the patients.*
>
> – Chief Nursing Officer

ESSENTIAL ELEMENT 3

Identify and Recruit Advisers

Forge successful partnerships with advisers by recruiting members of the public who are a good match with the needs of your organization or project, and making sure they are welcomed and oriented appropriately.

WHY DO THIS

Three key reasons:

1. Patients, families and community members are experts at using your services. Or, if you are a policy organization, your work will directly affect the way they experience health care. The closer the match of their expertise or experience to the task at hand, the more value they will deliver to the work.
2. Preparation and orientation will ensure they are ready to be active contributors to the work.
3. Supporting advisers as the work unfolds ensures that both they and your organization get maximum value for the time and effort expended.

HOW TO DO THIS

Identify what you need

Ideal advisers are individuals who:

- Are benefitting from their experiences with your organization or will be affected by the policies or other decisions you are making.
- Are willing to talk about their experiences and can effectively share insights and information.
- Demonstrate a passion for improving health care/services/policies for the benefit of others.
- Have the ability to listen well, respect the perspectives of others, interact with many different kinds of people, and work in partnership.
- Have interacted in the past 3-5 years with your organization, since their recommendations will most likely reflect current experience.

Plan to include more than one member of the public in the project so that s/he does not feel like an outsider. Think about the diversity of offerings of your organization and of the people you serve, and recruit advisers who reflect the diversity of experience and of the patient population or with the specific work you are reviewing under the project.

ADVISER RIGHTS AND RESPONSIBILITES

We promise to:

- Provide you with the resources and materials you need to fully participate.
- Identify a staff liaison to help you prepare for meetings, provide you with information, and be available if you have comments, questions, or concerns about your role.
- Listen and respond to your ideas and suggestions.
- Include all members in any substantive communications between meetings.

You promise to:

- Support and commit to the goals of the project.
- Prepare for meetings as needed by reviewing materials, reading a report, or completing a task before a meeting.
- Attend meetings as required. If for some reason, you cannot attend a meeting, please ask if there is another way you can participate (for example, by phone).
- Actively participate in meetings by sharing your input and opinions.
- Maintain confidentiality.
- Include all members in any substantive communications between meetings.

Recruit patients, families and community members

You may find advisers in a number of different ways.

- Consider individuals who have provided constructive feedback in the past (review letters or emails from patients).
- Request suggestions from professionals and staff. If you are part of a hospital or large health care organization, approach social workers, patient relations personnel, ombudsmen or others who interact with patients every day. For example, patient advisers at hospitals often say that a personal invitation from a clinician or other staff member is the deciding factor in encouraging them to become an adviser.

Plan to talk to each potential adviser. Questions you might explore include:

- reasons for wanting to help with your project,
- strengths and skills to contribute to the work involved,
- experiences in group work situations, and
- availability.

Be fully prepared to explain:

- goals of the work,
- time commitment involved,
- flexibility about attendance (in person/telephone),
- clear outline of their roles, and
- any background checks or additional training (such as training on confidential information) that will be required.

Prepare advisers and your organization

- Coordinate a meeting or conference call to introduce advisers to the project leader so there is an opportunity for all to ask questions.
- Decide internally about any compensation/reimbursement you can offer. Consider: travel expenses, compensation for lost work time, access to journals, computer and printer use, child care, etc. Be sure to discuss this with advisers early in the process.

TROUBLESHOOTING

"One person can't really represent the voice of all patients but we don't have room on the panel for too many people."

Having just one representative on your panel or group isn't ideal, for you or for them. That's a large responsibility for one person. Try to invite at least two members of the public to serve as advisers. While it may initially seem like extra effort, it allows your group to benefit from more than one perspective, similar to the way in which you might invite a series of 'experts' with different backgrounds to contribute to the project.

ENGAGE YOUR ADVISERS

Ask them questions like:

- When you interacted with our organization, did you think there were things we could have done better?
- Do you have ideas about how to make sure other patients and families get what they need from our organization?

"Finding meeting times that work for both staff and community members is too difficult."

Many organizations prefer in-person meetings, especially in the early stages of a project so that people get to know one another. This could be particularly important for members of the public since they won't likely have prior relationships with others at the table. To enable this, you will need to host meetings at times that minimize disruption of the community members' work schedules (e.g., early morning, late afternoon, or lunchtime). If necessary, consider compensating them for missed hours at work.

> *It's fulfilling to represent patients and families, to provide that point of view. I know I've made a difference and improved the health care experience for others.*
>
> – Patient representative

"When we seek volunteers for work like this, we hear from the same people all the time."

This is a problem for almost any organization that relies on volunteers. Some suggestions:

- Develop and distribute recruitment brochures. For example, if your project involves improvement to pediatric services or policies, print materials that parents may see when visiting their child's pediatrician's office. Or include the brochures with welcome packets, satisfaction surveys, or other patient-facing materials.
- Use your website or social media. Work with your organization's communications/marketing department to create a page on the website that contains information on advisory opportunities.
- Ask a local organization that works with the public on community projects, such as a neighborhood association, a hospital's Patient and Family Advisory Council, or parent board of a day care center.

SOURCES AND RESOURCES

Agency for Healthcare Research and Quality. Guide to Patient & Family Engagement: Tool 9. Adviser Orientation Manual. AHRQ. 2013. pp. 1–17.

Consumers United for Evidenced-Based Healthcare (CUE). Advisory Panel Engagement Resources. This comprehensive resource bank is for consumers interested in participating on advisory panels and health care professionals interested in involving consumers in advisory panels. www.consumersunited.org/engagement

Agency for Healthcare Research and Quality. Guide to Patient & Family Engagement: Tools 1 - 8. Become a Patient & Family Adviser. AHRQ. 2013.

The Community Tool Box Chapter 11. Recruiting and Training Volunteers www.ctb.ku.edu/en/table-of-contents/structure/volunteers

ESSENTIAL ELEMENT 4

Orient Advisers

It is not realistic to expect that every adviser on a working project will come to it with the same level of knowledge or understanding of the task(s), challenges, and array of possible outcomes. This is especially true when including members of the public in work related to health care quality, delivery, or policy. You may need to prepare your advisers in advance – and support them throughout – to be sure their contributions to the project and their experience are meaningful and positive.

> *We are listened to, and many of the things we suggest are put into practice.*
> – Patient representative

WHY DO THIS

Much of the answer is intuitive, but it bears mention:

1. Good preparation and support will enable community member advisers to feel more comfortable participating in what might be a new experience for them.
2. Satisfaction with contribution and participation leads to a stronger commitment to the eventual outcome of the project and its dissemination and acceptance by other patients, families or other constituents.
3. Organizations get more out of community members' perspective when the advisers feel genuinely valued. Investing even a small amount of time in training and orientation underscores their sense that they are making a needed contribution to the work ahead.

HOW TO DO THIS

- Start with this premise: We are committed to making sure you have the training you need to feel confident in your role as an adviser.
- Designate a member of your staff as a liaison to advisers. He or she will be the main point of contact, can offer additional support as needed and can gather ongoing feedback.
- Prepare and organize background materials into a manual, binder, or accessible online folder. The comfort level of participants increases if they know what to expect and what's expected of them. Be sure the tone is warm and welcoming. Include:
  - Meeting schedule and project milestones, including length and frequency of meetings, where they are hosted, if virtual attendance is encouraged or accommodated, and expectations for other time commitments such as periodic check-ins by phone, or review of documents.

  - Explanation of other tasks, such as being asked to review materials to prepare for a meeting. How will these be made available? Who can they get in touch with for questions? How much time to review? Preferences for sending: mail or email?
  - Name and contact information for the point person on the project.
  - Role of each participant on the panel or workgroup.
  - Background information on the topic, written without extensive jargon, acronyms, etc. Consider using newspaper clippings or other general media narratives on the topic, if relevant, as these are often more accessible than medical literature.
- Host one or more orientation sessions. This may be done one-on-one, or with a group. The goals of the session is to be sure the community advisers:
  - Understand their responsibilities as equal partners on the project team.
  - Feel comfortable in their role.
  - Have appropriate expectations for their participation.
  - Have a good understanding of the practical aspects of being an engaged adviser.
  - Have information about why and how the organization believes that including the voices of those who use the health care system will help improve the quality, safety or policies at the organization.
  - Understand how things work at the organization. Include a tour of the facility if possible.
  - Know how they can best contribute to the outcome of the project.
  - Know that they can ask questions if they are not sure of something.
  - Know that they, indeed, bring a lot to the table/conversation and are necessary to build the necessary bridge between the public and the health care professionals or policymakers.
  - If applicable, explain any HIPAA or other privacy training they will receive prior to joining the task force or committee.
- Advisers may also benefit from having a one-on-one meeting with the project/committee chair prior to attending the first meeting. This provides an opportunity for introductions and for advisers to ask questions about the project. The staff liaison may wish to attend this meeting, as well.

CASE STUDY

Community advisers help bridge linguistic and multicultural gaps

The **Cambridge Health Alliance** serves the culturally diverse communities of Cambridge and Somerville, as well as other "immigrant gateway" communities near Boston, Mass.

Since 2001, over 300 volunteers from these communities have been recruited by the Community Affairs Department to contribute to the Alliance's work. Collectively, these advisers speak 16 different languages and represent the local Haitian, Brazilian, Latino, South Asian, African-American and African communities.

Program staff work with these advisers to offer health fairs and screenings; provide basic health education in disease prevention and wellness; and educate the community about services.

At **Somerville Hospital**, the Patient and Family Advisory Council helps staff develop a deeper understanding of the needs of the community.

Hospital signs are all in four languages, and artwork in public spaces reflects the diversity of the cultures served. Patient and family informational materials and educational programs are offered in many languages.

Conway J, Johnson B, Edgman-Levitan S, Schlucter J, IFPCC. Partnering with patients and families to design a patient-and family-centered health care system. IPFCC/IHI. 2010.

- Advisers will also need specific orientation directed to the project work, particularly with regard to some of the technical aspects. Potential topics to address will depend on your specific project and goals, but may include:
    - quality improvement models and methodologies used at the organization,
    - types of data collected, or
    - a review of the importance of confidentiality and privacy.
- Choose a meeting time and location that will work for advisers. Ask if they need any accommodations to attend meetings in person or virtually.

TROUBLESHOOTING

"Our project is very technical/clinical. It will be hard to include people in the work group who don't have a health care background."

This may seem daunting, but it's helpful to know that this has and can be done. It takes some careful thought to avoid information overload. One rule of thumb: don't try to communicate everything at once.

- Break the information down into manageable pieces or elements.
- Consider background articles on the topic that were written for more general audiences whenever possible and appropriate; peer-review journal articles will be more approachable for non-experts once a foundation has been laid.
- Find visual and other ways to make complex issues understandable. Consider developing logic models, cause-and-effect diagrams, or other schematic diagrams. You'll find these may help everyone at the table.
- Be aware of the make up of your adviser group and adjust your training and orientation to each, as much as possible, in the group or individually. You might want to ask each adviser what subjects they feel they need preparation in.
- Leave a substantial amount of time for questions.

"The last time we tried this, one of the advisers struggled with his duties on the project. It was an awkward experience for all of us and we do not want to have a repeat of this."

Occasionally, despite careful recruitment, selection and orientation, an adviser struggles with his or her duties. If this is the case, find out why.

- Perhaps the project is a not a good match with the adviser's skills and interests, after all.
- Perhaps the adviser needs additional training or would benefit from working closely with a mentor.

- Perhaps the project team has difficulty coalescing to create a supportive environment and there is resistance from health care professionals, staff, or other advisers. In this case, it may be helpful to work with clinicians and staff to help them develop more effective partnership skills, depending on the timing of the project.

"How can we make advisers feel comfortable with the group process?"

- Try to ensure that there are at least two, if not three, members of the public on the project.
- Encourage advisers to identify potential allies in the group. There may be people in the group who come from a more patient-centered approach than others, or who have agreed with a community member on other points. Helping advisers to identify these people and to approach them at break times can help them to feel more supported when they raise topics in the main meetings.
- Encourage staff to participate in the orientation of advisers. This helps them feel welcome and facilitates their understanding of the purpose of and goals for the project.
- Ask the committee or workgroup chair to recruit experienced advisers (if you have them) to mentor a new adviser. Mentors can contact the adviser after each meeting to answer questions and make sure the adviser remains confident with his or her participation. This commitment does not need to be longstanding. It is likely only needed for the first three to four meetings. The staff liaison can check in with each adviser at the end of the first 3 or 4 months to determine if he or she needs the mentorship to continue.

SOURCES AND RESOURCES

Beinecke RH, Delman J. Commentary: Client involvement in public administration research and evaluation. The Public Sector Innovation Journal. 2008.

Agency for Healthcare Research and Quality. Guide to Patient and Family Engagement in Hospital Quality and Safety. Content last reviewed December 2017. www.ahrq.gov/professionals/systems/hospital/engagingfamilies/guide.html

Health Research & Educational Trust. (2015, December). Patient and Family Engagement Resource Compendium. Chicago, IL: Health Research & Educational Trust. Accessible at: www.hpoe.org/pfecompendium

Health Care Transformation Task Force. Addressing Consumer Priorities in Value-Based Care: Guiding Principles and Key Questions. August 2016

Guidelines International Network. G-I-N Public Toolkit: 2012. p. 50.

ESSENTIAL ELEMENT 5

Facilitate an Engaging Process

Spend time building a foundation for successful interactions and meetings. You, your organization, and the community members will all feel rewarded.

WHY DO THIS

1. Well-facilitated meetings lead to participants who will feel empowered about their own ideas and participation, stay invested in your organization, and take on responsibility and ownership of the project.
2. Facilitation skills are the “process” skills you can use to guide and direct your project’s/panel’s work effectively and purposefully. Facilitation focuses on how people participate in the process of learning or planning, not just on what gets achieved.
3. When community members join a project, the first interactions and experiences are critical. With extra effort and planning for the early meetings, you can help advisers to feel welcome and promote positive experiences that can be sustained throughout the process.

HOW TO DO THIS

1. Set a positive tone at your first meeting.
   - Include time on the agenda for introductions, and possibly an ice-breaker activity to help establish a good working relationship.
   - Distribute short biographies for everyone on the committee or work group and use name tent cards to help with name recognition.
   - Agree upon a set of group norms (see sidebar for sample).
   - Review the goals and tasks of the group to ensure everyone is on the same page.
2. Foster healthy group dynamics
   - Be mindful of how communication style and language can either create an inclusive or exclusive environment. The meeting facilitator or chair is responsible for ensuring a safe, inclusive atmosphere in the group.
   - Strongly discourage the use of professional/medical jargon in the meetings, which can make members of the public feel excluded).
   - Consider eliminating the use of titles in order to deemphasize status differences.

SAMPLE GROUP NORMS

We will:

- Make an effort to attend all meetings.
- Listen respectfully and be open to all ideas.
- Be concise when speaking to encourage others to participate.
- Strive to reach consensus.
- Start and end on time.
- Confidentiality is a priority.

- Seat advisers in the middle of the meeting participants so they do not feel isolated from the group. The facilitator/meeting chair should be conscious of bringing them into the conversations.
- Consciously work to overcome the power difference between health care professionals or other “experts” and patients. Remember that it can be intimidating for community members to posit alternative viewpoints in groups of professionals and staffers. Try these strategies:
    - Emphasize the importance of the public perspective and the expertise the advisers bring.
    - Reinforce to the full group that the patients, families and community members have equal status and their contributions are essential to the outcome off the project.
    - Give examples of successful community engagement in similar projects.

3. Keep meetings on track

- Start and end on time. Remember, there are volunteers at the table.
- Consistently encourage and model talking openly. Staff and advisers should be prepared ahead of time for honesty in these conversations.
- Leave time for questions.
- Identify a feedback loop at the end of the meeting so that members can contact project leads or presenters between meetings, if needed.
- Develop and share plans for follow-up.
- When committees are formed, ask – don’t assume – which tasks, if any, the advisers will have time and interest in undertaking.

4. Don’t lose momentum between meetings

- Provide more detailed materials that committee and workgroup members can review as needed. Be sure advisers have adequate time to review and ask questions about the materials before the next meeting.
- Be mindful that you don’t exclude the advisers from emails that should include all who are working on the project or subcommittee.
- Especially early on, have the staff liaison check in with advisers to see if they need additional support or have feedback to share with your organization.

> *“We see patients and families as essential partners in our work because they bring a perspective that only they can provide. You can’t improve the health care system without including the voices of those who are affected by it the most.*
>
> – Executive at a health care agency”

TROUBLESHOOTING

"How do we make sure that members of the public are fully integrated into, and satisfied with their participation in the project?"

Plan ahead (see Elements 3 and 4). Ask for and integrate feedback. The resources from Consumers United in the appendix may be particularly helpful to you.

"Some members of our work group/task force are more receptive to hearing from members of the public than others."

There are approaches you can take. Here are two:

1. Find ways to remind everyone of the purpose of having patients, families and community members helping with the work. Use examples of successes, either in your own organization or others.
2. Encourage advisers to identify potential allies in the group. There may be some in the room who come from a more patient-centered approach than others, or who have agreed with members of the public on other points. Helping advisers to identify these people and to approach them at break times can help them feel more supported when they raise topics in the main meetings.

"We aren't sure how to manage differing opinions, perceptions and, occasionally, tensions."

Acknowledge that there will be differences up front. If extreme differences in opinions or perceptions develop, the staff liaison should encourage the workgroup/project chair to consider facilitation methods to navigate and bridge these differences. Some examples:

- Ask for assistance from an organization staff member who is not part of the workgroup and who is recognized as a skilled facilitator.
- Delay a decision and gather additional information as needed; develop a timeline for final decision making.
- Appoint a task force or subcommittee for further study of the issue at the heart of the dispute.

| SOURCES AND RESOURCES

CUE: Advisory Panel Engagement Resources: www.consumersunited.org/engagement

The Community Tool Box is a free, online resource for those working to build healthier communities and bring about social change. It offers thousands of pages of tips and tools for taking action in communities. www.ctb.ku.edu/en/table-of-contents/leadership/group-facilitation/facilitation-skills/main

ESSENTIAL ELEMENT 6

Get Feedback and Iterate

A critical part of engaging members of the public in your panel or project is informing the entire organization and the community it serves about the work and accomplishments of community advisers. To do this well, you will need to document this involvement and collect illustrative examples to share. Decide what you are going to track or measure and be diligent about following your plan.

> *I think consistency in focus, in measurement, in feedback to the frontline... the consistency sends a message that this is an important long-term issue.*
>
> – Chief Medical Officer

WHY DO THIS

1. Fundamentally, your organization exists to meet the needs of your clients, patients or the general public. None of these needs can be met without fully partnering with them to redesign improve and evaluate the services you provide.
2. By monitoring/reviewing progress you can see when progress is being made so you can celebrate your successes. You will also be able to see if efforts to include the public in your work is faltering and needs more attention. Investing leadership time in reviewing your selected measures shows staff that strengthening patient or community engagement is an organizational priority.
3. You can only make a strong case for the continued need for engagement from members of the public in your organization's improvement efforts if you track and monitor that work. Data from hospital efforts, for example, shows that patient and family advisers contribute significantly to the efficacy of improvement initiatives at almost all levels.

HOW TO DO IT

- The staff liaison, perhaps with the help of any data development expertise in your organization, can devise a system for measuring and tracking:
  - adviser activities on the project/panel,
  - the outcome(s) of project in which advisers are involved, and if appropriate,
  - the growth of adviser engagement over the course of the project.
- Information to consider collecting and reporting, particularly when you've had more than one opportunity to engage advisers, includes:
  - The number of advisers recruited or total number of advisers on a project/panel.

  - The description of each of the distinct efforts in which advisers participate (e.g., councils, committees, training and orientation events, facility design planning, feedback sessions, and workgroups).
  - Total hours volunteered by advisers per project.
  - Examples of work completed (e.g., minutes from meetings; print, web, or video resources; or revisions to policies or procedures).
- Measure the benefit to advisers as members of a committee or work group.
  - What are the things you want to measure about how advisers viewed their experience? Some examples:
    - Was the role satisfying?
    - Did they feel like contributors?
    - Were their expectations met or exceeded?
    - Did they feel heard/respected?
    - Did they feel like an integral part of panel?
- Measure the benefit to the organization of participation from members of the public.
  - What are the organizational benefits you want to measure? Some examples:
    - better patient experience of your services,
    - broadening your reach, or
    - gaining additional buy-in for new ideas/policies.
- Invest leadership time in reviewing your selected measures to demonstrate that strengthening patient or community engagement is an organizational priority.

TROUBLESHOOTING

“The ‘n’s’ are too small for measurement to have any meaning.”

Even if imprecise or incomplete, most data are accurate enough to give you a general sense of whether or not you’ve made progress. Think of any qualitative data you collect in the same way you might think about information gleaned from an employee on an exit interview. While it may not tell you everything you need to know, you will learn something. See resources in the footnotes of this section for measures to consider.

EVALUATING THE MEETING

Quick written or verbal debriefs at the end of project meetings can help in making adjustments to panel operations and functions.

Spend a few minutes asking questions such as “What went well during this meeting?” and “How can we improve future meetings?”

Keep people focused on the process and not individual behaviors. For example, “I noticed the discussion around ’X’ got a little off topic” and not “’Someone’ spent too much time talking about an unrelated issue.”

Be sure to take time at each meeting and at the end of the project to celebrate accomplishments, both big and small.

“Besides measurement, what else can we do to sustain efforts to include community members in our work?”

There are other ways to build on your successes. Actively communicate adviser accomplishments. Here are some tips:

- Publicize information about activities that involved patient and family advisers in a variety of venues – annual report, employee newsletters, community newsletters, your website, hospital staff meetings, and display boards. Make sure the information you provide includes examples of ways that advisers had an impact.
- Share accomplishments with leadership. Develop a brief presentation for the leadership team or governing board and invite a community adviser to co-present.
- Share improvements and lessons learned with others at local, regional, and national meetings. Look for opportunities to present at conferences or to share your experiences with other workgroups in your organization or networks.
- Make sure to communicate with advisers about the status of the project and let them know how their input made a difference.

SOURCES AND RESOURCES

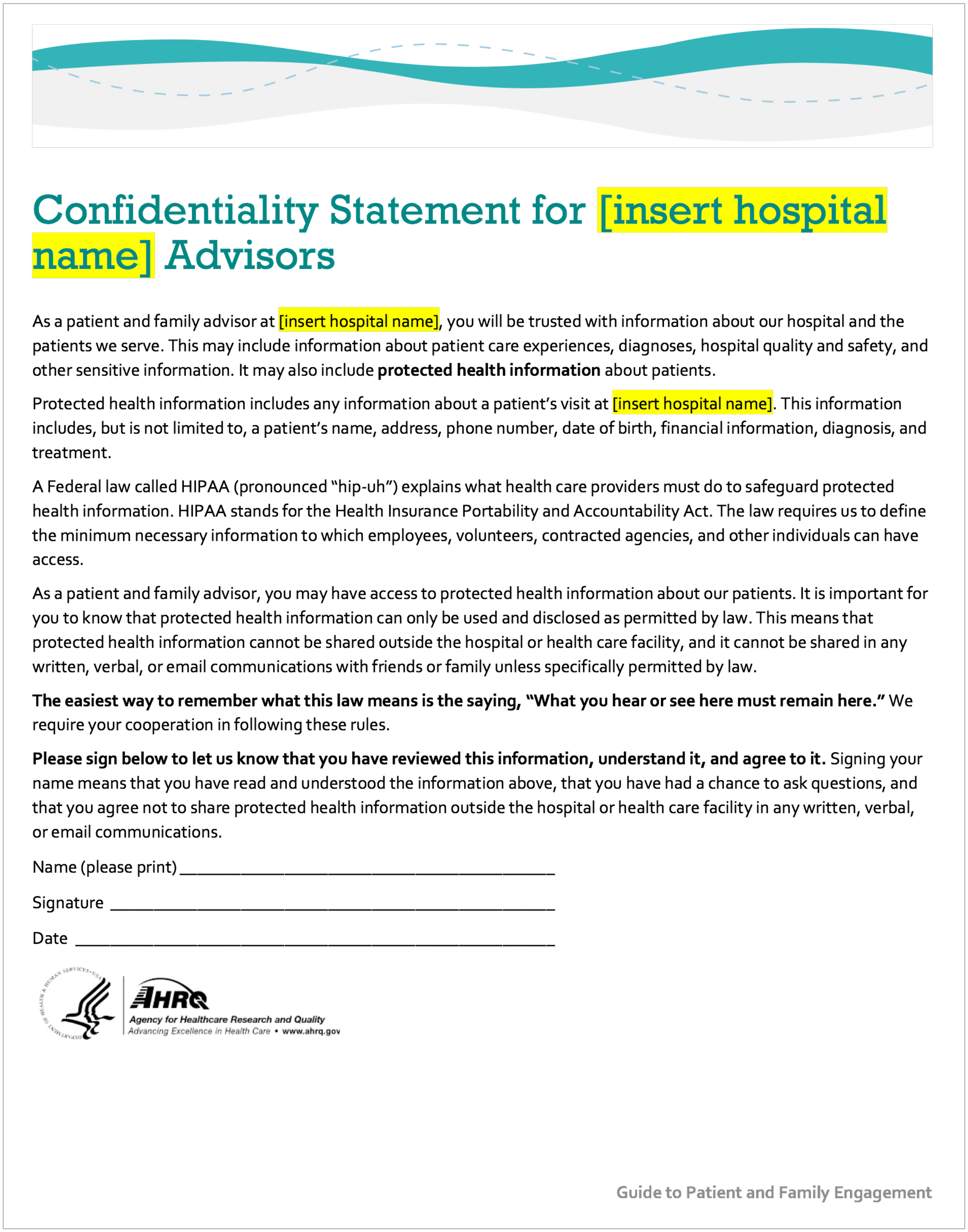
Agency for Healthcare Research and Quality. Guide to Patient & Family Engagement: Working with Patients & Families as Advisers (Strategy 1). AHRQ. 2013. pp. 1–62.

Guidelines International Network. G-I-N PUBLIC TOOLKIT. Patient and public involvement in guidelines: practical advice on developing effective patient and public involvement programs. Chapter 3: How to recruit and support patients and the public in guideline development. Authors: Sarah Chalmers Page,* Jane Cowl and Loes Knaapen (2012)

Public and Patient Engagement Tool: Participant Questionnaire V.1.June 2015. The Public and Patient Engagement Evaluation Tool has been licensed under a Creative Commons Attribution-NonCommercial-Share Alike 4.0 International License. © 2015, Julia Abelson and the PPEET Research-Practice Collaborative. McMaster University. All rights reserved.

Appendix

Appendix A: Sample Confidentiality Statement from Agency for Healthcare Research and Quality (AHRQ)



Confidentiality Statement for [insert hospital name] Advisors

As a patient and family advisor at [insert hospital name], you will be trusted with information about our hospital and the patients we serve. This may include information about patient care experiences, diagnoses, hospital quality and safety, and other sensitive information. It may also include **protected health information** about patients.

Protected health information includes any information about a patient's visit at [insert hospital name]. This information includes, but is not limited to, a patient's name, address, phone number, date of birth, financial information, diagnosis, and treatment.

A Federal law called HIPAA (pronounced "hip-uh") explains what health care providers must do to safeguard protected health information. HIPAA stands for the Health Insurance Portability and Accountability Act. The law requires us to define the minimum necessary information to which employees, volunteers, contracted agencies, and other individuals can have access.

As a patient and family advisor, you may have access to protected health information about our patients. 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 outside the hospital or health care facility, and it cannot be shared in any written, verbal, or email communications with friends or family unless specifically permitted by law.

The easiest way to remember what this law means is the saying, "What you hear or see here must remain here." We require your cooperation in following these rules.

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 understood the information above, that you have had a chance to ask questions, and that you agree not to share protected health information outside the hospital or health care facility in any written, verbal, or email communications.

Name (please print) ____

Signature ____

Date ____

AHRQ
Agency for Healthcare Research and Quality
Advancing Excellence in Health Care • www.ahrq.gov

Guide to Patient and Family Engagement

Appendix B: Tools for Advisory Panel Organizers from Consumers United for Evidenced-Based Healthcare (CUE)

Checklist for Advisory Panel Organizers

Before the Panel: Find at least Two Consumer Representatives

- ☐ Establish criteria for consumer representatives:
  - ☐ Demographics
  - ☐ Disease-specificity, if relevant
  - ☐ Knowledge of evidence-based healthcare
  - ☐ Knowledge of advisory panel process
  - ☐ Not tied to industry
  - ☐ At least two consumer representatives per panel
- ☐ Reach out to CUE or other consumer networks with a description of the opportunity
- ☐ Keep a record of all consumers with whom your organization partners:
  - ☐ Include their names, organization name, and contact information

Before the Panel: Prepare a Consumer-Friendly Environment

- ☐ Provide all panel members with:
  - ☐ Timeline of future meetings
  - ☐ Roles and responsibilities of each panel member
  - ☐ Conflict of interest statement
  - ☐ Glossary of relevant clinical terms
  - ☐ Payment and/or reimbursement information
  - ☐ Clear expectations in terms of work, time, and knowledge
- ☐ Create or use:
  - ☐ Manual of policy and procedures for guideline development
  - ☐ Resources and/or training on interpersonal skills
- ☐ Call all representatives as a group before the first meeting to discuss advisory panel process and answer questions

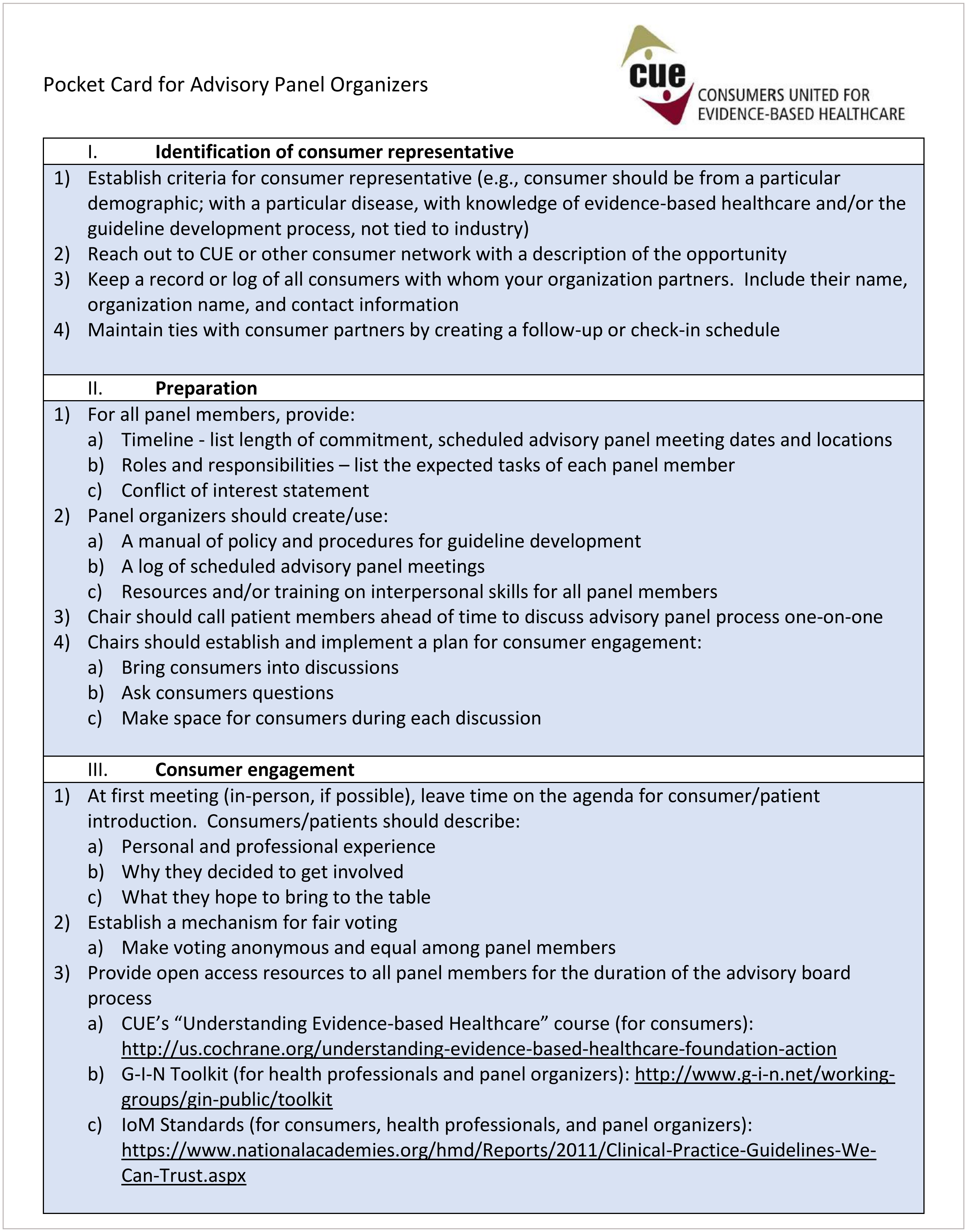
During the Panel: Ensure Consumer Engagement

- ☐ Allow sufficient time for consumer introductions, and elicit from everyone:
  - ☐ Personal and professional experience
  - ☐ Rationale for involvement
  - ☐ Desired contribution to panel
- ☐ Emphasize that perspectives from all stakeholder groups are equal and important
- ☐ Facilitate communication among potential allies on the panel by identifying members who can support one another's stakeholder role
- ☐ Encourage equal treatment in naming conventions when panel members address one another (e.g., all panel members use first names)
- ☐ Encourage participation from reticent consumer representatives by asking questions
- ☐ Provide positive reinforcement when consumers contribute to the discussion
- ☐ Discourage interruption of one panel member by another
- ☐ Establish an anonymous, democratic voting mechanism in which the consumer votes have equal weight with that of other stakeholders
- ☐ Provide open access resources to all panel members during the advisory panel process

After the Panel: Support Future Consumer Engagement

- ☐ Maintain ties with consumer representatives by creating a follow-up or check-in schedule

cue



Pocket Card for Advisory Panel Organizers

CONSUMERS UNITED FOR EVIDENCE-BASED HEALTHCARE

I. Identification of consumer representative

1) Establish criteria for consumer representative (e.g., consumer should be from a particular demographic; with a particular disease, with knowledge of evidence-based healthcare and/or the guideline development process, not tied to industry)
2) Reach out to CUE or other consumer network with a description of the opportunity
3) Keep a record or log of all consumers with whom your organization partners. Include their name, organization name, and contact information
4) Maintain ties with consumer partners by creating a follow-up or check-in schedule

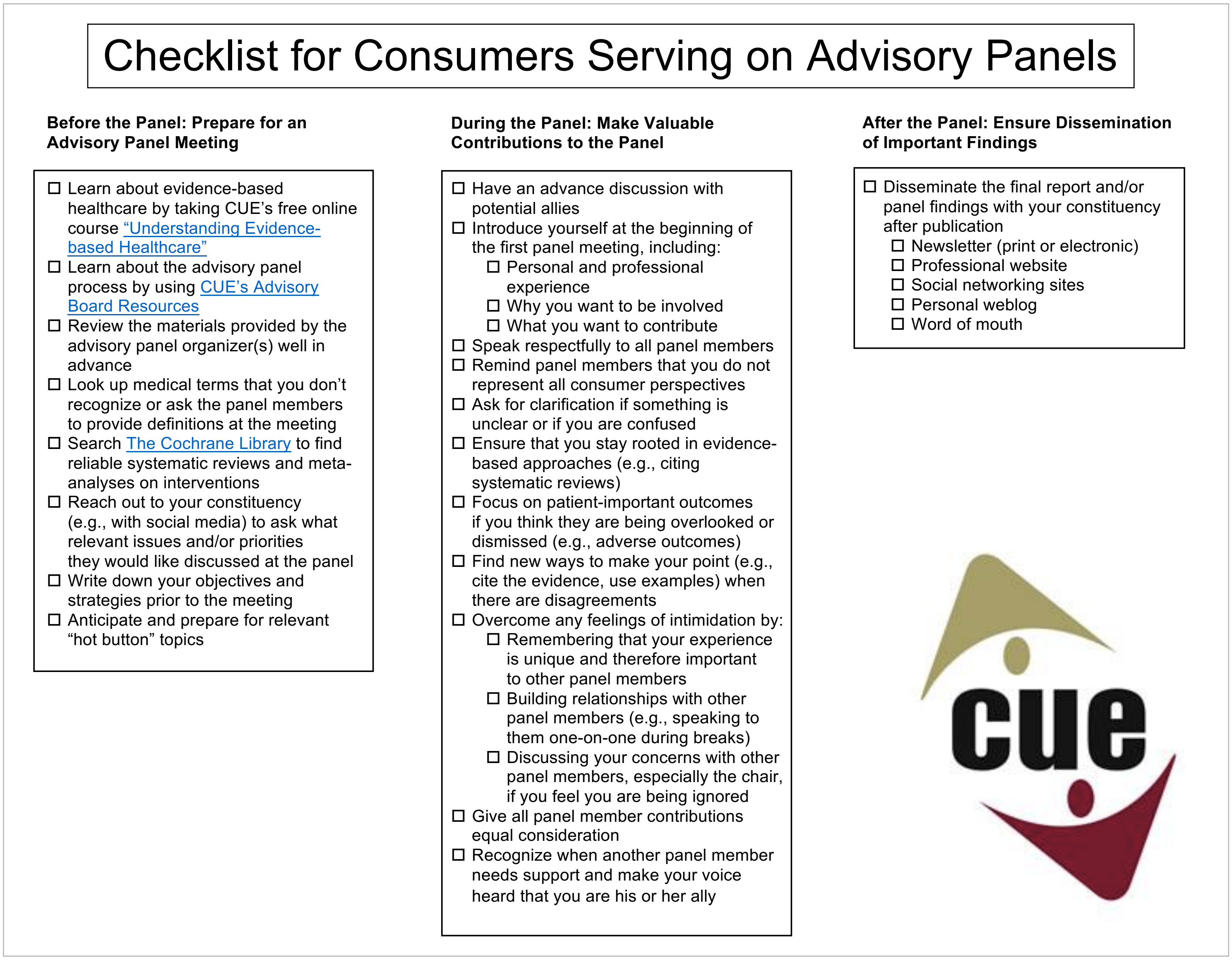
II. Preparation

1) For all panel members, provide:
    a) Timeline - list length of commitment, scheduled advisory panel meeting dates and locations
    b) Roles and responsibilities – list the expected tasks of each panel member
    c) Conflict of interest statement
2) Panel organizers should create/use:
    a) A manual of policy and procedures for guideline development
    b) A log of scheduled advisory panel meetings
    c) Resources and/or training on interpersonal skills for all panel members
3) Chair should call patient members ahead of time to discuss advisory panel process one-on-one
4) Chairs should establish and implement a plan for consumer engagement:
    a) Bring consumers into discussions
    b) Ask consumers questions
    c) Make space for consumers during each discussion

III. Consumer engagement

1) At first meeting (in-person, if possible), leave time on the agenda for consumer/patient introduction. Consumers/patients should describe:
    a) Personal and professional experience
    b) Why they decided to get involved
    c) What they hope to bring to the table
2) Establish a mechanism for fair voting
    a) Make voting anonymous and equal among panel members
3) Provide open access resources to all panel members for the duration of the advisory board process
    a) CUE's "Understanding Evidence-based Healthcare" course (for consumers): http://us.cochrane.org/understanding-evidence-based-healthcare-foundation-action
    b) G-I-N Toolkit (for health professionals and panel organizers): http://www.g-i-n.net/working-groups/gin-public/toolkit
    c) IoM Standards (for consumers, health professionals, and panel organizers): https://www.nationalacademies.org/hmd/Reports/2011/Clinical-Practice-Guidelines-We-Can-Trust.aspx

Appendix C: Tools for members of the public serving on advisory panels from Consumers United for Evidenced-Based Healthcare (CUE)



Checklist for Consumers Serving on Advisory Panels

Before the Panel: Prepare for an Advisory Panel Meeting

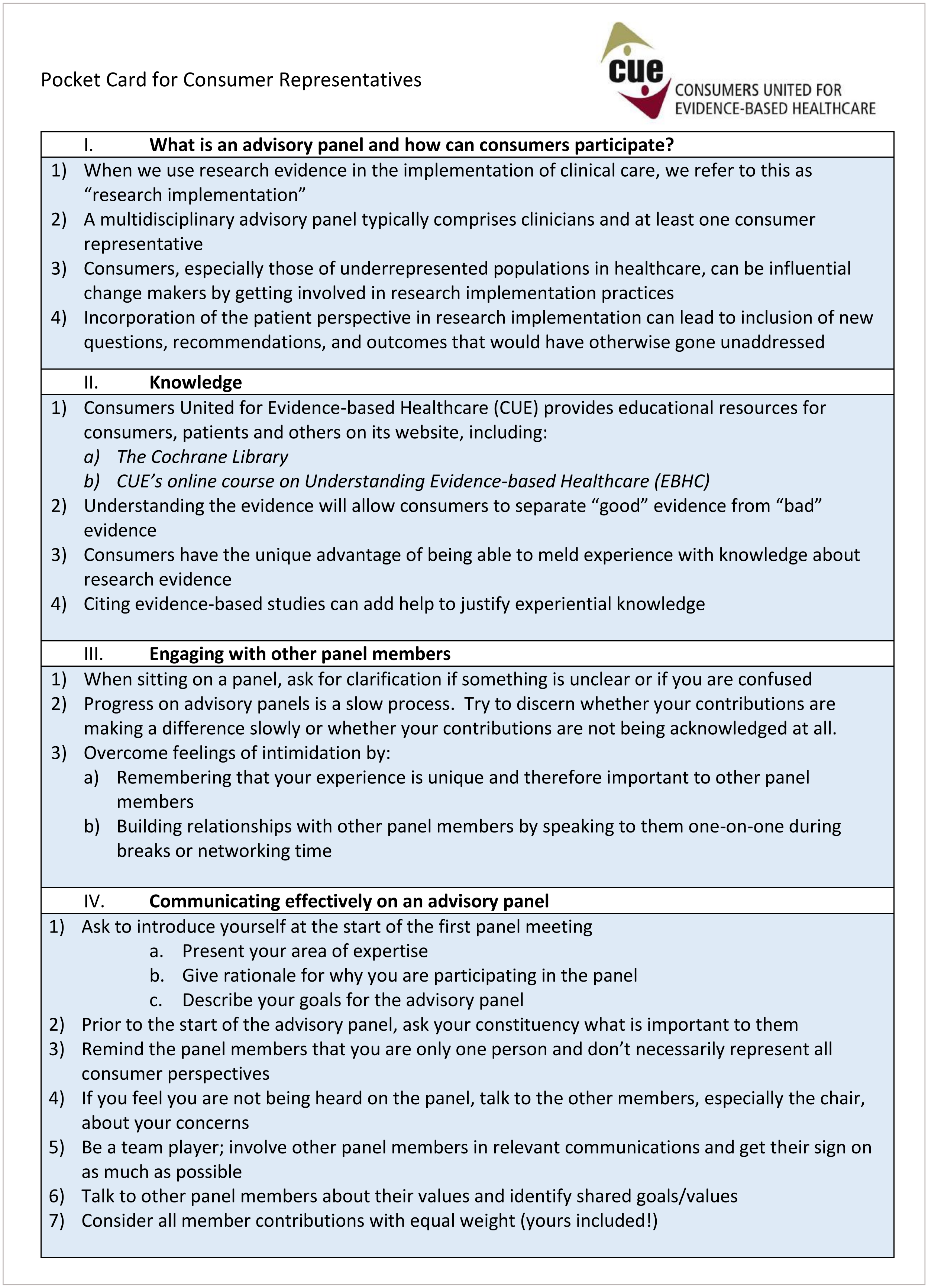
- ☐ Learn about evidence-based healthcare by taking CUE's free online course "Understanding Evidence-based Healthcare"
- ☐ Learn about the advisory panel process by using CUE's Advisory Board Resources
- ☐ Review the materials provided by the advisory panel organizer(s) well in advance
- ☐ Look up medical terms that you don't recognize or ask the panel members to provide definitions at the meeting
- ☐ Search The Cochrane Library to find reliable systematic reviews and meta-analyses on interventions
- ☐ Reach out to your constituency (e.g., with social media) to ask what relevant issues and/or priorities they would like discussed at the panel
- ☐ Write down your objectives and strategies prior to the meeting
- ☐ Anticipate and prepare for relevant "hot button" topics

During the Panel: Make Valuable Contributions to the Panel

- ☐ Have an advance discussion with potential allies
- ☐ Introduce yourself at the beginning of the first panel meeting, including:
  - ☐ Personal and professional experience
  - ☐ Why you want to be involved
  - ☐ What you want to contribute
- ☐ Speak respectfully to all panel members
- ☐ Remind panel members that you do not represent all consumer perspectives
- ☐ Ask for clarification if something is unclear or if you are confused
- ☐ Ensure that you stay rooted in evidence-based approaches (e.g., citing systematic reviews)
- ☐ Focus on patient-important outcomes if you think they are being overlooked or dismissed (e.g., adverse outcomes)
- ☐ Find new ways to make your point (e.g., cite the evidence, use examples) when there are disagreements
- ☐ Overcome any feelings of intimidation by:
  - ☐ Remembering that your experience is unique and therefore important to other panel members
  - ☐ Building relationships with other panel members (e.g., speaking to them one-on-one during breaks)
  - ☐ Discussing your concerns with other panel members, especially the chair, if you feel you are being ignored
- ☐ Give all panel member contributions equal consideration
- ☐ Recognize when another panel member needs support and make your voice heard that you are his or her ally

After the Panel: Ensure Dissemination of Important Findings

- ☐ Disseminate the final report and/or panel findings with your constituency after publication
  - ☐ Newsletter (print or electronic)
  - ☐ Professional website
  - ☐ Social networking sites
  - ☐ Personal weblog
  - ☐ Word of mouth



Pocket Card for Consumer Representatives

CONSUMERS UNITED FOR
EVIDENCE-BASED HEALTHCARE

I. What is an advisory panel and how can consumers participate?

1) When we use research evidence in the implementation of clinical care, we refer to this as “research implementation”
2) A multidisciplinary advisory panel typically comprises clinicians and at least one consumer representative
3) Consumers, especially those of underrepresented populations in healthcare, can be influential change makers by getting involved in research implementation practices
4) Incorporation of the patient perspective in research implementation can lead to inclusion of new questions, recommendations, and outcomes that would have otherwise gone unaddressed

II. Knowledge

1) Consumers United for Evidence-based Healthcare (CUE) provides educational resources for consumers, patients and others on its website, including:
    a) *The Cochrane Library*
    b) *CUE’s online course on Understanding Evidence-based Healthcare (EBHC)*
2) Understanding the evidence will allow consumers to separate “good” evidence from “bad” evidence
3) Consumers have the unique advantage of being able to meld experience with knowledge about research evidence
4) Citing evidence-based studies can add help to justify experiential knowledge

III. Engaging with other panel members

1) When sitting on a panel, ask for clarification if something is unclear or if you are confused
2) Progress on advisory panels is a slow process. Try to discern whether your contributions are making a difference slowly or whether your contributions are not being acknowledged at all.
3) Overcome feelings of intimidation by:
    a) Remembering that your experience is unique and therefore important to other panel members
    b) Building relationships with other panel members by speaking to them one-on-one during breaks or networking time

IV. Communicating effectively on an advisory panel

1) Ask to introduce yourself at the start of the first panel meeting
    a. Present your area of expertise
    b. Give rationale for why you are participating in the panel
    c. Describe your goals for the advisory panel
2) Prior to the start of the advisory panel, ask your constituency what is important to them
3) Remind the panel members that you are only one person and don’t necessarily represent all consumer perspectives
4) If you feel you are not being heard on the panel, talk to the other members, especially the chair, about your concerns
5) Be a team player; involve other panel members in relevant communications and get their sign on as much as possible
6) Talk to other panel members about their values and identify shared goals/values
7) Consider all member contributions with equal weight (yours included!)