

Steps for Achieving Meaningful Consumer Engagement in Health IT Initiatives

MARCH 2012

Ensuring substantive and meaningful consumer participation in a health IT initiative can help facilitate adoption of patient-centered innovations, and ultimately, speed and enhance the adoption of health IT in a community.

Consumer engagement, especially in a highly technical area like health IT, requires an intentional and thoughtful process consisting of four main stages:

1. Identifying likely collaborators
2. Initiating and building relationships
3. Involving and activating targeted consumer advocates
4. Supporting the activated consumer advocates

Identify Likely Collaborators

Identification of appropriate consumer advocates to involve in a particular initiative begins by researching the community's consumer groups to learn more about them and determine whether they are a good fit (Please see [Defining Consumer Representation](#) for a comprehensive description of authentic and robust consumer representation.) The extent of the evaluation should be sufficient to understand particular groups' history, including evolving programs and priorities.

In learning about the major policy issues that have an impact on the advocates' priorities, challenges and the environment in which they operate, consider especially:

- ▶ The organization's level of knowledge about health care generally, and health IT specifically, and where these issues fit into its priorities.
- ▶ Its number of paid staff, availability of resources, and constraints that may affect the advocates' ability to engage.
- ▶ Its reach, communication capabilities and interest in collaboration.

Note: It should **NOT** be assumed that organizations with limited resources or other constraints will not want to participate in the initiative.

Initiate and Build Relationships

Hearing from the consumer advocates directly will provide more insight into and clarity about their priorities, focus areas and capabilities.

It is important to seek out opportunities to increase understanding of factors that may affect the particular advocates' ability and willingness to collaborate, such as:

- ▶ What is their interest in health IT, and why is it on their radar/agenda? What other organizations have they worked with, and to what end?
- ▶ What constraints might they face in engaging in health IT work? (e.g., a fundraising objective, a legislative platform that does not include health care)
- ▶ What is the size and involvement of the organization's membership or constituency?
- ▶ What are their primary interests, and what challenges do they face in their day-to-day work?

The discussion is also an opportunity to promote your own initiative, cultivate interest in it and **convey the value you can provide to them** through a potential collaboration.

The ultimate goal of this outreach is to grow a pool of consumer advocates that you can turn to for some level of engagement with the initiative. This pool should be diverse and should reflect the population of the particular community, as well as the relevant target audience. Not everyone in the advocate pool has to engage with the initiative in the same way, and the list of potential ways for each to engage in the initiative's work can be long and diverse. For example, consumer advocates often:

- ▶ Participate on leadership teams;
- ▶ Manage an email group or participate as a member;
- ▶ Participate in media outreach or events;
- ▶ Assume roles in initiative workgroups;
- ▶ Engage in outreach to policy-makers and other stakeholders;
- ▶ Assist with vetting of materials;
- ▶ Reach out to additional consumers to promote the initiative's goals through their existing membership networks.

Work individually with advocates to determine the best roles for each to take on.

Activate Advocates in the Initiative

Invite Participation

After researching and compiling the community's consumer advocate pool, identify which advocates will be the best fit for the particular initiative. The National Partnership is available to help make connections with consumer organizations in your community and provide consultation with respect to the timing of recruitment, the right constituency representation, provision of resources and strengthening of relationships.

Jointly Identify Clearly-Articulated Roles for each Advocate

Once the consumer advocates have been approached and invited to participate in the initiative, they need to be “activated.” In conjunction with the advocates, identify the best and most appropriate role for each. Examples of possible roles are listed in the previous section.

Whatever the role, it is important that the expectations for the particular role are clearly articulated. For example:

- ▶ Is the advocate being asked to join a multi-stakeholder committee? What is the committee’s charge? And what will the advocate’s specific role be?
- ▶ What is the time commitment and how will the advocate’s skills be used?
- ▶ What kind of preparation does the consumer advocate need in order to participate effectively? What resources are available to support him or her?

The role of a consumer advocate in any initiative should never be to serve as a mere token or rubberstamp. Consumer involvement will be beneficial only if they feel their input is valued and used to strengthen the initiative in which they are involved. One of the best ways to achieve this is to offer consumer advocates leadership and decision-making opportunities.

For advocates on an initiative’s leadership team, subcommittee or working group, **being on equal footing with the other members is critical for their active and sustained involvement.** Consumer advocates have unique and valuable perspectives and skills to contribute just as other stakeholders do. One effective way to ensure equal footing is to outline member roles and responsibilities in a governing document, such as a committee charter. Such a document can make clear that each member, regardless of his or her perspective, has a role (and a vote) equal to that of every other member.

Both individual consumers and consumer advocates are more likely to remain involved in an initiative if they don’t feel isolated or overpowered. **It is important that the consumer perspective is represented in proportionate numbers to the other stakeholders.**

Engage advocates in the activities of the initiative as soon as possible, as it will not only help them learn more quickly, but will ensure that you incorporate a consumer perspective from the outset. This also sends a strong and vitally important message that consumer input is valued, and that their participation will be meaningful, rather than a rubber stamp to decisions made without their input.

Support the Activated Advocates

Provide Issue-Specific Information

Providing resources to support the advocates who have agreed to participate in the initiative may increase their understanding of complex health IT issues and help them engage in discussions in a more constructive manner.

The National Partnership has developed numerous health IT-specific resources for consumer advocates and can help coordinate educational webinars. Topics include but are not limited to:

1. Fundamentals of Health IT
2. HITECH and Meaningful Use
3. Privacy and Security
4. Health Reform
5. Disparities

The National Partnership's [website](#) houses these and many other resources for both consumer advocates and other stakeholders who seek robust representation of consumer views.

Cultivate Meaningful Consumer Advocate Participation

Consumer advocates will serve most effectively as members of leadership teams or workgroups if they are informed and prepared for discussions before meetings and conference calls. Whenever possible, identify opportunities to provide individualized, tailored assistance to the consumer advocates in advance to ensure the advocates are up to speed on the issues that will be discussed and prepared to effectively articulate their perspectives. It may be helpful to distribute agendas or other materials for consumers to review prior to the meeting/conference call. A glossary of key terms and commonly used acronyms is another useful preparation tool (one can be found [here](#) on the National Partnership's website). Make sure advocates know whom among the staff or leadership they can contact for information or assistance. Check in with the advocates on a regular basis to gauge their understanding and engagement, and to learn how to support them more effectively.

Initiative leaders can take steps to ensure consumer advocates remain engaged in the initiative by:

- ▶ Updating consumer advocates regularly on discussions among the initiative leadership team about initiative projects, objectives, etc. Whenever possible, identify opportunities for consumer advocates to contribute to those discussions.
- ▶ Assisting the advocates in being informed and connected by distributing relevant articles about health IT, as well as news of similar activities in other communities.
- ▶ Encouraging consumer advocates to reach out to their peers in other health IT initiatives.

The National Partnership facilitates peer-to-peer learning through electronic connection to other advocates across the nation. Advocates can participate by registering [here](#).

The National Partnership also provides assistance to initiative leaders. You can find initiative resources [here](#), and can contact the National Partnership staff for individualized advice and coaching by clicking the button at the bottom of the Initiative Resources page.

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