



TOOL/UTILITY

A Guide to Building Consumer Orientation Materials

Preparing Consumers for Successful Work in Health Care Improvement

July 2012

Introduction

This framework was designed to assist *Aligning Forces for Quality* (AF4Q) Alliances in building an onboarding toolkit for new consumers. Onboarding is a process used to orient new volunteers or staff to an organization. It typically includes a set of standard background materials and other relevant resources. An onboarding toolkit should be specific to each Alliance, standard for all new consumer stakeholders, and reflective of the current goals, projects, and vision of AF4Q and the local Alliance. This framework includes guidance for preparing onboarding components that have been successful in the past, specifically in engaging patients, families, and caregivers in health care quality improvement initiatives as members of leadership/governance teams, workgroups/committees, and as participants in other quality improvement projects. The goals of an onboarding toolkit are to build the relationship between consumer leaders and Alliance staff, prepare the consumers for their role, and provide a structure necessary for mutually beneficial collaboration. Ultimately, building an onboarding toolkit is the first step in the meaningful engagement of consumers.

Meaningfully engaged consumers improve stakeholder satisfaction, reduce attrition, and contribute to the sustainability of a project. By preparing consumers properly for their role in the Alliance and continuing to support them throughout their participation, staff members can increase the number of meaningfully engaged consumers in the Alliance.

Meaningful engagement is a set of practices established to activate stakeholders in all aspects of a project's design, governance, implementation and evaluation. Meaningful engagement for consumers is:

- **Effective**—Consumers' participation has an impact on programs and is an integral part of achieving the organization's vision/mission.

About Aligning Forces for Quality

Aligning Forces for Quality (AF4Q) is the Robert Wood Johnson Foundation's signature effort to lift the overall quality of health care in targeted communities, as well as reduce racial and ethnic disparities and provide real models for national reform. The Foundation's commitment to improve health care in 16 AF4Q communities is the largest effort of its kind ever undertaken by a U.S. philanthropy. AF4Q asks the people who get care, give care and pay for care to work together to improve the quality and value of care delivered locally. The Center for Health Care Quality in the Department of Health Policy at George Washington University School of Public Health and Health Services serves as the national program office. Learn more about AF4Q at www.forces4quality.org. Learn more about RWJF's efforts to improve quality and equality of care at www.rwjf.org/qualityequality/af4q/.

About the Author

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- *Equitable*—All stakeholder groups are engaged, including consumers, and stakeholder representation is balanced; consumers are offered equivalent opportunities in activities and shaping decisions regarding the organization’s work.
- *Purposeful*—Consumers feel the relationship allows them to achieve their respective goals; the organization respects consumers’ interests and uses their expertise.

Each heading in this framework represents a component that would be included in an onboarding toolkit. Some of these components will be the same in every community; others will need to be tailored to the local environment.

- ❖ **Onboarding Component 1: An Introduction to the Organization**
Section one suggests resources and methods for introducing a consumer stakeholder to the Alliance by sharing the Alliance’s vision, goals, operational details, and other information essential for orientation.
- ❖ **Onboarding Component 2. Making the Case for Health Care Quality Improvement**
Section two focuses on helping consumer stakeholders understand the need for quality improvement in health care and the value of working in a multi-stakeholder Alliance.
- ❖ **Onboarding Component 3. Roles and Responsibilities**
Section three outlines for Alliance staff how to determine roles and responsibilities, them with consumer stakeholders, and quantify how consumers have contributed to the Alliance.
- ❖ **Onboarding Component 4. Background Materials on Relevant Topics**
Section four includes suggestions for a number of resources that consumer stakeholders may find useful in learning about local and national health care quality issues.
- ❖ **Tips for Success: How To Present Onboarding Materials**
Successful methods for preparing and disseminating resources for consumer stakeholders.
- ❖ **Tips for Success: Continuing Support**
Successful methods for supporting consumer stakeholders throughout their AF4Q involvement, such as pre- and post-meeting recommendations, providing as-needed and integration support, reliability and recognition, and resources for consumer support.

Onboarding Component 1: An Introduction to the Organization

Section 1.1 — Mission statement and organizational vision

This section provides the consumer with a basic understanding of the organization and its long-term goals. This section, and all others throughout the framework, should be kept current and up to date. Questions to consider:

- What is the history of the organization?
- What is the organization trying to accomplish?
- What are the goals that guide the organization’s work?
- How do those goals relate to the mission of the organization?
- How are the goals selected and prioritized?

AF4Q Alliances may have two sets of goals to present to consumers: AF4Q’s mission and the parent organization’s mission. The information on AF4Q should be consistent with the materials provided by the Robert Wood Johnson Foundation and the AF4Q National Program Office (<http://forces4quality.org>).

For examples of descriptions of AF4Q and local efforts, please see [Appendix A](#).

Section 1.2 — Operational details

This section provides consumers with specific information about the way the organization operates, including boards, bodies, and decision-making processes. New consumers should be aware of how the organization's operations work and where they fit in an organizational map. Graphics can be helpful in this section, available in [Appendix B](#). Sharing detailed information about the various projects the organization has undertaken will help consumers understand the different health care-related and -focused projects and programs in the local Alliance community. The project overview should include the goals of each project, a list of the organizations involved (hospitals, health plans, employers, etc.), and a short description of current activities or major milestones. This section should be updated regularly to communicate any additions or relevant changes to project scope.

Questions to consider:

- What are the different boards and bodies, and how are they related to one another?
- How are decisions and recommendations made within the Alliance?
- What positions in the organization do consumers hold?
- What are the roles of the staff?
- Which projects involve consumers?
- What are the primary activities of each project?
- How are projects and operations funded?

Section 1.3 — Contact information

This section should include contact information (including the title, role, phone number, and email) of Alliance staff and other relevant stakeholders. This contact information should be shared along with clear instructions as to who consumers should contact in different situations. Clear and open channels of communication will help to ensure consumers feel supported and provide opportunities for ad hoc feedback. Questions to consider:

- What are the preferred methods of communication within your organization? Which does the individual prefer?
- What other methods of feedback exist for stakeholders?

Onboarding Component 2. Making the Case for Health Care Quality Improvement

Section 2.1 — Provide data supporting the need for quality improvement

Helping consumer stakeholders understand the need to improve our health care system gives them a better understanding of the value and need for the AF4Q initiative and why they should be involved. This section should include local and national data that demonstrate the importance of improving the quality of U.S. health care. Consider adding articles that highlight the benefits of quality improvement as well as the current state of health care quality in the United States. The goal is to introduce the consumer leader to quality concepts and connect these ideas to AF4Q goals and activities. An example of this information can be found in [Appendix C](#). Questions to consider:

- How does your community define quality? Is there more than one definition?
- Why is understanding quality so important in this work?
- What are the results of high-quality health care?

- What has been done so far to improve the quality of care in the community?
- What is the quality in your community?

Section 2.2 — Orientation to multi-stakeholder partnerships

Orienting consumers to the Alliance includes orienting them to the expectations of multi-stakeholder partnerships and to other stakeholders with whom they will be working. If any existing workgroups have a set of ground rules or codes of conduct, share them with the consumers. Identifying decision-making processes also are essential to ensure that consumers understand how to engage effectively in decision-making. If there are no written materials on these topics, consider creating them or sharing this information through discussion. Questions to consider:

- What are the processes by which information and recommendations are shared?
- How are conflicting views or priorities resolved among stakeholders?
- What stakeholder perspectives are important for consumers to understand?

Onboarding Component 3. Roles and Responsibilities

Section 3.1 — Stakeholders and staff

This section should include any material addressing staff and stakeholder roles and responsibilities. This could be a role description, a committee charter, code of conduct, and descriptions of processes such as how to submit recommendations. The goal of relating the roles and responsibilities of the staff and stakeholders to new consumers is to communicate clear expectations of one another. This could include, for example, a shared expectation that consumer leaders will share opinions and input drawn from their broader constituency when making recommendations on Alliance initiatives as well as bring information from the Alliance back to those constituents. Clear expectations are important because they help prevent attrition, confusion, and duplicative work. Clear expectations also help consumers recognize why they are important to the initiative. Questions to consider:

- In which activities will the new consumer participate?
- What responsibilities does the staff hold in this relationship?
- How have roles changed in the past? Are there any changes on the horizon?
- Who else holds similar roles and responsibilities to the new consumer?
- How are these roles and responsibilities related to project goals?

Thinking through a new representative's intended roles and responsibilities is part of the recruitment process. Collaborating with the new consumer stakeholders to communicate, shape, and define these responsibilities is an ongoing process. Some roles may be highly formal and standardized, like a board chair and co-chair, while others may be more fluid with shifting responsibilities, like a member of a subcommittee that is formed only for a short period of time. While roles and responsibilities should be laid out clearly at the time of recruitment, it is important to listen to the needs of the stakeholders throughout the process and make adjustments where possible. Consumer roles and responsibilities also may change as projects change. For more suggestions on orienting and supporting consumer leaders, please see [Leveraging Community Partnerships](#).

Section 3.2 — Outline specific ways volunteers have helped your organization

Consumers need to understand that the Alliance values their contributions and understands that engaging consumer leaders in the AF4Q initiative in meaningful ways helps to ensure that the initiative's end results meet the needs of the patients, caregivers, and consumers in the community. Alliance staff also should convey that genuine and effective consumer engagement in AF4Q is critical to the project's long-term sustainability. The items listed below can be used

as a starting point for staff and articulating the unique contributions they bring to the initiative. The addition of community-specific examples of the ways consumers have helped to shape the initiative will strengthen the value case that is presented to new consumer volunteers.

Consumer Advocate Strengths:

- **The ability to represent and give voice to consumer needs and wants.** Consumer advocates are in regular contact with their constituents. They understand their constituents' experiences and views and can offer a perspective that is informed by a diversity of patient experiences—from the underserved to seniors to patients with specific diseases—as well as their own personal encounters with the health care system.
- **The ability to reach consumers.** Consumer advocates can be highly effective trusted distributors of information to consumers. They typically have a variety of ways in which they communicate with their constituencies, including websites, newsletters, broadcast emails, conferences, and mailing lists. Additionally, the advocates also can connect you with their constituencies to solicit input on Alliance projects, products, and activities. You can then refine and tweak your Alliance work based on that feedback.
- **The trust of consumers and, therefore, the ability to educate and influence.** Consumer advocates and their organizations—like health care providers—often are a trusted source of health care information.

For some examples of successful consumer engagement, see the [Bright Spots](#) highlighted on the AF4Q website. Questions to consider:

- Where have consumers been most visible in the organization?
- What are some examples of a consumer perspective enhancing an activity, deliverable, or project?
- How are you going to share these successes with the consumers and other stakeholders?

Onboarding Component 4. Background Materials on Relevant Topics

Section 4.1 — Fact sheets from local and national sources

This section may include some nationally focused materials and some materials that are specific to the state, county, or city. The goal of sharing resources with new consumers is to prepare them for the issues addressed by the AF4Q initiative. However, the resources that are appropriate for consumers may not be the same resources appropriate for other stakeholders. For example, articles from medical journals may include industry vocabulary with which consumer stakeholders are not familiar. There are resources that are designed specifically for consumers, some that are even designed specifically for AF4Q consumer stakeholders. The best place to find AF4Q content materials is on the AF4Q website, <http://forces4quality.org> under the Consumer Engagement section. Other places to find reliable resources for consumer stakeholders include national and local consumer advocacy organizations, available in [Appendix D](#). Some questions to consider when identifying resources for consumers include:

- What are the topics with which consumers should be familiar to be effective members of the initiative?
- Within the AF4Q focus areas of quality improvement, performance measurement and public reporting, and consumer engagement, what are the specific issues being addressed in the local community?
- If consumer-specific materials don't exist for a particular topic, can the local Alliance produce them internally?

Section 4.2 — Acronym lists and glossaries

Onboarding materials always should include an acronym list and glossary. These resources allow all stakeholders to navigate and communicate in the complex and ever-changing world of health care. For examples of resources, see [Appendix E](#). Consider the following questions:

- What are some of the most-used acronyms in the Alliance?
- How can senior leadership and staff support a culture of language that is accessible to all stakeholders?

Tips for Success: How to Present Onboarding Materials

- ❖ **Hard copies.** Many communities have chosen to present new stakeholders with a folder full of fact sheets, contact information, glossaries, committee charters, etc. The benefit of having hard copies is that the consumers always will have access to the materials. However, handing over a stack of materials in no way ensures the volunteer will read the information. Walking through the information with them improves their understanding and the likelihood of achieving shared understanding.
- ❖ **Face-to-face interactions.** All new stakeholders should meet with the AF4Q staff personally during the recruitment process. If there are multiple volunteers recruited at once, this process could be a group orientation. Otherwise, a one-on-one session may be necessary. The benefits of personal interaction include the opportunity to walk through orientation with interpretation and discussion. It also gives the new stakeholder the opportunity to ask questions as they learn about the organization, their activities, and their role. These interactions may be time intensive, but they are necessary for stakeholders to make an informed commitment. Completing some activities by phone, especially at the request of the consumer, may be necessary as well.
- ❖ **Internet availability.** Making the onboarding materials available online ensures consumers with access to the Internet will be able to reference the documents at their convenience. Online access may be ideal for many stakeholders; however, staff must determine whether the Internet is every stakeholder’s preferred method for sharing information.

Tips for Success: Continuing Support

Onboarding is the beginning of an ongoing relationship

True meaningful engagement cannot be achieved overnight. The continuous support of consumer leaders is critical to maintaining their involvement and vital to ensuring your Alliance’s efforts and end results benefit all stakeholders. “Support” is defined as facilitating full participation in shaping AF4Q activities by providing opportunities to expand content knowledge, addressing questions or interpersonal issues, and raising awareness among other stakeholders about the value of consumer perspectives.

The more effectively Alliances support consumers, the more those stakeholders are able to make meaningful contributions and input into the AF4Q focus areas, including performance measurement, public reporting, quality improvement, and health care disparities. This support increases the likelihood consumers will remain engaged in Alliances, reducing turnover and the time-intensive orientation necessary to bring new stakeholders up to speed.

The following recommendations are intended to help Alliance staff implement formalized consumer support processes. They come from the experiences of Alliances that have successfully supported and retained activated, engaged consumers. While these recommendations focus on consumer leaders, they likely are good practices to use with all stakeholders.

Questions to consider:

- Are there formalized methods for consumer support?
- Who should the consumer stakeholders contact when they have questions?
- Are there ways to measure consumer stakeholder satisfaction, contributions, and attrition?

Meeting preparation recommendations

- ❖ **Distribute agendas prior to the meetings.** Effective decision-making requires an informed team. Sharing agendas early allows consumer stakeholders to familiarize themselves with new topics, raise concerns, and ask questions before the meeting. It also gives the consumer leaders time to do background reading, prepare talking points, and consult peers for additional input.
- ❖ **Provide background content.** Including fact sheets and supporting documents (or links to resources available for specific agenda items) that contextualize agenda topics is especially important when exploring new topic areas or concepts.
- ❖ **Explore consumer considerations.** Consumers bring a unique perspective to the table. Encourage them to explore agenda content and consider the specific needs of their constituencies as they relate to the discussion topics.
- ❖ **Discuss agenda.** Allocating time before meetings to discuss the agenda provides consumers and other stakeholders an opportunity to ask questions and discuss their considerations with Alliance staff. Alternatively, consider calling consumers the day before the meeting or setting aside time the week before to meet with them.

Post-meeting recommendations

- ❖ **Debrief.** Connect with consumer leaders immediately after meetings or within a few days to clarify any discussion topics, answer questions, reiterate next steps, and solicit feedback.
- ❖ **Conduct consumer surveys.** Consumer surveys are an effective way to identify challenges the consumer leaders may be facing, as well as to understand what is working well for them. A [sample consumer survey](#) is available on the forces4quality.org website.

As-needed support

- ❖ **Outreach.** Between meetings, reach out to consumers to share relevant information and reaffirm their value as stakeholders. This could include articles, community events, videos, or any type of information related to current activities and concepts. Consider any topics of special interest to consumer partners as well.
- ❖ **Assign mentors.** Some Alliances have paired consumers with stakeholders who have been involved with AF4Q for a significant amount of time. Mentors often can share an “insider perspective” that augments the orientation and integration process. Mentors can be other consumer representatives, but this is not necessary for success. Pairing consumers with employer or clinician mentors is a great way to facilitate relationship building.
- ❖ **Create peer-to-peer learning opportunities.** Like mentoring, peer-to-peer learning is an effective way to ensure that consumer stakeholders understand Alliance goals and key focus areas. Peer-to-peer learning also creates a support network for the consumer leaders, who might be represented in fewer numbers than the other stakeholders. Offer consumer leaders opportunities outside of scheduled meeting times to talk with one another, e.g., listservs, conference calls, etc.

Integration support

- ❖ **Orient other stakeholders.** Meaningful consumer engagement is not achievable without buy-in from all stakeholders. Allocate some time during meetings to highlight the important role the consumer stakeholders play in the Alliance and the ways they have made a difference in the AF4Q initiative.
- ❖ **Identify facilitation needs.** Good facilitation skills include observing the learning and communication styles of the various Alliance workgroups. If someone isn't participating, offer that person specific opportunities to get involved in the discussion—but take care not to put anyone on the spot. Implementing formalized meeting structures such as ground rules and consensus-building voting processes can help mitigate the effect of mixing different personalities and communication styles.

- ❖ **Address interpersonal issues.** Group dynamics are a factor in meetings, and managing relationships is crucial to achieving an environment that allows all group members to make meaningful contributions. Some stakeholders will dominate discussions, while others might remain silent. If there are problems with communication styles, address them candidly outside the meeting. One-on-one discussions with individual stakeholders framed around best methods for achieving their goals effectively can help avoid discomfort between workgroup members and ensure all stakeholders have an opportunity to share their perspectives.

Reliability and recognition

When working with volunteers, giving them an opportunity to provide feedback and following through on agreements improves relationships and keeps volunteers engaged. Recognition of their contribution also is needed to solidify the relationship between the consumer and the Alliance. This recognition may come in many forms (e.g., mentions in press releases and newsletters, certificates of recognition, telling the consumer directly how his or her work has influenced a project, etc.). Feeling valued is important to all stakeholders. Questions to consider:

- What mechanisms are in place to give the opportunity for consumers to give feedback to the Alliance? For the Alliance to give feedback to the consumers?
- How have consumers influenced the project in the past?
- What is the best way to communicate to consumers the value they bring to the Alliance?

Resources for consumer support

For ongoing consumer support, there are a number of fact sheets and toolkits that can provide guidance, including:

- [Leveraging Community Partnerships](#)
- [Quality Care Toolbox on Consumer Engagement](#)
- [Consumer Engagement Best Practices](#)
- [Supporting Consumers in AF4Q Alliances through the Four Stages of Consumer Engagement](#)
- [Guide to Engaging Consumer Advocates in AF4Q Alliances](#)

Well-oriented and supported consumer stakeholders provide the Alliance with a perspective crucial to the success of AF4Q: the community voice. The consumer stakeholder voice is grounded in the needs of the community and increases the chances of sustainability within an Alliance. Building an onboarding toolkit, and continuously supporting consumer stakeholders is critical to the long-term success of *Aligning Forces for Quality*.

Appendix A. Examples of Quality Improvement Efforts

The forces4quality.org website gives the following description of the initiative:

Aligning Forces for Quality (AF4Q) is the Robert Wood Johnson Foundation's (RWJF) signature effort to lift the overall quality of health care in targeted communities, reduce racial and ethnic disparities, and provide models for national reform. AF4Q asks the people who get care, give care, and pay for care to work together toward common, fundamental objectives to lead to better care. RWJF has made an unprecedented commitment to improve health care in 16 geographically, demographically, and economically diverse communities that together cover 12.5 percent of the U.S. population. Each of the Aligning Forces communities has built its initiative around a core, multi-stakeholder leadership alliance working to advance AF4Q's goals and activities at the local level. These alliances include participation from physicians, nurses, patients, consumers and consumer groups, purchasers, hospitals, health plans, safety-net providers, and others.

AF4Q communities aim to:

- Engage stakeholders to measure performance and publicly report on the quality of care;
- Help doctors, nurses, and other health care professionals learn how to deliver better care; and
- Help consumers and patients become more engaged in the quality of care they can demand and receive.

Working Locally to Transform the System

In each community, the alliances are moving quality forward at the local level through activities in three important areas of focus:

1. Performance measurement and public reporting—using common standards to measure the quality of care doctors and hospitals deliver to patients and making that information available to the public.
2. Consumer engagement—encouraging patients to be active and effective managers of their health care.
3. Quality improvement—implementing techniques and protocols that doctors, nurses, and staff in hospitals and clinics can follow to raise the level of care they deliver to patients.

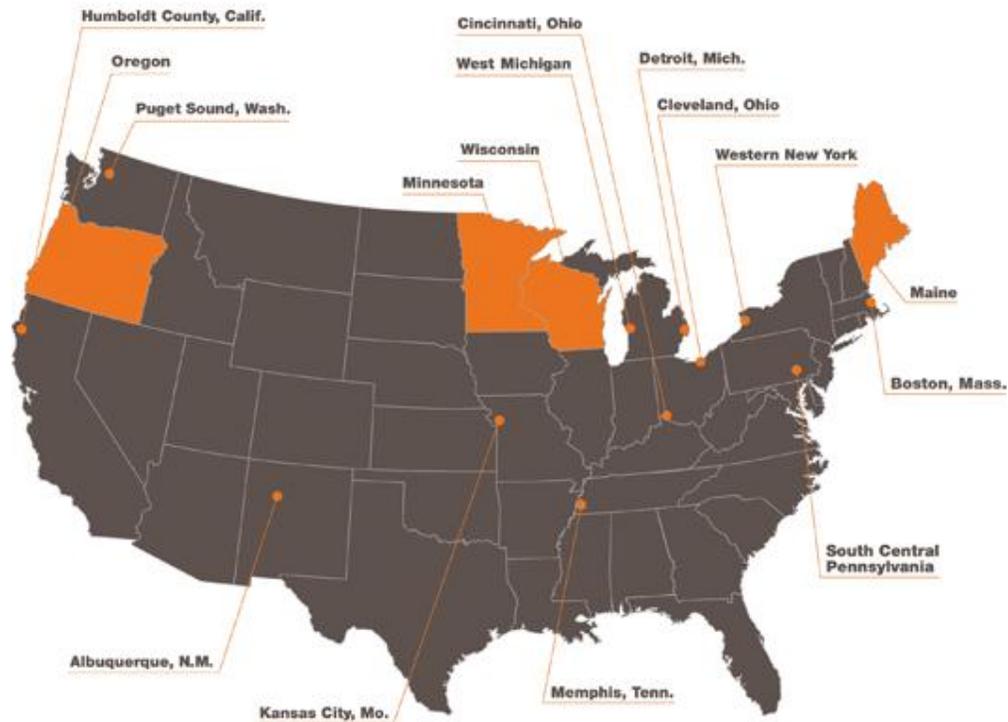
On the ground, the communities have developed and are implementing many local efforts, including:

- Training health care providers to improve their skills so they can provide better-quality care.
- Collaborating with employers and community organizations to disseminate tools and information to patients so they can make informed choices and become better partners with their doctors in managing their own health.
- Gathering best practices from nurses at local hospitals on how to reduce medical errors, update care processes, and decrease staff turnover.
- Producing reports that show the quality of care being delivered in local hospitals and doctors' offices so patients can effectively make decisions about their care.
- Helping hospitals and doctors' offices collect data on patients' race, ethnicity, and language to help identify and reduce disparities in care.
- Working with hospitals to improve language services so patients with limited English proficiency receive high-quality care.
- Implementing new health technologies to improve quality and streamline care.

Appendix B. Graphics of the AF4Q Project

The graphics below, from AF4Q, show the locations of AF4Q communities as well as the project's primary focus areas:

Aligning Forces for Quality Communities



Appendix C. Health care Quality Basics

Below is an article from the forces4quality.org website that provides a snapshot of health care quality.

The Quality Problem in America

Despite medical technology and scientific advances, health care in America remains fraught with uneven and often poor quality—especially in the treatment of chronic diseases affecting millions of Americans, like diabetes, asthma, and heart failure. Although we know many of the best practices to improve the quality of treatment, formidable barriers prevent these practices from taking hold and transforming care across the country. In most communities, health care is delivered through fragmented systems in which hospitals, clinics, doctors, nurses, and patients struggle to understand what high-quality care is and how to achieve it.

The result is that across America, dangerous gaps exist between the health care people *should* receive and the care they *actually* receive. From Puget Sound to Pennsylvania and everywhere between, the quality of health care varies widely—with both good and bad care being delivered in hospitals and doctors’ offices in every community.

Because the country spends *more* per capita than any industrialized nation in the world, Americans often mistakenly assume that the United States health care system delivers the *best* care in the world. But, compared to other countries, U.S. care is high in cost and low in quality. We do not live as long—ranking just 50th in life expectancy among major industrialized nations—and have much higher infant mortality rates than most.¹

Research shows that certain groups—from specific racial, ethnic, cultural, and socioeconomic backgrounds—persistently suffer the lowest-quality care. These gaps in quality persist even when other factors, such as insurance status and income level, are taken into account between minority and non-minority patients.

The U.S. health care system is rife with too many mistakes, too much miscommunication, and too much inequity. Now more than ever, improving the quality of health care in America is critical. Poor quality health care robs the system of precious resources, in both dollars and services, that could be used elsewhere.

What is “High-Quality” Health Care?

Put simply, high-quality care is care that: 1) works, 2) is safe, and 3) is tailored for patients. The federal Agency for Healthcare Research and Quality defines high-quality care as “doing the right thing for the right patient, at the right time, in the right way to achieve the best possible results.”

High-quality care is getting care *when* you need it; it’s getting *all* the care you need (and not the care that you *don’t* need); it’s getting care that is *safe* and doesn’t harm you; and it’s care tailored to you and, just as important, is delivered by professionals who respect you, communicate clearly with you, and involve you in decisions.

High-quality health care is care that is:

- ✓ **Safe:** Does not injure patients; it is supposed to help.
- ✓ **Effective:** Is based on sound science to all who can benefit and refrains from providing services to those who cannot.
- ✓ **Patient-centered:** Is respectful of and responsive to patients’ preferences, needs, and values.
- ✓ **Timely:** Reduces waiting time and potentially harmful delays.
- ✓ **Efficient:** Does not waste resources.
- ✓ **Equitable:** Does not vary because of someone’s race, gender, income, or location.

Appendix D. Reliable Resources

Below is a list of reliable resources. While Onboarding Toolkits should include some introductory materials, Alliance staff also should encourage consumer stakeholders to seek out health care information on their own, including how to recognize the difference between reliable and unreliable resources. Reliable resources include evidence-based conclusions and research. These resources are usually sponsored by respected institutions, foundations, government entities, and research or policy organizations.

Government entities include:

- Health and Human Services (www.hhs.gov)
- Agency for Healthcare Research and Quality (www.ahrq.gov)
- Health Resources and Services Administration (www.hrsa.gov)
- Centers for Disease Control & Prevention (www.cdc.gov)
- Affordable Care Act website (www.healthcare.gov)
- Administration on Aging (www.aoa.gov)

Foundations and policy organizations include:

- California Healthcare Foundation (www.ihealthbeat.org)
- The Commonwealth Fund (www.commonwealthfund.org)
- Kaiser Health Foundation (www.kff.org)
- Robert Wood Johnson Foundation (www.rwjf.org)

Appendix E. Glossary and Acronym List

Below is a glossary and newcomer's acronym list. These tools should be used as a baseline upon which each Alliance expands and should include local acronyms and language. Asking consumer stakeholders to maintain these documents and add (or subtract) when necessary ensures the resources will be helpful to the stakeholder group.

Health Care Quality Glossary

Accountable care organization (ACO) is a group of health care providers (e.g., primary care physicians, specialists, hospitals, and others) that agree to assume collective responsibility for the cost and quality of care of a group of patients and are paid in a way that incentivizes improved quality and efficiency of health care.

Admission (or hospital admission) is the process of being admitted to a hospital as a patient. The rate and quality of this process may be a good indicator of a health system's performance and the effectiveness of health plans in managing care.

Ambulatory care is medical care that does not require an overnight stay in a hospital. Ambulatory care can be provided in physicians' offices, clinics, emergency departments, outpatient surgery centers, as well as hospital settings that do not involve a patient staying overnight.

Benchmark (benchmarking) is a way for hospitals and doctors to compare data on quality of care, both internally and against data from other hospitals and doctors, to identify best practices of care and improve quality.

Best practices are the most up-to-date treatments for patients, which result in the best patient health and minimize patient risk of death or complications.

Chronic care model is a model of care that advocates for more productive interactions between patients and care teams. The model elements are: clinical information systems, decision support, delivery system design, self-management support, and community and organizational leadership.

Chronic disease/condition is a sickness that is long lasting or recurrent. Examples include diabetes, asthma, heart disease, kidney disease, and chronic lung disease.

Clinical practice guidelines (also called clinical care guidelines) are a set of recommendations based on scientific evidence that help physicians and their patients make decisions about appropriate health care for specific medical conditions. Clinical practice guidelines identify and evaluate the most current information about prevention, diagnosis, prognosis, therapy, risk/benefit, and cost effectiveness.

Comparative effectiveness research compares multiple medications or treatments to determine which is most effective for different types of patients.

Co-morbidity is the presence of additional diseases in addition to a previously diagnosed illness. For example, a patient may have both diabetes and heart disease.

Consumer/patient refers to an individual who has significant personal experience with the health care system, either as an individual receiving care or as a caregiver.

Consumer advocate (also called consumer representative) refers to individuals who work at nonprofit, mission-oriented organizations that represent a specific constituency of consumers or patients. What distinguishes consumer advocates is their primary emphasis on the needs and interests of consumers and patients. Another important characteristic of consumer advocates is they typically do not have a financial stake in the health care system. Examples of consumer advocacy organizations include AARP, YWCA, and faith-based organizations.

Consumer Assessment of Healthcare Providers and Systems (CAHPS) or Hospital Consumer Assessment of Healthcare Providers and Systems (H-CAHPS or CAHPS Hospital Survey) are surveys that ask consumers and patients to report on and evaluate their experiences with health care. The H-CAHPS survey focuses especially on hospital care, while CAHPS focuses on care in non-hospital settings (physician offices, nursing homes, etc.). These comprehensive and evolving sets of standardized surveys cover topics that are important to consumers, such as provider communication skills and the service accessibility. The results of CAHPS and H-CAHPS surveys are publically reported to allow valid comparisons to be made across all settings.

Consumer engagement is the act of working in partnership with consumers, consumer advocates, patients, and their families or caregivers to improve the health care delivery system.

Coordination of care ensures patients and all members of a patient's care team have access to and take into consideration all required information on a patient's conditions and treatments to ensure the patient receives appropriate health care services.

Cost refers to the actual amount of money paid to a health care provider for a health care service.

Effective care means health care services that are of proven value and have few, if any, significant tradeoffs. The benefits of the services so far outweigh the risks that all patients with specific medical needs should receive them. These services, such as beta-blockers for heart attack patients, are backed by medical theory and strong evidence of value, determined by clinical trials or other studies.

Episodes of care refers to a series of encounters or visits to health care facilities to treat a health condition. Thinking of care in this holistic way is useful for measuring both the quality of care received and the efficiency of the care provided.

Electronic health/medical record (EHR or EMR) is medical software that contains the electronic history of a patient's medical care. The use of electronic records makes the health care system more efficient, allows for better coordination of care, and provides patients the opportunity to view and control their own medical records.

Evidence-based medicine is the use of the most current, best-available scientific research and practices with proven effectiveness in daily medical decision making, including individual clinical practice decisions by well-trained, experienced clinicians. Evidence is central to developing performance measures for the most common and costly health conditions.

Federally qualified health center (FQHC) is a health organization that offers primary care and preventive health services to all patients regardless of their ability to pay. An FQHC may be a public or private nonprofit organization and must meet specific criteria, including 51 percent consumer representation in governance, to receive government funding.

Fee-for-service is an approach to payment for care under which patients or a third party (such as a health plan) pay physicians, hospitals, or other health care providers for each office visit or health care service a patient receives.

Health disparities are differences in health care delivery, access to health care services, and medical outcomes based on ethnicity, geography, gender, sexual orientation, and other factors that do not include socioeconomic status or insurance coverage. One of the goals of health care quality improvement efforts is stratifying quality data by **race/ethnicity/language (R/E/L)** to understand better where inequities exist and eliminate them.

Health information technology (Health IT or HIT) is a term that refers to the use of electronic medical (or health) records, as well as computers, software programs, electronic devices, and the Internet to securely store, retrieve, update, and transmit information about patients' health.

Health literacy is the degree to which individuals are able to obtain, process, and understand basic health information and services needed to make appropriate health decisions. Health literacy is not simply the ability to read. It requires a complex group of reading, listening, analytical, and decision-making skills and the ability to apply these skills to health situations. For example, health literacy allows people to understand instructions on prescription drug bottles and doctors' forms, as well as talk about health needs and concerns with a doctor or nurse.

Health/disease registries are lists of people diagnosed with a specific disease, such as diabetes.

Hospital discharge is the process by which a patient is released from the hospital by health care professionals.

Hospital readmission occurs when a patient is readmitted to the same hospital after discharge. Readmissions rates, usually within a certain time period (7-60 days), are viewed as an indicator of the quality of care delivered to patients, with low readmissions rates associated with better care.

Inpatient care is the delivery of health care services to a person who has been admitted to a hospital or other health facility for a period of at least 24 hours.

Intervention includes any type of treatment, preventive care, or test a person could take or receive to improve his or her health or help with a particular problem. Intervention also can be used to mean a method of improving quality of care.

Meaningful engagement is a set of practices established to activate stakeholders in all aspects of a project's design, governance, implementation, and evaluation. This is a term often used with respect to multi-stakeholder bodies.

Meaningful use is a federal program that gives health care providers funding for health information technology (HIT) adoption. Providers need to show they are using "certified electronic health record technology" in ways that improve the quality of care, individual access to health information, and the health of populations.

Medical error is a mistake that harms a patient. Adverse drug events, hospital-acquired infections, and wrong-site surgeries are examples of preventable medical errors.

Misuse (of care) occurs when an appropriate process of care has been selected, but a preventable complication occurs and the patient does not receive the full potential benefit of the service. Avoidable complications of surgery or medication use are misuse problems. Giving a patient penicillin for strep throat, despite a known allergy to that antibiotic, is an example of misuse.

Outcome refers to a patient's health—whether it improves, declines or stays the same—after an encounter with the health care system.

Outpatient care is medical or surgical care that does not include an overnight hospital stay.

Overuse (of care) describes unnecessary care or circumstances in which the potential for harm exceeds the potential for benefit. Prescribing an antibiotic for a viral infection like a cold, for which antibiotics are ineffective, is overuse. Overuse also can apply to repeated diagnostic tests and surgical procedures.

Patient activation measure (PAM) is a series of tools to measure how likely a patient is to be an informed, active participant in his or her own healthcare. Physicians sometimes use PAM to identify a patient's stage of activation and then work with that patient to individualize his or her care plans.

Patient-Centered Care is care that establishes a partnership among health care providers, patients, and their families (when appropriate) to ensure decisions respect patients' wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care.

Patient-centered medical home (PCMH) is not an institution, but a way of delivering outpatient care that emphasizes readily accessible, comprehensive, coordinated care and active involvement of the patient and family in health care decisions. In a medical home, the primary care doctor operates as a “home base” for patients, overseeing all aspects of patients' health and coordinating care with any specialists involved in the patient's care.

Patient experience data (also called patient satisfaction data) is information that reflects quality from the perspective of patients by capturing observations and opinions about what happened during the health care delivery process. Patient experience data include various indicators of patient-centered care, including access (whether patients obtain appropriate care in a timely manner), communication skills, customer service, helpfulness of office staff, and information resources. The CAHPS survey (see above) is an example of a tool for measuring patient experience.

Patient Protection and Affordable Care Act (also called the Affordable Care Act, or ACA) is the name of health reform legislation signed by President Obama in 2010. In addition to expanding access to health care, the law includes provisions aimed at improving quality of care, reforming the payment system, protecting patients' rights, and reforming health insurance.

Pay-for-performance (P4P) is a method of paying hospitals and physicians based on their demonstrated achievements in meeting specific health care quality objectives. The goal is to reward providers for the quality—not the quantity—of care they deliver.

Payers are the entities that pay for medical treatments. Examples include health plans, HMOs, self-insured employers, and uninsured patients.

Payment reform seeks to improve ways of reimbursing providers based on value instead of volume (as opposed to the fee-for-service method of payment).

Preventive care is health care services that prevent disease or its consequences. It includes primary prevention to keep people from getting sick (such as immunizations), secondary prevention to detect early disease (such as mammograms),

and tertiary prevention to keep ill people or those at high risk of disease from getting sicker (such as helping someone with lung disease to quit smoking).

Price transparency is making the charges of a given health care service at different facilities available to the public.

Primary care is basic or general health care traditionally provided by doctors trained in family practice, pediatrics, internal medicine, and occasionally gynecology.

Provider refers to a professional who provides health services, including primary care physicians, nurses, specialists (such as podiatrists or cardiologists), and other allied health professionals. Hospitals and long-term care facilities also are providers.

Provider incentives are used to motivate specific provider behavior within the health care system. Examples of incentives include monetary rewards for providers who provide high-quality care.

Public reporting makes information about hospital, physician, and physician group performance available for consumers and others. The expectation is that a comparative public report of local hospitals'/physicians' performance will motivate and improve performance and allow consumers to choose providers based on performance.

Purchasers are the entities that not only pay the premium for health care costs, but also control the premium dollar before paying it to the provider. Employers that provide health insurance to their employees are examples of purchasers.

Quality (of care) is the right care, at the right time, for the right reason, ideally at the right cost.

Quality/performance measures are ways to evaluate the care provided by doctors and hospitals based on accepted national guidelines. These measures evaluate access to medical care, the way care is given, patient's results after treatment (outcomes), patient experiences with care, and use of medical services.

Resource use is the amount of health care services used for a patient, including the number, cost, and intensity of services provided.

Risk adjustment in health care refers to the use of factors such as severity of illness or age to estimate the risk involved in a patient undergoing a particular intervention. Adjusting for risk when reporting performance measures allows for comparison of performance and quality across organizations and communities.

Self-management is the ability of individuals to manage their health problems or conditions on a day-to-day basis. It is a skill that enables individuals and their families to use existing health services, as well as make choices about health care providers, medication, diet, exercise, and other lifestyle issues that protect or damage health.

Shared decision making (SDM) is a process in which patients and their doctors make medical decisions together, while taking into account both clinical guidelines and the patient's preferences.

Stakeholder refers to any person, group, or organization that can affect or be affected by the health care system, such as patients, providers, employers, and health plans.

Transparency is the process of collecting and reporting health care cost, performance, and quality data in a format that can be accessed by the public and is intended to improve the quality of health care and ultimately improve the health care system as a whole.

Transition of care refers to the movement of a patient from one health care setting to another, such as from a hospital to a nursing facility.

Underuse (of care) refers to the failure to provide a health care service when it would have produced a good result for a patient. Examples include failure to provide appropriate preventive services to eligible patients (e.g., mammograms,

flu shots for elderly patients, screening for hypertension) and proven medications for chronic illnesses (steroid inhalers for people with asthma; aspirin or beta-blockers for patients who have suffered a heart attack).

Value-based purchasing refers to the concept of health care purchasers (e.g., employers) holding health care providers accountable for both cost and quality of care. Value-based purchasing brings together information on the quality of health care, including patient outcomes and health status, with information on cost of care. It focuses on managing the use of the health care system to reduce inappropriate care and identify and reward the best-performing providers.

(Unwarranted) variation refers to differences in the use of health care services that cannot be explained by differences in patient illness or patient preferences. Variation may occur because of differences in the degree to which providers follow clinical guidelines (meaning that the quality of care provided to patients is better or worse depending on how well a clinician follows these guidelines), as well as differences in the amount of service (such as tests, surgeries, etc.) delivered to different populations. Research on variations has shown that people living in areas where cost of care is higher and use of services is higher do not have longer life expectancy than those in areas where cost of care is lower. More care is not necessarily better care.

ⁱ Central Intelligence Agency. Country Comparison: Life Expectancy at Birth. The World Factbook, 2012. <https://www.cia.gov/library/publications/the-world-factbook/rankorder/2102rank.html>.

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