

## DEFINING CONSUMER REPRESENTATION

The inclusion of consumer representatives is crucial to ensuring that your Alliance's efforts and end-results meet the needs of the consumers in your community. Consumer representatives also can serve as agents of change, working alongside other stakeholders to advance the goals of the Alliance. To effectively engage consumers in the work of AF4Q, Alliances should seek out groups that truly represent consumers. Sometimes the lines appear blurry and it may seem like a health plan, employer group, or even a provider organization could serve as a consumer representative. While they may aim to speak for consumers and patients, these representatives have additional interests to consider, as with any stakeholder group, and cannot be regarded as authentic consumer voices. The definitions below are meant to assist you as you work to ensure that your Alliance includes genuine consumer representatives.

### Definition of an Individual Consumer

A consumer is an individual who has significant personal experience with the health care system, either as a patient or caregiver. A consumer draws upon these experiences to enrich Alliance initiatives. While there is great value in engaging consumers and patients, most individual consumers lack the ability to influence and communicate with a large network or constituency. Engaging both individual consumers and consumer representatives is recommended.

### Definition of a Consumer Representative (also called Consumer Advocate)

Consumer representatives/advocates are individuals who work at nonprofit, mission oriented organizations that represent a specific constituency of consumers or patients. What distinguishes consumer advocates from other Alliance stakeholders is their primary emphasis on the needs and interests of consumers and patients. Another important characteristic of consumer advocates, compared to other stakeholders, is they typically do not have a financial stake in the health care system.

The greatest strength of consumer advocates is they are a trusted source of information in your community. Unlike individual consumers, they speak from a global perspective and have experience representing the diverse needs and wants of groups of consumers and patients. They also have networks to empower and mobilize the community using email lists, websites, meetings, newsletters and conferences to share information and messages. And most consumer advocates have established relationships with the media, policy makers and elected officials they can leverage to support the Alliance.

Examples of Consumer Advocacy Organizations:

- Organizations serving specific constituencies such as women, children, older adults, minority patients and workers, such as the YWCA, AARP, NAACP and AFL-CIO.
- Disease specific organizations, such as the American Cancer Society, American Diabetes Association, American Heart Association and the National Kidney Foundation.
- Faith-based organizations, such as churches, mosques and synagogues.
- Broad-based or policy-focused organizations, such as Citizen Action, Consumers Union, League of Women Voters and Literacy Councils.

For assistance identifying the most appropriate consumer representatives to engage in your Alliance, contact Jennifer Sweeney at the National Partnership for Women & Families (NPWF) at 202-986-2600 or [Jsweeney@nationalpartnership.org](mailto:Jsweeney@nationalpartnership.org). For more information on effectively supporting consumer participation in the Alliance, visit [www.qualitycarenow.org](http://www.qualitycarenow.org)