



# CAMPAIGN FOR Better Care

February 6, 2015

The Campaign for Better Care (CBC) (led by the National Partnership for Women & Families) appreciates the opportunity to comment on the Medicare Shared Savings Program (MSSP) proposed rule. The CBC is a broad-based coalition of consumer organizations with a direct stake in improving the health and quality of life of patients and their family caregivers, particularly older adults with multiple health conditions. We are committed to ensuring that new models of care delivery and payment provide the comprehensive, coordinated, patient- and family-centered care patients want and need while helping to drive down costs.

We commend the work the Centers for Medicare and Medicaid Services (CMS) is undertaking to move us toward more accountable care. With this next cycle of the Medicare Shared Savings Program (MSSP), CMS now has the opportunity to promote approaches that go beyond payment initiatives to more fundamentally transform the way care is delivered. Specifically, MSSP Accountable Care Organizations (ACOs) should deliver high quality, high value care that treats the patient as a whole person and ensures coordination of care, improved communication, patient support and empowerment, and ready access to health care providers and services. We believe that the most successful ACOs will be grounded in comprehensive and well-coordinated primary care – a truly patient-centered medical home – and as CMS develops the framework for the next cycle of MSSP ACOs, these core elements must be a driving force.

Ensuring that the MSSP delivers on the vision of the Triple Aim requires partnering with patients and families at every level. This partnership goes beyond an occasional focus group or an annual patient experience survey to encompass meaningful systematic collaboration with patient and family caregivers at the point of care, in designing new models of care delivery, in policy and governance, and at the community level.

The following comments respond to specific items in the proposed rule and set out fundamental consumer policy priorities that must be central to the next generation of ACOs.

## COMMENTS ON SPECIFIC PROVISIONS

### **PROGRAM EVOLUTION**

We appreciate CMS's attention to supporting ACO success in the Medicare Shared Savings program by revising the program model to include a third track and to make transition to two-sided risk more attractive. We emphasize, however, that CMS's priority, first and foremost, must be on ensuring that all ACOs deliver high quality, coordinated, patient- and family-centered care to beneficiaries. CMS must hold all ACOs accountable for changing care delivery to achieve these goals. Accordingly, any proposed changes to ACO program tracks must be accompanied by strong accountability mechanisms. Modifications to risk tracks should include adequate consumer protections and quality criteria that prevent risk avoidance and gaming

and ensure delivery of improved care for beneficiaries. We strongly support CMS's intention to prohibit ACOs that perform poorly on quality metrics from being able to remain in Track 1 for a second performance cycle.

With respect to quality measurement, we strongly urge CMS to prioritize outcomes measures. A robust dashboard of measures is integral to improving care and evaluating ACO success with respect to meeting all prongs of the Triple Aim. Measures applied to ACOs should focus on coordination of care, including transitions of care, hospital admissions and readmissions, use of emergency departments, and medication management. Additionally, we urge CMS to prioritize the use of patient experience and patient-reported outcomes measures. Measuring patient experience is often the only way to evaluate elements of care that patients and family caregivers identify as most important to improving their health outcomes. Gauging a patient's experience of care is especially important for those who have multiple conditions and for whom condition-specific quality measures cannot provide an adequate picture of the total quality of care received. We urge CMS to identify additional measures that use patient-reported data to assess experience of care and outcomes, including functional status. Family caregiver experience data is also particularly helpful in assessing experience of care for those patients with cognitive impairments that prevent them from talking about their own experiences. It can also provide insight into areas patients themselves may be reticent to discuss.

## **GOVERNANCE**

### *Consumer/Beneficiary Representation in ACO Governance*

We strongly support requiring consumer/beneficiary involvement in ACO governance. Patient and family representatives bring unique perspectives that can help ACOs to achieve quality improvement and cost reduction goals. Bringing such insights to light, however, requires engaging patient and family representatives in meaningful ways.

We urge CMS to strengthen requirements for meaningful involvement of consumer/beneficiary representatives and to exercise greater oversight to ensure the success of engagement efforts. We define meaningful involvement of consumer/beneficiary representatives as follows:

- Proportionate representation. Proportionate representation requires having more than one patient, family caregiver, or consumer representatives on the ACO's governance board.
- Consumer representatives are "true" consumers. The primary interest of "true" consumers is the needs and interests of consumers, patients, and families. Consumers have no direct financial stake in the health care system.

Accordingly, we strongly support new language in the proposed rule that explicitly prohibits an ACO provider/supplier (current or former) from serving as the beneficiary representative on the ACO's governing body. We note, however, that increased CMS oversight will be needed to ensure that this requirement is carried out.

- Representatives include both consumer advocates and beneficiary representatives. While consumer advocates include, for example, non-profit organizations or faith-based groups, beneficiary representatives, on the other hand, are patients and/or family caregivers. Both bring unique and valuable perspectives to the table.
- Representatives are meaningfully involved in decision-making. Meaning, all representatives, including patients, families, consumers, and providers, have an equal seat at the table and an opportunity to share their perspectives as decisions are made.

### Alternative Approaches to Engagement

We are interested to learn more from CMS regarding alternative strategies ACOs are employing to engage beneficiaries and consumers in governance and care redesign. While Patient and Family Advisory Councils (PFACs) are a good strategy, CMS should also encourage ACOs to pursue additional approaches, such as involving patient/family representatives on ACO quality and safety improvement bodies. In general, while we understand the legal constraints some ACOs face in states with Corporate Practice of Medicine laws, it is critical that ACOs implementing alternative approaches to engaging beneficiaries and consumers ensure a strong link and process for regular communication between the PFAC and the governing body. Otherwise, there is risk that the consumer voice will be marginalized.

### Enhanced Support and Oversight

Historically, many health care entities, including ACOs, have struggled to meaningfully engage consumer/beneficiary representatives. Consequently, successful partnerships with consumer/beneficiary representatives on ACO governing boards, PFACs, quality and safety improvement bodies, and other entities will require a greater level of support and oversight from CMS.

An important – yet often overlooked – first step is providing orientation and onboarding support for consumer/beneficiary representatives. Successful orientation and onboarding strategies help to ensure that consumer and patient representatives are effective in their governance roles and ultimately help the ACO meet its quality, patient experience, and affordability goals. CMS should require ACOs to describe in their applications an orientation and onboarding process for consumer/beneficiary representatives on governance boards, other multi-stakeholder entities, and PFACs. CMS should monitor ACO adherence to these processes in evaluation and oversight processes. We encourage CMS to offer guidance and assistance to ACOs with respect to developing onboarding and orientation processes. For example, successful orientation and on-boarding processes include:

- Reaching out to representatives and/or PFAC members individually to detail the purpose and goals of the board/group, roles and responsibilities, time commitment involved, and why the consumer representative/PFAC member will play a vital role.

- Providing clear, concise, and targeted materials in advance, including a “welcome packet” with agendas, background materials, mission/vision/goals statements, a compact or “bylaws,” and contact information for a key ACO staff member (to whom consumer representatives and/or PFAC members may reach out with questions or concerns).
- Identifying a mechanism for consumer representatives and/or PFAC members to provide ACO staff with ongoing thoughts and recommendations about their involvement, as well as a plan for how staff will use that information to make improvements.
- Committing to regularly checking in with consumer representatives and PFAC members to ensure their needs are being met and they feel supported in their role – and work in partnership to make adjustments as needed.

In addition to implementing an orientation/onboarding process for beneficiary representatives and/or PFAC members, it is also essential to ensure seamless integration of consumer/beneficiary representatives into the board’s or other entity’s work. We urge CMS to work with ACOs in the application process to determine how they will:

- Communicate to other stakeholders the important role consumers/beneficiary representatives play in governance and decision making;
- Create an expectation that consumers/beneficiary input will be valued and respected and they will be considered as an equal; and
- Provide training and resources to support effective collaboration with consumer/beneficiary representatives.

## **BENEFICIARY ASSIGNMENT**

### *Definition of Primary Care Services*

We strongly support including transitional care management codes (CPT codes 99495 and 99496), and chronic care management codes (HCPCS code GXXXI) as primary care services. Transitional care management and chronic care management services are particularly important for the most vulnerable Medicare beneficiaries and those with multiple chronic conditions.

### *Definition of Primary Care Professionals*

We applaud CMS’s continued efforts to strengthen primary care and ensure ACOs are grounded in comprehensive, well-coordinated, patient- and family-centered primary care. We strongly support including Nurse Practitioners, Physician Assistants, and Clinical Nurse Specialists as primary care providers for the purposes of assignment. These professionals often play an especially important role for medically underserved communities, both urban and rural.

We also support including internal medicine providers with subspecialties in nephrology, oncology, rheumatology, endocrinology, pulmonology, and cardiology, as we know these providers play an important role in providing primary care—and coordinating care—for individuals with certain conditions.

### Voluntary Beneficiary Alignment

We support enhanced beneficiary choice with respect to their alignment with an ACO. However, before beneficiaries can be expected to elect into their primary care provider's ACO, they must have access to materials that help them understand what an ACO is, how this new model of care functions, what alignment means to them, and what their rights are with respect to accessing care inside and outside of the ACO. Such an outreach and education effort will require CMS, ACOs, and providers to take a more rigorous and focused approach to educating beneficiaries and communicating with them.

Indeed, CMS, Medicare ACOs, and participating ACO providers all have roles to play in facilitating the education and outreach necessary to help beneficiaries better understand ACOs and to understand the decision they would be asked to make under a voluntary alignment model:

- CMS should communicate basic information about the Medicare ACO model to all beneficiaries. This information should include the goals of the Medicare ACO programs; a brief description of the kind of care beneficiaries should be receiving in ACOs; how receiving care in an ACO may be different from previous experiences; and beneficiary rights and protections under Medicare law, with respect to accessing care.

CMS must be the “trusted source” for information about programs it sponsors. Consequently, CMS must also have a strong infrastructure in place to address beneficiary questions and concerns.

- ACOs should provide detailed information about participating providers and how care will be better coordinated in their integrated systems. ACOs are best equipped to provide more specific information about how care will be better coordinated in their specific integrated systems. To enable beneficiaries to learn more about how voluntary alignment with their primary care provider's ACO is intended to improve their care coordination and experience, we encourage CMS to consider to what extent ACOs should be able to include their own educational materials with or in addition to the packet of materials sent by Medicare. We encourage CMS to issue clear guidance on what types of educational materials ACOs will be permitted to send to beneficiaries. CMS also should provide clear guidance on the role it will play in reviewing ACO-developed materials sent to beneficiaries, to ensure that any such materials are accurate and neither coercive nor misleading.

- Providers participating in an ACO should serve as a trusted source of information for beneficiaries. Providers have a valuable role to play in discussing and supporting an individual's decisions around ACO alignment.

### Education and Outreach

As noted above, beneficiary education on Medicare ACO programs must accompany dissemination of any voluntary alignment materials. Educational materials sent by CMS should address all of the following:

- What is a Medicare ACO? Such information should include a general description of the ACO model and the goals of the Medicare Shared Savings Program (e.g., improved quality, coordination of care, and reduced costs). It should also include information outlining what an ACO is not (e.g., Medicare Advantage, Medigap, a HMO). Finally, this information should also provide a description of incentives, financial and otherwise, that are offered to participating ACO providers.
- Why the beneficiary is receiving information about the Medicare ACO program and being asked to identify his/her primary care provider.
- What it means to “align” with an ACO. Such information should be clear that alignment is a voluntary process. CMS should describe what happens if a beneficiary chooses to align, and what happens if she declines or chooses to do nothing. Additionally, such information should highlight whether the beneficiary has been aligned with this ACO in the past.
- How being aligned with an ACO may impact beneficiary access to care. Such information should include a clear explanation of beneficiary rights and consumer protections, including a clear statement that alignment with an ACO does not change a beneficiary's rights, including freedom of choice of Medicare provider, ability to seek a second opinion, file a complaint, etc. CMS should also make clear that a beneficiary has the right to opt out of the ACO, if this option is available.

### Implementation of Voluntary Alignment Outreach/Education

In addition to comprehensive content, a successful beneficiary outreach and education campaign requires a thoughtful approach to implementation. Key issues pertaining to implementation include:

- How and when beneficiaries are informed of the opportunity to align. CMS should consider how and when beneficiaries are notified: e.g., through the mail, at their first primary care service visit, or a combination of both.
- Ensuring that written materials and verbal communications resonate and effectively reach beneficiaries and their families. This includes planning, designing, and field-testing written communications with a diverse group of beneficiaries and their families. CMS must ensure that all forms of communication, of face-to-face, phone, or other, are equally accessible. Finally, CMS must ensure that written materials and verbal

communications are approved by patients/families/consumers for language accessibility. This includes ensuring that information is clear, uses plain language, and accounts for varying levels of health literacy and decision making abilities. It also includes ensuring full language access and cultural and linguistic appropriateness.

- Ensuring that beneficiaries are contacted by appropriate, trusted messengers. CMS, in consultation with consumers and other stakeholders, must determine the appropriate roles that CMS/Medicare, ACOs, and participating primary care providers will play with respect to education/outreach to beneficiaries. CMS must also determine and make transparent how existing legislative and/or regulatory parameters affect implementation of effective outreach and education efforts to beneficiaries. For example, CMS should determine whether providers should be allowed and/or encouraged to have proactive conversations with their patients and their families about alignment, and what legislative or regulatory changes must be made in order facilitate such communication.
- Ensuring that beneficiaries are able to contact assistors with questions and know whom to contact if they have questions. This includes ensuring that there is appropriate, trained staffing of 1-800-MEDICARE, the State Health Insurance Assistance Programs (SHIPs), and Medicare.gov. Information also should be available, as appropriate, in *Medicare & You*. Training and staffing requirements also should be required of Medicare ACOs participating in voluntary alignment programs. Finally, CMS should also determine under what circumstances providers should be able to answer beneficiaries' questions about the ACO.
- Ensuring maintenance and enforcement of necessary and appropriate consumer protections, particularly with respect to direct outreach and communication with Medicare beneficiaries. This includes protections against cherry-picking (e.g., ensuring ACOs are not trying to prevent low-income individuals from voluntarily aligning because of concerns that costs of care may affect a patient's ability to follow their care plan and thus affect an ACOs' chances to share in savings). Protections must be put in place to ensure that providers are having voluntary alignment conversations with all eligible patients.

#### *Financial Inducements To Incentive Voluntary Alignment Must Be Prohibited*

Finally, we strongly support the prohibition of the use of gifts or other financial inducements to beneficiaries or use of penalties as part of a voluntary alignment process.

#### *Assignment to ACOs that include FQHCs, RHCs, CAHs, and/or ETA Hospitals*

We continue to support including FQHCs, RHCs, CAHs, and ETA hospitals in ACOs. The beneficiaries who rely on these providers for care – many in rural and medically underserved populations – could benefit from the improved care coordination ACOs may provide.

Regarding the proposed assignment changes, we agree that Nurse Practitioners, Physician Assistants, and Clinical Nurse Specialists play an important role in primary care, particularly in FQHCs and RHCs, and support efforts to improve assignment procedures to better reflect the role NPs and PAs play.

## **BENEFICIARY NOTIFICATION AND DATA SHARING**

We recognize the important role data sharing can play in facilitating improved coordination and quality of care. Furthermore, patients understand the importance of electronic exchange of health information. However, ACOs must be open and transparent with beneficiaries and families about how patient information is being collected and used.

We support CMS's goals of improving beneficiary notification of data sharing and the opportunity to opt out. We are concerned about the changes proposed, however, which would replace individual notice to beneficiaries with non-specific/group notice provided via the *Medicare & You* handbook and signs posted in practice sites. These mechanisms are not sufficient to provide meaningful notice to beneficiaries.

Specifically, we are concerned that:

- The proposed notice procedures would result in fewer beneficiaries reading and comprehending the opt-out notifications (and those that do read the notice may not understand that it applies to them, specifically);
- The proposed change in process would not address confusion and questions raised by beneficiaries regarding the need for data sharing, and why providers do not already have this information;
- The mailed notifications currently sent by ACOs not only serve as notice of data sharing and the opportunity to opt out, but it also notifies beneficiaries that their provider is participating in an ACO. We believe it is important for patients to know about their providers' participation in an ACO, especially given new financial incentives – but the proposed changes would likely result in lower awareness.
- Finally, we are concerned the proposed changes would provide less effective notice to patients while simultaneously proposing to share more personally identifiable information and to collect and share information on a greater number of individuals. While we understand that data sharing can help to support greater coordination of care, it is essential that CMS and ACOs undertake this process in a careful and transparent way that provides beneficiaries with the information they need to understand their options and the right to opt out if they so choose.

Instead of the modifications shared in the proposed rule, we urge CMS to:

- Maintain individual notice of data sharing and the ability to opt out, but take steps to improve the notification letter template and any other materials or scripts used (by CMS, ACOs, or providers) to address beneficiary questions. Notices, scripts, and other



materials must be developed with the input of consumer advocates and be rigorously tested through focus groups with beneficiaries.

- Support communication between beneficiaries and their doctors (or practice staff) about ACOs and data sharing. It is important that patients be able to talk with someone in person, especially trusted professional staff in their doctor's office.
- Utilize community resources such as the State Health Insurance Assistance Programs (SHIPS) and Aging and Disability Resource Centers (ADRCs) to help beneficiaries understand their options. Incorporating phased, appropriate education from a trusted source may help to reduce beneficiary confusion and resistance. The ACO, through the provider, should be responsible for providing context and more information and referrals to unbiased sources for more information, like 1-800-MEDICARE and the SHIP network.
- Consider how offering patients real-time, electronic access to their health information may bolster trust and better equip beneficiaries to make more informed decisions regarding data sharing.

As CMS considers the above recommendations, we urge you to bear in mind the findings from a 2014 National Partnership nationwide consumer survey<sup>1</sup>. The survey found that patients see more value in electronic health records (EHRs) and health IT than paper records across a range of key care domains particularly important for ACOs. Specifically, consumers see significantly more value in EHRs than paper records in facilitating access to relevant information by all providers. However, survey findings also indicated that only about half felt their doctors and staff did a good job of explaining how their health information is used.

Among the survey findings:

- High numbers of both EHR and paper-record patients stated that it was important to them to know how their information was being collected and used (88% of EHR patients and 82% of paper-record), but:
- Less than 60% stated that their doctors and staff did a good job of explaining how their information is used (55% and 51%, respectively, reporting “well” or “very well” explained).
- Patients who feel well informed about the record systems trust their doctors more than patients who do not feel well informed trust their doctors (83 percent, compared with 56 percent).
- Patients with online access to EHRs trust their providers significantly more than patients with EHRs but without online access (77 percent, compared with 67 percent).

Findings suggested the more patients experience the benefits of EHRs and online access, the more they trust that their providers using them can protect patients’ privacy; and the

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<sup>1</sup> Engaging Patients and Families: How Consumers Value and Trust Health IT (2014). Harris Poll conducted the survey for the National Partnership for Women & Families online in April-May 2014 as a follow-up to one conducted in 2011 to gauge consumers’ perception of and experience with health IT. The 2,045 adult respondents had an ongoing relationship with a main doctor and knew what kind of record system their providers use. After weighting, this respondent pool represents 68% of the adult population (or an estimated 160 million Americans). Full report available at [www.nationalpartnership.org/PatientsSpeak](http://www.nationalpartnership.org/PatientsSpeak).

more patients trust that their privacy is protected, the more they use and benefit from EHRs and electronic health information exchange. Online access seems to be a catalyst for transparency and understanding that helps patients trust their records, and perhaps understand more about privacy rights. While having medical record systems explained well (whether systems are paper-based or electronic) can help people see advantages of each, having an actual view into their medical records is a major factor in increasing patient trust.

**Therefore, we strongly support requiring ACOs to give beneficiaries the ability to view, download, and transmit their health information in a manner consistent with Meaningful Use.** Offering patients real-time, electronic access to their health information will not only enhance patient engagement, but may bolster trust and alleviate concerns regarding data sharing, thereby minimizing the number of patients who opt-out.

Additionally, more work needs to be done to educate consumers about how their information is collected, used and protected. In developing templates for signs and written forms, for example, **we strongly urge CMS to require ACOs to work with beneficiaries and consumers to ensure language clearly describes why and how their health information will be stored, exchanged, used and protected, the opportunity to opt out, and other beneficiary rights.**

For example, information should answer such questions as:

- If I opt out of data sharing, will I still be in the ACO?
- What data will be shared?
- Who can see the data?
  - Will all data be available to anyone who has access, or is sharing done in a more targeted way?
  - Will financial information be included?
- What privacy protections do beneficiaries have?
  - If a beneficiary decides to opt out at a later date, what happens to previously shared records?

### Sensitive Health Information

We also urge CMS to carefully consider the sharing of certain types or categories of sensitive health data, such as behavioral health history, substance abuse history, or HIV/AIDS status and consider providing other ways of providing beneficiaries greater control over how this often more personal health information is shared. For example, continued development of technical solutions enabling patients to segment and authorize use of their data is important not only for enhancing consumer trust, but also advancing information exchange across the care continuum. This would also be consistent with many state statutes that provide beneficiaries with special protections for especially sensitive data.

## ELIGIBILITY REQUIREMENTS FOR MSSP ACOS

### Care Planning and Coordination

We strongly support requiring ACOs, as part of the application process, to have a mechanism in place for coordinating patient care and to detail the kinds of processes that will be used. Good care coordination is particularly important for the most vulnerable older Medicare beneficiaries with multiple chronic conditions.

We commend CMS's continued support for shared decision-making in ACOs. (Currently, an ACO is required to describe in its application how it will support shared decision-making – no changes were proposed). We urge the agency to include even more support for shared decision-making tools and processes through robust program requirements and quality measures.

Individualized care plans are a core element of effective care coordination, and we continue to support an emphasis on care planning in ACO requirements. We encourage CMS to think of them as **shared care plans**, which are jointly maintained and updated by patients, family caregivers, and members of their care team. In 2013, the National Partnership released a report detailing consumer priorities for health and care planning. We encourage CMS to draw upon the Consumer Principles (attached) as a resource.

### Patient-Centeredness Criteria

The proposed rule does not offer changes to requirements relating to the patient-centered criteria referenced in CFR 425.112. We strongly support maintaining the existing requirements in this section and continuing to require documentation of specific plans and processes for implementing these criteria as part of the ACO application process.

One of the requirements relates to beneficiary engagement. As CMS and ACOs pursue processes to enhance beneficiary engagement, we again emphasize that true engagement goes beyond an occasional focus group or an annual patient experience to encompass mutually beneficial partnerships at every level of care. Further, "beneficiary engagement" must go beyond the notion of "getting patients<sup>2</sup> to do what we want them to do." Patients and family caregivers must be systematically and meaningfully involved in all decisions concerning their care, and at every level – in care design and redesign, in policy and governance, and at the community level.<sup>3</sup>

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<sup>2</sup> We refer throughout our comments to "patient" and "care," given that ACO programs are rooted in the medical model. It is important to note, however, that meeting the goals of the *Triple Aim* will require a shift away from an exclusive medical model approach toward a more person- and family-centered approach that emphasizes wellness, prevention, and community-based supports, in addition to traditional medical interventions. People with disabilities frequently refer to themselves as "consumers" or merely "persons." Choice of terminology is particularly important for purposes of care planning and care coordination, when the worlds of independent living and health care provider often intersect, and for Medicaid beneficiaries or dually eligible persons.

<sup>3</sup> For a thorough definition of meaningful engagement and what it entails, please refer to the framework described in the Health Affairs article: "Patient and Family Engagement: A Framework for Understanding the Elements and Developing Interventions and Policies." We are also attaching a fact sheet that provides specific examples of meaningful engagement.

Additionally, as ACOs work to meet the criteria set out in this section, we encourage CMS to work with ACOs to support “hard-wiring” patient and family-centered care and partnerships, by:

- Incorporating patient- and family-centered care criteria and principles into hiring practices, job descriptions, performance reviews, and compensation; and
- Supporting strong leadership commitment to patient- and family-centered care (through, for example, designating a responsible management position, dedicating specific resources to patient- and family-centered care in the budget, and consistently reinforcing the value of partnering with patients and families to the organization).

Finally, evaluating ACOs’ progress on the plans described and holding them accountable for patient- and family-centered care criteria through enhanced oversight is critical to continued improvement. We would be interested to learn more in a final rule about how CMS monitors and evaluates implementation of these criteria and how the results are being used to foster ACOs’ continued improvement in engaging patients and families, and integrating a focus on patient-centeredness (**we would modify this term to “patient- and family-centeredness”**) that is promoted by the governing body and leadership.

#### *Requirement to Demonstrate Intent to Promote Acceleration of Health IT*

We strongly support CMS’s proposal to require MSSP ACO applicants to describe how it will promote use of health IT to improve care coordination, including plans to partner with long-term and post-acute care providers, and to identify performance targets for assessing progress. Data from the National Partnership’s 2014 survey underscore the importance of EHRs and health IT: consumers see significantly more value in EHRs than paper records in helping patients to **follow instructions for treatment or care, and helping patients take and refill medications as prescribed** – behaviors that are critical to the success of ACOs.

To improve both care quality and health outcomes, it is absolutely critical that ACO systems facilitate the safe and secure sharing of information, not just between its providers, but among patients, families, and other designated caregivers. Giving beneficiaries the tools to access and manage their own health information electronically is essential to the effective sharing of information, as well as patient engagement and high quality care.

Our 2014 survey found that patients with online access to the health information in their providers’ EHRs overwhelmingly use this capability: 86 percent log on at least once a year, and more than half (55 percent) log on three or more times per year. The data clearly show that online access has a positive impact on a wide range of activities that are essential to better care and improved health outcomes, including **knowledge of health** and **ability to communicate with providers**.

More frequent online access has an even more dramatic impact. Patients who used online access three or more times per year reported a markedly greater impact (20 percentage points higher) across these domains of care. Even more significantly, **the more often individuals**

**access their health information online, the more they report that it motivates them to do something to improve their health** – 71 percent, compared with 39 percent who used online access less frequently. This frequency of access clearly has profound implications for engaging patients and improving health status.

**We encourage CMS to consider requiring ACOs to delineate their plans for partnering with patients and families to make health information electronically available and useful to patients and families.** As we previously stated, ACOs should have - at a minimum - standards and processes in place for beneficiaries to electronically access their health information in a way that is aligned with the “View/Download/Transmit” criteria in Meaningful Use. Potential milestones or performance targets the ACOs could use to assess performance each year could include the number and/or percentage of patients using online access, exchanging secure messages with ACO providers, submitting corrections or amendments to their medical record, or setting/tracking individual health goals.

To facilitate and enhance patient and caregiver engagement in care, the information made available must be accessible and useful to all consumers. All patient-facing information and communication platforms should be displayed in plain language (rather than medical jargon), in patients’ preferred languages, with links to explanatory, contextual information as needed, and accessible to those with visual, hearing, cognitive, and communication impairments. Using culturally and linguistically appropriate information and platforms to tailor information to the unique needs of patients and their family caregivers could significantly improve health equity for patients experiencing health disparities, and is also directly aligned with the mission of the National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health and Health Care. CMS should encourage ACOs to partner with patients and families in developing discharge instructions, summary of care records, patient education materials, and other critical information available electronically to maximize its utility.

We acknowledge the current state of interoperability between EHR systems remains a challenge. However, the very development of entities like ACOs provides the incentives necessary for providers to overcome many barriers to electronic information exchange. Furthermore, we encourage CMS to regard beneficiary electronic access to and sharing of health information as core elements that will **advance** interoperability efforts.

#### *Partnering with Long-Term and Post-Acute Care Providers*

We strongly support CMS’s proposal to require ACOs to describe in the application process how they will partner with long-term and post-acute care providers to enhance care coordination across the care continuum. Enhanced communication and coordination with these providers is an important step toward improving transitions of care for the most vulnerable populations.

## **POSSIBLE REGULATORY WAIVERS**

CMS has proposed to waive certain restrictions for Track 3 ACOs, including requirements relating to Skilled Nursing Facilities, Post-Acute Care facilities, home health, and telehealth. While we support waiving requirements that may be unnecessary in two-sided risk arrangements and make it more difficult for beneficiaries to get needed care, we agree that any such waivers must be accompanied by strong quality criteria and consumer protections to prevent potential for abuse. Strong consumer protections and quality measures must be in place to ensure beneficiaries are getting appropriate, high quality, well-coordinated, patient- and family-centered care.

If ACOs are permitted to affiliate themselves more closely with certain providers, such as SNFs or Post-Acute Care providers, for the purposes of referrals, strong quality measures must be in place to ensure recommended entities deliver the highest standards for care. For example, preferred entities should demonstrate achievement of a minimum level of quality ratings.

ACOs must also be transparent about these affiliations and continue to make beneficiaries aware of the full range of providers available to them, beyond the recommended few. We do agree that careful selection of “priority” providers, if done in the right way, could provide patients and families with important information about the quality of care and other important characteristics and help them to make more informed decisions that are consistent with their needs and preferences. To achieve these goals, we suggest working with beneficiaries and families to develop these preferred referral lists based on factors that go beyond outcomes and cost to include factors such as communication skills, cultural and linguistic appropriateness, or other areas that are important to patients and families.<sup>4</sup> Partnering with patients and families in this way will help to achieve the goals of developing more streamlined relationships with high quality providers that provide the kind of care desired by patients and families.

### *Waiver of 3-Day Inpatient Rule for SNF Services*

We generally support the opportunity to waive the 3-day inpatient requirement for SNF care, however, strong beneficiary protections and quality standards must be in place to prevent abuse and ensure ACOs are providing high quality, patient- and family-centered discharge planning that meets the needs and preferences of all patients (including, but not limited to, people with disabilities, patients with cognitive issues, dual eligibles, patients with limited literacy skills, and patients who need translation services).

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<sup>4</sup> ‘ACO Referral Data Needs to Include More Than Cost, Outcome.’ Retrieved from: <http://www.healthdatamanagement.com/news/ACO-Referral-Data-Needs-to-Include-More-Than-Cost-Outcome-49672-1.html>

In waiving this requirement, we emphasize the importance of having in place strong quality measures that assess care coordination, outcomes including functional status, patient experience, and patient-reported outcomes (please refer to earlier comments for additional detail).

Further, any proposal to waive this requirement must include strong beneficiary protections, including:

- **Assurances that beneficiaries would not be liable for the cost of SNF care.** For example, if the patient were to later move outside the ACO coverage area, become ineligible for assignment, or if, in the case of Track 2 ACOs, the predicted assignment is not accurate, the beneficiary should not be liable for the cost of their SNF care.
- **Significant educational efforts to explain the waiver and its limitations** to beneficiaries, family caregivers, discharge planners, and SNF service providers (who are often under-informed about Medicare payment rules for SNF stays and services). There is great potential for confusion, particularly given that many beneficiaries do not know they are in an ACO. Consider, for example:
  - A married couple enrolled in fee-for-service Medicare in which one spouse is aligned with a Track 3 ACO, and one is not. The husband may be subject to the 3-day requirement, while the wife is not.
  - A beneficiary who is aligned with a Track 3 ACO one year, but not the following year. The rules would change.
- **Network adequacy protections.**
- **Patient choice protections**, especially for those patients who do not need the waiver to receive SNF care. As the proposed waiver appears to only apply to the ACO-affiliated SNFs, we are concerned that ACOs may have strong incentives to discharge patients quickly to those specific SNFs without taking into account patient and family needs and preferences.

Additionally, the waiver should not be structured in a way that creates carve-outs or financial incentives that encourage an inappropriate level of care. Finally, we urge CMS to clearly require ACOs to elicit and accommodate patient and family preferences when it comes to discharge planning and transitions of care, including referrals to SNFs.

#### Referrals to Post-Acute Care Settings

If designed appropriately, such a waiver could help patients and families to identify high quality long term care providers – however, given the potential for abuse, strong quality requirements and consumer protections must be in place and must be enforced by CMS.

We support language in the proposed rule that would require hospitals (1) to inform the patient or patient’s family of their freedom to choose among participating providers and (2) to provide a complete list of qualified providers available to the patient (and not limit the list to

the recommended providers). We do note that care and discharge planning must be a collaborative process conducted in partnership with patients and families and urge CMS to strengthen language concerning respect for patient and family preferences by striking the language “when possible.” The choice of post-acute care, including the choice of homecare provider, is often personal and family-driven. Services must be appropriate and able to meet the needs and preferences of all patients (including patients with disabilities, patients with cognitive issues, dual eligibles, patients with limited literacy skills, patients who need translation services, and others).

Additionally, this waiver must be accompanied by strong oversight, monitoring, and enforcement mechanisms to ensure that:

- Patients understand the full list of post-acute care providers that are available to them, even while some may be recommended as high quality providers;
- Full and proper discharge planning is occurring in collaboration with patients and families; and
- Patients are not being steered to certain providers inappropriately.

Strong quality protections must be in place to ensure ACOs are affiliating themselves with and referring patients to the highest quality providers. We again underscore the importance of having in place strong quality measures that assess care coordination, outcomes including functional status, patient experience, and patient-reported outcomes (please refer to earlier comments for additional detail).

#### *Billing and Payment for Telehealth Services*

We support allowing ACOs the flexibility to expand use of telehealth services to improve patient care, and believe effective use of telehealth services could improve communication between patients and families and health care providers, support more timely treatment and support, and address barriers to access for certain populations.

We do note that there are times telehealth may not be appropriate, for example, when there is a cognitive impairment, when diagnostic testing is needed, when the condition is severe, when a hands-on examination is needed, or if there is an uncertain diagnosis. It is also important to consider how language barriers and the potential loss of nonverbal cues may affect the delivery of some types of care by telehealth services. While we believe telehealth could significantly improve care and access for beneficiaries, we agree with CMS that there is potential for abuse and support the agency’s intent to implement enhanced monitoring and auditing of ACOs making use of this waiver. As part of its monitoring, CMS should specifically consider how telehealth is supporting or diminishing care for more vulnerable beneficiaries, especially dually eligible beneficiaries.

#### *Homebound Requirement for Home Health Services*

We support the opportunity to waive the Medicare homebound requirement for home health services for Track 3 ACOs. Once again, it is important to ensure beneficiaries retain choice of



home health providers to the greatest extent possible, especially for patients who would not need this waiver in order to receive home health services.

### Other Waivers

The notice invited comments on possible additional waivers of certain Medicare payment or other program requirements that might be necessary to permit effective implementation of two-sided performance based risk. We understand that this may include waiving beneficiary cost-sharing or implementing other financial incentives.

We do not oppose waiving some restrictions on financial incentives provided any such waivers are focused on removing barriers to care, alone (for example, waiving or reducing copays for office visits or medications related to chronic care management). Such waivers should be accompanied by (1) robust beneficiary outreach and education, and (2) beneficiary access to quality and performance information that is presented in clear, understandable, actionable language.

We do not support allowing ACOs or participating ACO providers to offer gift cards or other “reward” inducements to beneficiaries. We have consistently shared that in order for ACOs to be effective and keep beneficiaries aligned, they must provide the care that patients want and need. We believe accomplishing this foundational goal requires meaningful collaboration with patients and families at all levels of delivery system redesign. We believe that true partnerships with beneficiaries not only will serve as the most successful strategy for ensuring the delivery of patient- and family-centered care that meets the needs of beneficiaries, but will also bolster an ACO’s ability to meet quality and savings goals as well.

We also strongly encourage CMS to think beyond financial incentives and invest in providing consumers with clear, understandable information that will help them understand the value ACOs can provide to them as a patient (i.e. better coordination and higher quality care).

## **ADDITIONAL PROGRAM REQUIREMENTS AND BENEFICIARY PROTECTIONS**

### Transparency of Information: Participating ACO Providers

We support CMS’s efforts to improve the integrity and timeliness of information about ACO participants, providers, and suppliers and to improve the process for reporting changes in a more timely manner. We support requiring each ACO to create and maintain a dedicated webpage on which it must report information in a standardized way. To be successful, the webpage must be easy to find, contain easy-to-read information about the providers, and be updated regularly. Further, the webpage should not just include the names of the participating providers but also information about the physical accessibility of the office as well as information about languages spoken. We also encourage requiring ACOs to provide non-online sources of information for beneficiaries, such as mailing this information to beneficiaries once per year. Finally, we encourage standardized reporting of complaints and problems into a centralized unified tracking system (like the complaint tracking module).

### Transparency of Information: Quality Performance

CMS proposes to require participating ACOs to publicly report performance on all quality measures used to assess the quality of care furnished by the ACO. While we agree that requiring an ACO to publicly report its performance on all quality measures would assist consumers and other stakeholders in getting a more accurate picture of the ACO's performance, we urge CMS to go further.

Specifically, we urge CMS also to require ACOs to publicly report cost information in a consumer-friendly manner. ACOs should publicly report Medicare total costs for beneficiaries assigned to the ACO and total costs for the commercially insured receiving care in the ACO. ACOs also should publicly disclose their prices for routine procedures for Medicare and an average price (blended fee schedules) for commercial payers.

Additionally, we urge CMS to require ACOs to report quality and cost information at the provider level, as well as at the ACO level. Research has shown that much of the variation in quality and cost occurs at the individual provider level, not the practice site, group, or health system level. Providing beneficiaries with transparent information on cost and quality performance at the individual provider level as well as the ACO level will help consumers to make informed decisions with respect to choice of provider and care setting. Making this cost and quality information more transparent may also help beneficiaries to understand the potential benefits that an ACO can provide (specifically, higher quality care).

### **ADDITIONAL PRIORITIES**

#### Grievance and Appeals Processes

We are concerned that the Medicare Shared Savings Program creates new financial incentives for ACOs that are not taken into account in the traditional Medicare grievance and appeals system. The goals of Medicare Shared Savings Program are to reduce costs by providing higher value care and reducing unnecessary care through better coordination, however, we are concerned that there remain financial incentives to provide less care when it may not be in the best interest of the patient and without accompanying safeguards.

CMS should ensure appropriate grievance and appeals processes for beneficiaries in ACOs and clearly communicate these rights to beneficiaries. Processes should be standardized across plans, with regular reporting to a CMS official with oversight authority.

ACOs should:

- Require providers to state all treatment options available to a beneficiary
- Communicate to beneficiaries that they have the option to seek a second opinion by a non-ACO provider; and
- Assist beneficiaries in submitting complaints or grievances.

*Dually Eligible Beneficiaries*

Dually eligible beneficiaries – individuals who hold health coverage through both Medicare and Medicaid – represent many of the individuals who most need the high quality, well-coordinated care that may be furnished through an integrated system. We continue to believe that all ACOs – whether or not they have a high proportion of dual eligibles – should be able to manage and coordinate the full spectrum of dual eligibles’ needs (including through individualized care planning), include within their network providers with expertise in managing this population’s unique needs, and foster strong linkages with community resources including those that provide non-medical services and supports to vulnerable populations, such as persons with disabilities.

**CONCLUSION**

We appreciate the opportunity to comment on the proposed evolution of the Medicare Shared Savings Program. We look forward to working with you to ensure that Shared Savings ACOs truly transforms the way care is delivered to all patients.

Sincerely,  
National Partnership for Women & Families  
American Association on Health and Disability  
American Cancer Society Cancer Action Network  
Caring from a Distance  
Community Catalyst  
Empowered Patient Coalition  
Family Caregiver Advocacy  
Medicare Rights Center  
National Health Law Program (NHLP)

# Examples of Beneficiary Engagement

SEPTEMBER 15, 2014

In health care policy discussions, the term “engagement” is often synonymous with “getting patients to do what we want them to do,” whether that’s following a treatment plan created by their doctor, adhering to medication regimens, or participating in healthy behaviors like exercise. But creating policies based on this definition of engagement will result in programs and initiatives that neither meet the needs of patients and families nor help CMS meet the goals of better quality and lower cost.

Engagement goes beyond the notion of “behavior change,” and, instead, is defined as collaborative partnerships between patients/families and their providers. Engagement means supporting patient and family participation as **equal partners** in not only their own health and health care decisions, but also at the care redesign and governance levels as new models of care delivery are designed and implemented.

Below, we have provided specific examples of meaningful engagement. We hope these examples (and further examples provided in the *Health Affairs* article ‘Patient and Family Engagement: A Framework...’) will be helpful as you consider your approach to beneficiary engagement in new models of care.

## Individual Care and Health

- ▶ Engagement IS:
  - ▶ Health care teams work collaboratively with patients and family caregivers to create and update a shared care plan that reflects mutually agreed upon goals of the patient/family and health care team and is consistent with the individual’s values, preferences, and abilities.
    - ▶ NOT – Getting patients to comply with a treatment plan developed without their/their family caregiver’s meaningful involvement.
- ▶ Engagement IS:
  - ▶ Clinicians using shared decision-making tools to provide high quality, complete, unbiased, current information to patients and families that enables them to assess all of their treatment options and make informed decisions in partnership with their health care team.
    - ▶ NOT – Providers telling patients which treatments they recommend without discussing all options available and the potential risks and benefits of each.

## Care Delivery Redesign

- ▶ Engagement IS:
  - ▶ Partnering with patient and family advisors to assess and redesign patient self-management support programs, such as programs for people with chronic or high risk conditions.
    - ▶ NOT – Planning a self-management support program based on what providers think patients and families want and need, without asking them what may make it most difficult to care for themselves or when it is convenient to hold such meetings.
  - ▶ Health care facilities or organizations work in partnership with patient/family advisors throughout the process of choosing, designing, implementing, and evaluating a patient portal to ensure it includes functions that are important to patients and is easy to use.
    - ▶ NOT – Asking a focus group to review completed plans for the portal's implementation when it is too late to influence the process.

## Governance

- ▶ Engagement IS:
  - ▶ Partnering with patient and family advisors to assess the effectiveness of beneficiary engagement programs and identify improvements.
    - ▶ NOT – Evaluating beneficiary engagement programs absent discussion with patient and family advisors about what would make them more effective, from the patient/family perspective.
  - ▶ Involving a proportionate number of patient and family advisors on boards and other decision-making bodies and preparing them to participate effectively.
    - ▶ NOT – Asking a token consumer to sit on the board, and not preparing him/her to participate effectively or preparing other members to understand and accept the value of consumer perspectives.

# Care Plans 2.0

Consumer Principles for Health and Care  
Planning in an Electronic Environment

**NOVEMBER 2013**



Consumer  
Partnership  
for **eHealth**

Many organizations are working to enhance communication and care coordination across the health care system. These *Consumer Principles for Health and Care Planning* are currently endorsed by:



CENTER FOR MEDICAL CONSUMERS



# Care Plans 2.0

## Consumer Principles for Health and Care Planning in an Electronic Environment

NOVEMBER 2013

**T**he lack of coordination and communication is one of the most ubiquitous consumer complaints about the U.S. health care system, and is a key driver of poor quality and unaffordable care. A major contributor to this problem has been the failure to plan and communicate effectively across settings and clinicians, with active engagement by all members of the care team – including individuals and their family and other designated caregivers.

Care plans are gaining increasing attention among federal health policy makers as a tool to enhance care coordination and optimize health outcomes. While the concept of a care plan is not new, there is little uniformity in what these plans look like or how they are used. To achieve robust and effective planning and communication, we must move beyond our mental construct of a care plan as a document fixed in time, to a multidimensional, person-centered health and care planning process built on a dynamic, electronic platform.<sup>1</sup> This next generation of care plans – Care Plans 2.0 – should function as a roadmap for patients, families, and health care providers to follow toward the best possible health or functioning.



### Care Plans 2.0:

A multidimensional, person-centered health and care planning process facilitated by a dynamic, electronic platform that connects individuals, their family and other personal caregivers, paid caregivers (such as home health aides), and health care and social service providers, as appropriate. The care plan supports all members with actionable information to identify and achieve the individual's health and wellness goals.

- 1 Health and care plans should be goal-oriented, dynamic tools (not static documents).**
- 2 Tools that facilitate health and care planning should enable all members of the care team to securely access and contribute information, according to their roles.**
- 3 Health and care plans should identify and reflect the ability and readiness of an individual (and caregiver) to successfully meet the individual's goals, as well as potential barriers.**
- 4 Health and care planning and tools should facilitate decision-making and specify accountability.**
- 5 Every individual would benefit from health and care planning and tools.**



As the health care system moves toward a focus on wellness, these next-generation care plans offer the opportunity for patients and their loved ones to play leading roles with their care team in identifying and pursuing the health and wellness goals most meaningful to them. Of course, early efforts to develop care plans will, and should, focus first on those with the greatest need – individuals needing more complex care, such as those with chronic conditions. However, our approach to care planning should evolve from episode- or illness-based care planning to proactive, all-encompassing wellness planning, from which all individuals stand to benefit. Proactive development of a care plan for all individuals who want one will require a shift in cultural norms and expectations. To begin the transition, the process could build upon pre-established interactions with the health care system, such as childhood immunizations, annual wellness visits, or pneumonia vaccinations for seniors.



“As the health care system moves toward a focus on wellness, these next-generation care plans offer the opportunity for patients and their loved ones to play leading roles with their care team in identifying and pursuing the health and wellness goals most meaningful to them.”

While human interaction drives the process of care planning, technology can help make necessary information more readily available and actionable, connect all people who have a role in an individual’s care plan, and provide a shared platform for the ongoing maintenance and management of an individual’s care and wellbeing. Electronic platforms also make it possible to scale plans according to individual needs and various stages of life – supporting, for example, a woman during her childbearing years, helping to manage chronic or debilitating conditions, and ultimately guiding her advance directives toward the end of life.

If the care plan depends on having a family caregiver, the caregiver’s own needs for information and training should be identified in the planning process to ensure that the caregiver has the capacity to meet the expected responsibilities in the care plan and achieve better outcomes for the individual’s goals. Proactively and explicitly engaging an individual’s family and caregivers in the development of a care plan helps to ensure that the individual’s abilities, culture, values, and faith are respected and care instructions and action steps are more likely to be understood and followed.

The Electronic Health Record “Meaningful Use” Incentive Program offers one immediate opportunity to advance the technological foundation for care plans, and the process of care (and ultimately wellness) planning. The following set of overarching principles is a consumer-directed starting place for building the functionality to support care planning into health IT.

# Consumer Principles

## 1 Health and care plans should be goal-oriented, dynamic tools (not static documents).

- Care plans should be centered on the achievement of goals identified by the individual (or designated caregiver), supported by appropriate clinical goals.
  - Information about an individual's needs, preferences, and values should be captured as part of the care plan and updated as needed.
  - Care plans should address the unique needs of individuals and diverse populations.
- Care plans should contain specific and measurable action steps necessary for meeting agreed-upon goals.
  - Longer-term goals should be broken down into short-term, incremental steps.
- Care plans should be flexible and accommodate real-time updates based on changing circumstances and previous experience. This may include revision of the goals themselves, as well as the individual steps in the plan.
- Care plans should reflect actions for healthy living, and should not be developed exclusively from a medical perspective.

## 2 Tools that facilitate health and care planning should enable all members of the care team to securely access and contribute information, according to their roles.

- Relevant information from care plans should be accessible across health care settings and to non-health care supports in the community to enable refinement and updating at the point of care.
  - Care plans should allow individuals to select and share selected information with different care team members, as the individual chooses.
  - A list of care team members and contact information should be included.
- Individuals, family and other designated caregivers, and health care providers granted access by the patient should be able to initiate modifications and record progress related to care plans, including new barriers to achieving goals and changes in circumstances or lifestyle.
  - A record of when the care plan was last updated and who made modifications should be kept.
- Care plans should be organized or customizable into different views in order to enable each care team member to see clearly what his or her assigned actions are, relative to the comprehensive plan.
  - Care plans should be displayed to patients and families in plain language and leverage accessible, consumer-friendly interfaces.



**3 Health and care plans should identify and reflect the ability and readiness of an individual (and caregiver) to successfully meet the individual's goals, as well as potential barriers.**

- Care planning should reference and consider race, ethnicity, language, culture, faith, sexual orientation, gender identify, and disability status, which may inform an individual's perspective on health and health goals and influence the development and implementation of care plans.
- Information about an individual's knowledge, skills and confidence related to managing one's own health and care, the individual's needs for reasonable accommodation, as well as health and health IT literacy needs, should be captured as part of the care plan and updated regularly.
- Care plans should take into consideration both barriers and facilitators to achieving stated goals.
  - Social assessment information and environmental barriers relevant to an individual's ability to achieve the agreed-upon goals should be integrated into the care plan.
  - Arrangements for additional information and supports necessary to address barriers should be included in the care plan. This may require coordination with and management of non-medical community resources and supports ("enabling services"), such as transportation, interpretation, case management, child care, and health education, in concert with medical interventions.



**4 Health and care planning and tools should facilitate decision-making and specify accountability.**

- Care plans should include a method of monitoring both patient and care team member progress in completing action steps, as well as in meeting agreed-upon goals to improve health outcomes and maximize functionality.
- Care plans should clearly reflect what action is to be taken, by whom, and when, in order to ensure clarity of responsibility and support coordination of care.
  - An initiation or revision of a care plan should always be followed by mutual confirmation of each relevant actor's understanding of the plan and his or her role in the plan.
- Care plans should connect to clinical decision support (CDS) tools so that clinicians are able to receive automated prompts based on patient-specific goals, preferences, and clinical information.
  - Identification of high-risk behaviors or adverse health events should trigger the modification or addition of action steps in the care plan.

## 5 Every individual would benefit from health and care planning and tools.

- Every individual should have the ability to initiate the care planning process and care planning should be advanced as a routine activity.
  - Development of care plans should initially be prioritized for individuals with needs that would most greatly benefit from better care coordination and planning, such as individuals with disabilities or multiple chronic conditions.
- Care plans should be established prior to a crisis situation, when possible. Care plans should be scalable to support individual needs and stages of life.
  - Care planning may not be a priority for every individual at any given time. Individuals should be able to initiate (and suspend) the care planning process consistent with their needs and priorities.



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The National Partnership for Women & Families is a nonprofit, nonpartisan advocacy group dedicated to promoting fairness in the workplace, access to quality health care and policies that help women and men meet the dual demands of work and family. More information is available at [www.NationalPartnership.org](http://www.NationalPartnership.org).

The Consumer Partnership for eHealth (CPeH) is a coalition of more than 50 consumer, patient, and labor organizations working at the national, state, and local levels to advance private and secure health information technology in ways that measurably improve the lives of individuals and their families. The combined membership of CPeH represents more than 127 million Americans.

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<sup>1</sup> For purposes of brevity, we refer in places to “patient” and “care plan,” although these terms to some could imply a medical model with a focus on episodes of illness. The independent living movement uses the terminology “integrated person-centered planning” in lieu of “care planning,” which we support. Choice of terminology is particularly important for purposes of care planning and care coordination, when the worlds of independent living and health care provider intersect.

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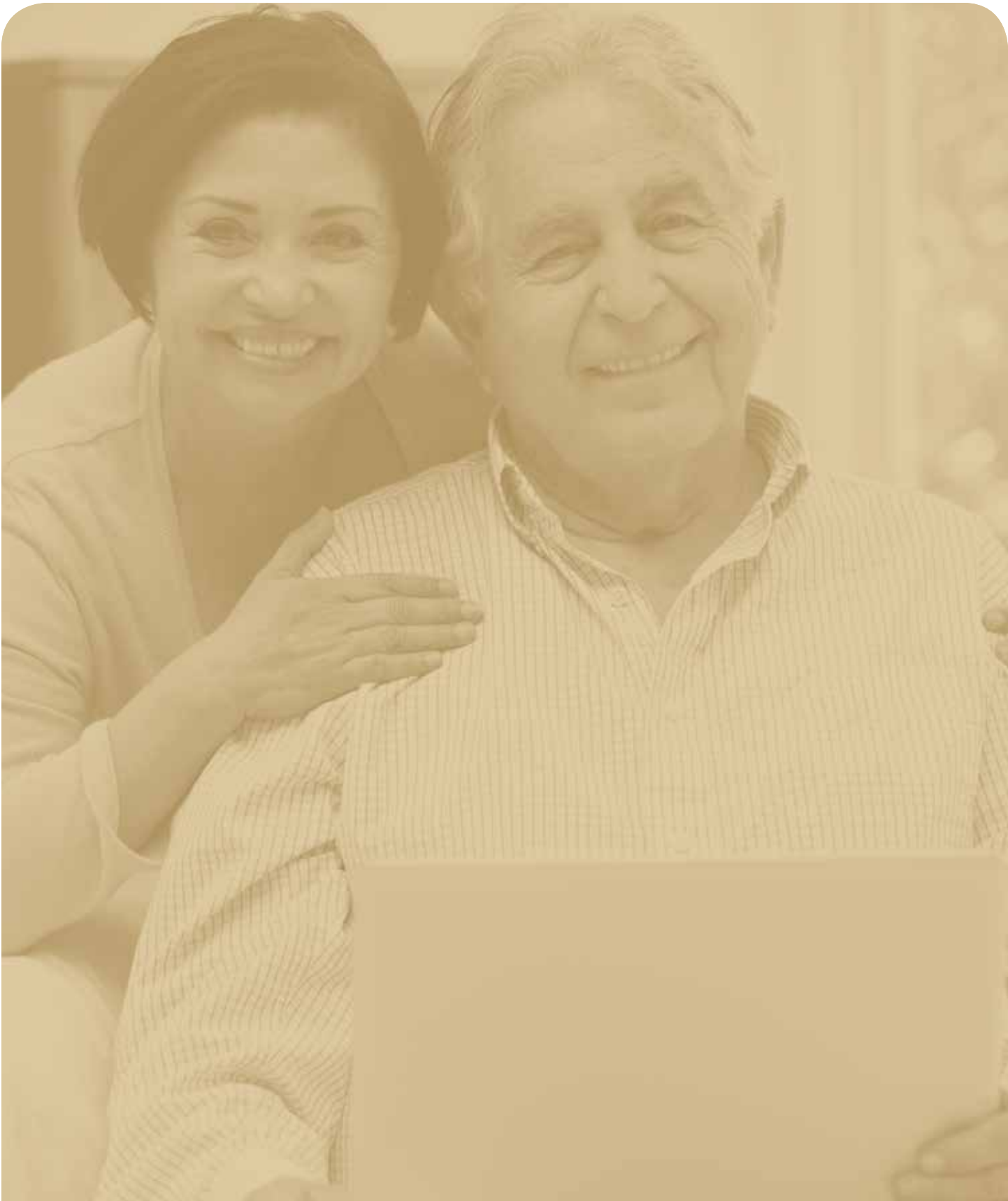
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# Patient And Family Engagement: A Framework For Understanding The Elements And Developing Interventions And Policies

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## Abstract

Patient and family engagement offers a promising pathway toward better-quality health care, more-efficient care, and improved population health. Since definitions of patient engagement and conceptions of how it works vary, we propose a framework. We first present the forms engagement can take, ranging from consultation to partnership. We discuss the levels at which patient engagement can occur across the health care system, from the direct care setting to incorporating patient engagement into organizational design, governance, and policy making. We also discuss the factors that influence whether and to what extent engagement occurs. We explore the implications of our multidimensional framework for the development of interventions and policies that support patient and family engagement, and we offer a research agenda to investigate how such engagement leads to improved outcomes.

[Consumer Issues](#) [Quality Of Care](#) [Organization And Delivery Of Care](#)  
[Health Reform](#)

## Articles citing this article

Context-based Strategies for Engaging Consumers with Public Reports about Health Care Providers  
Med Care Res Rev October 2014 71:5\_suppl17S-37S  
[Abstract](#) [PDF](#)

The Pediatric Inpatient Family Care Conference: A Proposed Structure Toward Shared Decision-Making  
hospital pediatrics September 2014 4:5305-310  
[Abstract](#) [Full Text](#) [PDF](#)

Patient Engagement: Four Case Studies That Highlight The Potential For Improved Health Outcomes And Reduced Costs  
Health Aff (Millwood) September 2014 33:91627-1634  
[Abstract](#) [Full Text](#) [PDF](#)

Patient-centered Guideline Development: Best Practices Can Improve the Quality and Impact of Guidelines  
Otolaryngol Head Neck Surg August 2014 0:20140194599814544878v1-194599814544878  
[Abstract](#) [Full Text](#) [PDF](#)

A Comparison of In-person, Telephone, and Secure Messaging for Type 2 Diabetes Self-Management Support  
The Diabetes Educator July 2014 40:4516-525  
[Abstract](#) [Full Text](#) [PDF](#)

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Cancer

J Natl Cancer Inst Monogr December 2013 2013:47162-168

[Abstract](#) [Full Text](#) [PDF](#)

The patient is in: patient involvement strategies for diagnostic error mitigation

BMJQS October 2013 22:Suppl\_2ii33-ii39

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